

BARRIERS TO OBTAINING ANNUAL DIABETIC EYE EXAMS  
AMONG ADULT RURAL PATIENTS

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By

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BARRIERS TO OBTAINING ANNUAL DIABETIC EYE EXAMS  
AMONG ADULT RURAL PATIENTS

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## Dedication

I would like to dedicate this effort to my husband, Doug. You kept my spirits up with stories of the challenges of your own PhD journey, you calmed me down through the 'flea biting and barking,' and always told me that it would be all right. You are the reason I achieved this goal.

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# Chapter I

## Introduction

Diabetic retinopathy (DR) is the leading cause of newly diagnosed blindness in Americans who are 20-74 years old (American Academy of Ophthalmology, 2016). Over four million adults in this country currently have DR, with the number projected to reach six million by 2020. The medical costs of DR, including prescription medications, outpatient, and inpatient services, already at \$500 million annually, will continue to rise (Prevent Blindness America, 2007). With the major risk factor for the development of DR being length of time with diabetes, older adults are at the greatest risk of developing this disabling disease (American Academy of Ophthalmology, 2016; Klein, Klein, Moss, Davis, & DeMets, 1984).

Clinical trials show that treatment for DR is 90% effective in stopping severe loss of vision with early diagnosis (American Academy of Ophthalmology, 2016) and that treatment is cost effective (Javitt & Aiello, 1996). Unfortunately, efforts over the past 20 years to encourage patients to obtain their annual diabetic eye exams (DEE) have been ineffective. The 1989 National Health Interview Survey, with a sample of 84,572 participants, found only 49% of adult patients diagnosed with diabetes had received a DEE in the previous year (Brechner et al., 1993). More recent reports, including analysis of Medicare claims data from 2003, and a more recent analysis (National Committee for Quality Assurance, 2013), show that rates still remain around 50% (Garg & Davis, 2009; Lee, Feldman, Ostermann, Brown, & Sloan, 2003; National

Committee for Quality Assurance, 2013). Thus, almost half of patients are not receiving their annual DEE when diagnosis and treatment are most successful at preventing subsequent blindness (Brechtner et al., 1993; Garg & Davis, 2009; Lee et al., 2003; Moss, Klein, & Klein, 1995; National Committee for Quality Assurance, 2013; Schoenfeld, Greene, Wu, & Leske, 2001).

Healthy People 2020, an initiative from the U.S. Department of Health and Human Services, emphasized preservation of sight and prevention of blindness from undetected and untreated DR, because the prevalence of DR is increasing (U.S. Department of Health and Human Services, 2013). The National Eye Institute stressed vulnerable populations, such as people with diabetes, need to be identified earlier and access to specialists for patients in rural areas needs to be increased (National Eye Institute, 2012). It is well established that patients who suffer from DR need to receive appropriate eye care to prevent blindness.

Since 1992, guidelines have been published that provide direction on appropriate referral of patients for DEE for patients with diabetes (American College of Physicians, American Diabetes Association, and American Academy of Ophthalmology, 1992). Updated in 1998 and now revised annually, the guidelines indicate that patients with diabetes should receive a DEE annually by either an ophthalmologist (MD) or an optometrist (OD) with advanced education in the detection of DR (American Academy of Ophthalmology, 2016; American Diabetes Association, 2016). This comprehensive examination should include a review of the patient's past medical history, evaluation of best-corrected vision with either glasses or contacts, slit-lamp biomicroscopy, measurement of

intraocular pressure (often thought of as the “glaucoma check” by patients), and detailed assessment of the inside of the eye through dilated pupils with special lenses used by the eye doctor, all of which are non-invasive (American Academy of Ophthalmology, 2016). Patients with type 2 diabetes should have their initial exam shortly after their diabetes diagnosis because, though the onset of DR is initially slow and progressively worsening, the diagnosis of type 2 diabetes may come many years after the onset of the damaging effects of the disease.

Patients with type 1 diabetes may wait 5 years for their initial DEE because this form of diabetes has a rapid onset and the date of diagnosis is known. Due to the slow and progressively worsening development of DR, many patients are unable to detect the gradual changes to their vision in the early stages, when treatment is most successful in preventing severe vision loss (American Academy of Ophthalmology, 2016).

For individuals living in rural areas with limited access or other barriers to health care, obtaining DEE may be particularly challenging. Patients living in rural areas experience decreased rates of preventive health care services in general compared with those living in urban areas (Khoong, Gibbert, Garbutt, Sumner, & Brownson, 2014), including annual DEE (Chou et al., 2012). Greater distance to access health care is a known barrier for rural patients (Khoong et al., 2014), in addition to the same barriers urban patients experience, including high costs, lack of insurance, and lack of knowledge of the potential benefits of preventive health care services (Cook et al., 2007; Sloan, Brown, Carlisle, Picone, & Lee, 2004).

Elderly adults face additional challenges beyond an increased prevalence for development of DR (American Academy of Ophthalmology, 2016). Functional limitations from diabetes and loss of vision from DR include increased feelings of isolation, leaving the elderly more vulnerable to depression (Corriere, Rooparinesingh, & Kalyani, 2013). Visual loss leads to a higher risk of falls, and difficulty administering medication including insulin. Decreased vision can lead to loss of driving privileges, which contributes to increased difficulty or inability to access health care appointments (Fenwick et al., 2012). Further research is needed that will focus on the unique barriers for adult patients in rural areas to inform the development of interventions to help patients obtain their annual DEE.

## **Background**

### **Health Care Providers**

Despite years of effort by health care providers to encourage patients to obtain their annual DEE, through education and referral of patients to eye care providers, studies have shown that half of patients are not receiving this important exam (Brechner et al., 1993; Garg & Davis, 2009; Lee et al., 2003; Moss et al., 1995; National Committee for Quality Assurance, 2013; Schoenfeld et al., 2001). In recent years, federally governed organizations, such as the Center for Medicare and Medicaid, have focused on placing the responsibility for ensuring that patients receive a DEE on health care providers, such as physicians, nurse practitioners, and physician assistants. To incentivize providers to facilitate patients obtaining their DEE in 2008, the Center for Medicare and Medicaid established the Physician Quality Reporting System

(PQRS) (Centers for Medicare and Medicaid Services, 2014). PQRS was developed to provide financial incentives to eligible providers to report on clinical quality measures, such as the percentage of adult patients who had a DEE in the previous year. Currently, participation in this incentive program is voluntary; there is no penalty for those failing to report.

## **Electronic Health Records**

The implementation and use of electronic health records (EHR) has been promoted as technology to improve clinical care and management of chronic conditions, such as diabetes and prevention of DR through patient compliance with obtaining DEE (Cordero, Kuehn, Kumar, & Mekhjian, 2004; Hillestad et al., 2005; Hunt, Haynes, Hanna, & Smith, 1998; Jayawardena et al., 2007; Shekelle, Morton, & Keeler, 2006). Political influences have moved us toward improving and expanding the capabilities and usage of EHR throughout healthcare, though studies have shown that improved quality of care through achievement of clinical quality benchmarks is not guaranteed (Keyhani et al., 2008; Linder, Ma, Bates, Middleton, & Stafford, 2007; Linder, Schnipper, & Middleton, 2012).

## **Significance of the Study**

The rate of annual DEE has remained unchanged over the past two decades when early diagnosis and treatment of DR is most successful at preventing blindness (Brechtner et al., 1993; Garg & Davis, 2009; Lee et al., 2003; Moss et al., 1995; National Committee for Quality Assurance, 2013; Schoenfeld et al., 2001). Little research has focused on the unique barriers to obtaining DEE experienced and described by patients, in particular adults living

in rural areas. Findings from this study will inform the future development of interventions by health care providers to improve compliance with recommended guidelines for aging adult patients with diabetes residing in rural areas.

## **Purpose**

The purpose of this study was to examine the barriers to obtaining annual DEE experienced by adults with diabetes who live in rural areas. A secondary purpose was to re-evaluate the validity and reliability of the newly developed **Compliance with Annual Diabetic Eye Exams Survey (CADEES)** instrument.<sup>1</sup>

(see Appendix 1 ).

## **Specific Aims and Research Questions**

The study addressed the following specific aims and research questions:

*Specific Aim 1:* Examine the validity and reliability of the CADEES instrument in adults with diabetes who live in rural areas.

*Research Question 1-1:* How strong is the validity of the CADEES instrument?

*Research Question 1-2:* How strong is the reliability of the CADEES instrument?

*Specific Aim 2:* Identify the barriers to obtaining annual DEE experienced by adults with type 2 diabetes.

*Research Question 2-1:* What are the differences in barriers for participants who had a DEE in the previous year compared to those who did not have a DEE?

*Research Question 2-2:* What are the differences in barriers to obtaining annual DEE experienced by patients with type 2 diabetes age 45-64 compared to those 65+ years old?

*Research Question 2-3:* What are the differences in barriers to obtaining annual DEE experienced by patients with type 2 diabetes living in rural compared non-rural areas?

## **Summary**

This report consists of the following: chapter one provides a background of the research problem; chapter two is a review of the literature; chapter three reports the methods used to conduct the study; chapters four and five are manuscripts detailing the results of Specific Aims 1 and 2, respectively; and chapter six offers conclusions for the overall research study.

## Chapter II

### Review of the Literature

#### **Barriers and Facilitators to Managing Multiple Chronic Conditions: A Systematic Literature Review**

A manuscript published: 2015, *Western Journal of Nursing Research*, 37(4), 498–516

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#### Abstract

The prevalence of multiple chronic conditions (MCC) is increasing, creating challenges for patients, families, and the health care system. A systematic literature search was conducted to locate studies describing patient's perceptions of facilitators and barriers to management of MCC. Thirteen articles met study inclusion criteria. Patients reported nine categories of barriers, including financial constraints, logistical challenges, physical limitations, lifestyle changes, emotional impact, inadequate family and social support, and the complexity of managing multiple conditions, medications, and communicating with health care providers. Four facilitators were found, including health system support, individualized care education and knowledge, informal support from

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family and social systems, and having personal mental and emotional strength. Existing research on management of MCC from the patient's perspective is limited. Interventions are needed to improve management practices with particular attention to the knowledge and skills required by this unique population.

**Keywords**

review, systematic, chronic disease, qualitative research

Estimates indicate that 133 million people in the United States have at least one chronic health condition, with 25% or more than 33 million experiencing two or more conditions (Machlin & Soni, 2013). Individuals with multiple chronic conditions (MCC) have greater difficulty performing normal daily activities and higher health care utilization and health care expenditures (U.S. Department of Health and Human Services [USDHHS], 2010). The continued increase in life expectancy and growing number of patients diagnosed with MCC will further challenge the ability of the health care system to assist patients with their health care management while restraining growth in health care expenditures.

### **Compound Effects of MCC**

As patients develop MCC, there is a compound effect on the difficulty in managing the physical, financial, and competing demands and effects of their diseases (Bayliss, Ellis, & Steiner, 2009). Care for patients with MCC is often guided by clinical guidelines developed with only one specific medical condition in mind (USDHHS, 2010). Although many interventions have been created to assist patients to manage specific chronic conditions (Beverly et al., 2013; Joseph et al., 2013; Wakefield, Boren, Groves, & Conn, 2013), far fewer studies have identified successful approaches to assist patients in managing MCC (Protheroe, Blakeman, Bower, Chew-Graham, & Kennedy, 2010). Identification of the unique management support required of patients with MCC is the first step in the development of patient-centered interventions to improve patient outcomes for this growing population.

## **Purpose**

Patients with MCC require individualized assistance that addresses the fluctuating and competing needs of their health care. The purpose of this study was to conduct a systematic review of the literature on patients' perceptions of facilitators and barriers to effective management of MCC. With the expected increase of MCC in the population, health care providers must better understand and address care barriers and facilitators associated with the needs of these patients to provide optimal care.

## **Method**

### **Literature Search**

This study began with a systematic search of the literature to locate all articles describing patient's perceptions of barriers and facilitators to managing their MCC. The search was conducted from October 2012 through December 2012. No articles were excluded based on date of publication. The initial yield totaled 1,814,544 citations across the databases Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and Scopus, using key terms (see Figure 1). The yield was markedly reduced to 1,784 by adding the second and third groups of search terms. Once database limits, exclusion criteria, and duplicate articles were removed, the yield was further reduced to 58. After an additional 15 articles were included from review of reference lists, a total of 73 full text articles were then assessed for relevance by the authors. At that point, a total of 20 articles from 17 original qualitative and quantitative studies were included in the review. However, on further discussion and refinement of the

focus of this review by the authors, it was determined that the quantitative studies did not address this article's review question regarding perceived barriers and facilitators. A total of 13 articles were included in the final analysis (see Figure 1).

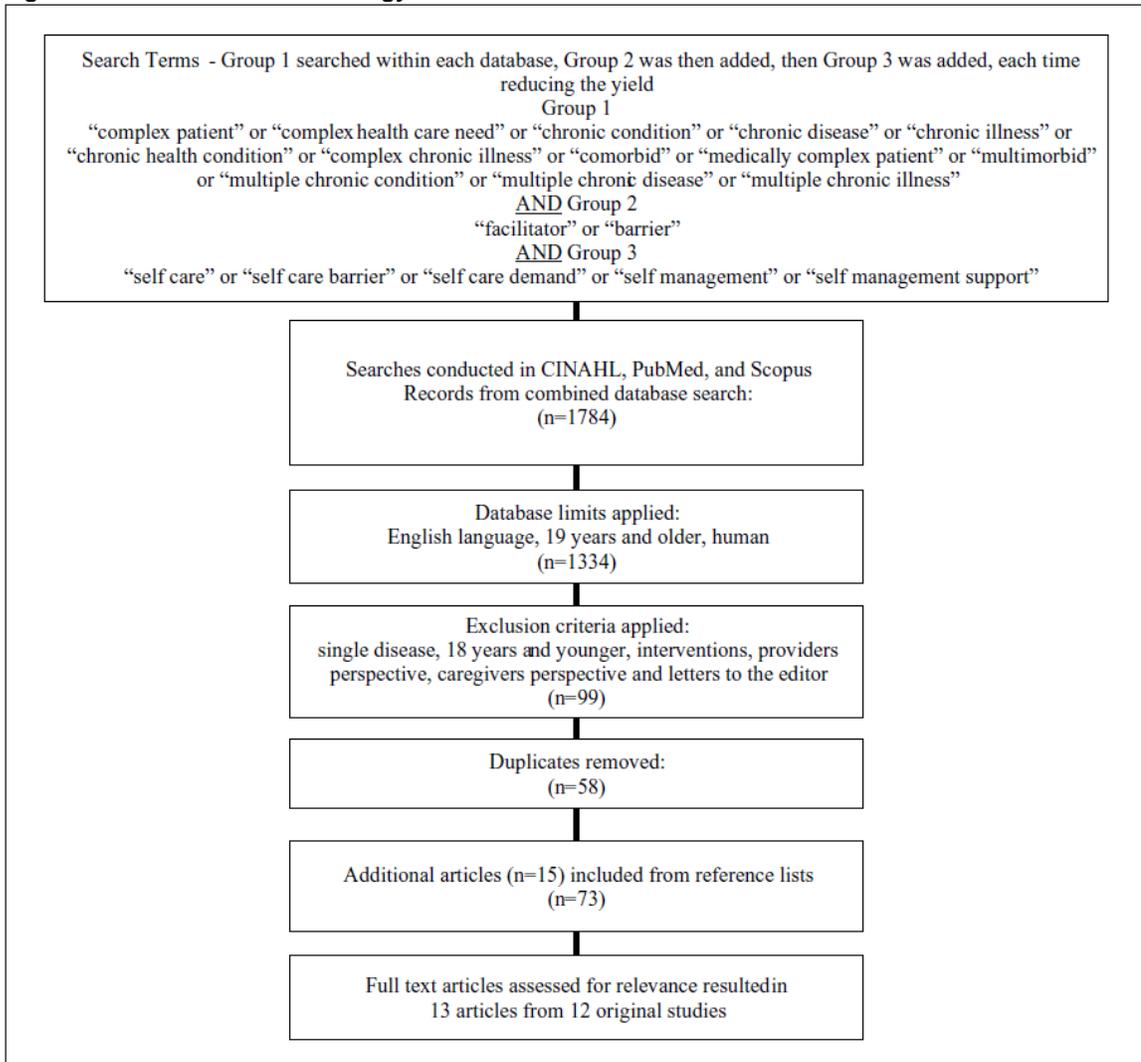
### **Inclusion and Exclusion Criteria**

Inclusion criteria were limited to peer-reviewed publications in English, adult's age 18 and above, studies that evaluated the burden of care from the patient's perspective, and a focus on patients with two or more chronic health conditions. Studies were excluded if they were focused on patient's age less than 18, single diseases, evaluation of specific interventions (e.g., care management, guided care), providers or informal caregiver's perspective, and non-research based publications such as letters to the editor.

### **Data Analysis**

To evaluate the studies, articles were entered into a literature review matrix, identifying the specific aims of the study, demographics, methods, major findings, limitations, and article focus. Data were analyzed using content analysis to produce a descriptive summary of the content (Sandelowski, 2000). Data analysis began with one investigator (GK) coding the data for individual themes

**Figure 1: Literature Search Strategy**



within each article. Results were independently reviewed by a second investigator (B.J.W.). Investigators then discussed the coding framework until consensus was reached. All but two of the articles (Townsend, 2011; Townsend, Wyke, & Hunt, 2006) either explicitly or implicitly (e.g., through interview questions) addressed barriers and/or facilitators to care management. The two investigators then independently evaluated each article for barriers and facilitators, and subthemes under each. For the two that did not address barriers

and facilitators, data were analyzed to identify them. Following discussion between the two investigators, consensus was reached on themes and subthemes for the articles.

## **Results**

A total of 13 articles from 12 original studies using qualitative research methods met criteria for inclusion in the study (2 articles with differing research objectives, reported on the same study participants, see Townsend et al., 2006, and Townsend, 2011). Study sample size ranged from 11 to 98 patients with a mean of 35 participants (median of 25 participants) across studies. Data collection methods varied across the studies and included individual interviews, focus groups, observation, and diary entry review. Surveys and chart reviews were also included in some studies to supplement the qualitative research. The average age of patients was not reported across all articles. In 6 articles, the average age of patients was 63 years. In 6 articles from 5 studies that reported age categories, 82% of patients were older than 50. No patients younger than 30 were included in any of the studies. The majority, 68%, was female. Not all studies reported race. In 9 studies that reported race, 63% of participants were Caucasian, 26% were African American/Black, 2% were Hispanic/Latin/Asian/Pacific Islander, and the remaining 9% were not identified as belonging to a specific race.

Across the studies, patients reported nine categories of barriers to care management, and four categories of facilitators to care management.

**Table 1: Included Studies**

Citation	Purposes/Aims	Study Design	Sample and Setting	Major Findings
Bayliss, Steiner, Fernald, Crane, and Maan (2003)	Identify barriers to self-care management by patients with multimorbidities	Qualitative interviews	16 adult patients from 4 urban family practices, with 2 or more comorbidities, in metropolitan Denver, CO	Identified 15 areas of potential barriers to self-care management. Do not seem to be influenced by perceived severity of health status. Compound effects of conditions. Physical limitations/adaptations to limitations caused by conditions. Compound effects of medications (therapeutic and side effects). Schedule and coordination of medications. Total burden of medications. Side effects of medications. Lack of knowledge about conditions. Financial constraints. Low self-efficacy or sense of loss of control. Burden of the dominant effects of a single condition. Emotional impact of diseases. Inadequate communication with providers. Need for or use of social support. Logistical issues. Need for understanding conditions.
Bayliss, Edwards, Steiner, and Main (2008)	Identify self-care processes desired by pt with multimorbidity with competing demands	Semi-structured, qualitative interviews	26 community-dwelling men and women aged 65-84, with at least DM, depression and osteoarthritis enrolled in not-for-profit HMO	Patients desired a single point of contact for care coordination and care that responds to fluctuating needs of patients.
Corser and Donije (2011)	Evaluate the self-management and primary care office visit experiences of patient with at least four comorbid conditions	Exploratory qualitative, semi-structured focus group interviews, chart reviews	18 heavily comorbid participants recruited from a Midwestern academic-based family medicine clinic	Patients reported a decreased ability to self-manage due to physical limitations and a fear of their own mortality. Strategies used to assist with self-management include prioritizing symptoms, conditions, and behaviors, as well as making behavior changes to help manage their health. Having positive personal attitudes and beliefs are helpful. Information obtained from formal and informal sources can be helpful and/or frustrating, if contradictory or if overwhelming. Managing multiple conditions and medications, and keeping track of lab tests and results, is challenging. Interacting with different providers with differing personal beliefs and attitudes, some supportive, others non-supportive to personal self-management practices. Each patient identified limitations of their formal health care systems that impair their ability to self-manage.
El-Mullali (2006)	Identify factors that determine health beliefs and adherence to DM self-care. Also develop a theory of self-care for patients with comorbid schizophrenia/schizoaffective disorder and DM	Grounded theory—qualitative interviews and observation of respondent blood glucose monitoring techniques	11 respondents recruited from 5 sites of a regional community mental health center from a city in a South central state in the United States	Theoretical model—Evolving Self-Care for Schizophrenia and DM. Three components— 1. Mastering mental illness—acknowledging vulnerability to mental illness, maintaining stability; take meds as directed 2. Accommodating DM—personalize observations, acknowledge vulnerability to DM and apply acquired knowledge of mental illness to DM self-care—take medications so that you can perform adequate self-care 3. Striving for health—take responsibility, do your best to care for yourself and hope to maintain stabilization of mental illness so that you can perform self-care adequately

(continued)

**Table 1. (continued)**

Citation	Purpose/Aims	Study Design	Sample and Setting	Major Findings
Jerant, Friederich-Fitzwater, and Moore (2005)	Discuss the findings a series of focus groups regarding the CDSPMP to identify perceived barriers to self-management and access to support of services that assist with self-management. This will inform the development of HICH	Audio-taped focus group interviews	54 adults (home-reading) with MCC (as self-reported) recruited from University of California-Davis Primary Care Network	Barriers to self-management include depression, problems with weight control, difficulty exercising regularly, fatigue, poor communication with physicians, lack of support from family, pain, financial difficulty. Barriers to accessing assistance include lack of awareness, physical symptoms, transportation problems, cost, health insurance, interest in self-management services delivered in-home.
Mishra, Gioia, Childress, Barnes, and Webster (2011)	Identify patients' perspectives of the barriers and facilitators to taking multiple medications and managing self-care	Focus groups	50 adults, in 5 focus groups of 9 to 11 participants each, between February and March 2008, obtained from an urban outpatient clinic in Baltimore, MD. Eligible participants: 40 yrs or older, 2 or more chronic conditions and were prescribed 2 or more medications to be taken on a daily basis. Currently not pregnant	Barriers—personal contextual including family responsibilities, financial constraints or lifestyle preferences and health system related, including frustration when medications did not work as expected, cost, and frustration with media messages from pharmaceutical companies. Facilitators—self-discipline, sense of responsibility, faith, support from family and friends. The personal context of polypharmacy management revealed three main themes—reaching a personal limit for taking medication, lack of shared information and decision making, and taking fewer medications.
Morris, Sanders, Kennedy, and Rogers (2011)	Examine the shifting influences of self-management by patients with multiple long-term conditions	Longitudinal qualitative interviews	21 adults with one or more comorbid conditions (must have at least one of three conditions—IBS, COPD, or DM), recruited from 2 general practices in economically depressed Northwest of England	Patients reported fluctuating competing priorities, which can be aided by health care providers and difficulties with taking medications. Multiple conditions are not necessarily considered as increasing their burden but were better managed with assistance.
Noel, Fruel, Larne, and Pugh (2005)	Explore the collaborative care needs and preferences in primary care patients with multiple chronic illnesses.	Focus groups	60 patients with two or more chronic health conditions from eight PCP clinics from the U.S. VA health administration throughout the country	Problems include physical symptoms and how they affect their normal daily functioning both at home and work, difficulties with multiple medications and interacting with HCP. Preferences include the use of walk-in clinics, group visits, the use of technology such as automated telephones and email, and for monitoring and educational purposes, and team health care consisting of physicians, nurse practitioners, and other health care providers.

(continued)

**Table 1. (continued)**

Citation	Purpose/Aims	Study Design	Sample and Setting	Major Findings
Singleton (2002)	Identify facilitators and barriers to the ability of women home care workers with chronic illness to perform their own health care plan	Qualitative interviews	29 women with chronic illness, living in New York City who provide home care services to others, participated in 5 focus groups, ranging in age from 30 to more than 50 years old, living in New York City who provide home care services to others, participated in focus groups. Majority had more than one chronic illness	Barriers—high cost of health care benefits, loss of employment, stress and isolation in their work, heavy labor, poor working conditions, difficulty obtaining time for health care appointments, obstacles in their work environment including lack of telephone service, clients not permitting use of the refrigerator for personal food storage, lack of bathroom facilities Facilitators—when good communication exists between patient and provider, financial resources are adequate, when patient has time and ability to perform care, patients must be motivated, and has spiritual support.
Townsend, Wyke, and Hunt (2006)	Understand how patients manage MCC in the context of daily life	Qualitative interviews	23 patients in early 50's recruited from community health survey in Scotland from 2000-2003. Each had 4 or more chronic illnesses. Each was interviewed twice.	Patients manage their MCC based on their moral obligation to themselves. Sometimes the need to maintain social roles, identities, and normal lives, take precedence over managing symptoms. When this occurs, patients face moral dilemmas over how their choices affect their health.
Townsend (2011)	Explore the lived experience of multi-morbidity using Bourdieu's theory	Qualitative interviews and diary entry reviews	8 participants were sampled from a longitudinal survey of 23 participants in Scotland from 2000 to 2003. Inclusion criteria were that patients had 4 or more chronic illnesses.	Four themes related to Bourdieu's theory: 1. Habitus, capitals and the illbody—complex illness with debilitating symptoms over-whelming guide the flow of daily life 2. Relational positioning—how to act in daily living based on hierarchical structure 3. Illness and symbolic violence—putting on a brave face to avoid negative labeling 4. GP as dispenser of capitals—facilitates sick or disability pay and validates illness and benefits claims
Warren-Finlow and Prochaska (2008)	Examine the type of family assistance provided to older African American women regarding management of their chronic conditions	Qualitative interviews	12 AA women, 50 and older, recruited by cardiologists and nurses from an urban hospital serving low-income and minority population in Chicago. Dx with non-obstructive CAD via cardiac cath, had not had MI or invasive surgical procedure. Additional chronic illness included HTN, arthritis, obesity, GERD, asthma, apnea, and DM. Participants were taking between 4-13 different medications.	Participants reported family members provide positive and negative support from living in multi-generational and interdependent family situations. Positive support included informational support among one another that can be used to make health comparisons and to evaluate their own heart health. Negative support can come from reinforcement of harmful lifestyle behavior.

(continued)



**Table 1. (continued)**

Citation	Purpose/Aims	Study Design	Sample and Setting	Major Findings
Whitson et al. (2011)	Examine how comorbidity impacts patients ability to undergo low vision rehabilitation and to develop a framework to help health care providers address comorbidities in the intervention (low vision rehab)	Qualitative interviews	98 participants from the Duke Eye Center in low vision rehabilitation program along with their companions Age 65 and above; September 2007 to March 2008	Five themes within the developed framework were identified related to the impact of comorbidity on low vision rehabilitation: 1. Good days, and bad days related to fluctuating health status may impact ability to attend appts 2. Communication barriers related to pt hearing and cognitive impairment, and providers communication (rapid speech and fast paced visits) 3. Overwhelmed—multiple provider appts, emotionally "giving up" 4. Delays—both from comorbidities that delayed vision rehabilitation and vision rehabilitation that postponed attention to comorbidities 5. Value of companion—companion described themselves as advocate, information support, and functional assistant (though no patients described specific instances of benefits of companion involvement)

Note: Pt = patient; DM = diabetes mellitus; HMO = health maintenance organization; CDSMP = Clinical Diabetes Self-Management Program; MCC = multiple chronic conditions; HOH = Honoring in on Health; IBS = irritable bowel syndrome; HCP = health care providers; appts = appointments; GP = general practitioner; AA = African American; CAD = coronary artery disease; MI = myocardial infarction; GERD = gastroesophageal reflux disease.

## **Barriers to Effective Management**

*Emotional impact.* The negative emotional impact of having MCC was reported in eight articles (Bayliss, Steiner, Fernald, Crane, & Main, 2003; Corser & Dontje, 2011; Jerant, Friederichs-Fitzwater, & Moore, 2005; Morris, Sanders, Kennedy, & Rogers, 2011; Noël, Frueh, Larme, & Pugh, 2005; Townsend, 2011; Warren-Findlow & Prohaska, 2008; Whitson et al., 2011). Specifically, depression (Jerant et al., 2005), fear (Corser & Dontje, 2011; Noël et al., 2005), and “a sense of giving up” (Whitson et al., 2011) were reported. Low self-efficacy and lack of control were described as barriers to management (Bayliss et al., 2003; Jerant et al., 2005; Morris et al., 2011). Problems controlling weight was described specifically as a result of a lack of control (Jerant et al., 2005).

*Complexity of management of multiple conditions.* Ten articles found that care management was complicated by the need to simultaneously manage MCC (Bayliss et al., 2003; Corser & Dontje, 2011; El-Mallakh, 2006; Jerant et al., 2005; Mishra, Gioia, Childress, Barnet, & Webster, 2011; Morris et al., 2011; Noël et al., 2005; Townsend, 2011; Townsend et al., 2006; Whitson et al., 2011). Examples included dealing with the escalating challenges of understanding a growing number of different clinical conditions while attempting to monitor combinations of different symptoms (Bayliss et al., 2003; Corser & Dontje, 2011; Morris et al., 2011; Townsend et al., 2006; Whitson et al., 2011), and reporting symptom and functional status changes to multiple providers from different specialties (Bayliss et al., 2003; Corser & Dontje, 2011; Jerant et al., 2005; Mishra et al., 2011; Noël et al., 2005; Townsend, 2011). In addition, patients

reported difficulty in accurately adhering to different medication administration and other care plans while recognizing when there is a need to prioritize one condition over another. Participants cited a lack of knowledge about their own health conditions as well as deficits by family and society in general about chronic conditions as barriers to selfcare (Bayliss et al., 2003).

*Physical limitations.* Seven articles from 11 studies reported physical limitations resulting from having MCC (Bayliss et al., 2003; Corser & Dontje, 2011; Jerant et al., 2005; Morris et al., 2011; Noël et al., 2005; Townsend, 2011; Whitson et al., 2011). Specific concerns were described as inability to exercise (Morris et al., 2011), pain, and fatigue (Jerant et al., 2005).

*Financial constraints.* Participants reported financial constraints as barriers to managing care in seven articles (Bayliss et al., 2003; Jerant et al., 2005; Mishra et al., 2011; Noël et al., 2005; Singleton, 2002; Townsend, 2011; Warren-Findlow & Prohaska, 2008), with three articles detailing a lack of health insurance and high cost of medications as significant barriers to care management (Jerant et al., 2005; Mishra et al., 2011; Singleton, 2002).

*Complexity of communication with health care providers.* Nine articles described participants' difficulty communicating with and having access to their personal health care providers (Bayliss, Edwards, Steiner, & Main, 2008; Bayliss et al., 2003; Corser & Dontje, 2011; Jerant et al., 2005; Mishra et al., 2011; Morris et al., 2011; Noël et al., 2005; Singleton, 2002; Whitson et al., 2011). Participants reported difficulty interacting with health care providers that included non-supportive attitudes toward the patient's care management beliefs and

abilities, contradictory health care management information from multiple providers (Corser & Dontje, 2011), inability to obtain information and management strategies across conditions, disagreement between patient and provider on the plan of care (Morris et al., 2011), physicians overlooking or ignoring concerns (Noël et al., 2005), and suspicion about physicians' motivation for prescribing medication because of the relationship their doctor has with pharmaceutical companies (Mishra et al., 2011). Patients with cognitive impairment and hearing loss reported further difficulty communicating with their health care providers when accommodations are not made for these specific comorbidities (Whitson et al., 2011). Two articles reported patient barriers due to inadequate communication between multiple providers (Corser & Dontje, 2011; Noël et al., 2005). Examples included disagreement or lack of coordination between providers regarding diagnosis, medications, and diagnostic testing.

*Inadequate family and social support.* Five articles described inappropriate or lack of family and social support as barriers to care management (Bayliss et al., 2003; Jerant et al., 2005; Noël et al., 2005; Townsend, 2011; Warren-Findlow & Prohaska, 2008). Townsend (2011) described an unwillingness of patients with MCC to discuss their deteriorated health with others in an attempt to maintain identity and avoid negative labeling. Warren-Findlow and Prohaska (2008) found that participants with MCC were reluctant to discuss their health with family members. They indicated that some family members were noted to impact care in ways that was helpful, such as assisting with transportation. Other times, family members were described as less helpful or interfering, such as

when the family member was financially unstable or discouraging to the patient's attempts to initiate or maintain healthy lifestyle choices.

*Logistical challenges.* Patients with MCC may be seen by multiple providers from different specialties. Scheduling and attending clinic visits as well as purchasing and using prescribed medications and other supplies represented a major logistical challenge. Seven articles identified barriers due to logistical problems (Bayliss et al., 2003; Corser & Dontje, 2011; Jerant et al., 2005; Morris et al., 2011; Singleton, 2002; Warren-Findlow & Prohaska, 2008; Whitson et al., 2011). Difficulties obtaining health care due to limitations of the health care system include the need to see multiple providers in multiple locations (Corser & Dontje, 2011), inability to interact with health care services (Morris et al., 2011), challenges to scheduling and coordinating medications (Bayliss et al., 2003) and inadequate transportation (Jerant et al., 2005; Warren-Findlow & Prohaska, 2008) were commonly mentioned. Lack of time due to commitments such as work and other health care appointments were listed as barriers (Singleton, 2002; Whitson et al., 2011). In addition, though participants in one study expressed interest in obtaining self-management services, many were unaware of resources that could help them (Jerant et al., 2005).

*Complexity of medication management.* Five articles reported on the complicated nature of taking medication for MCC (Bayliss et al., 2003; Corser & Dontje, 2011; Mishra et al., 2011; Morris et al., 2011; Noël et al., 2005). Lack of knowledge about medications, fear of combining medications, and complexity of medication regimens were reported as barriers to taking their medications

appropriately. Personal experience with negative side effects of medications, as well as the total burden of taking multiple medications at different times, was also identified as a barrier to medication adherence (Bayliss et al., 2003; Mishra et al., 2011).

*Lifestyle changes.* Five articles identified lifestyle changes that participants described as barriers to their ability to manage their conditions (Morris et al., 2011; Noël et al., 2005; Singleton, 2002; Townsend, 2011; Townsend et al., 2006). Symptoms due to illness affected participants' ability to work and work-related stress and poor working conditions negatively affected participants' health (Singleton, 2002). However, participants reported the importance of maintaining employment for financial stability, health insurance, and a sense of identity (Noël et al., 2005; Singleton, 2002; Townsend, 2011; Townsend et al., 2006).

Participants also reported that their conditions created a burden and inability to function routinely in their daily lives as individuals, as well as with family and friends (Morris et al., 2011; Townsend, 2011; Townsend et al., 2006). Managing multiple medications and isolation due to the physical challenges of maintaining familial and societal roles through pain and fatigue were found to disrupt daily living and care.

### **Facilitators to Effective Management**

*Personal strengths.* In five studies, participants identified several mental and emotional facilitators to their ability to manage their care (Bayliss et al., 2008; El-Mallakh, 2006; Mishra et al., 2011; Noël et al., 2005; Singleton, 2002). A commitment to self-discipline to achieve optimal health (El-Mallakh, 2006; Mishra

et al., 2011) and self-reliance (Noël et al., 2005; Singleton, 2002) was reported. Active participation in one's own health care decisions (Bayliss et al., 2008; Noël et al., 2005; Singleton, 2002) was identified as giving a sense of empowerment. Having faith in the ability to manage one's own health was noted as an important aspect of care (Mishra et al., 2011; Singleton, 2002).

*Informal support.* Facilitators to care were found to exist within family and social support systems in seven articles (Bayliss et al., 2008; Mishra et al., 2011; Noël et al., 2005; Singleton, 2002; Townsend et al., 2006; Warren- Findlow & Prohaska, 2008; Whitson et al., 2011). The support of family and social relationships (Mishra et al., 2011; Singleton, 2002; Townsend et al., 2006; Warren-Findlow & Prohaska, 2008; Whitson et al., 2011) were found to serve as motivators for many participants. Support included hands-on, financial, emotional, informational, and behavioral support, and conversely, participants reciprocated similar support to their family and friends (Warren-Findlow & Prohaska, 2008). Examples included reminders to take medication and avoidance of eating unhealthy foods.

*Individualized care education and knowledge.* Four articles in the review that identified facilitators within the health care system found that participants desired focused health education tailored to them as individuals (Mishra et al., 2011; Noël et al., 2005; Singleton, 2002; Townsend et al., 2006). In a survey conducted in a Veterans Affairs hospital, compared with those with single chronic health conditions, participants with MCC were more likely to respond that they “definitely” wanted to learn management skills (Noël et al., 2005). Participants

also found the Internet to be beneficial as a source for seeking additional information about their health care conditions (Noël et al., 2005).

*Health system support.* Three articles described facilitators in formal health care systems for patients with MCC (Bayliss et al., 2008; Noël et al., 2005; Singleton, 2002). Participants described the importance of access to an empathetic provider (Bayliss et al., 2008; Singleton, 2002), nurse practitioners, a health care “team” approach, and ability to use walk-in clinics when their personal providers were unavailable (Noël et al., 2005). Participants also reported the use of technology as a facilitator to communication between health care providers and participants (Noël et al., 2005). Automated telephone systems, standard phone calls, email, and faxes were mentioned as helpful to monitoring and for education.

## **Discussion**

Thirteen articles were found that identified barriers and facilitators encountered by patients diagnosed with MCC. Barriers were more common than facilitators. Patients reported nine categories of barriers to management, including financial constraints, logistical challenges, physical limitations, lifestyle changes, emotional impact, inadequate family and social support, and the complexity of managing multiple conditions, medications, and communicating with health care providers. Four categories of facilitators to management were found, including health system support, individualized care education and knowledge, informal support from family and social systems, and having personal mental and emotional strength.

Patients with MCC is not a new phenomenon. However, with the advent of evidence-based practice guidelines and quality performance metrics that focus on single disease conditions, there has been an increased focus on the issues surrounding managing patients with MCC. This is evidenced by the development of frameworks (USDHHS, 2010), policy reports (Bodenheimer & Berry-Millett, 2009) consensus conferences (Weiss, 2007; Working Group on Health Outcomes for Older Persons With MCC, 2012), and editorials (Dawes, 2010; Starfield, 2011; Tinetti, Fried, & Boyd, 2012) focused on MCC in recent years. As our review found, patients with MCC report seeing multiple providers in addition to their primary care provider. Seeing multiple providers increased the complexity of management, including medication management, coordinating advice across providers, and the logistical challenges of accessing care. As the number of patients with MCC continues to increase, the complexity of and need for care coordination will increase. Although not a panacea for all communication issues, use of an electronic integrated medical records system may facilitate communication and care coordination across providers.

The focus of this review was the patient's perception of managing MCC. A recent review summarized management practices from the perspective of the person living with a single illness (Schulman-Green et al., 2012). The review used similar inclusion criteria to our study, but focused on single disease conditions. Schulman-Green and colleagues identified three primary management processes: focusing on illness needs, activating resources, and living with chronic illness. Although the themes from our study are similar to

Schulman-Green et al., the complexity of applying management processes to multiple conditions presents particular challenges to patients with MCC. In particular, patients with MCC may have a range of severities among their multiple conditions. Thus, both the increase in the number of MCCs and their severity can create a compound effect not experienced by patients with only one chronic condition.

One theme identified across facilitators and barriers was formal (health system, communication with providers) and informal support for the patient. In particular, the role of family members has greatly expanded in the provision of care for patients with MCC. Families assist with medications, schedule medical appointments and transportation, perform or assist with complex treatment regimens, and monitor the patient's health status between medical appointments (Donelan et al., 2002). Thus, the health system and providers increasingly need to focus on the patient's informal support system to both assist the patient and better manage MCC.

Our review identified that some patients believe health care providers do not understand their personal health goals (Mishra et al., 2011; Morris et al., 2011; Noël et al., 2005). Optimal health care outcomes are not possible if patient goals for their own health are not incorporated into care plans. The ability to provide patient-centered care can be complicated for providers caring for individuals with MCC, particularly given the multiple and interacting barriers identified in this review. One solution to provide "whole person care" currently being implemented is the "medical neighborhood" (Greenberg, Barnett, Spinks,

Dudley, & Frolkis, 2014) and the patient-centered medical home (PCMH) approach. Evidence to date is mixed on the effectiveness of PCMH (Hochman et al., 2013; Nelson et al., 2014; Van Berckelaer et al., 2012; Werner, Duggan, Duey, Zhu, & Stuart, 2013), thus further work is needed to evaluate the effectiveness in supporting patients with MCC.

Certain limitations to this research should be mentioned. The methodological quality of the articles included in this review was not formally evaluated. Unlike quantitative research, there are no generally accepted criteria for evaluating study quality in qualitative studies (Mackey, 2012). The researchers reviewed all studies prior to inclusion to evaluate study quality, addressing issues such as recruitment of an appropriate size and composition of the sample, clearly identified and appropriate data collection and analysis methods, data saturation, and conclusions drawn from the data (Miles & Huberman, 1994). Comprehensive search strategies were used to identify potentially relevant articles. Due to the broad focus on barriers and facilitators, it is possible that permutations of the terms may have failed to capture all potential articles in the search.

There is a large body of research focused on management interventions for single conditions, for example, diabetes, and asthma, but it is not clear if, when, and how these interventions should be applied to patients with MCC. Future research should address both the appropriate combinations of existing interventions and development of new interventions, and care models for patients with MCC. Research is needed to identify appropriate outcomes and

performance measures for patients with MCC (USDHHS, 2010). Given the importance of medications in managing MCC, research should address optimal medication management and adherence strategies for patients with MCC. Finally, how and in what ways can electronic communication improve care for patients with MCC, including an interoperable electronic health record, patient portals, personal health records, and symptom tracking and monitoring.

The challenges faced by patients with MCC are numerous and health care providers must be able to assist them with their management tasks. Identification of the barriers and facilitators that prevent patients from obtaining optimal health is the initial step in developing interventions to assist them. The results of this review show that patients want to participate in their care, but require assistance from health care providers (Bayliss et al., 2008; El-Mallakh, 2006; Mishra et al., 2011; Noël et al., 2005; Singleton, 2002; Townsend et al., 2006). Existing research is limited in the numbers of studies that show the specific types of knowledge and skills necessary for patients with MCC. This study revealed the need for further assessment of patient's requirements for management of their MCC. Health care providers must understand these requirements to provide the most appropriate patient support.

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## Chapter III

### Design and Methods

Chapter III explains the research design and methods used in the study. The first section describes the research design, participants, setting, and recruitment process. The second section details data management and analysis, actions taken to protect human subjects, and limitations of the study.

#### **Design, Setting, Sample**

*Research Design.* A cross-sectional, descriptive design was used for this study. This design enabled the investigator to address two specific aims.

*Setting.* Callaway Physicians Clinic and Central Ozarks Medical Center, two primary care clinics located in rural, central Missouri.

*Sample.* Participants were adult patients 45 and older, with a diagnosis of type 2 diabetes. The researcher obtained only patient names and addresses that met inclusion criteria.

*Inclusion Criteria.* Adult patients age 45 and older, with a diagnosis of type 2 diabetes were eligible for participation.

*Exclusion Criteria.* Patients under the age of 45, and all patients with type 1 diabetes were excluded. Additionally, non-English-speaking adults were excluded.

## **Procedures**

**Recruitment.** Potential participants received a mailed letter from their physician, indicating that the PI would be sending them a packet, asking for their participation in the study (see Appendix 2). Contact information for the researcher was included in the letter for individuals who wished to decline participation. One week later, a mailed packet was sent. The packet included a cover letter explaining the purpose of the survey (see Appendix 3), the survey with an assigned identification number to minimize identifying information, and a self-addressed, stamped envelope to return the survey. A monetary incentive of \$5 was also included in the packet. Monetary incentives up to \$5 in mailed surveys have been shown to have a positive impact on response rates (Edwards, Cooper, Roberts, & Frost, 2005). The cover letter also informed the potential participants that they would be entered into a drawing for a \$100 Visa gift card upon return of the completed survey. A drawing was held for two gift cards (one for a participant from each clinic). Potential participants were instructed to use the enclosed self-addressed, stamped envelope provided in the mailed packet to return the questionnaire. The University of Missouri address was pre-printed in the mailing address and return address locations on the envelope to discourage the subject's ability to place their own return address on the envelope. Participants indicated their informed consent to participate in the study by returning the questionnaire.

One month following the initial mailing, a follow-up letter (see Appendix 4) and duplicate survey were sent to those who did not respond to the first survey. A second monetary incentive was not included in the follow-up packet.

Recruitment and data collection began after permission was granted from the physician directors of the primary care clinics to obtain patient contact lists and following approval from the dissertation committee and Health Sciences Institutional Review Board, Project Number 2004457. Data collection continued until no more surveys were returned; a total of nine weeks.

## **Data Collection**

**Instrument.** Data were collected using the Compliance with Annual Diabetic Eye Exams Survey (CADEES) (Sheppler, Lambert, Gardiner, Becker, & Mansberger, 2014). Development of the CADEES instrument was based upon the Health Belief Model (HBM) (Rosenstock, 1974; Rosenstock, Strecher, & Becker, 1988). The HBM framework has been used extensively to explain, predict, and influence compliance with numerous preventive health care behaviors. The HBM is based upon two characteristics of an individual's stance on their health and health behaviors: perceived threat and behavioral evaluation (Abraham & Sheeran, 2007). Explicitly, the HBM theorizes that health behavior is based on six constructs: 1) *perceived susceptibility* of contracting a health concern and 2) *perceived severity* of the effects of the health concern, 3) *perceived benefit* of taking an action to prevent or reduce the effects of a health concern must outweigh 4) *perceived barriers* to taking that action, 5) *a cue to*

*action*, initiating the decision-making process (Janz & Becker, 1984), and 6) *self-efficacy* must exist to take an action (Rosenstock et al., 1988).

The survey includes 61 questions including 17 clinical and demographic questions with 1 open-ended question, and 43 health belief statements recorded with 5-point Likert scale responses scored from strongly disagree to strongly agree. The survey takes approximately 15-20 minutes to complete.

**Reliability and Validity of Original CADEES Instrument.** The dichotomous outcome variable of interest in this study was adherence or non-adherence to having had a DEE during the past year. Content analysis following initial development of this survey showed good content and predictive validity (Sheppler et al., 2014). No floor-ceiling effects (90% or more participants recording 1 or 5 on response scale) were identified. CADEES questions addressed 89% of participant's reasons for not obtaining annual DEE. Construct validity was assessed using principal components analysis. A three-component solution accounted for 32% of the variance. Components 1 and 2 contained a mixture of items from multiple constructs from the HBM; however, component 3 clearly identified items from the HBM barriers construct. Reliability analysis was assessed showing Cronbach's alpha for components 1, 2, and 3 were 0.88, 0.69, and 0.62, respectively. Acceptable score range from .70 to .95 (Bland & Altman, 1997). Predictive validity was assessed with significant adherence predictors identified as follows: years diagnosed with diabetes ( $P = 0.01$ ), hemoglobin A1C ( $P = 0.01$ ), there are many things that make it hard to get an eye examination

every year ( $P < 0.01$ ), and my insurance covers most of the cost of an eye examination ( $P = 0.02$ ).

Dr. Christina Sheppler, original member of the instrument development team, granted permission for the researcher to use the CADEES instrument (personal e-mail communication, March 26, 2015) (Appendix 5).

### **Human Participants Protection.**

*Potential Risks.* Safeguarding privacy of individuals minimized potential risks. Confidentiality of data was maintained by allowing no one other than the researcher, the doctoral committee members, and the biostatistician access to the raw data. Participation in the study was voluntary and subjects were able to discontinue participation at any point before completion of the survey without penalty or loss of benefit. If a patient declined to participate in the survey by contacting the researcher, he or she did not receive any additional study-related contact.

The potential for unforeseen risks to patients who participate in this research was minimal, compared to the benefit expected from the knowledge gained.

*Potential Benefits.* Participants may perceive that their eye health is of greater importance due to the subject of the research study, which may result in improved compliance with eye health guidelines. Participants may not benefit directly from the study, but the knowledge gained through the study is expected to contribute to future interventions to improve rates of DEE.

*Inclusion of Women, Children, and Minorities.* This study focused on the knowledge of adults, 45 and older, with a diagnosis of type 2 diabetes; therefore, individuals 44 and younger were not contacted for recruitment into the study. According to the Centers for Disease Control and Prevention (2015), the gender for this population is 49.9% female. Black, African American, Asian, Native Hawaiian and other Pacific Island, and Hispanic or Latino backgrounds, made up 19.4% of the population with the remaining 80.6% reporting as White. Because patients meeting inclusion criteria were contacted for recruitment, it was expected that the sample should closely resemble geographic population norms of women and minority patients. A substantial proportion of minority patients were not expected.

The original lists of potential participants were kept on a secure MU server and were only accessible by the investigator, the doctoral committee, and biostatistician. The potential participants were assigned an identification number, which was the only type of identifier on the mailed survey. The returned paper surveys were kept in a locked file cabinet in the investigator's home.

The original list of potential participants was destroyed after all data had been collected. The encoded data on the MU server, only accessible by the investigator, doctoral committee, and biostatistician, will be erased 7 years after completion of the study. The paper surveys will be stored for 7 years after the completion of the study, at which point they will be destroyed in a commercial paper shredder.

**Data Management.** Data were entered into an Excel spreadsheet, using double data entry. The two data entry spreadsheets were compared using SPSS software. Discrepancies were identified and corrected, using original survey data, to ensure accuracy of data in preparation for analysis.

**Data Analysis.** Basic descriptive statistics were used to summarize demographic data. The sample was divided into two groups based upon the four Rural-Urban Commuting Area (RUCA) codes determined by population. Participants residing in rural and small town areas (<10,000 residents) comprised one group, and participants living in micropolitan and metropolitan areas (10,000+ residents) comprised the second group (RUCA Rural Health Research Center, 1998, 2005). Participants were divided into rural and non-rural groups to evaluate differences in barriers as a component of Specific Aim 2.

Aim 1: Examine the validity and reliability of the CADEES instrument in adults with diabetes who live in rural areas.

Responses to the open-ended question in the CADEES instrument, “We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?” were used to assess content validity. Factor analysis was used to examine construct validity of the CADEES instrument. Logistic regression, with self-reported adherence as the outcome of interest, was used to determine predictive validity (RQ 1-1). Cronbach’s alpha was used to evaluate internal consistency as a measure of scale reliability. (RQ 1-2).

Aim 2: Identify the barriers to obtaining annual DEE experienced by adults with type 2 diabetes.

A two-sample independent t-test for means was used to compare the barriers described by the participants who had a DEE in the previous year to those who did not have a DEE (RQ 2-1). A two-sample independent t-test for means compared the barriers experienced by the 45-64-year age group to the 65+ year age group (RQ 2-2). A two-sample independent t-test for means compared barriers experienced by the rural to the non-rural group (RQ 2-3).

*Limitations.* One potential methodological limitation in this study is the use of a mailed survey. There is no control over the setting where the participant completes the survey, nor assurances that the participant completed the survey (i.e., a spouse may complete it for them without the participant's assistance). An additional limitation is the potential for participants to misunderstand and potentially record incorrect answers to the survey questions due to self-administration. Another limitation is that the small sample size may not allow for the results to be generalized to the larger population, particularly since the population was primarily Caucasian and Midwestern.

## Chapter IV Results

### **Psychometric Evaluation of the Compliance with Annual Diabetic Eye Exams Survey (CADEES)**

Diabetic retinopathy (DR) is the leading cause of newly diagnosed blindness in 20-74 year old Americans, and projections indicate that over six million people will have the condition by 2020 (American Academy of Ophthalmology, 2016). The medical costs of DR are already at \$500 million annually, and that number will continue to rise (Prevent Blindness America, 2007). Length of time with diabetes is the major risk factor, and aging adults are at the greatest risk for development of the disease (American Academy of Ophthalmology, 2016; Klein et al., 1984).

Annual dilated eye exams (DEE) are recommended for patients with diabetes (American Academy of Ophthalmology, 2016). Detection of DR at the earliest stages is key to prevention of severe vision loss (American Academy of Ophthalmology, 2016) and when treatment is most beneficial and cost effective (Javitt & Aiello, 1996). Since 1992, guidelines have been published to inform health care providers of the importance of educating their diabetic patients to receive annual dilated eye exams (DEE) when treatment is 90% effective in stopping severe vision loss (American College of Physicians, American Diabetes Association, and American Academy of Ophthalmology, 1992).

Significant resources have been directed toward the encouragement and facilitation of health care providers to increase rates of annual diabetic exams among their patients over the past 20 years (Centers for Medicare and Medicaid

Services, 2014; Cordero et al., 2004; Hillestad et al., 2005; Hunt et al., 1998; Jayawardena et al., 2007; Shekelle et al., 2006). Financial incentives to increase referral and improved electronic health record capabilities to prompt providers to direct patients to eye doctors have been implemented to achieve this goal. Despite these efforts, only half of patients are receiving their annual DEE (Garg & Davis, 2009; Lee et al., 2003; National Committee for Quality Assurance, 2013).

A better understanding of the factors that impact adherence to obtaining annual DEE by patients is needed if improvement is to be achieved. The researcher selected a rural adult population to explore the factors, using the Compliance with Annual Diabetic Eye Exams Survey (CADEES) (Sheppler et al., 2014) (appendix 1).<sup>1</sup> The CADEES was developed using the theoretical framework from the Health Belief Model (HBM) (Rosenstock, 1974; Rosenstock et al., 1988). The HBM has been used extensively in preventive health research to explain and predict behavior. The framework suggests that behavior is driven by six constructs: 1) *perceived susceptibility* of contracting a health concern and 2) *perceived severity* of the effects of the health concern, 3) *perceived benefit* of taking an action to prevent or reduce the effects of a health concern must outweigh 4) *perceived barriers* to taking that action, 5) *a cue to action*, initiating the decision-making process (Janz & Becker, 1984), and 6) *self-efficacy* must exist to take an action (Rosenstock et al., 1988).

### **Reliability and Validity of the Original CADEES Instrument**

The CADEES includes 61 questions, with 17 clinical and demographic questions, and a single open-ended question (Sheppler et al., 2014). A total of

43 health belief statements are answered with responses to a 5-point Likert scale, scored from strongly disagree to strongly agree. Participants should be able to complete the survey in 15-20 minutes.

The dichotomous outcome variable of interest in this study was adherence or non-adherence to having had a DEE during the past year. Content analysis following initial development of this survey showed good content and predictive validity (Sheppler et al., 2014). No floor-ceiling effects (90% or more participants recording 1 or 5 on response scale) were identified. CADEES questions addressed 89% of participant's reasons for not obtaining annual DEE. Construct validity was assessed using principal components analysis. A three-component solution accounted for 32% of the variance. Components 1 and 2 contained a mixture of items from multiple constructs from the HBM; however, component 3 clearly identified items from the HBM barriers construct. Reliability analysis was assessed showing Cronbach's alpha for components 1, 2, and 3 were 0.88, 0.69, and 0.62, respectively. Predictive validity was assessed with significant adherence predictors identified as follows: years diagnosed with diabetes ( $P = 0.01$ ), hemoglobin A1C ( $P = 0.01$ ), there are many things that make it hard to get an eye examination every year ( $P < 0.01$ ), and my insurance covers most of the cost of an eye examination ( $P = 0.02$ )

Dr. Christina Sheppler, from the original instrument development team, granted permission for the researcher to conduct this study using the CADEES instrument (personal e-mail communication, March 26, 2015) (appendix 5).

## Methods

The current study consisted of two aims: 1) Examine the validity and reliability of the revised CADEES instrument in adults with diabetes who live in rural areas; and 2) Identify the barriers to obtaining annual DEE experienced by adults with type 2 diabetes. The results of the second aim are reported in Chapter 5.

**Participants.** Adult patients, 45 years and older, with type 2 diabetes, were recruited from two rural clinics in central Missouri. Data collection began after permission was obtained from the physician directors of the clinics, and upon review and approval of the study protocol from the University of Missouri Health Sciences Institutional Review Board, Project Number 2004457.

**Data Analysis.** All statistical analysis was conducted using SPSS software, Version 23 (*IBM SPSS Statistics for Macintosh*, 2014). Basic descriptive statistics were used to summarize demographic data. The sample was divided into two groups based upon the four Rural-Urban Commuting Area (RUCA) codes determined by population. Participants residing in rural and small town areas (<10,000 residents) comprised one group, and participants living in micropolitan and metropolitan areas (10,000+ residents) comprised the second group (RUCA Rural Health Research Center, 1998, 2005).

Responses to the open-ended question in the CADEES instrument, “We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?” were used to assess content validity. Factor analysis was used to examine construct validity of the CADEES

instrument. Logistic regression, with self-reported adherence as the outcome of interest, was used to determine predictive validity. Cronbach's alpha was used to evaluate internal consistency as a measure of scale reliability.

## **Results**

A total of 351 potential participants were contacted for participation. A total of 142 surveys were returned. Participants with a type 1 diagnosis were excluded, leaving 122 surveys included in the final analysis, for a response rate of 35%.

**Content Validity.** An open-ended question with the CADEES instrument was used to assess content validity, the degree to which an instrument assesses the intended topic (Carmines & Zeller, 1979; Cicchetti, 1994; Polit & Beck, 2011). Content analysis of the CADEES was evaluated using the open-ended question, "We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?" A total of 51 participants provided a response. To evaluate the responses, each was placed into one of two categories, substantive (e.g., "Do not have the ability to pay") or non-substantive (e.g., "I think you pretty well covered them all"). The 47 substantive comments were then separated into 92 individual statements. (e.g., "No insurance, no transportation, hard to get off work" was divided into three individual statements). The individual statements were coded and placed into "reason" categories (Table 2).

**Table 2: Comments from participants**

	cost	transportation	insurance	does not understand importance or need/ guidelines/lack of education	time	other commitments/ work	does not care	afraid	no vision problems	accessibility	health issues/pain	dislikes eye exam/eye doctor	provider availability	self-efficacy
"We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?"	18,33	20	34	5,9,10,14,15,16,17,26,32	45,21	45,21	23,40	13	2,39	27,41	24	3,22	27,41	4,12,21,28,29
"Reason" addressed by question #46	X			X					X					
"No. Cost and need, if you can see well, why go?"														
"No. Cost and ability to travel and make appointments are all I can think of"	X	X												X
"My husband does not because he fears they will find something wrong"								X						
"I have friends that don't have eye exams because they can't afford them on retirement income. Once you retire you lose your eye insurance and medicare does not cover it"	X		X	X										
"Eye Dr. only sees you at certain times. Means you have to take off work. It's hard to get in to see the eye Dr"					X	X							X	
"Don't like people fooling with their eyes. Don't think it's necessary"				X								X		
"Don't care about their health, are just noncompliant"				X			X							
"Cost perhaps the biggest reason, accessibility being next, and perhaps no eye Dr. suggested, or no primary care Dr. either"	X			X						X				
"Are you in a wheel chair or need assistance walking. Do you have any limbs amputated due to diabetes."											X			

Results were independently reviewed by a second investigator (B.J.W.). The two investigators discussed the coding and consensus was reached on categorization for each reason. It was determined that items on the CADEES instrument covered all of the reasons written in the open-ended question.

**Construct Validity.** Construct validity is the degree to which the relationships identified within a study relate to each other as predicted by the theory from which the study is based (Carmines & Zeller, 1979). Construct validity was examined using factor analysis (FA). FA is a statistical process used to uncover and identify latent factors within the items of a data set, then group the items based on the common attributes of those factors into descriptive categories, or constructs (Yong & Pearce, 2013). In this study, FA was conducted on the 43 health belief statements (1-40, 43-45), from the CADEES instrument, to identify statements that support the presence of constructs from the HBM.

The six constructs of the HBM are:

- *susceptibility* – of contracting a health concern
- *severity* – of the effects of the health concern
- *benefit* – of taking an action to prevent or reduce the effects of a health concern, which, in turn, must outweigh the *barriers*
- *barriers* – to taking that action
- *cue to action* - initiating the decision-making process
- *self-efficacy* - must exist to take an action

## Requirements for Factor Analysis

**Linear relationship.** There must be a linear relationship between the items and descriptive categories (constructs) to calculate the relationships (Yong & Pearce, 2013). Continuous or ordinal level data, such as Likert scales, may be used as the scale represents responses on a continuum.

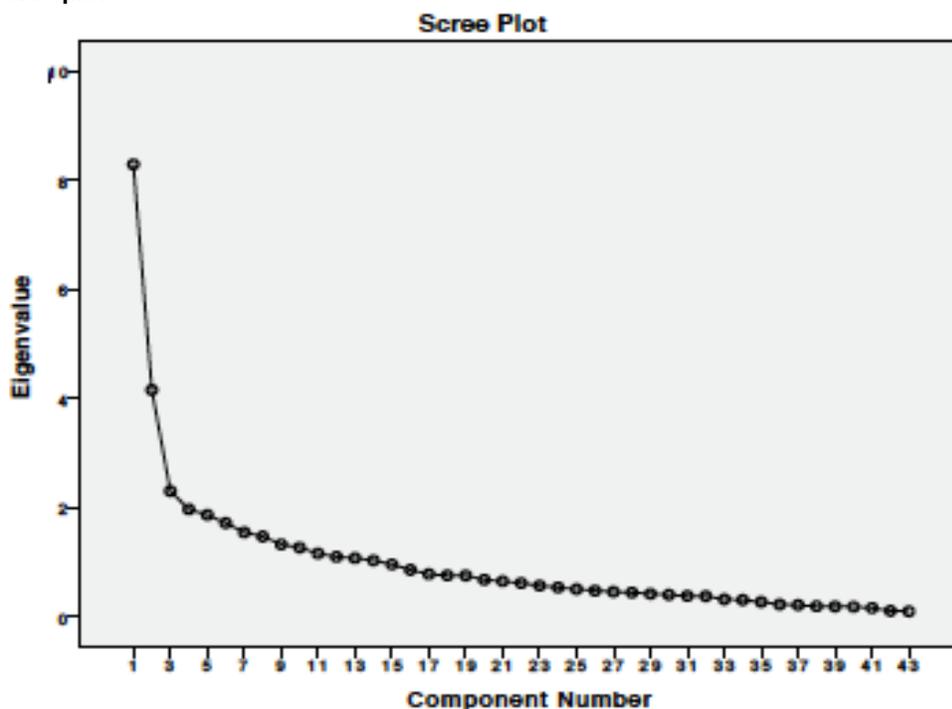
**Minimum sample size.** Various recommendations exist for determination of the minimum number of participants for factor analysis, including specification of minimum sample size, such as  $n=200$ , or subject-to-variable ratio (SVT), such as 3:1 (Garson, 2009; Hogarty, 2005). Other researchers suggest that a minimum number is dependent upon too many aspects of the study design to require a specific minimum sample size (MacCallum, Widaman, Zhang, & Hong, 1999). The sample size in this study was 122, with 43 items, for an SVT of 2.8:1. Some researchers may suggest that the sample size or SVT may be too small for factor analysis; however, this researcher believed that the analysis was important to conduct and evaluate in the context of the study.

Reverse coding of the negatively worded health belief items was necessary, prior to conducting factor analysis. Reverse coding inverted the Likert scale responses of the negatively worded items to match positively worded items. The purpose was to facilitate scoring on like scales. This resulted in the replacement of 17 of the 43 items, identified by the extension “\_r.” For example, “visit” after reverse coding, was labeled “visit\_r”.

FA was performed on the 43 health belief items using Principal Components Extraction and Varimax rotation. Kaiser-Meyer-Olkin (KMO) Measure of

Sampling Adequacy value (cut-off above .50) was .72, indicating that the data were adequate for EFA. Bartlett's test of sphericity, Chi-Square (903) = 1608.62,  $p < .001$  showed that patterned relationships were present between items. The number of significant factors extracted (Eigenvalues  $> 1$ ) was 14, accounting for 73.8% of the total variance. Review of the scree plot supported that the three to six component solutions should be retained for further analysis, which was of note, because the CADEES instrument was based on the HBM, consisting of six constructs. Using an Eigenvalue cut-off near 1 as a guide, in addition to prior research on adherence to DEE and the constructs of the HBM, it was determined that the 4-component solution provided the most useful explanation of the structure of the CADEES instrument.

Figure 2: Scree plot



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The 4-component solution accounted for a cumulative variance of 38.91.

Table 3 shows that all 122 cases were used in the analysis, with missing values replaced by the mean, to facilitate the use of all data possible.

**Table 3: Descriptives of 4-component solution**

<b>Descriptive Statistics</b>				
	Mean	Std. Deviation <sup>a</sup>	Analysis N <sup>a</sup>	Missing N
eyehlth	3.13	1.223	122	3
conf	4.23	1.094	122	2
prev	4.28	.964	122	0
others	3.47	1.178	122	2
iknow	3.84	.900	122	3
fx	4.21	.628	122	3
appt	4.42	.755	122	3
severe	4.23	.779	122	2
benefit	4.43	.677	122	2
mp	3.66	1.263	122	2
impt	4.45	.689	122	3
genhlth	2.76	1.171	122	3
exam	3.81	.823	122	4
bloodvs	4.02	.760	122	5
eyedr	3.18	1.106	122	3
fam	2.59	1.269	122	3
eyeprb	4.17	.660	122	3
bldsg	3.61	.936	122	4

**Descriptive Statistics**

	Mean	Std. Deviation <sup>a</sup>	Analysis N <sup>a</sup>	Missing N
save	4.13	.691	122	3
covers	3.32	1.360	122	3
prevent	3.83	.816	122	2
blind	3.89	.801	122	1
mprb	3.31	1.172	122	1
iwant	4.35	.650	122	3
remind	3.90	.975	122	23
happy	4.13	.830	122	25
deechg_r	2.3504	.97333	122	5
plsnt_r	3.5250	1.19200	122	2
trbl_r	3.2562	1.33317	122	1
deprs_r	3.3388	1.42326	122	1
mysight_r	3.1500	1.08063	122	2
idont_r	4.4576	.63823	122	4
ctrl_r	2.9750	1.06377	122	2
cost_r	2.7731	1.17436	122	3
tx_r	3.6000	.88514	122	2
trvl_r	3.9076	1.09085	122	3
yr_r	3.5932	1.11516	122	4
dilate_r	2.9316	1.19729	122	5
unlike_r	4.0168	.84289	122	3
afford_r	3.3782	1.20599	122	3
iseek_r	3.7167	1.12949	122	2
prior_r	3.7500	1.15171	122	2
visit_r	3.9495	.80673	122	23

a. For each variable, missing values are replaced with the variable mean.

A second factor analysis was performed on the data, excluding cases listwise, and similar results were obtained. Table 4 shows the percentage of variance explained by each of the 4 components.

**Table 4: Total variance explained by 4-component solution, first six components shown**

Total Variance Explained									
Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	.302	19.307	19.307	.302	19.307	19.307	.517	15.155	15.155
2	.158	9.669	28.977	.158	9.669	28.977	.035	9.384	24.539
3	.303	5.356	34.332	.303	5.356	34.332	.295	7.663	32.202
4	.967	4.574	38.906	.967	4.574	38.906	.883	6.705	38.906
5	.866	4.339	43.245						
6	.715	3.987	47.232						

Extraction Method: Principal Component Analysis.

Table 5 shows the 33 items that loaded into the 4 components.

**Table 5: Rotated component matrix**

	Component			
	1	2	3	4
eyehlth		.697		
conf			.719	
prev			.509	
others	.403			
iknow			.600	
fx	.692			
severe	.651			
benefit	.764			
mp			.488	
impt	.767			
genhlth		.639		
exam			.568	
bloodvs	.406		.638	
eyeprb	.549			
bldsg		.442		
save	.655			
prevent	.420			
blind	.486			
mprb		-.620		
iwant	.737			
remind	.476			
happy	.455			
trbl_r		.656		

deprs_r		.581		
mysight_r		.689		
idont_r	.541			
<b>cost_r</b>				<b>.811</b>
<b>tx_r</b>				<b>.442</b>
<b>trvl_r</b>		.488		<b>.448</b>
<b>yr_r</b>				<b>.562</b>
<b>afford_r</b>				<b>.712</b>
prior_r	.560			
visit_r	.459			

Extraction Method: Principal Component Analysis.  
 Rotation Method: Varimax with Kaiser Normalization.  
 a. Rotation converged in 7 iterations.

Component one consisted of items from each of the six CADEES constructs, in addition to items that did not clearly fit into a particular construct, identified as “other.” Component two consisted of items from the susceptibility, self-efficacy, and barrier constructs, as well as the other category. Component three also consisted of items from the susceptibility, benefit, cue to action, and self-efficacy constructs. The fourth component distinctly showed a barriers construct, with five items identified to measure barriers to an individual’s ability to obtain an annual DEE. (See Table 6 for categorization of CADEES items into Health Beliefs constructs.)

- Eye exams cost too much
- There is no treatment for diabetic eye diseases
- It is hard for me to travel to an eye doctor
- There are many things that make it hard to get an eye exam every year
- I cannot afford an eye exam

**Table 6: Koch CADEES factors grouped by constructs**

<b>Variable Name</b>	<b>Question in Survey</b>	<b>Construct</b>
afford_r	I cannot afford an eye exam.	barrier
cost_r	Eye exams cost too much.	barrier
dilate_r	I do not like having my eyes dilated with eye drops that make my pupils large.	barrier
idont_r	I do not want to know if I have an eye disease.	barrier
plsnt_r	Having an eye exam is not pleasant.	barrier
prior_r	Getting an eye exam every year is not one of my top priorities.	barrier
trvl_r	It is hard for me to travel to an eye doctor.	barrier
tx_r	There is no treatment for diabetic eye diseases.	barrier
visit_r	Visiting the eye doctor takes too much time.	barrier
yr_r	There are many things that make it hard to get an eye exam every year.	barrier
covers	My insurance covers most of the cost of an eye exam.	benefit
exam	Diabetic eye disease can be seen with an eye exam.	benefit
impt	I think it is important to have an eye exam every year.	benefit
prev	Having an eye exam once a year can help me prevent losing my eyesight.	benefit
benefit	I would benefit from having an eye exam every year.	benefit or cue to action
iwant	I want to get an eye exam every year.	benefit or cue to action
eyedr	There are many eye doctors where I live.	benefit or other
happy	I am happy with the care I get from my eye doctor.	benefit or other
eyeprb	Eye exams can find many different kinds of eye problems.	benefit or susceptibility
save	Having a yearly eye exam will help me to save the eyesight I have now.	benefit or susceptibility or cue to action
mp	My medical provider (i.e., doctor, nurse, NP) talks to me about the importance of eye exams.	cue to action
remind	I receive a reminder from my eye doctor's office when it is time to schedule an exam.	cue to action
iseek_r	I only seek eye care when I am having trouble with my vision.	cue to action or barrier
deprs_r	Over the past 4 weeks I have felt blue, downhearted, or depressed.	other
genhlth	My overall general health is excellent.	other
trbl_r	I have trouble reading a book or newspaper, even if I use my glasses or contacts.	other
appt	I am confident I can keep a scheduled appointment with an eye doctor.	self-efficacy
bldsg	I am confident I can control my blood sugar.	self-efficacy
conf	I am confident in my ability to make an appointment for an eye exam.	self-efficacy
prevent	There are things I can do to prevent losing my vision from diabetes.	self-efficacy
fam	My family members or friends help me make doctor appointments.	self-efficacy
blind	Diabetic eye diseases often cause blindness.	severity or susceptibility
severe	Diabetes can cause severe eye problems.	severity or susceptibility
bloodvs	Diabetes can damage the blood vessels in the eye.	susceptibility

Variable Name	Question in Survey	Construct
deechg_r	Early diabetic eye disease usually causes changes in vision.	susceptibility
fx	Diabetes can result in a loss of visual function (e.g., difficulty reading, driving).	susceptibility
iknow	I know a lot about diabetes and the effect it can have on health.	susceptibility
mprb	I have medical problems from diabetes.	susceptibility
mysight_r	I think I will lose some or all of my eyesight because of diabetes.	susceptibility
others	I know someone who has lost some or all of his/her eyesight because of problems from diabetes.	susceptibility
unlike_r	People with diabetes are unlikely to get an eye disease.	susceptibility
ctrl_r	People who have good control of their diabetes are unlikely to have eye problems.	susceptibility or barrier
eyehlth	My eyes are healthy.	susceptibility or other

**Predictive Validity.** Predictive validity is the degree to which an instrument predicts or explains a behavior (Carmines & Zeller, 1979). Logistic regression is a method used to evaluate the relationship, and subsequently determine the likelihood that a set of the explanatory variables will influence an outcome of interest (Hosmer & Lemeshow, 2004). This method was used to evaluate the barrier statement items, rurality (rural or non-rural residential categorization) of the participants, and age, with self-reported adherence to obtaining annual DEE as the outcome of interest.

Assumptions must be met prior to conducting logistic regression (Menard, 2002).

1. The dependent variable must be dichotomous.
2. The independent variables must be either continuous or categorical.
3. The participant responses must be independent and exclusive of others.
4. A linear relationship must exist between the natural log of a continuous variable and the dependent variable. Using the natural log of the

continuous variable allows prediction or estimation of the relationship beyond the actual ends of the range, in this case, age 45 to 88 years. If multiple continuous variables were to exist within the model, collinearity can occur. Additional steps would then be taken and discussed; however, this requirement is beyond the scope of this study, as only one continuous variable was evaluated within logistic regression analysis.

The first three assumptions were determined to have been met prior to statistical analysis, with assumption four evaluated and met during analysis.

Evaluation of the logistic regression model process was based on (Table 7).

**Table 7: Logistic regression model evaluation**

<b>Consideration</b>	<b>Evaluation</b>
Significance of the individual explanatory variables (Peng, Lee, & Ingersoll, 2002)	Each of the seven variables was included based upon their clinical significance, not statistical significance.
Significance test of the individual explanatory variable tests (Peng et al., 2002)	Variables in the equation with higher significance are desirable ( $p < .05$ )
Significance of the inclusion or exclusion of the individual explanatory variables (Bewick, Cheek, & Ball, 2005)	Evaluation of the variables in the equation at stepwise elimination or addition, retaining variables with higher significance ( $p < .05$ )
Goodness-of-fit (Bewick et al., 2005; Peng et al., 2002; Polit & Beck, 2011)	1) The Hosmer-Lemeshow test for overall goodness of fit, compares the explanatory model to a hypothetical perfect or null model. A nonsignificant result is desired ( $p > .05$ ), demonstrating little difference between the explanatory model and a perfect model, indicating a good fit. 2) Nagelkerke R Square - does not directly measure goodness of fit, but gives a general estimation of the predictive ability of the explanatory variables; primarily beneficial when comparing one model to another.
Assessment and discussion of the relationship between the independent variables on the dependent variable in the final model (Bewick et al., 2005; Peng et al., 2002)	In this study, discussion of the probability of an adult patient obtaining annual DEE, based upon one unit of change in the independent variables in the final model.

Logistic regression was conducted to determine the effects of age, rurality, as well as the five barrier statements identified through factor analysis, a total of seven independent variables, on adherence to obtaining annual DEE for adult patients, the dependent variable (Table 8). Demographic variables were not included, as in the original study, as the barriers to adherence to annual DEE were the primary focus of the study. The model explained 26% (Nagelkerke R square = .257) of the variance in adherence, with 65% of the cases correctly

classified. One of the barrier statements, “there are many things that make it hard to get an eye exam every year” was a significant explanatory variable in the model.

**Table 8: Logistic regression final model  
Variables in the Equation**

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
								Lower	Upper
Step 1 <sup>a</sup>	cost_r	.217	.210	1.075		.300	1.243	.824	1.875
	tx_r	.513	.284	3.260		.071	1.670	.957	2.914
	yr_r	.632	.273	5.344		.021	1.882	1.101	3.216
	RUCA2(1)	.193	.526	.134		.714	1.213	.432	3.402
	age	.017	.025	.498		.480	1.017	.970	1.068
	Constant	-6.797	.955	12.089		.001	.001		

a. Variable(s) entered on step 1: cost\_r, tx\_r, yr\_r, RUCA2, age.

**Reliability.** Scale reliability as a measure of internal consistency (Bland & Altman, 1997; Tavakol & Dennick, 2011) was evaluated for each of the four components from the EFA. The 33 items had factor loadings of .4 or more.

Cronbach’s alpha was as following:

Component one = .85 (range .84 – .86)

Component two = .57 (range .43 – .75)

Component three = .74 (range .68 – .75)

Component four = .77 (range .68 – .78)

Item-total statistics for each component revealed that alpha levels would not increase significantly with individual item removal with one notable exception.

Component two, item “I have medical problems from diabetes,” showed that

Cronbach’s alpha would increase to .75 if deleted. Component two was

reevaluated with the item deleted, resulting in an increase in Cronbach's alpha as follows,

Component 2 = .75 (range .69 - .75).

A second FA was run with the item, "I have medical problems from diabetes" removed. No significant difference was found between the original and second EFA with regard to identification of additional constructs of the HBM, item placement within components, or significance of factor loadings.

## **Discussion**

The purpose of this study was to examine the validity and reliability of the CADEES instrument in adults with type 2 diabetes who live in rural areas. The findings will be used to inform the development of interventions to help patients improve adherence with obtaining their annual DEE. The results of the study suggest that the CADEES instrument has good content validity, good construct and predictive/explanatory validity, as demonstrated by identification of a strong barriers construct, in addition to good internal consistency as a measure of scale reliability. These findings were consistent with the results reported by original instrument developers (Sheppler et al., 2014)The results also support the evidence that the HBM is a valuable framework for identification of factors, particularly barriers, to adherence of annual DEE for rural patients.

Findings of the evaluation of the CADEES instrument were consistent with previously published results. Content analysis found that all of the reasons provided by participants in the open-ended question, "We are interested in why some people do not have yearly eye exams. Can you think of any reasons we

did not ask about in this survey?” were included in the instrument. The original developers of the instrument identified a few themes in their coding of responses that were not directly measured in the instrument, such as “procrastination” or “forgetting,” but this was not found in the current study.

Results from the EFA showing the presence of a strong barriers construct strongly predicting/explaining adherence was similar to those found in the analysis of the original instrument development. Items from the six HBM constructs were present in the first three components of the final solution, but the fourth component clearly identified the barriers construct, with five barriers items present. The items were,

- I cannot afford an eye examination
- eye exams cost too much
- it is hard for me to travel to an eye doctor
- there is no treatment for diabetic eye diseases
- there are many things that make it hard to get an eye exam every year

These findings were consistent with the results of the original study that identified the presence of a strong barriers construct. Further, in a review examining the usefulness of the HBM by Janz and Becker (1984), the barriers construct was the most highly predictive in studies promoting preventive health care behaviors. Additionally, in a review of the reasons patients do not seek recommended eye care among adults with diabetes, cost or lack of insurance and no transportation, were among the most commonly reported (Chou et al., 2013).

An interesting finding was that the barrier statement “there are many things that make it hard to get an eye exam every year” was significant for the current study as well as for the original CADEES developers. The statement is something of a “catch all” as opposed to most of the barriers statements from CADEES that ask about specific concerns, such as transportation, cost, or insurance coverage. The significance of this statement may be related to the participant’s inability to identify why they are unable to obtain an annual DEE. For example, Chou, et al, identified several specific barriers (no need, cost or lack of insurance, no eye doctor, no transportation, and could not get appointment), as reasons for nonadherence to recommended annual diabetes exams in their review from 2013; however, “other” was reported 21.5% of the time.

The statement, “there is no treatment for diabetic eye diseases,” was marginally statistically significant. This statement clearly reflects a participant’s lack of knowledge about the benefits of annual DEE and/or misconceptions. Previous research supports the need for more patient education as well as health care providers (Alexander, Miller, Cotch, & Janiszewski, 2008; Chou et al., 2014; Coon & Zulkowski, 2002).

Scale reliability, as a measure of internal consistency, was evaluated on each of the four components retained from the EFA. All but one of the scores was acceptable. The score was shown to increase to .75 (range .69 - .75) with the removal of item “I have medical problems from diabetes.” Recommendations for future use of the CADEES would benefit from the removal of this item.

**Limitations.** A limitation for this study was the sample size. Over-sampling was necessary to obtain the maximum number of willing participants in this limited population, particularly when face-to-face contact will not occur. The original number of requested names was 200 but the researcher was provided with contact information for 351. The opportunity to over-sample provided 122 usable surveys, a higher number than expected, allowing for the statistical analysis desired.

**Implications.** Results of examination of the CADEES were consistent with the original instrument developers' findings, showing good strength in validity and reliability, with strong support for the barriers construct. This study provides additional evidence that the CADEES is a valuable instrument that can be used by health care providers with their patients.

**Recommendations for Future Research.** Patients experience barriers to care as evidenced by the findings of this study and in the lack of increase in adherence to annual DEE over the past 20 years. Current methods to increase adherence, including continued education and financial incentives for health care providers, and mandated achievement of clinical quality benchmarks, have not brought about marked improvement. If patients are to experience a significant improvement, we must talk to them about their diabetic eye care. Further research using the CADEES is recommended with additional populations of patients to determine if similar or additional barriers to care are found.

## Chapter V

### Results – Barriers to Annual Dilated Eye Exams

Over four million people over the age of 20 are diagnosed with diabetic retinopathy (DR), the leading cause of newly diagnosed blindness in adult Americans, and it is projected that over six million people will have the condition by 2020 (American Academy of Ophthalmology, 2016). DR costs Americans over \$500 million annually, including prescription medications, and inpatient and outpatient services (Prevent Blindness America, 2007). It may be impossible to calculate the emotional and psychological cost to an individual with vision loss to a condition that is treatable. Length of time with diabetes is the major risk factor for development of DR, making aging adults most vulnerable to the incapacitating effects of the disease (American Academy of Ophthalmology, 2016; Klein et al., 1984).

Clinical trials show that treatment for DR is 90% effective in stopping severe loss of vision with early diagnosis (American Academy of Ophthalmology, 2016), and that treatment is cost effective (Javitt & Aiello, 1996). Unfortunately, efforts over the past 20 years to encourage patients to obtain their annual diabetic eye exams (DEE) have been ineffective. The 1989 National Health Interview Survey, with a sample of 84,572 participants, found only 49% of adult patients diagnosed with diabetes had received a DEE in the previous year (Brechner et al., 1993). More recent reports, including analysis of Medicare claims data from 2003, and a more recent analysis (National Committee for Quality Assurance, 2013), show that rates still remain around 50% (Garg &

Davis, 2009; Lee et al., 2003; National Committee for Quality Assurance, 2013).

Thus, almost half of patients are not receiving their annual DEE when diagnosis and treatment are most successful at preventing subsequent blindness (Brechtner et al., 1993; Garg & Davis, 2009; Lee et al., 2003; Moss et al., 1995; National Committee for Quality Assurance, 2013; Schoenfeld et al., 2001).

Since 1992, guidelines have been published that provide direction on appropriate referral of patients for DEE for patients with diabetes (American College of Physicians, American Diabetes Association, and American Academy of Ophthalmology, 1992). Updated in 1998 and now revised annually, the guidelines indicate that patients with diabetes should receive a DEE annually by either an ophthalmologist (MD) or an optometrist (OD) with advanced education in the detection of DR (American Academy of Ophthalmology, 2016; American Diabetes Association, 2016). Patients with type 2 diabetes should have their initial exam shortly after their diabetes diagnosis because, although the onset of DR is initially slow and progressively worsening, the diagnosis of type 2 diabetes may come many years after the onset of the damaging effects of the disease. Patients with type 1 diabetes may wait 5 years for their initial DEE, because this form of diabetes has a rapid onset and the date of diagnosis is known. Due to the slow and progressively worsening development of DR, many patients are unable to detect the gradual changes to their vision in the early stages, when treatment is most successful in preventing severe vision loss (American Academy of Ophthalmology, 2016).

For individuals living in rural areas with limited access or other barriers to health care, obtaining DEE may be particularly challenging. Patients living in rural areas experience decreased rates of preventive health care services in general compared with those living in urban areas (Khoong et al., 2014), including annual DEE (Chou et al., 2012). Greater distance to access health care is a known barrier for rural patients (Khoong et al., 2014), in addition to the same barriers urban patients experience, including high costs, lack of insurance, and lack of knowledge of the potential benefits of preventive health care services (Cook et al., 2007; Sloan et al., 2004).

Elderly adults face additional challenges beyond an increased prevalence for development of DR (American Academy of Ophthalmology, 2016). Functional limitations from diabetes and loss of vision from DR contribute to increased feelings of isolation, leaving the elderly more vulnerable to depression (Corriere et al., 2013). Visual loss leads to a higher risk of falls, and difficulty administering medication, including insulin. Decreased vision can lead to loss of driving privileges, which contributes to increased difficulty or inability to access health care appointments (Fenwick et al., 2012). Further research is needed, focused on the unique barriers for adult patients in rural areas, to inform the development of interventions to help patients obtain their annual DEE.

## **Purpose**

The purpose of this study was to examine the barriers to obtaining annual DEE experienced by adults with diabetes who live in rural areas. The rate of annual DEE has remained unchanged over the past two decades, when early

diagnosis and treatment of DR is most successful at preventing blindness (Brechner et al., 1993; Garg & Davis, 2009; Lee et al., 2003; Moss et al., 1995; National Committee for Quality Assurance, 2013; Schoenfeld et al., 2001). Little research has focused on the unique barriers to obtaining DEE experienced and described by patients, in particular adults living in rural areas. Findings from this study will inform the future development of interventions by health care providers to improve compliance with recommended guidelines for aging adult patients with diabetes residing in rural areas.

## **Methods**

Two aims were evaluated in this study: 1) Examine the validity and reliability of the CADEES instrument in adults with diabetes who live in rural areas; and 2) Identify the barriers to obtaining annual DEE experienced by adults with type 2 diabetes. The results of the first aim are reported in chapter 4.

**Participants.** Patients with type 2 diabetes, over the age of 44, were recruited from two primary care clinics in mid-Missouri. Data collection began after permission was granted by: 1) the physician directors of the two clinics, and 2) University of Missouri Health Sciences Institutional Review Board, Project Number 2004457, following approval of the study protocol.

**Instrument.** Data were collected using the Compliance with Annual Diabetic Eye Exams Survey (CADEES) (appendix 1).<sup>1</sup> Development of the CADEES instrument was based upon the Health Belief Model (HBM) (Rosenstock, 1974; Rosenstock et al., 1988). The HBM framework has been used extensively to explain, predict, and influence compliance with numerous

preventive health care behaviors. The HBM is based upon two characteristics of an individual's stance on their health and health behaviors: perceived threat and behavioral evaluation (Abraham & Sheeran, 2007). Explicitly, the HBM theorizes that health behavior is based on six constructs: 1) *perceived susceptibility* of contracting a health concern and 2) *perceived severity* of the effects of the health concern, 3) *perceived benefit* of taking an action to prevent or reduce the effects of a health concern must outweigh 4) *perceived barriers* to taking that action, 5) a *cue to action*, initiating the decision-making process (Janz & Becker, 1984), and 6) *self-efficacy* must exist to take an action (Rosenstock et al., 1988).

The survey includes 61 questions, including 17 clinical and demographic questions with 1 open-ended question, and 43 health belief statements recorded with 5-point Likert scale responses scored from strongly disagree to strongly agree. The survey takes approximately 15-20 minutes to complete.

One additional question was added to the CADEES for this study. Do you tell your family doctor about your dilated eye exams? This question was added to explore the information-sharing relationship between patients and their primary care physicians.

Dr. Christina Sheppler, from the original instrument development team, provided permission for the researcher to use the CADEES instrument for this study (personal e-mail communication, March 26, 2015) (Appendix 2).

**Data Analysis.** Analysis of the data was completed using SPSS software, Version 23 (*IBM SPSS Statistics for Macintosh*, 2014). The aim was to identify the barriers to obtaining annual DEE experienced by adults with type 2

diabetes. Demographic data was evaluated using basic descriptive statistics. The sample was separated into two groups based upon the four Rural-Urban Commuting Area (RUCA) codes. Participants residing in rural and small town areas (<10,000 residents) were placed into the “rural” group, and participants living in micropolitan and metropolitan areas (10,000+ residents) were placed into the “non-rural” group (RUCA Rural Health Research Center, 1998, 2005).

Two-sample independent t-test for means was used to compare the barriers described by the participants who had a DEE in the previous year within three subgroups. Differences in barriers were identified in the adherent compared to non-adherent groups, the 45-64-year age group compared to the 65+ year age group, and the rural compared to the non-rural group.

## **Results**

A paper survey packet was mailed with a \$5 incentive and a self-addressed stamped envelope was provided for return of the survey. The cover letter, including contact information for the researcher, also indicated that participants who returned their completed survey would be entered into a drawing for a \$100 Visa gift card. A total of 351 potential participants were contacted, with 142 surveys returned. A drawing was held for two gift cards (one for a participant from each clinic) and mailed to the winners with a congratulatory note, thanking them for their participation. At the end of data collection, and following initial analysis excluding participants reporting a type 1 diabetes diagnosis, a total of 122 usable surveys were included in the analysis.

Descriptive statistics were used to summarize demographic characteristics for all participants (Table 9). Only 35.2% (n=43) had obtained a DEE within the past year, although 91.8% (n=112) reported having health insurance coverage. Most had knowledge about what an A1C test measured (n=80; 65.6%), with the average length of time since their last A1C at 2.9 months. When asked to report whether or not participants had diabetes-related comorbidities, heart disease (n=105; 86.1%), high cholesterol (n=66; 54.1%), and problems with their feet (n=66; 54.1%), were indicated most often.

Mean age was 64 (SD: range 45-88), with females making up 52% of the sample. Among all participants, 79% (n=96) reported their race as white. Slightly more than half of participants reported being married (n=66; 54%). Most had obtained a high school diploma or GED (n=41; 33.6%), and a quarter of all participants (n=30; 24.6%) reported earning an income of less than \$15,000. Nearly 78%, lived in metropolitan or micropolitan areas, defined as an area with a population equal to or greater than 10,000 (RUCA, 2005) (Table 10).

Most of the participants (n=105; 86.1%) reported being able to complete the survey on their own, without the assistance of others. Responses to the question, "Do you tell your family doctor about your dilated eye exams?" found that only half (n=40; 51%) of participants told their physicians about having a DEE.

Survey responses to the question, "When were you diagnosed with diabetes?" did not provide results suitable for analysis. The question asked participants to indicate the number of months since diagnosis (if under one year),

or the number of years since their diagnosis. Only 60% (n=73) of participants provided a number for their response. Directions to provide a numeric response in the provided box were not clear to many participants; 5 participants marked “x” beside the months box, 43 participants marked “x” beside the years box, and 3 participants did not provide a response. Future research using the survey should revise the formatting to provide clear directions to participants regarding how to answer the question.

Several differences were noted between the adherent (participants who had obtained an annual DEE within the past year) and non-adherent (participants who had not obtained an annual DEE within the past year) groups. Nearly 91% of the adherent group was white (n=39) and they indicated that they tell their doctor about having a DEE (n=35; 81.4%). A statistically significant difference was found between the adherent and non-adherent groups regarding knowledge of their A1C results ( $p = .025$ ), with the adherent group possessing more knowledgeable about their A1C results (n=34; 79.1%). Unexpectedly, among participants who knew the results of their last A1C, the adherent group (7.1) reported an overall higher A1C than the non-adherent group (6.8). No statistically significant difference was found between the adherent versus non-adherent groups regarding relationship status, education, and income.

Table 9: Descriptive and demographic data

	<b>All Eligible Participants</b>	<b>Adherent<sup>a</sup></b>	<b>Non-adherent<sup>b</sup></b>
	<b>n=122 (100%)</b>	<b>n=43 (35%)</b>	<b>N=79 (65%)</b>
<b>Age, years, mean (SD)</b>	<b>64.3 (9.725)</b> range = 45-88	<b>66.2 (9.784)</b> range = 47-88	<b>63.33 (9.622)</b> range = 45-86
<b>Gender, female %</b>	<b>51.6</b>	<b>46.5</b>	<b>54.4</b>
<b>Rural (%) population &lt;10,000</b>	<b>22.1</b>	<b>20.8</b>	<b>22.8</b>
<b>Last Dilated Eye Exam, adherent, within past year %</b>	<b>35.2</b>	<b>100</b>	<b>0</b>
<b>Health insurance coverage, yes (%)</b>	<b>91.8</b>	<b>93</b>	<b>91.1</b>
<b>Race (%)</b>			
White	78.7	90.7	72.2
AA/Black	9	7	10.1
Am Indian or Alaska Native	2.5	0	3.8
Hispanic or Latino	1.6	2.3	1.3
No response	8.2	0	12.7
<b>Relationship status (%)</b>			
Married	54.1	58.1	51.9
Single	16.4	14	17.7
Divorced	12.3	14	11.4
Widowed	7.4	7	7.6
Separated	4.1	2.3	5.1
Domestic partnership	3.3	4.7	2.5
No response	2.5	0	3.8
<b>Education %</b>			
Primary school (grades 1-6)	1.6	2.3	1.3
Secondary school (grades 7-12)	21.3	16.3	24.1
High school graduate (diploma or GED)	33.6	30.2	35.4
Some college (1-4 yrs after high school)	26.2	30.2	24.1
College graduate (bachelor's degree)	3.3	2.3	3.8
Some post-graduate (1-3 years after college)	4.9	9.3	2.5
Post-graduate degree (master's degree)	6.6	9.3	5.1

	<b>All Eligible Participants</b>	<b>Adherent<sup>a</sup></b>	<b>Non-adherent<sup>b</sup></b>
or higher)			
No response	2.5	0	3.8
<b>Income %</b>			
Less than \$15,000	24.6	23.3	25.3
\$15,000 to \$24,999	16.4	9.3	20.3
\$25,000 to \$34,999	15.6	20.9	12.7
\$35,000 to \$49,999	10.7	18.6	6.3
\$50,000 to \$74,999	13.1	16.3	11.4
\$75,000 to \$99,999	3.3	2.3	3.8
\$100,000 or more	2.5	2.3	2.5
No response	13.9	7	17.7
<b>Survey completion/self-completed %</b>	<b>86.1</b>	<b>90.7</b>	<b>83.5</b>
<b>Knowledge of A1C<sup>c,d</sup> yes %</b>	<b>65.6</b>	<b>79.1</b>	<b>58.2</b>
<b>Last A1C, reading, mean (SD)</b>	<b>6.9 (1.2)</b> range = 5 - 11	<b>7.1 (1.2)</b> range = 5 - 9.6	<b>6.8 (1.1)</b> range = 5.6 - 11
<b>Date of last A1C, in months, mean (SD)</b>	<b>2.9 (2.3)</b> range = 1 - 12	<b>2.3 (1.7)</b> range = 1-9	<b>3.3 (2.6)</b> range = 1-12
<b>Comorbidities %</b>			
Heart disease	86.1	90.7	83.5
History of stroke	8.2	0	12.7
High cholesterol	54.1	51.2	55.7
Kidney disease	9	14	6.3
Thyroid problems	19.7	25.6	16.5
Problems with feet	54.1	53.5	54.4
No response	2.5	0	3.8

<sup>a</sup> Adherent = participants who had obtained an annual DEE within the last 12 months

<sup>b</sup> Non-adherent = participants who had not obtained an annual DEE within the last 12 months

<sup>c</sup> A1C = blood test, indication of average blood glucose levels over past 3 months

<sup>d</sup> Difference between non-adherent and adherent groups statically significant (p = .025)

**Table 10: Rural urban commuting area coding for the 122 participants**

<b>RUCA Label</b>	<b>Study Group</b>	<b>Population</b>	<b>RUCA codes</b>	<b>Participants (n=122)</b>
Metropolitan	Non-rural	50,000	1, 2, 3	10
Micropolitan	Non-rural	10,000 - 49,999	4, 5	85
Small Town	Rural	2500 - 9999	7	1
Rural	Rural	0 - 2499	10, 10.5, 10.6	26

Examination of the CADEES instrument identified five items that were barriers to obtaining annual DEE experienced by adults with type 2 diabetes.

The barrier statements were:

1. I cannot afford an eye examination
2. Eye exams cost too much
3. It is hard for me to travel to an eye doctor
4. There is no treatment for diabetic eye diseases.
5. There are many things that make it hard to get an eye exam every year.

Two-sample, independent t-tests for means were used to assess differences in barriers, comparing participants who were adherent to obtaining annual DEE to the non-adherent group, participants in the 45-65 year age group to the 65+ year age group, and participants living in rural areas to non-rural areas. Levene's test for equality of variances was evaluated for each set of t-tests prior to determination of results.

**Adherent vs. Non-adherent.** Differences in barriers were determined for participants who had a DEE in the previous year, the adherent group, compared to those who did not have a DEE, the non-adherent group (Table 11). This study found no statistically significant difference between the reported barriers statements for the adherent and non-adherent groups; “it is hard for me to travel to an eye doctor” however, a statistically significant difference was found between the adherent and non-adherent groups on the following reported barrier statements; “I cannot afford an eye examination,” “eye exams cost too much,” “there is no treatment for diabetic eye diseases,” and “there are many things that make it hard to get an eye exam every year.”

**Table 11: Comparison of reported barriers between adherent vs. non-adherent groups**

<b>Barriers Construct Survey Item</b>	<b>Adherent Group N Mean (Standard Deviation)</b>	<b>Nonadherent Group N Mean (Standard Deviation)</b>	<b>t(df)</b>	<b>P Value</b>	<b>Confidence Interval 95%</b>
I cannot afford an eye exam	<b>N=42</b> 3.74 (1.06)	<b>N=77</b> 3.18 (1.26)	t(98) = 2.42	.012	[0.12, 0.99]
Eye exams cost too much	<b>N=41</b> 3.22 (1.19)	<b>N=78</b> 2.54 (1.13)	t(117) = 3.07	.003	[0.24, 1.12]
It is hard for me to travel to an eye doctor	<b>N=42</b> 4.12 (.97)	<b>N=77</b> 3.79 (1.16)	t(117) = 1.55	.123	[-0.09, 0.74]
There is no treatment for diabetic eye diseases	<b>N=42</b> 3.95 (.80)	<b>N=78</b> 3.41 (.89)	t(118) = 3.30	.001	[0.22, 0.87]
There are many things that make it hard to get an eye exam every year	<b>N=41</b> 4.12 (.81)	<b>N=77</b> 3.31 (1.18)	t(109) = 4.38	<.001	[0.44, 1.18]

**Age Differences.** Differences in barriers were determined for participants with type 2 diabetes age 45-64 compared to those 65+ years old (Table 12). This study found no statistically significant difference between the reported barriers statements; “eye exams cost too much,” “it is hard for me to travel to an eye doctor,” and “there is no treatment for diabetic eye diseases.” A statistically significant difference was found for the following reported barrier statement; “there are many things that make it hard to get an eye exam every year.” The following statement was marginally statistically significant; “I cannot afford an eye examination.”

**Table 12: Comparison of reported barriers between 45-64 year age group and 65+ age group**

<b>Barriers Construct Survey Item</b>	<b>45-64 Year Age Group</b> N Mean (Standard Deviation)	<b>65+ Age Group</b> N Mean (Standard Deviation)	<b>t(df)</b>	<b>P Value</b>	<b>Confidence Interval 95%</b>
I cannot afford an eye examination	<b>N=53</b> 3.13 (1.26)	<b>N=62</b> 3.58 (1.81)	t(113) = 1.97	.051	[-0.00, 0.90]
Eye exams cost too much	<b>N=53</b> 2.62 (1.21)	<b>N=61</b> 2.89 (1.19)	t(112) = 1.17	.245	[-0.18, 0.71]
It is hard for me to travel to an eye doctor	<b>N=53</b> 3.85 (1.03)	<b>N=61</b> 3.93 (1.17)	t(112) = .41	.681	[-0.33, 0.50]
There is no treatment for diabetic eye diseases	<b>N=53</b> 3.47 (.87)	<b>N=62</b> 3.68 (.92)	t(113) = 1.23	.222	[-0.13, 0.54]
There are many things that make it hard to get an eye exam every year	<b>N=52</b> 3.33 (1.18)	<b>N=61</b> 3.82 (1.03)	t(102) = 2.35	.021	[0.08, 0.91]

**Rural vs Non-Rural Residence.** Differences in barriers were determined for participants living in rural compared to non-rural areas (Table 13). This study found no statistically significant difference between the reported barriers statements; “I cannot afford an eye examination,” “eye exams cost too much,” “it is hard for me to travel to an eye doctor,” “there is no treatment for diabetic eye diseases,” and “there are many things that make it hard to get an eye exam every year.”

**Table 13: Comparison of reported barriers between the rural group and non-rural group**

<b>Barriers Construct Survey Item</b>	<b>Rural Group</b> N Mean (Standard Deviation)	<b>Non-rural Group</b> N Mean (Standard Deviation)	<b>t(df)</b>	<b>P Value</b>	<b>Confidence Interval 95%</b>
I cannot afford an eye examination	<b>N=26</b> 3.23 (1.31)	<b>N=93</b> 3.42 (1.20)	$t(117) = .70$	.489	[-0.35, 0.73]
Eye exams cost too much	<b>N=26</b> 2.73 (1.19)	<b>N=93</b> 2.78 (1.20)	$t(117) = .21$	.838	[-0.47, 0.58]
It is hard for me to travel to an eye doctor	<b>N=26</b> 4.08 (.89)	<b>N=93</b> 3.86 (1.16)	$t(51) = -1.02$	.311	[-0.64, 0.21]
There is no treatment for diabetic eye diseases	<b>N=26</b> 3.46 (.95)	<b>N=94</b> 3.64 (.88)	$t(118) = .89$	.374	[-0.22, 0.57]
There are many things that make it hard to get an eye exam every year	<b>N=26</b> 3.65 (.98)	<b>N=92</b> 3.58 (1.18)	$t(48) = -.34$	.734	[-0.54, 0.38]

## Discussion

Differences were evaluated between the adherent and non-adherent groups, the 45-64 year age and 65+ age groups, and the rural and non-rural groups. More significant barriers were found between the adherent and non-adherent groups, with fewer found in the 45-64 year age group. No significant differences were found in the rural group compared to the non-rural group (See Table 14).

In the adherent-non-adherent group comparison, adherence to annual DEE was associated with four of the five barriers statements, with the most significant being, "there are many things that make it hard to get an eye exam every year" ( $p < .000$ ). The other statements identified cost, inability to afford an eye exam, and lack of knowledge about the benefits of annual DEE which are consistent with previous research on adherence (Chou et al., 2013).

Significant barriers between the 45-65 year age group and the 65+ age group included the statement, "there are many things that make it hard to get an eye exam every year," also found as a barrier in the non-adherent group. The barrier statement related to inability to afford an eye exam was a significant finding, as it was among the adherent and non-adherent groups.

An unexpected finding was that there were no significant barrier differences between the rural and non-rural groups, including barriers related to travel. In fact, this barrier was not identified as significant among any of the three groups. It is possible that the participants did not believe that travel was a barrier because both clinics were located in relatively rural areas of Missouri, although

greater distance to access health care is a barrier identified in previous research for rural patients (Khoong et al., 2014). Patients living in rural areas experience decreased rates of preventive health care services, in general, as compared to their urban counterparts.

**Table 14: Statistically significant barriers to obtaining annual DEE among groups**

<b>Barrier Statements</b>	<b>Adherent vs Non-adherent Group</b>	<b>45-64 year vs 65+ year Group</b>	<b>Rural vs Non-rural Group</b>
I cannot afford an eye examination	X	X (marginally significant)	
Eye exams cost too much	X		
It is hard for me to travel to an eye doctor			
There is no treatment for diabetic eye diseases	X		
There are many things that make it hard to get an eye exam every year	X	X	

Previous research has identified several categories of barriers and facilitators for patients managing multiple chronic conditions such as diabetes (Koch, Wakefield, & Wakefield, 2015) The barriers identified in the study reported here are consistent with the categories identified in that study, including financial constraints related to affordability and cost of eye exams, logistical challenges such as travel to eye doctors, and communication with health care providers related to inability to obtain important education about their health conditions. Although identification of facilitators was not a specific aim, knowledge about how to assist patients to obtain annual DEE may be gleaned from the findings. Two questions on the CADEES instrument provided insight into how additional education by health care providers can make a significant contribution to increasing rates of annual DEE.

Responses to the open-ended question, “We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?” provided unique information. Several of the individual comments indicated misconceptions about barriers to DEE. The majority of responses pertained to cost and affordability; however, cost for an eye exam for glasses was often listed as the barrier to an annual DEE. This finding shows that some patients may not understand the difference between an eye exam for refractive error, corrected with glasses and often paid for with a vision benefit, compared to an annual DEE, which is a covered benefit under medical insurance.

The other question that may provide insight, “Do you tell your family doctor about your dilated eye exams?” was added to the CADEES in this study. The majority of the adherent group (81.4%) indicated that they tell their doctor about their DEE, with only half (50.7) of the non-adherent group telling their doctor. It is possible that if providers ask their patients about their DEE, it can provide an opportunity to educate the patient on the benefits, which may facilitate annual DEE.

**Limitations.** One potential methodological limitation in this study is the use of a mailed survey. There is no control over the setting where the participant completes the survey, nor assurances that the participant completed the survey (i.e., a spouse may complete it for them without the participant’s assistance). An additional limitation is the potential for participants to misunderstand and potentially record incorrect answers to the survey questions due to self-

administration. Another limitation is that the small sample size may not allow for the results to be generalized to the larger population, particularly since the population was primarily Caucasian and Midwestern.

**Implications.** In addition to examining significant barriers explicitly stated in the CADEES, responses to the open-ended question showed that some perceived barriers were actually misconceptions. Patients must be educated on the difference between vision insurance benefits for eyeglasses, and health insurance benefits that cover eye examinations for diabetes. Health care providers should inquire about patients' knowledge to clarify information and dispel misunderstandings about the two exams to facilitate annual DEE.

**Future research.** Future research should focus on identification of the unique barriers with new populations of patients. Unexpectedly, travel for rural patients was not a significant barrier in this study. Different populations of patients may experience barriers that have not been unidentified. Use of the CADEES instrument can help health care providers focus their communication to identify barriers, clarify misconceptions, and educate their patients about the importance of annual DEE.

## Chapter VI

### Conclusions

The dual purpose of this study was to examine the validity and reliability of the CADEES instrument in adults with type 2 diabetes who live in rural areas, and to examine the barriers to obtaining annual DEE experienced by adults with diabetes. The findings will be used to inform the development of interventions to help patients improve adherence with obtaining their annual DEE.

The first aim of the study was to examine the validity and reliability of the CADEES. The results of the study suggest that the CADEES instrument has good content validity, good construct and predictive/explanatory validity, as demonstrated by identification of a strong barriers construct, in addition to good internal consistency as a measure of scale reliability. Results of this study support the evidence that the HBM is a valuable framework for identification of factors, particularly barriers, to adherence of annual DEE for rural patients.

Findings of the validity and reliability evaluation of the CADEES instrument were consistent with previously published results. Content analysis found that all of the reasons provided by participants in the open-ended question, “We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?” were included in the instrument. The original developers of the instrument identified a few themes in their coding of responses that were not directly measured in the instrument, such as “procrastination” or “forgetting,” but this was not found in the current study.

Results from the EFA showing the presence of a strong barriers construct strongly predicting/explaining adherence, were similar to those found in the analysis of the original instrument development. Items from the six HBM constructs were present in the first three components of the final solution, but the fourth component clearly identified the barriers construct, with five barrier items present. The items were,

- I cannot afford an eye examination
- eye exams cost too much
- it is hard for me to travel to an eye doctor
- there is no treatment for diabetic eye diseases
- there are many things that make it hard to get an eye exam every year

These findings were consistent with the results of the original study that identified the presence of a strong barriers construct. Further, in a review examining the usefulness of the HBM by Janz and Becker (1984), the barriers construct was the most highly predictive in studies promoting preventive health care behaviors. Additionally, in a review of the reasons patients do not seek recommended eye care among adults with diabetes, cost or lack of insurance and no transportation, were among the most commonly reported (Chou et al., 2013).

An interesting finding was that the barrier statement “there are many things that make it hard to get an eye exam every year” was significant for the current study as well as for the original CADEES developers. The statement is something of a “catch all” as opposed to most of the barriers statements from CADEES that ask about specific concerns, such as transportation, cost, or

insurance coverage. The significance of this statement may be related to the participant's inability to identify why they are unable to obtain an annual DEE. For example, Chou, et al, identified several specific barriers (no need, cost or lack of insurance, no eye doctor, no transportation, and could not get appointment), as reasons for non-adherence to recommended annual diabetes exams in their review from 2013; however, "other" was reported 21.5% of the time.

The statement, "there is no treatment for diabetic eye diseases," was marginally statistically significant. This statement clearly reflects a participant's lack of knowledge about the benefits of annual DEE and/or misconceptions. Previous research supports the need for more patient education as well as health care providers (Alexander et al., 2008; Chou et al., 2014; Coon & Zulkowski, 2002).

Scale reliability as a measure of internal consistency, was evaluated on each of the four components retained from the EFA. All but one of the scores were acceptable, with Cronbach's alpha values ranging from .74 to .85 (Bland & Altman, 1997; Tavakol & Dennick, 2011). The fourth score was shown to increase from .57 to .75 (range .69 - .75). with the removal of item "I have medical problems from diabetes." Recommendations for future use of the CADEES would benefit from the removal of this item.

The second aim of this study was to identify the barriers to obtaining annual DEE experienced by adults with type 2 diabetes. Differences were evaluated between the adherent and non-adherent groups, the 45-64 year age

and 65+ age groups, and the rural and non-rural groups. More significant barriers were found between the adherent and non-adherent groups, with fewer found in the 45-64 year age group. No significant differences were found in the rural group compared to the non-rural group (Table 14).

In the adherent-non-adherent group comparison, adherence to annual DEE was associated with four of the five barriers statements, with the most significant being, "there are many things that make it hard to get an eye exam every year" ( $p < .001$ ). The other statements identified cost, inability to afford an eye exam, and lack of knowledge about the benefits of annual DEE, which are consistent with previous research on adherence (Chou et al., 2013).

Significant barriers between the 45-65-year age group and the 65+ age group included the statement, "there are many things that make it hard to get an eye exam every year," also found as a barrier in the non-adherent group. The barrier statement related to inability to afford an eye exam was a significant finding, as it was among the adherent and non-adherent groups.

An unexpected finding was that there were no significant barrier differences between the rural and non-rural groups, including barriers related to travel. In fact, this barrier was not identified as significant among any of the three groups. Greater distance to access health care is a barrier identified in previous research for rural patients (Khoong et al., 2014). Patients living in rural areas experience decreased rates of preventive health care services, in general, as compared to their urban counterparts.

Previous research has identified several categories of barriers and facilitators for patients managing multiple chronic conditions such as diabetes (Koch et al., 2015). The barriers identified in the study reported here are consistent with the categories identified in that study, including financial constraints related to affordability and cost of eye exams, logistical challenges such as travel to eye doctors, and communication with health care providers related to inability to obtain important education about their health conditions. Although identification of facilitators was not a specific aim, knowledge about how to assist patients to obtain annual DEE may be gleaned from the findings. Two questions on the CADEES instrument provided insight into how additional education by health care providers can make a significant contribution to increasing rates of annual DEE.

Responses to the open-ended question, “We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?” provided unique information. Although the response categories of the reasons were covered within the CADEES instrument, several of the individual comments indicated misconceptions about barriers to DEE. The majority of responses pertained to cost and affordability; however, cost for an eye exam for glasses was often listed as the barrier to an annual DEE. This finding shows that some patients may not understand the difference between an eye exam for refractive error, corrected with glasses and often paid for with a vision benefit, compared to an annual DEE, which is a covered benefit under medical insurance. Health care providers should inquire about patients’ knowledge to

clarify information and dispel misunderstandings about the two exams to facilitate annual DEE.

The other question that may provide insight, “Do you tell your family doctor about your dilated eye exams?” was added to the CADEES in this study. The majority of the adherent group (81.4%) indicated that they tell their doctor about their DEE, with only half (50.7) of the non-adherent group telling their doctor. It is possible that if providers ask their patients about their DEE, it can provide an opportunity to educate the patient on the benefits, which may facilitate annual DEE.

### **Strengths and Limitations**

A strength of this study was the method of data collection, mailed survey, to reach adult patients with diabetes living in rural Missouri. Obtaining participants for research can be challenging, especially in rural areas (Cudney, Craig, Nichols, & Weinert, 2004). Barriers to accessing rural participants for research can include: suspicion or resistance by the population to want to help an outsider; the need for the researcher to develop rural-sensitive recruiting materials; and the need for over-sampling. Each of these aspects was considered prior to attempts to recruit from the target population.

Concern about inadequate sampling was addressed by obtaining permission from the two physicians from the geographic region to contact their adult patients with diabetes. Potential participants were then contacted with a letter of introduction from the physicians with information about the research study and request for them to participate. Contact by the physician, the

monetary incentive included with the introductory letter, and opportunity to win a \$100 gift card, may have contributed to the high response rate.

Rural-sensitive recruitment materials, in particular, the CADEES, was reviewed and revised by the researcher and doctoral committee prior to distribution. The language was clarified, and layout of the content was altered to minimize the potential time participants would spend on completion. Additionally, a self-addressed stamped envelope was included for convenience and to encourage participation.

Over-sampling is beneficial when face-to-face contact will not occur. The need to obtain all willing participants in rural and often sparsely populated areas is important to obtain the most accurate results. The original number of requested names totaled 200, but the number of patients on the lists provided by the physicians allowed for contact of 351. The opportunity to over-sample definitively provided a higher number of usable surveys than expected.

A few limitations are associated with this study. The use of a mailed survey did not offer the researcher control over the setting, nor assurances that the participant provided the responses. An additional limitation was the potential for participants to misunderstand and potentially record incorrect answers to the survey questions due to self-administration. Further, the small sample size may not allow for the results to be generalized to the larger population, particularly since the population was primarily Caucasian and Midwestern.

## **Implications**

Several implications exist for this study. Examination of the validity and reliability of the CADEES was consistent with the original instrument developers' findings, showing good strength in validity and reliability. The barriers construct was clearly supported in the present study. The open-ended question showed that patients might misunderstand their perceived barriers. Health care providers need to help patients overcome their individual barriers by exploring them.

Results of examination of the barriers to obtaining annual DEE showed that transportation was a barrier, but not statistically significant. Transportation has been identified as a barrier in multiple studies (Chou et al., 2013; Khoong et al., 2014). This study has demonstrated that transportation may not be at the root of non-adherence.

## **Future research**

This study builds upon the body of knowledge regarding barriers to adherence to obtaining annual DEE, by examining adults living in rural areas. Interventions are needed to increase rates of adherence, and the CADEES has shown that it is a helpful tool that can be used by health care professionals to examine their own patient's unique barriers. This study has also shown that additional education can assist patients by educating them on the benefits of annual DEE. Further research using the CADEES in different populations of patients is recommended to determine if additional barriers are present that have not been identified.

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## Footnote

<sup>1</sup> The instrument was adapted with the addition of one yes/no question, “Do you tell your family doctor about your dilated eye exams?” and minimal layout changes for clarity.

# Appendix 1

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CADEES

Participant ID: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**Compliance with Annual Diabetic Eye Exams Survey (CADEES)**

**Please answer each question by checking or circling the correct answer.**

**A. Have you ever had an exam when the doctor put drops in your eyes that made your pupils large?  
If yes, when was your last exam like that?**

<input type="checkbox"/>	Never
<input type="checkbox"/>	Within the past year
<input type="checkbox"/>	Within the past 1 - 2 years
<input type="checkbox"/>	Within the past 2 - 5 years
<input type="checkbox"/>	More than 5 years ago
<input type="checkbox"/>	More than a year ago, but unsure of the exact time
<input type="checkbox"/>	Don't know

**Please read the following statements. For each statement, circle the number that best represents how you feel.**

	Strongly Disagree	Disagree	No Opinion/ Don't Know	Agree	Strongly Agree
1. My eyes are healthy.	1	2	3	4	5
2. Early diabetic eye disease usually causes changes in vision.	1	2	3	4	5
3. Having an eye exam is not pleasant.	1	2	3	4	5
4. I am confident in my ability to make an appointment for an eye exam.	1	2	3	4	5
5. Having an eye exam once a year can help me prevent losing my eyesight.	1	2	3	4	5
6. I have trouble reading a book or newspaper, even if I use my glasses or contacts.	1	2	3	4	5
7. Over the past 4 weeks I have felt blue, downhearted, or depressed.	1	2	3	4	5

	CADEES					
	Strongly Disagree	Disagree	No Opinion/ Don't Know	Agree	Strongly Agree	
8. I know someone who has lost some or all of his/her eyesight because of problems from diabetes.	1	2	3	4	5	
9. <b>I know a lot about diabetes and the effect it can have on health.</b>	1	2	3	4	5	
10. Diabetes can result in a loss of visual function (e.g., difficulty reading, driving).	1	2	3	4	5	
11. <b>I think I will lose some or all of my eyesight because of diabetes.</b>	1	2	3	4	5	
12. I am confident I can keep a scheduled appointment with an eye doctor.	1	2	3	4	5	
13. <b>I do not want to know if I have an eye disease.</b>	1	2	3	4	5	
14. People who have good control of their diabetes are unlikely to have eye problems.	1	2	3	4	5	
15. <b>Diabetes can cause severe eye problems.</b>	1	2	3	4	5	
16. I would benefit from having an eye exam every year.	1	2	3	4	5	
17. <b>My medical provider (i.e., doctor, nurse, nurse practitioner) talks to me about the importance of eye exams.</b>	1	2	3	4	5	6 no provider
18. Eye exams cost too much.	1	2	3	4	5	
19. <b>There is no treatment for diabetic eye diseases.</b>	1	2	3	4	5	
20. It is hard for me to travel to an eye doctor.	1	2	3	4	5	

	CADEES					
	Strongly Disagree	Disagree	No Opinion/ Don't Know	Agree	Strongly Agree	
21. There are many things that make it hard to get an eye exam every year.	1	2	3	4	5	
22. <b>I do not like having my eyes dilated with eye drops that make my pupils large.</b>	1	2	3	4	5	
23. I think it is important to have an eye exam every year.	1	2	3	4	5	
24. <b>My overall general health is excellent.</b>	1	2	3	4	5	
25. Diabetic eye disease can be seen with an eye exam.	1	2	3	4	5	
26. <b>Diabetes can damage the blood vessels in the eye.</b>	1	2	3	4	5	
27. There are many eye doctors where I live.	1	2	3	4	5	
28. <b>My family members or friends help me make doctor appointments.</b>	1	2	3	4	5	
29. Eye exams can find many different kinds of eye problems.	1	2	3	4	5	
30. <b>I am confident I can control my blood sugar.</b>	1	2	3	4	5	
31. Having a yearly eye exam will help me to save the eyesight I have now.	1	2	3	4	5	
32. <b>People with diabetes are unlikely to get an eye disease.</b>	1	2	3	4	5	
33. I cannot afford an eye exam.	1	2	3	4	5	
34. <b>My insurance covers most of the cost of an eye exam.</b>	1	2	3	4	5	6 no insurance
35. There are things I can do to prevent losing my vision from diabetes.	1	2	3	4	5	

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>No Opinion/ Don't Know</b>	<b>Agree</b>	<b>Strongly Agree</b>
36. Diabetic eye diseases often cause blindness.	1	2	3	4	5
37. I have medical problems from diabetes.	1	2	3	4	5
38. I want to get an eye exam every year.	1	2	3	4	5
39. I only seek eye care when I am having trouble with my vision.	1	2	3	4	5
40. Getting an eye exam every year is not one of my top priorities.	1	2	3	4	5

41. I have an eye doctor I can go to for diabetic eye exams.

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

42. Do you tell your family doctor about your dilated eye exams?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If YES

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>No Opinion/ Don't Know</b>	<b>Agree</b>	<b>Strongly Agree</b>
43. I receive a reminder from my eye doctor's office when it is time to schedule an exam.	1	2	3	4	5
44. I am happy with the care I get from my eye doctor.	1	2	3	4	5
45. Visiting the eye doctor takes too much time.	1	2	3	4	5

46. We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?

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B. Are you able to complete this survey by yourself, or did a family member or friend assist you?

Completed by myself
Family member or friend assisted

C. When were you diagnosed with diabetes?

Months (if under one year)
Years

D. Do you have Type I or Type II diabetes? Type I is often known as juvenile onset or insulin-dependent diabetes, and Type II is often known as adult onset diabetes that sometimes is insulin-dependent and sometimes is not.

Type I
Type II
Uncertain

E. Most doctors follow diabetes with a blood test that measures long-term blood sugar control. This test measures something called Hemoglobin A1c. Do you know what your Hemoglobin A1c level was the last time you were tested?

Yes
No, or Not Sure

If YES

F. What was your last A1c level and when was that test?

A1C level
Date (month/year)

**G. Do you have problems with any of the following?**

Yes/No	Condition	Comments
	Heart disease, high blood pressure, heart attack	
	Stroke	
	High cholesterol	
	Kidney disease	
	Thyroid problems	
	Problems with the nerves in your feet	

**H. Do you have health insurance?**

	Yes
	No

**I. Sex**

	Male
	Female

**J. How old were you on your last birthday?**

	Age
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**K. What is your relationship status?**

	Single
	Married
	Separated
	Divorced
	Widowed
	Domestic Partnership

**L. What is the highest level of education you have finished?**

	None
	Primary School (grades 1-6)
	Secondary School (grades 7-12)
	High School Graduate (diploma or GED)
	Some College (1-4 years after high school; trade school, associates degree)
	College Graduate (bachelor's degree)
	Some Post-Graduate (1-3 years after college)
	Post-Graduate Degree (master's degree or higher)

**M.** The next few questions will ask about your race and ethnicity.

Yes/No	Ethnicity
	American Indian or Alaskan Native
	Hispanic or Latino
	Asian
	African American or Black
	Pacific Islander or Native Hawaiian
	White
	Other (please list)

**N.** What is the **total combined annual income**, before taxes and deductions, of everyone who lives in your home?

	Yearly Annual Income
	Less than \$15,000
	\$15,000 to \$24,999
	\$25,000 to \$34,999
	\$35,000 to \$49,999
	\$50,000 to \$74,999
	\$75,000 to \$99,999
	\$100,000 or more

**Thank you for participating in this important research study!**  
**Gina Koch, MSN, APRN, FNP-BC**  
**573-579-7225**

## Appendix 2



Family Medicine-Callaway  
110 N. Hospital Drive  
Fulton, MD 21551  
PHONE: 573-642-5911  
FAX: 573-642-3015  
WWW: mhealth.org

March 1, 2016

First Name Last Name  
Address 1, Address 2  
City, State Zip

Dear First Name:

I am writing to let you know that you will be invited to participate in a research study titled "Barriers to Obtaining Annual Diabetic Eye Exams Among Adult Rural Patients." I am inviting you to participate in this study because you are receiving care at my office at University Physicians – Callaway Physicians Clinic, live in a rural area, and have diabetes.

The purpose of this study is to understand the barriers that prevent rural patients from obtaining their annual diabetic eye exams. The findings may help health care providers and policy makers to better serve patients with diabetes living in rural areas.

Participation in the study involves completion of a survey, which should take approximately 20 minutes of your time. I would like to invite you to participate in the study by completing the survey, which you can expect to receive in approximately one week.

Your participation in the project is voluntary and all information collected will be kept confidential.

If you have any questions, please contact Gina Koch, MSN, APRN, FNP-BC at 573-579-7225.

Thank you,

A handwritten signature in blue ink, appearing to read 'James Stevermer'.

James Stevermer, MD

## Appendix 3

# UNIVERSITY *of* MISSOURI

SINCLAIR SCHOOL OF NURSING

Date

Address

Dear {patient name}:

I am writing to invite you to participate in a research study titled "Barriers to Obtaining Annual Diabetic Eye Exams Among Adult Rural Patients." I am inviting you to participate in this study because you are receiving care at the University Physicians-Callaway Physicians Clinic, live in a rural area, and have type 2 diabetes.

The purpose of this study is to understand the barriers that prevent rural patients from obtaining their annual diabetic eye exams. The findings may help health care providers and policy makers to better serve patients with diabetes living in rural areas.

Participation in the study involves completion of the enclosed questionnaire, which should take approximately 15-20 minutes of your time. I would like to invite you to participate in the study by completing the survey. I have enclosed a self-addressed stamped envelope for return of the survey.

Your participation in the project is voluntary and all information collected will be kept confidential. Your name will not appear on any reported information. All data will be reported as grouped data.

There are no foreseeable risks for participating in the study. While you will not directly benefit from the study, the study findings may assist those who work with patients with diabetes to better serve those in need of care.

By returning a completed questionnaire in the provided envelope, you have indicated your informed consent to take part in this study.

Please accept this gift of \$5 for participating in this important study.

Additionally, for your participation in this study, upon return of your survey you will be entered in a drawing for a \$100 Visa gift card along with other patients from your area, who have been asked to participate, and respond.

If you have questions about this letter or survey, please contact Gina Koch, at 573-579-7225, or you may contact the University of Missouri, Institutional Review Board, at 573-882-3181, or [IRB@Missouri.edu](mailto:IRB@Missouri.edu)

Thank you in advance for your time and participation,



Gina Koch, MSN, APRN, FNP-BC  
PhD candidate in Nursing  
University of Missouri- Columbia



Sinclair School of Nursing  
*University of Missouri Health*

School of Nursing Building Columbia, MO 65211-4120

Phone: 800-437-4339 Fax: 573-884-4544 Web: [nursing.missouri.edu](http://nursing.missouri.edu)

## Appendix 4

# UNIVERSITY *of* MISSOURI

SINCLAIR SCHOOL OF NURSING

March 31, 2016

First Name Last Name  
Address 1, Address 2  
City, State Zip

Dear First Name:

I recently contacted you, asking you to participate in a study titled "Barriers to Obtaining Annual Diabetic Eye Exams Among Adult Rural Patients." If you have completed and returned the survey, thank you. If you have not completed and returned the survey, I wanted to provide you with another opportunity to assist in this important research. I have enclosed a second copy of the survey and self-addressed stamped envelope for your convenience.

You were invited to participate in this study because you are receiving care at the University Physicians-Callaway Physicians Clinic, live in a rural area, and have type 2 diabetes.

The purpose of this study is to understand the barriers that prevent rural patients from obtaining their annual diabetic eye exams. The findings may help health care providers and policy makers to better serve patients with diabetes living in rural areas. Participation in the study involves completion of the enclosed questionnaire, which should take approximately 15-20 minutes of your time. I would like to invite you to participate in the study by completing the survey. I have enclosed a self-addressed stamped envelope for return of the survey.

Your participation in the project is voluntary and all information collected will be kept confidential. Your name will not appear on any reported information. All data will be reported as grouped data.

There are no foreseeable risks for participating in the study. While you will not directly benefit from the study, the study findings may assist those who work with patients with diabetes to better serve those in need of care.

By returning the completed questionnaire in the provided envelope, you have indicated your informed consent to take part in this study.

As indicated in the first survey packet, you will be entered into a drawing for a \$100 Visa gift card along with other patients from your area upon completion and return of the survey.

If you have questions about this letter or survey, please contact Gina Koch, at 573-579-7225, or you may contact the University of Missouri, Institutional Review Board, at 573-882-3181, or [IRB@Missouri.edu](mailto:IRB@Missouri.edu)

Thank you in advance for your time and participation,



Gina Koch, MSN, APRN, FNP-BC  
PhD candidate in Nursing  
University of Missouri- Columbia



Sinclair School of Nursing  
*University of Missouri Health*

School of Nursing Building Columbia, MO 65211-4120  
Phone: 800-437-4339 Fax: 573-884-4544 Web: [nursing.missouri.edu](http://nursing.missouri.edu)

## Appendix 5

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**From:** Christina Sheppler <[christina\\_sheppler@gmail.com](mailto:christina_sheppler@gmail.com)>  
**Sent:** Thursday, March 26, 2015 12:29 AM  
**To:** Koch, Gina L. (MU-Student)  
**Cc:** Steve Mansberger  
**Subject:** Re: request to use the CADEES instrument

Hello Gina,

I'm glad to hear you are working on such an important project.

I consulted with Steve Mansberger (the PI for the project that focused on developing the CADEES tool), and you have our permission to use the CADEES for your dissertation research.

I am very interested in what the CADEES reveals for the population you are focusing on in your study, so please keep me informed of your findings. For future correspondence, please contact me at [christina\\_sheppler@gmail.com](mailto:christina_sheppler@gmail.com).

Best,  
Christina

On Fri, Mar 20, 2015 at 10:01 AM, Koch, Gina L. (MU-Student) <[glkbcf@mail.missouri.edu](mailto:glkbcf@mail.missouri.edu)> wrote:

Good morning Dr. Sheppler. My name is Gina Koch, and I am a PhD candidate in nursing at the University of Missouri, Columbia. I would like to ask your permission to use the CADEES instrument in my doctoral research.

Part of my background as an advanced practice registered nurse (FNP-BC) was in primary and urgent care in Southeast Missouri. My background as a registered nurse is in tertiary ophthalmology care/retinal surgery. Obtaining access to and uptake of diabetic eye exams in this rural area has always been difficult due to economics, distance, education, etc.

I would be delighted to have the opportunity to use CADEES in my dissertation work, of course, with my doctoral committee's oversight.

- Dr. Greg Alexander

- Dr. Bonnie Wakefield

- Dr. Lori Popejoy

- Dr. Lanis Hicks

Thank you in advance for your consideration of my request and happy to be post comprehensive exams :)

Gina Koch, MSN, APRN, FNP-BC

## Vita

Gina Koch was born in Cape Girardeau, MO, on September 12, 1968. After finishing high school in 1986, she went on to work as a retinal technician and surgical assistant, first for Anwar Shah, MD, in St. Louis, then for David Westrich, MD, in Cape Girardeau, MO. She received her BS in Nursing, at Southeast Missouri State University, in December 2002, and worked in critical and tertiary care settings. She became a family nurse practitioner after completing her MS in Nursing, at Southeast Missouri State University, in December 2008. After working in primary care and urgent care settings as a health care provider for several years, she started the doctoral program at the University of Missouri-Columbia, in 2012, and earned her PhD in Nursing, in December 2016.