

ACTIVITIES AND SUPPORT PROVIDED BY FAMILY CAREGIVERS OF PERSONS WITH  
TYPE 2 DIABETES

Lisa J. Scarton

Submitted to the faculty of the University Graduate School  
in partial fulfillment of the requirements  
for the degree  
Doctor of Philosophy  
in the School of Nursing  
Indiana University

April 2016

Accepted by the Graduate Faculty, Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

---

Tamilyn Bakas, PhD, Co-Chair

Doctoral Committee

---

Wendy Miller, PhD, Co-Chair

---

Susan M. McLennon, PhD

March 11, 2016

---

Lesa Huber, PhD

## DEDICATION

This dissertation is dedicated to my wonderful, courageous, and wise grandmother, Ruby Davis, my role model in what it means to love unconditionally. This work also is dedicated to my husband and best friend, Michael, who has supported and encouraged me throughout graduate school and through the ups and downs of life and who has provided me with the ever needed and constant technical assistance. I could not have made it through this journey without you. To my son, Zachary, thank you for your love, understanding, and patience during this program. I love you more than you will ever know. I am grateful to my sister, Ami, for believing in me when I doubted myself and for her continuous support through weekly telephone calls that left me laughing and ready to conquer the dissertation. To our parents—John and Alberta Comer and Chuck and Jeanne Scarton—thank you for your continuous support and encouragement over the years. Mom and Dad, thank you for your love and support throughout my life and for encouraging me in my many moments of crisis. Thank you for believing that I had the ability to reach my goals. Without your love and support this dissertation would not have been possible. Thank you to my many friends, especially to Lisa who was there for me throughout the program, who laughed with me and cried with me and provided an endless amount of support. And, finally, to my cohort who played such an important role along this journey as we mutually supported one another through challenges and victories and provided encouragement to one another when we felt we could no longer continue.

## ACKNOWLEDGMENTS

Without the support of many people this final project would not have been possible. First and foremost, I want to thank my mentor and PhD adviser, Tamilyn Bakas, for your guidance, expertise, and understanding throughout this program. Thank you for your faith in me and for encouraging and pushing me into becoming an independent thinker and researcher. Your mentorship provided me the courage to begin my next journey. I would also like to thank the members of my research committee, Wendy Miller, Susan McLennon, and Lesa Huber, for your invaluable insight, support, and expertise. Wendy, you were the first to encourage me to apply for the doctoral program, and you have been my role model and one of my strongest advocates. Susan, you have offered a wealth of expertise in the area of family caregivers, and you have continuously helped to propel me forward. Lesa, you have been a wonderful mentor in the area of gerontology, and you have generously shared your expertise throughout my program.

I want to thank Mary de Groot, from the Diabetes Translational Research Center at Indiana University for your mentorship, support, and advice not only in the area of diabetes but on how to navigate the world of academia. I would like to thank the American Indian Center of Indiana, specifically the director Doug Poe, for collaborating with me on grants and for your support in recruiting participants for the studies, but most importantly for your friendship. I also want to thank Margie Hull for sharing your knowledge and expertise in diabetes and working so diligently in recruitment of family caregiver participants for the studies.

I would also like to thank all the funding agencies that provided financial support to make this research possible. Research reported in this dissertation was supported in part by grants from Indiana Minority Health Coalition, the Jonas Center for Nursing Excellence, Indiana University School of Nursing, and the William and Doris Rodie Scholarship.

Lastly, I want to thank all the caregivers who participated in the studies and who were willing to share their knowledge and experiences in providing care to those you love. You are the true heroes of this dissertation.

Lisa J. Scarton

ACTIVITIES AND SUPPORT PROVIDED BY FAMILY CAREGIVERS OF PERSONS WITH  
TYPE 2 DIABETES

Type 2 diabetes, a chronic condition affecting millions, continues to rise in epidemic proportions. Type 2 diabetes, managed through lifestyle changes, affects the entire family. Family caregivers provide vital support to these individuals; however, little research has been conducted surrounding the perceived difficulty or ease of caregiver activity and supportive behaviors. The purpose of this dissertation was to develop and psychometrically test a scale that measures this difficulty or ease of activities and behaviors. This was accomplished through the compilation of three distinct manuscripts. First, an integrative review was conducted to identify what is known regarding needs and concerns of family caregivers of persons with type 2 diabetes; findings revealed a need for more research. Then, based on these recommendations, a qualitative study was conducted that explored the needs and concerns identified by 33 American Indian, African American, and White family caregivers. All these caregivers had similar concerns related to needing general diabetes information, providing support to the family member, and taking care of their own health. Study themes were used to develop items for a new instrument, the Diabetes Caregiver Activity and Support Scale (D-CASS) that was psychometrically tested with 101 American Indian, African American, and White family caregivers of persons with type 2 diabetes. This study used a cross-sectional, descriptive-correlational design and provided evidence of internal consistency reliability ( $\alpha = .82$ ) and two-week test-retest reliability (intraclass correlation coefficient = .70) for the D-CASS. Criterion-related validity was established using a single-item criterion measuring overall how easy or difficult it was for caregivers to provide care for their loved ones ( $r = .65, p < .01$ ). Unidimensionality was supported by factor analysis, with loadings ranging from .45 to .70, with 32% of the variance explained by the first factor (eigenvalue = 4.02). Model testing through a series of three hierarchical multiple regressions

guided by a conceptual model provided further evidence of construct validity for the D-CASS. This dissertation provided better understanding of needs and concerns of family caregivers of persons with type 2 diabetes and led to the development of a psychometrically sound diabetes-specific instrument for future research.

Tamilyn Bakas, PhD, Co-Chair

Wendy Miller, PhD, Co-Chair

TABLE OF CONTENTS

Chapter 1 ..... 1

    Background ..... 2

    Problem Statement ..... 4

    Specific Aims of the Dissertation..... 5

    Conceptual and Operational Definitions ..... 6

        Needs and Concerns..... 6

            Conceptual definition..... 6

            Operational definition ..... 6

    Caregiver Characteristics ..... 7

        Conceptual definition..... 7

        Operational definition ..... 7

    Care Recipient Characteristics ..... 7

        Conceptual definition..... 7

        Operational definition ..... 7

    Co-morbidities ..... 7

        Conceptual definition..... 7

        Operational definition ..... 8

    Optimism ..... 8

        Conceptual definition..... 8

        Operational definition ..... 8

    Caregiving Activities and Support Difficulty ..... 8

        Conceptual definition..... 8

        Operational definition ..... 9

Threat Appraisal .....	9
Conceptual definition.....	9
Operational definition.....	9
Depressive Symptoms.....	9
Conceptual definition.....	9
Operational definition.....	9
Life Changes.....	10
Conceptual definition.....	10
Operational definition.....	10
Unhealthy Days.....	10
Conceptual definition.....	10
Operational definition.....	11
Conceptual Model.....	11
Connection among the Three Manuscripts .....	13
Chapter 2.....	15
Chapter 2 Acknowledgements.....	15
Chapter 2 Abstract.....	16
Method and Search Strategy.....	18
Theoretical/Empirical Traditions.....	29
Results .....	29
Need for Information Related to Type 2 Diabetes.....	29
Dealing with Emotions and Behaviors of the Care Recipient .....	30
Providing Physical Care.....	31
Providing Instrumental Care.....	32
Dealing with One’s Own Personal Responses to Caregiving .....	32



Limitations.....	33
Summary .....	33
Chapter 3.....	36
Chapter 3 Acknowledgments .....	37
Chapter 3 Abstract.....	37
Design.....	40
Sample and Setting.....	40
Procedures .....	44
Data Analysis .....	44
Results .....	46
Information on Type 2 Diabetes: Needs and Concerns .....	47
Emotions and Behaviors: Needs and Concerns .....	48
Physical Care: Needs and Concerns .....	48
Instrumental Care: Needs and Concerns.....	49
Personal Responses to Caregiving: Needs and Concerns.....	50
Cultural Differences in Needs and Concerns.....	50
Discussion .....	51
Limitations.....	54
Implications for Practice.....	55
Implications for Future Research .....	55
Chapter 4.....	57
Chapter 4 Abstract.....	58
Conceptual Definitions.....	60
Conceptual Model .....	61
Background and Significance.....	61
Methods.....	63

Instrument Development.....	63
Content Validity.....	64
Psychometric Testing of the D-CASS .....	65
Design and Sample for Pilot Testing .....	65
Procedures.....	65
Instrumentation .....	67
Data Analysis.....	69
Internal consistency reliability .....	69
Test-retest reliability .....	69
Criterion-related validity.....	69
Construct validity.....	70
Results .....	70
Sample Characteristics.....	70
Measures .....	74
Item Analysis .....	74
Internal Consistency Reliability.....	78
Criterion-related Validity.....	78
Construct Validity Using Factor Analysis .....	78
Construct Validity Guided by a Conceptual Model.....	79
Discussion .....	83
Limitations.....	88
Conclusion.....	89
Chapter 5.....	90
Summary Chapter 2.....	91
Summary Chapter 3.....	92
Summary Chapter 4.....	93

Strengths.....	94
Limitations.....	95
Future Research.....	95
Conclusion.....	96
Appendix A Diabetes Caregiver Activity and Support Scale (D-CASS) .....	97
Appendix B Demographic Questions .....	98
Appendix C Telephone Interview Questionnaire Guide.....	101
Appendix D Institutional Review Board Exemption and Approval .....	102
References.....	108
Curriculum Vitae	

## LIST OF TABLES

Table 1 Needs and Concerns Framework .....	18
Table 2 Summary of Articles from Review .....	20
Table 3 Demographic Characteristics of Caregivers and Care Recipients .....	42
Table 4 Caregiver Needs and Concerns .....	45
Table 5 Sample Characteristics.....	72
Table 6 Descriptive Statistics for Measures.....	74
Table 7 Item Statistics and Factor Loadings for the Final D-CASS Scale .....	76
Table 8 Hierarchical Multiple Regression PHQ-8.....	80
Table 9 Hierarchical Multiple Regression BCOS.....	81
Table 10 Hierarchical Multiple Regression Unhealthy Days .....	82

## LIST OF FIGURES

Figure 1	The new D-CASS instrument operationalizes the activities and support that family caregivers provide.....	6
Figure 2	PRISMA diagrams the full search and screening process that underpinned the review .....	19
Figure 3	The bar chart displays the categories of needs and concerns of caregivers across cultures .....	47

## LIST OF ABBREVIATIONS

ACS	Appraisal of Caregiving Scale Threat Subscale
ADA	American Diabetes Association
BCOS	Bakas Caregiving Outcome Scale
CDC	Centers for Disease Control and Prevention
CVI	Content validity index
D-CASS	Diabetes Caregiver Activity and Support Scale
DFBC-II	Diabetes Family Behavior Checklist
ICC	Intra-class correlation
I-CVI	Content validity index of each item
LOT-R	Revised Life Orientation Test
MDQ	Multidimensional Diabetes Questionnaire
OCBS	Oberst Caregiving Burden Scale
PHQ	Patient Health Questionnaire

## Chapter 1

Diabetes is a serious disease affecting approximately 29.1 million people in the United States (American Diabetes Association [ADA], 2014). More than 90% of these individuals have type 2 diabetes (ADA, 2014). Type 2 diabetes is especially prevalent among racial and ethnic minorities including American Indians, African Americans, Asians, and Hispanics (ADA, 2014). American Indians are 2.2 times more likely to be diagnosed with type 2 diabetes than non-Hispanic Whites, giving them the highest prevalence rate among all racial and ethnic groups in the U.S. (ADA, 2014; O'Connell, Wilson, Manson, & Acton, 2012). Diabetes is the leading cause of complications, including stroke, heart disease, kidney disease, blindness, and lower-limb amputations (ADA, 2014). Additionally, those diagnosed with diabetes have twice the risk of death compared to those without diabetes (Centers for Disease Control and Prevention [CDC], 2014).

Type 2 diabetes is managed through lifestyle changes such as healthy meal plans, physical activity, weight loss, daily blood glucose monitoring, pharmacotherapy, and routine visits to a healthcare provider (Look AHEAD Research Group, 2007). Most lifestyle changes that are required to manage diabetes take place in the home environment and adherence to diabetes treatment is often challenging. Family caregivers play an important role in the management of diabetes and often provide necessary support to promote individuals' self-management of this disease (Strom & Egede, 2012; Trief, Himes, Orendorff, & Weinstock, 2001). Caregivers may perform activities such as assisting with medication management, preparing meals, reminding the care recipient to check his or her blood glucose levels, or driving the care recipient to appointments (Paddison, 2010; Sinclair, Armes, Randhawa, & Bayer, 2010). Care recipients who have other co-morbidities (e.g., stroke or heart disease) or diabetes-related complications (e.g., glaucoma, amputation, or kidney disease) may need additional care such as assistance with walking, dressing, eating, etc.

## **Background**

Although more research is needed in the area of family caregivers of persons with type 2 diabetes (Fisher et al., 1998; Rintala, Jaatinen, Paavilainen, & Astedt-Kurki, 2013; Scarton, Bakas, Miller, Poe, & Huber, 2014), some connections are being developed between family caregiver support and patients' health behaviors and their psychological well-being (Martire & Schultz, 2007). Two systematic reviews of persons with type 2 diabetes and their caregivers underscored the limited research that exists on caregivers (Rintala et al., 2013; Scarton, Bakas, Miller et al., 2014). Rintala and colleagues' systematic review revealed that only 13 of the 29 studies addressed the caregiver, with the majority of these focusing on the impact caregiver support had on diabetes self-management outcomes from the patient's perspective—e.g., improved A1C levels, weight loss (Rintala et al., 2013). A paucity of studies examines the perceived difficulty of caregiver activities and supportive behaviors from the family caregiver perspective.

Findings from an integrative review (Scarton, Bakas, Miller et al., 2014) on the needs and concerns of family caregivers of persons with type 2 diabetes revealed that caregivers have a perceived lack of knowledge regarding how to help support care recipients in managing their diabetes, as well as how to support care recipients who are experiencing depressive symptoms. Caregivers also struggled with finding information and resources about type 2 diabetes and dealing with their own personal responses to their caregiving role. These needs and concerns were further studied in 33 family caregivers of persons with type 2 diabetes, providing further evidence of these areas of concern among African American, American Indian, and Caucasian caregivers (Scarton, Bakas, Poe et al., 2014). Based on these needs and concerns, a better understanding of what activities caregivers perceive as being easy or difficult is needed to identify the type of supportive interventions that would be most helpful. (See Chapter 2 for complete review.) However, before an intervention can be developed, one must have an outcome measure with evidence of reliability and validity that can measure the perceived difficulty or ease



of caregiver activities and support behaviors. This type of tool is essential in not only helping to better understand priority areas for intervention development but also to serve as an outcome measure from which to evaluate an intervention for caregivers of persons with type 2 diabetes.

A number of diabetes-specific tools are available to measure family support behaviors including the Diabetes Family Behavior Checklist-II (DFBC-II; Glasgow & Toobert, 1988) and the Multidimensional Diabetes Questionnaire (MDQ; Talbot et al., 1996). The DFBC-II has evidence of reliability and validity in measuring family members' supportive versus unsupportive behaviors toward the person with diabetes, whereas the MDQ measures perceptions of the person with diabetes regarding social support, diabetes management, and positive versus misguided family support behaviors such as nagging (Talbot et al., 1996). These tools are helpful in understanding how family support behaviors affect self-management outcomes such as adherence for the person with type 2 diabetes; however, these tools are not useful in understanding how caregivers perceive the care activities and support behaviors they perform on a regular basis. For example, items on the MDQ ask questions such as, "To what extent does your spouse (or significant other) support you with your diabetes?" (Talbot et al., 1996).

A variety of tools have been developed to measure caregiver activities in other chronic diseases such as cancer and stroke. The Oberst Caregiving Burden Scale (OCBS; Bakas, Austin, Jessup, Williams, & Oberst, 2004; Carey, Oberst, McCubbin, & Hughes, 1991) was originally developed to measure time spent and task difficulty in caregivers of cancer survivors. This instrument has been psychometrically tested in caregivers of cancer and stroke survivors (Bakas et al., 2004). Although the OCBS is a useful assessment tool, a more sensitive diabetes-specific tool is needed to determine care activity difficulty or ease for caregivers of persons with type 2 diabetes. Another instrument that measures caregiver outcomes is the Bakas Caregiving Outcome Scale (BCOS; Bakas & Champion, 1999; Bakas, Champion, Perkins, Farran, & Williams, 2006). This instrument measures stroke-specific life changes experienced by caregivers of stroke survivors. Although this tool has been useful in measuring caregiver changes in social

functioning, subjective well-being, and physical health, it does not measure caregivers' perception of difficulty or ease with caregiver activities or support.

Much of the current diabetes research focuses on how to improve diabetes self-management outcomes for persons with type 2 diabetes. Although it is now acknowledged that family caregivers play a vital role in this process, little attention has been directed toward the caregivers and how their caregiving activities and support may affect their own emotional and physical health.

### **Problem Statement**

A neglected focus in the diabetes literature is that of family caregivers. Gaining an understanding of the gaps in the literature is a first step to better understanding where to focus future research. Additionally, there is a lack of knowledge surrounding the needs and concerns of family caregivers of persons with type 2 diabetes. Once these needs and concerns are better summarized from the literature, potential implications for family caregivers can be further explored.

It is well established that caregivers who provide care for individuals with chronic diseases, such as diabetes, have been noted to experience reduced physical well-being, impaired social life, increased anxiety, and increased likelihood of depression (Awadalla, Ohaeri, Al-Awadi, & Tawfiq, 2006; Hennessy & John, 1995; Sinclair et al., 2010). Interventions are needed to support these family caregivers and to help decrease negative health effects (Rintala et al., 2013); however, an essential step in developing interventions is to understand and measure the difficulty or ease of caregiving activities and supportive behaviors caregivers are faced with on a daily basis. Unfortunately, no instruments were found in the literature with documented evidence of reliability and validity to help measure these diabetes-specific caregiving activities in this population. Because of the key role family members play, such a tool is needed to study this population and to serve as an important outcome measure for future interventions.

## **Specific Aims of the Dissertation**

This dissertation is divided into three distinct, but related, articles.

I. The specific aims for manuscript one, “Needs and Concerns of Family Caregivers of Persons with Type 2 Diabetes: An Integrative Review of Cross-Cultural Literature with Implications for the American Indian Population,” are:

Aim 1: To identify what is known regarding the needs and concerns of family caregivers of persons with type 2 diabetes.

Aim 2: To develop recommendations for future research on family caregivers of American Indians with type 2 diabetes.

II. Manuscript two, “Needs and Concerns of Family Caregivers of American Indians, African Americans, and Caucasians with Type 2 Diabetes,” address the following research questions:

Research Question 1: What are common needs and concerns identified by family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes?

Research Question 2: What approaches do family caregivers use to manage their needs and concerns?

III. Manuscript three, “The Diabetes Caregiver and Support Scale: Development and Psychometric Testing,” address the following research questions:

Research Question 1: Does the Diabetes Caregiver Activity and Support Scale (D-CASS; see Appendix A) show evidence of internal consistency reliability and test-retest reliability?

Research Question 2: Does the D-CASS show evidence of content validity?

Research Question 3: Does the D-CASS show evidence of criterion-related validity?

Research Question 4: Does the D-CASS show evidence of construct validity using factor analysis?

Research Question 5: Does the D-CASS show evidence of construct validity guided by a conceptual model (see Figure 1) derived from Bakas, Champion et al. (2006) and Lazarus and Folkman (1984)?

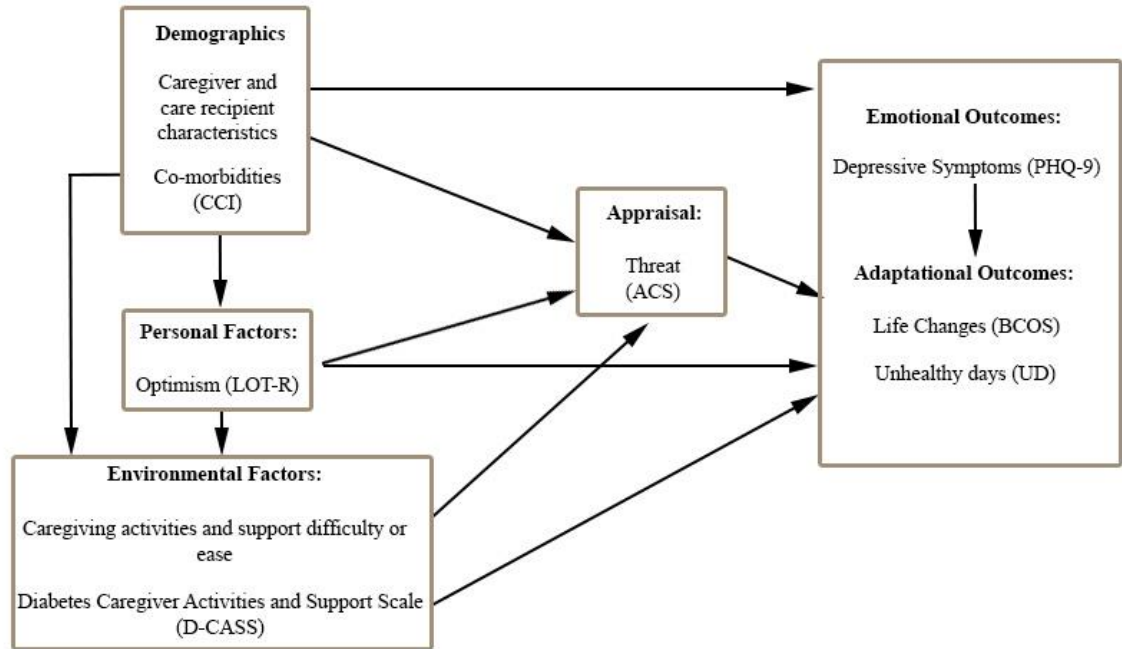


Figure 1. The new D-CASS instrument operationalizes the activities and support that family caregivers provide.

### Conceptual and Operational Definitions

#### Needs and Concerns

**Conceptual definition.** Needs and concerns were defined conceptually as caregiver perceptions of their caregiving situation commonly reflected within five main areas (information about the condition, managing emotions and behaviors, providing physical care, providing emotional care, and dealing with one’s own responses to caregiving (Bakas et al., 2002; Scarton, Bakas, Miller et al., 2014; Welch et al., 2013).

**Operational definition.** Needs and concerns were operationalized through qualitative analysis of open-ended questions with family caregivers of persons with type 2 diabetes resulting in five major themes: information and resources related to type 2 diabetes; dealing with emotions

and behaviors of the care recipient; providing physical care; providing instrumental care; dealing with one's own personal responses to caregiving.

### **Caregiver Characteristics**

**Conceptual definition.** Demographic characteristics for the caregiver including age, gender, race/ethnicity, education, type of housing, number of years providing support, employment status, relationship to patient, and household income was collected from eligible participants and used to describe the sample.

**Operational definition.** An investigator-designed demographic data sheet (see Appendix B) was used to measure the caregiver characteristics. Descriptive statistics (e.g., frequencies, percent, means, standard deviations, and ranges) were used to describe the sample using SPSS version 22.0.

### **Care Recipient Characteristics**

**Conceptual definition.** Demographic characteristics for the care recipient including age, gender, race/ethnicity, education, type of housing, number of years with diabetes, employment status, and household income were collected from eligible participants and used to describe the sample. Descriptive statistics (e.g., frequencies, percent, means, standard deviations, and ranges) were used to describe the sample using SPSS version 22.0.

**Operational definition.** An investigator-designed demographic data sheet was used to measure the care recipient characteristics as reported by the family caregiver. Descriptive statistics (e.g., frequencies, percent, means, standard deviations, and ranges) were used to describe the sample using SPSS version 22.0.

### **Co-morbidities**

**Conceptual definition.** Co-morbidity was conceptually defined as the existence of one or more conditions or diseases in addition to the index disease, which in this case is diabetes (Feinstein, 1970). For example, an individual would have comorbidities if he or she were diagnosed with diabetes (the index disease) and had high blood pressure and neuropathy.

**Operational definition.** Chronic Conditions Index is an 18-item scale (Cornoni-Huntley, Brock, Ostfeld, Taylor, & Wallace, 1986) that was used to measure chronic conditions using a response scale of 1 (*yes*) or 2 (*no*). Diabetes-specific items were added to the index such as kidney problems, neuropathy, retinopathy, foot problems, and depression. Caregivers reported their own and the care recipients' co-morbidities. This instrument has evidence of face validity (Cornoni-Huntley et al., 1986) and has been used in other caregiver studies (Schulz, O'Brien, Bookwala, & Fleissner, 1995).

### **Optimism**

**Conceptual definition.** Optimism was conceptually defined as the degree to which people hold widespread favorable expectations for their future (Carver, Scheier, & Segerstrom, 2010). Caregiver optimism is an important concept to measure and may give insight into how some caregivers are able to have better outcomes than others. People who tend to be more optimistic were found to have a better chance at meeting goals that have been threatened due to stressors (Scheier, Carver, & Bridges, 1994).

**Operational definition.** The Revised Life Orientation Test (LOT-R) was used to measure caregiver optimism (Scheier et al., 1994). The scale consists of six scored items. Respondents indicate the degree of agreement using a 5-point Likert scale with summed scores ranging from 0 (*strongly disagree*) to 4 (*strongly agree*) with higher scores indicating greater optimism. The LOT-R has been used in various settings including with family caregivers (Bakas, Champion et al., 2006) and has shown evidence of reliability and validity (Scheier et al., 1994).

### **Caregiving Activities and Support Difficulty**

**Conceptual definition.** Caregiver activities and support was conceptually defined as activities and supportive behaviors that caregivers engage in to assist their loved ones with type 2 diabetes. The five main categories of caregiver activities and support are information and resources support, emotional and behavioral support, physical care, instrumental care, and dealing with one's own personal responses to caregiving.

**Operational definition.** D-CASS (see Appendix A) is a new 51-item instrument that measures the perceived difficulty or ease of caregiver activities and supportive behaviors for family caregivers using a 7-point response scale ranging from -3 (*extremely difficult*) to +3 (*extremely easy*). Items were recoded from 1 to 7 to provide positive numbers for analysis with summed higher scores indicating less difficulty with caregiver activity and support.

### **Threat Appraisal**

**Conceptual definition.** Threat appraisal was conceptually defined as anticipated harm or loss that had not yet taken place (Lazarus & Folkman, 1984). Threat appraisal is one of the key concepts derived from Lazarus' theory (Lazarus & Folkman, 1984) that has been found to be associated with negative caregiver outcomes (Bakas & Burgener, 2002; Nauser, Bakas, & Welch, 2011; Pressler et al., 2013).

**Operational definition.** The Appraisal of Caregiving Scale Threat Subscale (ACS) was used to measure perceived threat related to the caregiver's role (Carey et al., 1991). Items are rated on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree*. Individual item scores are summed for a total score with higher scores reflecting higher levels of threat. Internal consistency reliability has been reported in studies of family caregivers of stroke patients (Bakas & Burgener, 2002; Bakas, Champion et al., 2006) as well as in family caregivers of persons with heart failure (Nauser et al., 2011; Pressler et al., 2013).

### **Depressive Symptoms**

**Conceptual definition.** Depressive symptoms were conceptually defined as a cluster of symptoms that occur together and are associated with depression. Some symptoms that individuals experience are fatigue, loss of interest in doing activities, difficulty concentrating, or change in appetite (Kroenke, Sitzer, & Williams, 2001).

**Operational definition.** The Patient Health Questionnaire-8 (PHQ-8) is a 8-item questionnaire based on criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (4th edition) and was used to measure depressive symptoms experienced by caregivers

(Kroenke & Spitzer, 2002; Kroenke et al, 2001). Item responses are scored on a 4-point scale ranging from *not at all* to *nearly every day* with summed scores ranging from 0 (*no depression*) to 27 (*all symptoms occurring daily*). The PHQ-8 has established reliability and validity in the primary care population (Kroenke & Spitzer, 2002; Kroenke et al, 2001) with acceptable internal consistency reliability in family caregivers of stroke survivors and heart failure patients (Bakas, Champion et al., 2006; Nauser et al., 2011).

### **Life Changes**

**Conceptual definition.** Life changes were conceptually defined as the changes in social functioning and in physical and emotional well-being, specifically as a result of providing care (Bakas & Champion, 1999; Bakas, Champion et al., 2006). Examples of changes are the caregivers' ability to find a work–life balance, financial well-being, perception of their role in life, general health, time for social activities, and ability to cope with stress.

**Operational definition.** The BCOS is a 15-item scale used to measure life changes as a result of providing care (Bakas, Champion et al., 2006). The 15 items are scored on a 7-point scale ranging from -3 (*changed for the worse*) to +3 (*changed for the best*). Items were recoded from 1 to 7 to provide positive numbers for analysis with summed lower scores indicating more caregiving-related negative life changes. Evidence of reliability and validity has been shown in family caregivers of stroke patients (Bakas & Champion, 1999; Bakas, Champion et al., 2006).

### **Unhealthy Days**

**Conceptual definition.** Unhealthy days were conceptually defined as the number of days during the previous 30 days when the caregiver felt that his or her physical or mental health was not good (CDC, 2000). Caregivers are less likely to seek preventive health care than non-caregivers and are more likely to experience depressive symptoms and decreased subjective well-being (Collins & Swartz, 2011; Kelly, Reinhard, & Brooks-Danso, 2008; Schulz & Sherwood, 2008).



**Operational definition.** Unhealthy Days, a 4-item questionnaire, was used to measure health-related quality of life. Item one, self-perceived health, is scored using a scale from 1 (*poor*) to 5 (*excellent*). Unhealthy days are calculated by summing responses to questions two and three with a total score ranging from 0 days to 30 days with higher numbers indicating more unhealthy days. Acceptable evidence of reliability and validity have been reported for this instrument (CDC, 2000; Hennessy, Moriarty, Zach, Scherr, & Brackbill, 1994).

### **Conceptual Model**

The conceptual model guiding this dissertation was derived from Lazarus and Folkman's (1984) theory of stress, appraisal, and coping and Bakas and colleagues' caregiver conceptual model (Bakas, Champion et al., 2006). Figure 1 depicts the relationships among caregiver and patient characteristics and co-morbidities; personal factors of caregiver optimism; environmental factors of caregiver activities and support difficulty; mediating variables of threat appraisal; emotional responses of depressive symptoms; and adaptational outcomes of life changes and unhealthy days.

The premise of Lazarus' theory (Lazarus & Folkman, 1984) as applied to family caregiving is that personal and environmental factors, which are mediated by threat appraisal, result in emotional and adaptational outcomes specific to a particular situation (Bakas, Champion et al., 2006). Personal and environmental factors such as optimism or perceived difficulty or ease of caregiver activities (i.e., D-CASS), respectively, influence how a caregiver appraises his or her ability to provide future care (i.e., threat), which then is associated with emotional and adaptational outcomes. Depressive symptoms represent emotional outcomes, whereas life changes and unhealthy days represent adaptational outcomes.

Lazarus and Folkman's (1984) theory has been employed extensively in family caregiving research and used to guide the development of stress and coping strategies and interventions to help family caregivers. Mukwato, Mweemba, Makukula, and Makoleka (2010) incorporated the theory as a guide to understand the mechanics of stress and coping for family

caregivers of persons with cancer. The theory also has been used to identify predictors of caregiver emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors as well as heart failure patients (Bakas & Burgener, 2002; Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Nauser et al., 2011; Pressler et al., 2013). Bakas and colleagues (2009b) also used their caregiver conceptual model, derived from Lazarus and Folkman's (1984) theory, as a framework to evaluate the Telephone Assessment and Skill-building Kit (TASK) intervention, an individualized intervention designed to address the needs and concerns of family caregivers of stroke.

Because the role of a family caregiver, across many chronic conditions such as stroke, cancer, and heart disease, often is found to be stressful, deriving a similar conceptual model that is applicable to caregivers of those with type 2 diabetes is appropriate. Type 2 diabetes is a chronic condition that can result in serious complications such as kidney disease, blindness, and lower-limb amputation. Individuals with this chronic condition often have other co-morbidities that further complicate their health. Family caregivers are challenged in providing support and care for these individuals. These challenges include supporting healthy dietary choices, providing emotional support, and learning about diabetes-related complications, all while also managing their own physical and mental health as well as coping with life changes caused specifically as a result of providing care.

To fully utilize this model (see Figure 1) and provide adequate measurement and reflection of the actual caregiving situation, a comprehensive understanding of the needs and concerns of the specific population is needed. Using a similar needs and concerns framework established through qualitative analysis and used with different chronic conditions (e.g., stroke, home hemodialysis, and heart failure; Bakas et al., 2002; Bakas et al., 2009b; Sullivan et al., 2015; Welch et al., 2013), the needs and concerns of caregivers of persons with type 2 diabetes were explored in the literature and analyzed qualitatively to provide a clear understanding of the context of family caregiving of persons with type 2 diabetes. To

operationalize the environmental antecedent factor reflected in the conceptual model and to provide the framework underlying item development for the new D-CASS instrument, the needs and concerns reflective of environmental factors in the conceptual model in Figure 1 served as the major focus to operationalize the activities and support that these family caregivers provide.

### **Connection among the Three Manuscripts**

This dissertation has been assembled using the compilation of three distinct manuscripts as a way to convey the results of the primary study. The first manuscript (see Chapter 2) provides a look at the state of the science related to what is known regarding the needs and concerns of family caregivers of persons with type 2 diabetes. This integrative review provided an opportunity to identify existing knowledge about the needs and concerns of these family caregivers. Findings indicated a need to conduct further research to gain a better understanding of the needs and concerns of family caregivers of persons with type 2 diabetes.

Findings from the integrative review identified a paucity of research related to the needs and concerns of these caregivers and revealed the need to conduct further research in this area using a qualitative viewpoint, allowing a deeper understanding through the eyes of the caregiver. These findings led to the second manuscript (see Chapter 3), a pilot study that explored common needs and concerns identified by 33 family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes. The findings from this small exploratory study revealed few differences among these caregivers. Identifying the needs and concerns of these caregivers and having the ability to measure the difficulty or ease of caregiving activities and supportive behaviors with which caregivers are faced is a prerequisite to designing future intervention studies to support these caregivers.

Currently there are no tools available to measure these diabetes-specific caregiving activities for this population. Many of the available tools for this population are patient centered—designed to measure the help caregivers provide from the patient’s perspective. Findings from the qualitative study (see Chapter 3) as well as the diabetes literature were used to

develop an instrument specifically designed to measure the difficulty or ease of caregiver activities and supportive behaviors for family caregivers of persons with type 2 diabetes. The main focus of this dissertation was to psychometrically test the D-CASS in a pilot study using a convenience sample of 101 family caregivers of persons with type 2 diabetes. Items for the D-CASS were developed using the needs and concerns framework derived from the literature (Scarton, Bakas, Miller et al., 2014) and needs and concerns revealed based on qualitative analyses (Scarton, Bakas, Poe et al., 2014). Psychometric properties for the D-CASS were assessed using item and reliability analyses, factor analyses, and model testing (e.g., construct validity) guided by the conceptual model (see Figure 1) derived from Lazarus's theory (Lazarus & Folkman, 1984) and Bakas and colleagues' model applied to family caregiving (Bakas, Champion et al., 2006). The goal was to provide an outcome measure with evidence of reliability and validity that can be used in future studies to evaluate interventions designed to support these family caregivers.

## Chapter 2

This chapter presents the results of the manuscript, “Needs and Concerns of Family Caregivers of Persons with Type 2 Diabetes: An Integrative Review of Cross-Cultural Literature with Implications for the American Indian Population.”

Scarton, L. J., Bakas, T., Miller, W. R., Poe, G. D., & Huber, L. L. (2014). Needs and concerns of family caregivers of persons with type 2 diabetes: An integrative review of cross-cultural literature with implications for the American Indian population. *The Diabetes Educator*, 40(4), 444–452.

Lisa S. Scarton, BSN, RN  
Jonas Scholar and PhD Student  
Indiana University School of Nursing  
Indianapolis, Indiana

Tamilyn Bakas, PhD, RN, FAHA, FAAN  
Professor and Chair  
Science of Nursing Care  
Indiana University School of Nursing  
Indianapolis, Indiana

Wendy R. Miller, PhD, RN, CCRN  
Assistant Professor  
Indiana University School of Nursing  
Bloomington, Indiana

G. Doug Poe, BS  
Executive Director/CEO  
American Indian Center of Indiana

Lesa L. Huber, PhD  
Associate Clinical Professor  
Indiana University School of Public Health-Bloomington  
Bloomington, Indiana

### Chapter 2 Acknowledgements

The work was supported in part by grants from the Indiana Minority Health Coalition, Indiana University School of Nursing, and the Jonas Center for Nursing Excellence funded by the

Jonas Family Fund. The authors would like to acknowledge the assistance of Phyllis Dexter, PhD, RN, Indiana University, for her helpful review of this manuscript and Lee Ann Blue, MSN, RN, Executive Vice President for Patient Care Services and Chief Nursing Officer for Eskenazi Health for her support. There are no conflicts of interest to disclose.

### **Chapter 2 Abstract**

**Purpose:** The purpose of this review was to identify needs and concerns of family caregivers of persons with type 2 diabetes and to develop recommendations for future research on family caregivers of American Indians with type 2 diabetes. Searching CINAHL, Ovid, and PubMed, an extensive literature review was conducted using 10 search terms for articles published from 1990–2013. References of retrieved studies also were searched.

**Conclusion:** Based on search criteria, six studies exploring needs and concerns of family caregivers of persons with type 2 diabetes were identified. Findings were placed in five predetermined categories derived from Bakas and colleagues' needs and concerns framework: (a) finding information and resources related to type 2 diabetes, (b) dealing with emotions and behaviors of the care recipient, (c) providing physical care, (d) providing instrumental care, and (e) dealing with own personal responses to caregiving. The cross-cultural literature helped identify common ground and specific literature about the experiences of American Indian caregivers. Further research is needed on the needs of caregivers of persons with type 2 diabetes, particularly those in the Native American and other minority populations. Findings can be used to develop interventions to improve outcomes for these caregivers.

**Key words:** type 2 diabetes, family caregiver, cultures, integrative review, needs

Diabetes affects 347 million people worldwide with 25.8 million of those living in the U.S., making diabetes the seventh leading cause of death in the U.S. (ADA, 2013; CDC, 2011). Adults diagnosed with type 2 diabetes make up approximately 90%–95% of all diagnosed cases of diabetes (CDC, 2011). Racial and ethnic minorities have higher rates of diabetes than their White counterparts, with American Indians having the highest prevalence of diabetes among all racial and ethnic groups in the U.S. (Chow, Foster, Gonzalez, & McIver, 2012).

Although diabetes may be considered an individual disease, it usually affects the entire family. Family caregivers often assist with managing medication, meeting dietary requirements, encouraging exercise, and assisting with personal care and transportation needs (Sinclair et al., 2010). The demand for family caregivers is increasing due to shorter hospital stays and an increase in home care technology (Collins & Swartz, 2011). More than 65 million people consider themselves unpaid family caregivers and that number is expected to increase due to an aging population (National Alliance for Caregiving [NAC] & AARP, 2009).

Although there has been extensive research on family caregivers of children with type 1 diabetes, little is known regarding family caregivers of adults with type 2 diabetes (Sinclair et al., 2010) and even less in the context of the American Indian population (Goins et al., 2011). Exploring current literature about family caregivers is the first step to develop culturally sensitive interventions to help this small but significant population; however, a framework also is helpful to organize the findings of a review. For this review, the framework used, derived from the caregiver needs and concerns framework created by Bakas and colleagues (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002), postulates five categories of caregiver needs (see Table 1): (a) finding information and resources related to type 2 diabetes; (b) dealing with emotions and behaviors of the care recipient; (c) providing physical care (e.g., meal planning, physical activity, medication, and glucose monitoring); (d) providing instrumental care (e.g., finances, transportation, and care while away); and (e) dealing with one's own personal responses to caregiving (e.g., caregiver emotions and life changes). The purpose of this review was to identify

what is known regarding the needs and concerns of family caregivers of persons with type 2 diabetes in general and then to develop recommendations for future research on family caregivers of American Indians with type 2 diabetes.

Table 1

*Needs and Concerns Framework*

<b>Category</b>	<b>Subcategory</b>
Information and resources related to type 2 diabetes	Information on diabetic diet and exercise How to find local resources Information on preventing complications
Dealing with emotions and behaviors of the care recipient	Helping the care recipient with their emotions How to help keep care recipient socially active How to communicate with care recipient
Providing physical care	Helping care recipient with meal planning and medication Managing fluctuations in blood glucose Skin care Activity and exercise
Providing instrumental care	Paying for medical expenses Transportation Finding care while away
Dealing with one's own personal responses to caregiving	Own emotions and health Dealing with new responsibilities Keeping social life active

*Note.* Framework derived from Bakas et al. (2002).

**Method and Search Strategy**

Whittemore and Knafl's (2005) integrative review method was used to identify the needs and concerns of family caregivers of persons with type 2 diabetes. This method provided the broadest type of research review and allowed inclusion of many types of studies, including experimental as well as non-experimental designs (Whittemore & Knafl, 2005). An extensive literature review was conducted using CINAHL, Ovid, and PubMed. The key words used in the search were: caregiver, family caregiver, carer, diabetes, diabetes mellitus, education, support, quality of life, American Indian, and Native American. Studies that met the following criteria



were included in the review: (1) published in English, (2) published between 1990 and 2013, and (3) focused on family caregivers of persons with type 2 diabetes. Articles focusing only on patients with diabetes were excluded. Searches were conducted for studies published in 1990 and onward to yield the most comprehensive and up-to-date information on this relatively neglected area.

Based on review of titles and abstracts of each article to determine relevance, the initial 584 articles (see Figure 2) were narrowed to 48, which were then compared to the inclusion criteria. Out of these 48 articles, six met all inclusion criteria. Studies excluded were those deemed not relevant to the topic ( $n = 14$ ), did not involve family caregivers of persons with diabetes ( $n = 26$ ), or were written in languages other than English ( $n = 2$ ). Figure 2 is a PRISMA diagram that outlines the full search and screening process that underpinned the review. Findings related to the needs and concerns of family caregivers of persons with type 2 diabetes were extracted from these studies (see Table 2).

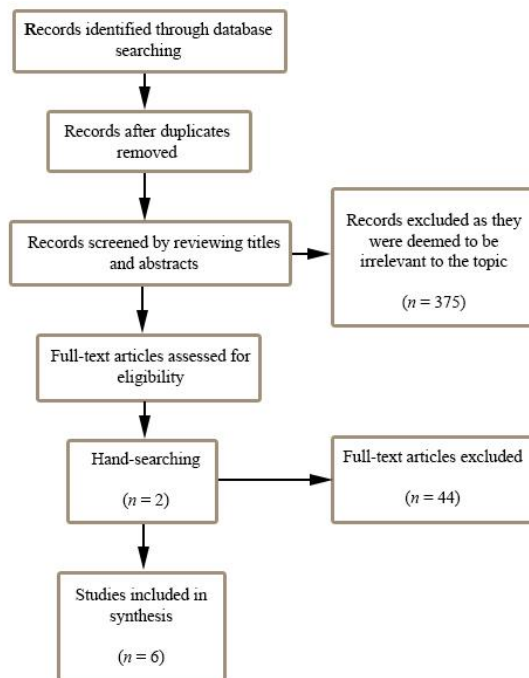


Figure 2. PRISMA diagrams the full search and screening process that underpinned the review.

Table 2

*Summary of Articles from Review*

Source	Purpose	Design & Sample	Measurement Tools	Key Findings	Limitations
Anaforoglu, Ramazanogullari, Algun, & Kutanis (2012)	To examine the quality of life among family caregivers of persons with type 2 diabetes by assessing for depression and anxiety then relating these to socio-demographic features.	Quasi-experim. N = 50 family caregivers N = 54 controls  Caregivers recruited randomly from records of endocrinology clinic (Trabzon, Turkey) by random sampling. The control group was chosen from among healthy relatives of the hospital staff. Controls were matched on educational, socioeconomic, occupational, and marital status	Short Form 36 Quality of Life (Turkish version) to evaluate participant's health status  Beck Depression Inventory (Turkish version) was used to measure depressive symptoms (Cronbach $\alpha$ reliability of 0.8)  State Trait Anxiety Inventory form was used to assess trait and state of anxiety	Dealing with one's own personal responses to caregiving:  Depression: Family caregivers had a greater risk of depression than controls. Depression was significantly higher in caregivers than in controls ( $p = 0.001$ )  Social function was much lower for caregiver than control group ( $p < 0.005$ )  Female caregivers had lower quality of life and State Trait Anxiety Inventory scores but higher BDI scores	Did not use a theoretical framework; small sample from one clinic.

Table continues

Brod (1998)	Examined the impact of lower extremity ulcers on the quality of life of care recipients with diabetes and their caregivers in order to help develop a measurement instrument for a disease-specific quality of life scale	Qualitative-Focus groups  <i>N</i> = 14 persons with type 2 diabetes and lower extremity ulcers  <i>N</i> = 11 family caregivers  Study conducted at Sheffield, UK	Used semi-structured interview guides based on a review of literature and discussions with physicians and nurses. Groups were audio-taped and transcribed and lasted approx. 3 hours	Managing emotions and behaviors of care recipient:  Caregivers felt they were brunt of patients' anger or frustration  Restricted social activities with care recipient.  Providing instrumental care:  Problems related to taking care recipient to healthcare appoint., loss of work/income  Dealing with one's personal responses to caregiving:  Changes in daily routine due to patients' limited mobility; new role and additional responsibility for caregiver; caregivers disregarded their own needs in order to meet the needs of the patient	Small sample size
-------------	---	--	--	---	-------------------

---

Table continues

Mobility issues of care recipient led to a change in leisure activities for caregiver. Caregiver experienced increased strain, tension, stress due to new responsibilities

Caregivers experienced change in their role. Caregivers were now doing tasks that care recipient previously did.

Caregivers restricted social activity and often felt guilty if they did things without care recipient.

Caregiver often felt frustrated and angry because there was no endpoint to the illness.

Lack of sleep, not taking care of their own health

---

Table continues

Hennessy, John, & Anderson (1999)	To use focus groups to examine challenges faced by family caregivers of American Indian elders with type 2 diabetes	<p>Qualitative study-focus groups</p> <p><math>N = 45</math></p> <p>Five focus groups were formed: three groups consisted of caregivers from five tribes in New Mexico (reservation) and two groups involved caregivers from a tribe in Oklahoma (rural, non-reservation setting)</p> <p>Recruitment took place by local aging services programs directors.</p>	Focus group discussion lasted between 1.5–3 hours. Participants were asked three questions. The sessions were audio-taped and transcribed then examined using the comparative method of Strauss and Corbin	<p>Information and resources related to type 2 diabetes:</p> <p>Need more info on nature and expected course of diabetes, how to handle post-operative situations, in-home dialysis machines, and diabetes crisis</p> <p>Managing emotions and behaviors of the care recipient:</p> <p>Caregivers have concerns regarding dealing with depressive symptoms of elders and with noncompliance behaviors.</p> <p>Providing physical care:</p> <p>Caregivers assisted with glucose monitoring, administering medication, meal planning</p>	Small sample size
-----------------------------------	---	---	--	--	-------------------

---

Table continues

Providing instrumental care:

Inadequate healthcare resources, lack of continuity of care, poor living conditions, transportation problems

Communication of understanding of the disease to other family members who were also assisting the elder

Dealing with one's own personal responses to caregiving:

New responsibilities

Anxiety about caring for elder; not knowing how to care for someone with a bilateral knee amputation, how to manage complications with medication, and fluctuations in blood glucose levels

---

Table continues

Shilubane & Potgieter (2007)	To elicit diabetic and caregiver knowledge and views about diabetes and make recommendations on how to strengthen support for care recipients and their family caregivers	<p>Quantitative descriptive survey design</p> <p><i>N</i> = 32 diabetic patients</p> <p><i>N</i> = 32 family caregivers</p> <p>A convenience sample was obtained through snowball sampling</p> <p>Study conducted at Hkhensani Hospital in the Limpopo Province, South Africa</p>	<p>Used self-report questionnaires to collect data based on literature review. Most questions were closed ended.</p> <p>Content validity of the instruments was achieved by using a variety of questions based on information from the literature review and then submitted to another researcher and statistician.</p>	<p>Information and resources related to type 2 diabetes:</p> <p>Caregiver needed more information on diabetes in general-warning signs of hypoglycemia, diet management, and how to avoid complications</p> <p>Managing emotions and behaviors of the care recipient:</p> <p>Caregiver working with care recipients who have feelings of denial, hurt, shock, uncertainty and depression when first diagnosed</p> <p>Providing physical care:</p> <p>Diet control, proper exercise</p> <p>Providing Instrumental care:</p> <p>Expense of going to clinic on a regular basis and purchasing healthy food</p>	Did not use a theoretical framework; small sample size taken from one hospital.
------------------------------	---	---	---	---	---

---

Table continues

Sinclair et al. (2010)	To examine the burden on family caregivers of persons with diabetes and highlight their input into diabetes care	<p>Quantitative questionnaires</p> <p><i>N</i> = 83 Caregivers</p> <p>Part of a larger cross-cultural research program involving care recipients from specific ethnic backgrounds. Only data from participants who stated they were White were included in this study</p> <p>Conducted in urban areas of West Midlands in England</p>	<p>A structured interview</p> <p>Used a modified version of Robinson's Caregiver Strain Index called the burden of caring; General Health Questionnaire and the Diabetes Knowledge Questionnaire</p>	<p>Information and resources related to type 2 diabetes:</p> <p>Caregivers need information on local services and support and on diabetes in general</p> <p>Providing Instrumental care:</p> <p>Caregivers had concerns related to financial strain and needed respite care</p> <p>Dealing with one's own personal responses to caregiving:</p> <p>Caregivers felt overwhelmed, lacked sleep, and had concerns about keeping up their social life</p>	<p>Did not use a theoretical framework; sample was from outpatient clinics of hospitals and only looked at the White population</p>
------------------------	--	---	--	---	---

---

Table continues



Vincent, Clark, Zimmer, & Sanchez (2006)	To describe factors that affect diabetes self-management and how to create a culturally competent diabetes self-management program for Mexican Americans.	<p>Qualitative Descriptive design</p> <p><i>N</i> = 20 diabetic Mexican American patients</p> <p><i>N</i> = 20 caregivers of Mexican Americans with diabetes</p> <p>Qualitative descriptive design using focus groups</p> <p>A purposive sample was obtained from a community health clinic in the Western U.S. and consisted of Latino men and women with type 2 diabetes and their caregivers</p> <p>Participants were assigned to a focus group</p>	<p>Two research team members observed each session and took field notes to assess mood of the group, body language, and identification of themes</p> <p>Two members of the team developed a moderator's guide that was based on previous research, clinical experience, and review of the literature.</p> <p>Content validity of the guide was established by a literature review and from consensus of the group</p>	<p>Information and resources related to type 2 diabetes:</p> <p>Lack of information regarding symptom management and complications of diabetes, how to manage the disease, and coping strategies.</p> <p>Some wanted a hot line answered by a nurse or healthcare worker</p> <p>Managing emotions and behaviors of the care recipient:</p> <p>How to help manage the stress the care recipient experiences due to being diagnosed with diabetes and what effects stress has on diabetes</p>	Small sample from one clinic.
--	---	--	---	---	-------------------------------

---

Table continues

Providing physical care:

Caregivers expressed need for information on helping family member with managing diet and they wanted it specific to their culture; not sure what the person with diabetes can eat, how it affects their blood sugar

Caregiver also wanted culturally relevant information on exercising.

---

## **Theoretical/Empirical Traditions**

The theoretical framework used to organize the findings of this integrative review was derived from Bakas and colleagues' caregiver framework (2002), which is based on Lazarus and Folkman's (1984) theory of stress, appraisal, and coping. The five main categories of the framework are (a) finding information and resources related to type 2 diabetes, (b) dealing with emotions and behaviors of the care recipient, (c) providing physical care, (d) providing instrumental care, and (e) dealing with one's own personal responses to caregiving. These categories were derived from previously identified needs and concerns of stroke caregivers (Bakas et al., 2002; Bakas et al., 2009a).

Four of the six studies reviewed had qualitative designs, one was quasi-experimental, and one was a quantitative study. Participants were recruited from a variety of settings, including two from specialty clinics (Anafroglu et al., 2012; Sinclair et al., 2010) and three from community settings (Hennessy et al., 1999, Shilubane & Potgieter, 2007; Vincent et al., 2006; one author did not report this information (Brod, 1998). In all of the studies, the majority of caregivers were non-employed women between the ages of 40 and 64. Three studies focused on specific ethnic groups: Latinos (Vincent et al., 2006), American Indians (Hennessy et al., 1999), or Caucasians (Sinclair et al., 2010). One author stated only that most clients at the hospital from which participants were recruited were Black (Shilubane & Potgieter, 2007), and two of the articles did not give information on race (Anafroglu et al., 2012; Brod, 1998).

## **Results**

As mentioned, six studies (see Table 2) were found based on the search criteria. The findings were placed into five predetermined categories, discussed in the following sections, derived from Bakas and colleagues' (2002) needs and concerns framework.

### **Need for Information Related to Type 2 Diabetes**

The authors of four studies (Hennessy et al., 1999; Shilubane & Potgieter, 2007; Sinclair et al., 2010; Vincent et al., 2006) discussed the need for family caregivers to have more

information and resources regarding type 2 diabetes. For example, findings revealed caregivers needed more information on type 2 diabetes in general (Shilubane & Potgieter, 2007; Sinclair et al., 2010), the warning signs of complications such as hypoglycemia (Hennessy et al., 1999; Shilubane & Potgieter, 2007; Vincent et al., 2006), and how to manage and avoid other diabetic complications (Shilubane & Potgieter, 2007; Vincent et al., 2006). Two studies found a need for more family caregiver education on dietary restrictions (Shilubane & Potgieter, 2007; Vincent et al., 2006). In these studies, caregivers expressed a lack of knowledge about counting carbohydrates, recognizing healthy foods, and knowing what foods to limit. Vincent and colleagues (2006) specifically studied the Latino population and found that family caregivers were struggling with integrating the ADA recommendations into the typical Latino diet. In addition, Sinclair and colleagues (2010) found that 37% of family caregivers in their study wanted more information on local services. Lastly, it was noted that family caregivers wanted to know more about the expected course of diabetes and how to cope with assisting care recipients in managing diabetes long-term (Hennessy et al., 1999; Vincent et al., 2006). For example, Hennessy and colleagues (1999) conducted a qualitative study using five focus groups made up of family caregivers of American Indians with type 2 diabetes from six different tribes. Caregivers in this study expressed concerns regarding the lack of information they had received on the progression of diabetes and how to handle future crises. These four studies (Hennessy et al., 1999; Shilubane & Potgieter, 2007; Sinclair et al., 2010; Vincent et al., 2006) found that family caregivers had not received adequate information to successfully support the care recipient.

### **Dealing with Emotions and Behaviors of the Care Recipient**

Several studies found that family caregivers routinely supported patients with type 2 diabetes who were experiencing depressive and behavioral symptoms (Brod, 1998; Hennessy et al., 1999; Shilubane & Potgieter, 2007; Vincent et al., 2006). For example, Shilubane and Potgieter (2007) reported more than half of the patients who participated in their study experienced feelings of uncertainty, depression, and fear once diagnosed with diabetes. Another

study (Brod, 1998) found that in addition to depression patients experienced anger, frustration, and guilt related to feelings of being a burden to their family. Patients who were depressed and had a chronic illness such as type 2 diabetes were less likely to follow their plan of care, which could lead to behaviors such as not adhering to appropriate diet and exercise regimens (Ciechanowski, Katon, & Russo, 2000; Schram, Baan, & Pouwer, 2009). Hennessy and colleagues (1999) discovered similar concerns from their focus groups of family caregivers of American Indians with type 2 diabetes. These caregivers reported a lack of support in effectively handling difficult behaviors. Family caregivers needed to be creative when dealing with emotions or behaviors that could potentially cause family members to stray from following their care regimens (Hennessy et al., 1999).

### **Providing Physical Care**

Family caregivers are an important extension of the healthcare system. Caregivers of persons with type 2 diabetes often helped care recipients with meal planning, physical activity, medication, and blood glucose monitoring. Authors from three of the six studies (Hennessy et al., 1999; Shilubane & Potgieter, 2007; Vincent et al., 2006) discussed aspects of providing physical care to the care recipient. Shilubane and Potgieter (2007) found that almost half of caregivers in their study had not been formally educated on dietary requirements. Two studies (Hennessy et al., 1999; Vincent et al., 2006) found that family caregivers struggled with managing care recipients' blood glucose levels. For example, Hennessy and colleagues (1999) noted that American Indian caregivers had difficulty in helping elders stabilize their blood glucose. One such caregiver expressed concerns about the care recipient's blood glucose fluctuating between extremely low levels and extremely high levels. This fluctuation in blood glucose levels is known to be very concerning to caregivers of persons with diabetes in general (Hennessy et al., 1999). Other demands that made caregiving difficult for the American Indian population, especially on reservations, were substandard living conditions such as the lack of central heating, washers or dryers, or even indoor plumbing (Hennessy et al., 1999).

### **Providing Instrumental Care**

Findings from four (Brod, 1998; Hennessy et al., 1999; Shilubane & Potgieter, 2007; Sinclair et al., 2010) of the six studies revealed needs and concerns related to transportation to medical appointments, financial concerns regarding medical expenses, purchase of healthy foods, and respite care. In Brod's (1998) focus group, family caregivers reported having a difficult time concentrating while at work due to their caregiving responsibilities. Other caregivers reported a loss of work or using vacation days to perform caregiving tasks. In addition, some caregivers worked past retirement age in order to meet financial needs. Similarly, Latino family caregivers within the Shilubane and Potgieter (2007) study revealed needs and concerns related to the financial strain from taking patients to medical appointments and purchasing healthy foods.

Hennessy and colleagues' (1999) study focused on specific needs and concerns related to providing instrumental care to participants who lived on Indian reservations. Caregivers in this group were concerned about the perceived lack of public health nurses. When a healthcare provider was not available, family caregivers often called tribal police for assistance or drove the patient to an off-reservation medical clinic.

### **Dealing with One's Own Personal Responses to Caregiving**

Authors from four studies (Anafroglu et al., 2012; Brod, 1998; Hennessy et al., 1999; Sinclair et al., 2010) looked at the personal responses to caregiving. For example, family caregivers often neglected their own well-being to care for family members. Two studies (Anafroglu et al., 2012; Brod, 1998) underlined how caregivers struggled with their own social functioning. For example, Anafroglu and colleagues (2012) conducted a quasi-experimental study on family caregivers of persons with type 2 diabetes. The findings showed no significant differences in quality of life indicators between caregivers and the control group except for social functioning. Brod (1998) found similar results in his study, reporting that caregivers had limited social activities because of feeling too guilty to leave the patient.

Two studies (Hennessy et al., 1999; Vincent et al., 2006) looked at the cultural implications of being a caregiver and the stress associated with that role. Vincent and colleagues (2006) found that Latino participants in their study believed they experienced more stress than other ethnic groups due to the role of the family within that culture. One participant in the focus group explained that it was common in the Latino culture to have more than one family living together which can add stress (Vincent et al., 2006). It is also common in American Indian culture for family caregivers to be a part of a multigenerational family that focuses on the need of the group rather than on the individual (Hennessy & John, 96; Hennessy et al., 1999).

### **Limitations**

One of the major limitations of this integrative review was the paucity of research that examined the needs and concerns of family caregivers of persons with type 2 diabetes, especially in the American Indian population. The published research used small samples and, additionally, the two quantitative studies (Shilubane & Potgieter, 2007; Sinclair et al., 2010) did not use a guiding theoretical framework. Despite the limitations, this study extends understanding of the needs and concerns of this population. The study also may help illuminate future areas of needed research.

### **Summary**

This integrative review provided an opportunity to identify existing knowledge about the needs and concerns of persons with type 2 diabetes. The findings of the review were organized by using the caregiver needs and concerns framework of Bakas and colleagues (2002). The studies found caregiver concerns in all five categories proposed in the framework. The model worked very well for this review, and no caregiver concerns outside of these five categories were identified. Findings indicated that caregivers have a perceived lack of understanding about diabetes due in part to healthcare providers' focus on educating patients but not caregivers. This practice may be changing, fortunately, because current projects such as Better Outcomes by

Optimizing Safe Transitions (BOOST) and Project Re-Engineered Discharge (RED) underline the importance of involving family caregivers in the discharge practice.

Caregivers across the studies identified some common ground issues regarding supporting patients who are dealing with depression and the need for further education related to managing low blood glucose levels. Although it is known that persons with type 2 diabetes are twice as likely to be depressed as those without the chronic disease (Ali, Stone, Peters, Davies, & Khunti, 2006), this review revealed that some caregivers still did not believe that healthcare providers adequately addressed concerns surrounding such emotional issues. Although potentially negative outcomes have been studied for family caregivers of patients with other chronic diseases (Lim & Zebrack, 2004; Schultz & Sherwood, 2008; Tremont, 2011), there is currently a gap in the literature for this population, with even less known about family caregivers from minority cultures such as American Indians. This integrative review included studies that sampled minority cultures including Blacks from Africa, Latinos, and American Indians; however, little was discussed about the potential cultural effects on the caregiving role. For example, personal responses to caregiving are likely to vary depending on the culture. Hennessy and John (1995) found that Pueblo family caregivers of individuals who were functionally disabled were less likely to express resentment toward the care recipient than White caregivers. Cultural expectations discouraged the expression of negative feelings toward other members of the tribe (Strong, 1984). Another difference was discovered by Strong (1984), who conducted a small qualitative study of perceived caregiver burden and coping styles among American Indians and White caregivers of elderly relatives. The findings of the study revealed a coping strategy used by the American Indian caregivers she called *passive forbearance*. Strong found that compared to White caregivers American Indians perceived themselves as having less control over the caregiving situation and thus accepted the circumstances instead of attempting to control them.

The cross-cultural literature helped identify common ground among cultures and revealed specific literature about the experiences of American Indian caregivers that contributed more



understanding to their needs and concerns. This review revealed a great need for further research looking at the particular needs of caregivers of those with type 2 diabetes across cultures. These needs could then be used as the basis for development and testing of interventions to improve outcomes. However, it is necessary to first determine the appropriateness, reliability, and validity of various instruments across cultures. Crowder and Broome (2013) discussed the importance of advancing culturally specific interventions by evaluating the cultural appropriateness and effectiveness using a framework such as the ecological validity model (Bernal, Bonilla & Bellido, 1995). Future research could be guided by the needs and concerns framework (Bakas et al., 2002) adapted for this review, along with theoretical perspectives from the ecological validity model (Bernal et al., 1995). This approach may be best suited for the selection of culturally appropriate measures and for the development and testing of future interventions designed to provide more education and social support for family caregivers of American Indians with type 2 diabetes.

### Chapter 3

This chapter presents the results of the manuscript, “Needs and Concerns of Family Caregivers of American Indians, African Americans, and Caucasians with Type 2 Diabetes.”

Scarton, L. J., Bakas, T., Poe, G. D., Hull, M. A., Ongwela, L. A., & Miller, W. R. (2014). Needs and concerns of family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes. *Clinical Nursing Research*, 1–18, doi:10.1177/1054773814562879

Lisa J. Scarton, BSN, RN  
Jonas Scholar and PhD Student  
Indiana University School of Nursing  
1111 Middle Drive, NU 413  
Indianapolis, IN 46202  
Office: 812-345-0523  
Fax: 317-274-2996

Tamilyn Bakas, PhD, RN, FAHA, FAAN  
Professor and Chair  
Science of Nursing Care  
Indiana University School of Nursing  
1111 Middle Drive, NU 413  
Indianapolis, IN 46202

G. Doug Poe, BS  
Executive Director/CEO  
American Indian Center of Indiana  
2236 East 10th St  
Indianapolis, IN 46201

Margie A. Hull, M.Ed., MSN, ACNS-BC, CDE, RN  
Diabetes Clinical Nurse Specialist, Certified Diabetes Educator  
Eskenazi Health  
720 Eskenazi Ave  
Indianapolis, IN 46202

Loice A. Ongwela, MSN, RN, ACNS-BC, CDE  
Specialist Diabetes Educator  
Eskenazi Health  
720 Eskenazi Ave  
Indianapolis, IN 46202

Wendy R. Miller, PhD, RN, CCRN  
Assistant Professor  
Indiana University School of Nursing  
1033 E. Third St.  
Bloomington, IN 47405

### **Chapter 3 Acknowledgments**

The work was supported in part by grants from the Indiana Minority Health Coalition, Indiana University School of Nursing, and the Jonas Center for Nursing Excellence funded by the Jonas Family Fund. The authors would like to acknowledge the assistance of Phyllis Dexter, PhD, RN, Indiana University, for her helpful review of this manuscript and Lee Ann Blue, MSN, RN, Executive Vice President for Patient Care Services and Chief Nursing Officer for Eskenazi Health for her support of the Jonas Scholarship and completion of this project.

Parts of this study were presented in abstract form at the Midwest Nursing Research Society Conference in March 2014. There are no conflicts of interest relevant to this study.

### **Chapter 3 Abstract**

Although type 2 diabetes is a chronic illness affecting the entire family, scant literature exists in this area. This study's purpose was to identify needs of family caregivers of persons with type 2 diabetes across cultures. Using a semi-structured interview guide with open-ended questions, a convenience sample of 33 family caregivers of American Indians ( $n = 14$ ), African Americans ( $n = 11$ ), and Caucasians ( $n = 8$ ) with type 2 diabetes were interviewed by telephone. Qualitative content analysis was conducted based on five pre-determined categories derived from an existing conceptual model. Results were similar across groups and provided support for the conceptual model with themes emerging within the five pre-determined categories: (a) information about type 2 diabetes, (b) managing emotions and behaviors, (c) physical care, (d) instrumental care, and (e) personal responses to caregiving. No additional themes emerged. Although small and exploratory, findings provide information that may be useful to the future development of culturally-based interventions.

Key words: type 2 diabetes, family caregiver, cultures, needs, qualitative research

Type 2 diabetes, the seventh leading cause of death in the U.S., currently affects 25.8 million adults (CDC, 2011) and can result in major complications such as blindness, amputation, heart disease, and stroke (ADA, 2013; CDC, 2011). Type 2 diabetes is especially prevalent in the American Indian and African American populations, with American Indians 2.3 times and African Americans 1.8 times more likely to be diagnosed with diabetes than non-Hispanic Whites. Though Caucasians have a relatively lower risk, 7.1% of Caucasians have been diagnosed with type 2 diabetes (ADA, 2013; CDC, 2011).

Families play an integral role in type 2 diabetes management and are often the first line of support for helping persons with that condition, yet they often have limited information and resources to assist in diabetes management (Hennessy et al., 1999; Shilubane & Potgieter, 2007). Not only have caregivers expressed needs and concerns about information and resources, but they also have expressed other needs and concerns regarding how to manage emotional and behavioral issues of the care recipients (Brod, 1998; Hennessy et al., 1999); physical care issues in managing diets, glucose management, monitoring of complications, assisting with adherence to suggested treatment regimens (Hennessy et al., 1999; Shilubane & Potgieter, 2007); instrumental care concerns regarding finances and transportation (Brod, 1998; Hennessy et al., 1999); and meeting caregivers' own personal needs (Anaforoglu et al., 2012; Brod, 1998; Hennessy et al., 1999). Because of unmet needs and concerns, particularly in meeting their own personal needs, caregivers of persons with type 2 diabetes commonly experience a number of negative outcomes. These negative outcomes are consistent with those found in other chronic caregiving situations and include reduced physical well-being, impaired social life, increased anxiety, and increased likelihood of depression (Awadalla et al., 2006; Hennessy & John, 1995; Sinclair et al., 2010). Addressing the needs and concerns from the family caregivers' perspectives could serve as the basis for supportive intervention programs that may potentially reduce negative outcomes (Scarton, Bakas, Miller et al., 2014). Identifying these needs and concerns in stroke family caregivers provided the framework for the Telephone Assessment and Skill-Building Kit

(TASK), which has shown preliminary efficacy and satisfaction (Bakas et al., 2009a; Bakas et al., 2009b) and is currently being tested in a large randomized controlled clinical trial. Similarly, identifying the concerns of family caregivers of persons with type 2 diabetes is prerequisite to building an intervention program specifically designed for this population. To ensure the future development of a culturally sensitive intervention program, concerns of American Indian, African American, and Caucasian caregivers were elicited in this small exploratory study. Future controlled studies with larger and more representative samples should be extended to other cultural groups that face diabetes disparities such as Hispanic and Asian populations.

### **Design**

Content analysis was used to explore the needs and concerns of American Indian, African American, and Caucasian family caregivers of persons with type 2 diabetes. Using a semi-structured interview guide (see Appendix C), 12 open-ended questions were asked during audio-recorded telephone interviews that were transcribed verbatim for analysis.

Specific research questions used in this study were as follows:

Research Question 1: What are common needs and concerns identified by family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes?

Research Question 2: What approaches do family caregivers use to manage their needs and concerns?

### **Sample and Setting**

A convenience sample of participants were recruited from American Indian events in the Midwest, such as Pow Wows and Talking Circles, and from a large city-county hospital located in a Midwestern U.S. city. Emphasis was placed on recruiting a diverse sample of American Indians, African Americans, and Caucasians to ensure a culturally rich perspective within the unit of analysis focused on family caregiving within the context of type 2 diabetes. Because there are a lack of American Indian reservations in the Midwest, the American Indian participants were recruited from the community although many did express affiliation with various tribes. A

majority of the American Indians lived in or near a large Midwestern city. Those interested in participating in the study completed a contact information card. The study researcher contacted potential participants by telephone to explain the study and screen for eligibility. Participants were eligible to participate if they were 18 years of age or older, able to read and converse in English by telephone, and were the primary caregiver of an adult diagnosed with type 2 diabetes. Family caregivers were defined as unpaid family members or significant others who assisted individuals with type 2 diabetes. Participants consisted of 33 unpaid adult family caregivers who were recruited over a span of seven months. At the end of data collection, saturation had been reached as no new themes emerged (Sandelowski, 1995). As shown in Table 3, the sample consisted of American Indians ( $n = 14$ ), African Americans ( $n = 11$ ), and Caucasians ( $n = 8$ ), and they were primarily spousal females. Caregivers had been providing care for an average of eight years. See Table 3 for other detailed characteristics of the sample.

Table 3

*Demographic Characteristics of Caregivers and Care Recipients*

Caregivers	American Indian <i>n</i> = 14 (43.7%)		African American <i>n</i> = 11 (31.3%)		Caucasian <i>n</i> = 8 (25.0%)		Total <i>N</i> = 33	
	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range
Age		47.8 (15.2) 20–65		52.5 (15.8) 29–81		42.75 (13.8) 24–64		48.0 (15.1) 20–81
Gender								
Male	7(50%)		1(10%)		2(25%)		10(31.2)	
Female	7(50%)		9(90%)		6(75%)		22(68.8)	
Years of education		12.75 (4.3) 3–22		13.70 (2.31) 11–18		11.88 (1.55) 10–15		12 (3.22) 3–18
Income								
Comfortable	3(21.4%)		5(50%)		2(25%)		10(31.2)	
Just enough to make ends meet	9(64.3%)		4(40%)		4(50%)		17(53.1)	
Not enough to make ends meet	2(14.3%)		1(10%)		2(25%)		5(15.6)	

Table continues



Relationship					
Spouse	6(42.9%)	3(30%)	5(62.5%)	14(43.8)	
Son or daughter	3(21.4%)	4(40%)	0(0%)	7(21.9)	
Other relative	5(35.7%)	2(20%)	0(0%)	7(21.9)	
Friend	0(0%)	1(10%)	3(37.5%)	4(12.5)	
Years of caregiving	9.14 (8.2) 1–30	9.25 (11.1) 1–34	5.00 (5.1) 2–14	8.4 (8.57) 1–34	

---

Care Recipients

---

Age	58.36 (12.34) 30–75	57.2 (9.05) 42–75	54.6 (12.95) 39–75	58 (11.3) 30–75	
Gender					
Male	6(42.9%)	6(60%)	6(75%)	18(56.3)	
Female	8(57.1%)	4(40%)	2(25%)	14(43.7)	
Years of Education	12.5 (2.4) 8–16	11.1 (2.7) 4–14	11.8 (5.1) 0–16	11.83 (3.28) 0–16	
Years with type 2 diabetes	12.93 (9.5) 3–40	9.33 (6.4) 2–20	10.5 (14.7) 2–40	11.31 (9.75) 2–40	

---

## **Procedures**

Ethical considerations for the study were reviewed by an institutional review board for the protection of human subjects. After the study received institutional review board approval (see Appendix D), the 33 family caregivers of individuals diagnosed with type 2 diabetes who comprised the convenience sample were invited to participate. The study was explained in detail to potential participants, and interviews were conducted by telephone after verbal informed consent was obtained from those interested. Informed consent included the use of a mailed study information sheet that detailed the purpose of the study, risks and benefits, confidentiality, and voluntary participation. The study information sheet was reviewed with the participant by telephone, and any questions that potential participants had about the study were addressed. A waiver of written informed consent was approved by the institutional review board. Telephone interviews were conducted to improve access to diverse participants with limited resources for transportation and for those who lived in remote areas. The interviews took place using a semi-structured interview guide (see Appendix C). Demographic data were then collected using a demographic data form (see Appendix B). Each interview lasted approximately 30 minutes, and each was audio-recorded and transcribed for analysis. Team members consisted of individuals who were experts in the areas of caregiving and diabetes research and also had experience recruiting from diverse populations. Additionally, two of the researchers had qualitative analysis expertise. The lead researcher conducted all of the interviews while the co-researchers assisted with data mining and coding for inter-rater reliability.

## **Data Analysis**

A directed content analysis approach was used to interpret the meaning of the text data (Hsieh & Shannon, 2005). Transcripts were coded into themes based on a pre-determined code list to capture key needs and concerns common to family caregivers in a way that would not bias the identification of relevant text (Hsieh & Shannon, 2005). Table 4 displays the pre-determined list that was derived and adapted from previously identified needs and concerns of stroke

caregivers (Bakas et al., 2002; Bakas et al., 2009a) and daily home hemodialysis caregivers (Welch et al., 2013). The list includes (a) finding information and resources about type 2 diabetes; (b) managing emotions and behaviors of the care recipient; (c) providing physical care (e.g., meal planning, physical activity, medication, and glucose monitoring); (d) providing instrumental care (e.g., finances, transportation, care while away); and (e) dealing with personal responses to caregiving (e.g., caregiver emotions and life changes). No additional themes or categories emerged, indicating that the pre-determined list was broad enough to be applicable to this population. Data saturation was achieved within each group of American Indian, African American, and Caucasian caregivers as evidenced by the recurring themes within each group.

Table 4

*Caregiver Needs and Concerns*

<b>Category</b>	<b>Subcategory</b>
Information about type 2 diabetes	General information on type 2 diabetes Talking to health care providers Difficulty getting patient to go to healthcare provider Where to find resources (e.g., written materials, websites, services)
Managing emotions and behaviors of the patient	Care recipient emotions Care recipient self-esteem Care recipient behaviors Care recipient communication Care recipient socially active
Providing physical care	Adherence to plan of care Diet Medication and pill boxes Glucose monitoring and fluctuations Skin and healing issues, foot care Activity and exercise Mobility Personal Care

Table continues

Providing instrumental care	Finances Transportation Finding care while away
Taking care of oneself as a caregiver	Own emotions New responsibilities Asking for help Managing multiple responsibilities Taking care of own health Keeping energy level up Keeping own social life going

---

Segments of the transcripts were entered into a spreadsheet, and ongoing content analysis was used to code the data (Bakas et al., 2009a). One member of the research team placed data into the pre-determined categories; this was similar to the needs and concerns analysis by Bakas et al. (2002) and Welch et al. (2013). Other team members then independently rated relevance of caregiver quotes to each theme (0 = *not relevant* to 4 = *highly relevant*). Triangulation was achieved by conducting in-depth interviews and using field notes and by co-researchers participating in the interpretation and coding of the data. Additionally, an audit trail was maintained to ensure neutrality of the results (Lincoln & Guba, 1985).

### Results

The needs and concerns framework, derived from Bakas et al. (2002) and Welch et al. (2013) and adapted to caregivers of persons with type 2 diabetes, was supported by the findings in this study and consisted of (a) information and resources about type 2 diabetes; (b) managing emotions and behaviors of the care recipient; (c) providing physical care (e.g., meal planning, physical activity, medication, and glucose monitoring); (d) providing instrumental care (e.g., finances, transportation, care while away); and (e) dealing with personal responses to caregiving (e.g., caregiver emotions and life changes). Figure 3 shows the number of caregivers in each group who expressed needs and concerns within each category. Though results were similar across groups, a few culture-related differences were identified. Not all sub-themes were discussed in detail; Table 4 shows the complete list.

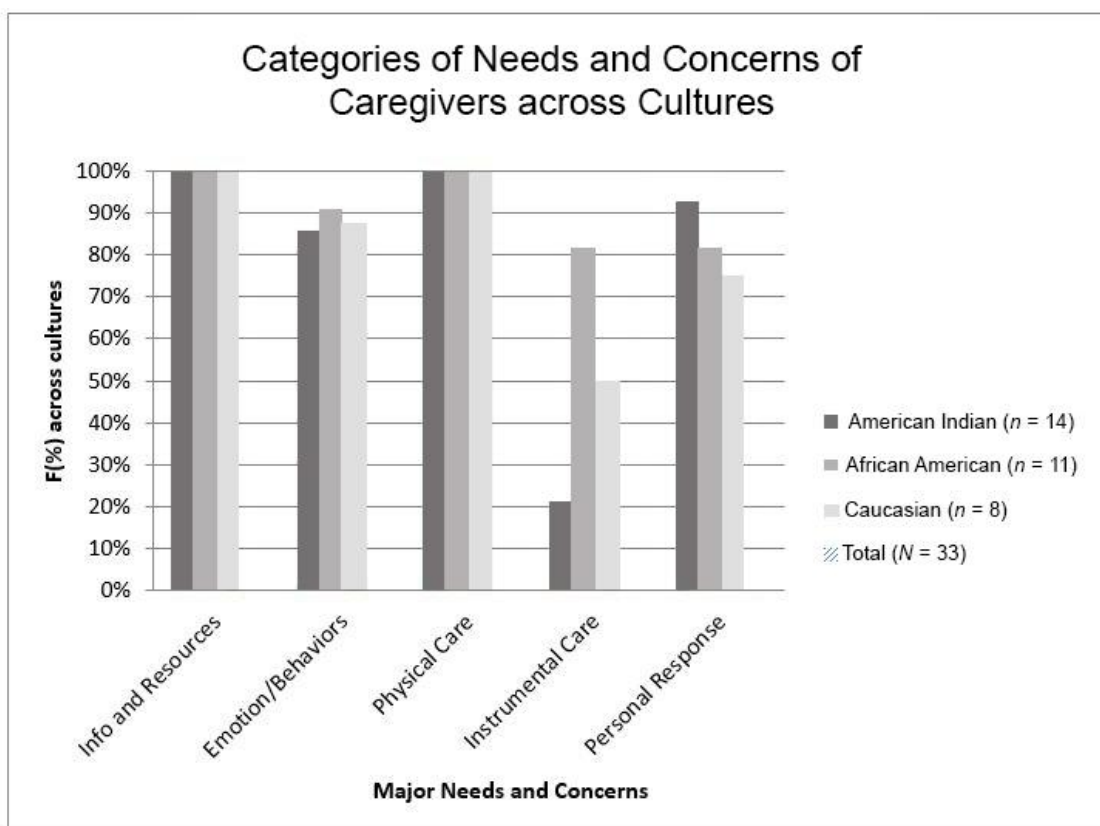


Figure 3. The bar chart displays the categories of needs and concerns of caregivers across cultures.

### Information on Type 2 Diabetes: Needs and Concerns

Most caregivers expressed a need for more information regarding type 2 diabetes. They had concerns about managing fluctuations in the care recipient's blood glucose, recognizing symptoms for low and high blood glucose, and knowing what foods to cook for the care recipient. One caregiver explained, "I've been around people that are diabetic but that doesn't mean that I know anything about it." Other caregivers needed information about where to find resources, such as support groups for the caregiver and care recipient. One caregiver expressed a need to have someone with whom to talk when she had questions.

Many caregivers expressed concerns that care recipients would not tell the healthcare provider everything that needed to be discussed. For example, one said, "I help her remember what to ask [during the doctor visit] and if she doesn't ask about something and I'm worried

about her I tell the doctor about it.” Another caregiver believed the care recipient needed support because “sometimes healthcare professionals can be intimidating.... He feels more comfortable if he has somebody with him asking questions.”

### **Emotions and Behaviors: Needs and Concerns**

Caregivers described difficulties experienced when providing emotional support. One explained, “Well, some days he complains, he’s moody, he’s grouchy, and other days he’s real happy and nice and sweet. He’s a nice person but he’s just miserable.” Many discussed care recipients’ emotions being erratic and most attributed it to frustration with dietary restrictions. One caregiver said, “Basically, I let him vent. It’s a lot of frustration, with his condition, with diabetes... you watch other people enjoy things, and you want to be able to do whatever everybody else does but you can’t.... So I try to be encouraging.”

Another caregiver, talking about how her husband’s behavior changed when he forgot to eat, said, “He becomes angry because he gets confused and so he starts acting like he’s drunk.... So he’ll be angry with himself, nothing’s going right, and so you have to work him through that to get him to realize that he needs to eat so that he can function normally.” A second caregiver spoke about the importance of communication. She said that “sitting down and talking with each other [helps] manage our emotions and stress. We talk out things.... We never keep nothing bottled up.”

### **Physical Care: Needs and Concerns**

Caregivers expressed many concerns about providing physical care for care recipients, such as ensuring an adequate diet, helping them adhere to the plan of care, managing medication, monitoring blood glucose, and encouraging exercise, but dietary management was mentioned most frequently. One caregiver said, “My biggest concern [is] trying to maintain a proper diet.” Many caregivers were concerned with serving a variety of food. One caregiver said, “I don’t know what to cook for him anymore because I’m afraid I’m cooking wrong for both of us.” In addition to being concerned with managing diet, caregivers had concerns about care recipients

adhering to their plan of care. For example, one caregiver said, “[What I am] most concerned about is his binge eating and diet because he’ll sit down and eat a whole bag of candy in one sitting.... If I’m with him at the store, he wants to buy it.”

Many caregivers worried about managing medication usage; some reminded the care recipient to take medicine or assisted by drawing up the insulin in the syringe, whereas others directly administered the medication. The biggest concern was ensuring that the care recipient received medication at the appropriate times. One caregiver, who had created a system to help with this concern, explained, “We have a little system at home, little sorting boxes for his medications and so my husband knows at what time he needs to take his medicines.”

Many caregivers also were concerned with fluctuations in the care recipient’s blood glucose. One explained it by saying, “This disease is just a hard reality fact. If you don’t eat, you can pass out. You eat too much, your sugars will go high.” Another caregiver, sharing an experience she had had with her sister’s blood glucose dropping during the night, said that “she was fine when we went to sleep. The next morning... I patted her on the hand, and she still didn’t respond.... I realized she was unconscious, and I had to call the ambulance again.”

Some caregivers had concerns that care recipients were not exercising regularly. One exercised with her husband, saying that “unless I’m the one that initiates the exercising, he will not do it.” Another said, “I usually park further away from the entrance at Wal-Mart so she has to walk further.”

### **Instrumental Care: Needs and Concerns**

Instrumental concerns of caregivers included those related to finances, transportation, and respite care. Regarding finances, some cited the cost of medication and healthcare visits. For example, one caregiver said, “The only thing that is really going to be hard on us is they said he has to pay for his medicine.” Another explained, “She’s more concerned what it’s going to cost her to go to the doctor than what it actually consists of.... She said if we had better insurance then she would go more often.”

One caregiver who had difficulty with providing transportation for his wife said, “We only have one vehicle right now.... Money and gas and stuff like that, it’s pretty hard right now.” Another, expressing concerns with finding care for her husband while she was at work, explained, “If...I’m at work, I’ll call and ask him did he take it [medicine] and if my daughter or my son comes over...I ask them to check on him and see if he took his medicine.”

### **Personal Responses to Caregiving: Needs and Concerns**

It was not uncommon for family caregivers to neglect their own health and emotional well-being while caring for loved ones. One caregiver said, “I have no life.... We keep our grandchildren after school and so I just feel like I’m always going, always, always, going.”

Family caregivers also often placed the welfare of their family members before their own. For example, one explained, “I just go with the flow and I put everybody first and me last. Well, it’s just like when I cook dinner...I make sure everybody’s got their plate and then I fix mine.”

Some caregivers had their own health problems while they were trying to support care recipients. One stated, “Well, I am on oxygen so my life is pretty wrapped up anyway right in this house and trying to worry about him and me both it gets pretty hard to do.”

### **Cultural Differences in Needs and Concerns**

Few differences were found in needs and concerns among American Indian, African American, and Caucasian caregivers. One noticeable difference was related to instrumental care. While all three cultural groups discussed concerns related to instrumental care, 81.8% of the African American caregivers were concerned with issues such as transportation, finances, and respite care. That is significant compared to 21.4% of American Indian caregivers and 50% of Caucasian caregivers who expressed concerns with this category. Interestingly, as shown by Table 5, when separated out by income, there were more African Americans (50%) who expressed their incomes were “comfortable” as opposed to American Indians (21.4%) and Caucasians (25%).



In addition, American Indian participants perceived some cultural disparities in care. For example, one caregiver believed that her husband was treated differently by healthcare providers because he was not White. She asserted,

There's a difference based on what color skin you have.... I mean, if it's a White man, he gets in immediately, there's no hurry up and wait for him.... [If my husband] comes along, or anyone that's a little bit darker or anything and you can forget it.... So getting the care that he needs is a fight.

Another caregiver took her husband to the hospital after he began to experience signs of a stroke while attending a Pow Wow. The caregiver reported that healthcare providers did not take them seriously because they thought her husband had been drinking alcohol. She explained,

When we got to the hospital, I said "he's had a stroke," and they said, "oh no, he wouldn't have a stroke at his age." I said, "he can't stand up, his speech is impaired.... Look at the corner of his mouth, it's sagging." I said, "The man has had a stroke." [The hospital attendants said,] "No, he hasn't had a stroke, he's just drunk." I said, "He doesn't drink, he never drinks.... The strongest thing he drinks is iced tea." Three and a half to four hours later, they finally decided, yes, he's had a stroke.

A few other caregivers struggled with helping the care recipient adhere to his or her meal plan at American Indian social gatherings such as Pow Wows. For example, one caregiver said, "When we go to the Pow Wows, [we] try to steer away from some of those foods...very sugary, deep-fried."

## **Discussion**

This study revealed needs and concerns identified by family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes. Other studies that have looked at the needs and concerns of family caregivers have had similar findings; however, family caregivers of stroke survivors and home hemodialysis caregivers documented greater needs for instrumental care such as respite care (Bakas et al., 2002; Welch et al., 2013). It is possible that family caregivers of stroke survivors and those on home hemodialysis may require more physical care than family caregivers of persons with type 2 diabetes. In this study, caregivers in the three groups generally had the same concerns related to type 2 diabetes management. They all shared

an overwhelming need to have more general information about type 2 diabetes; such as symptom management, warning signs of high or low blood glucose, and dietary needs. These findings were similar to those in other studies (Hennessy et al., 1999; Scarton, Bakas, Miller et al., 2014; Shilubane & Potgieter, 2007; Vincent et al., 2006). Another concern of caregivers was finding resources, such as a medical help line. These findings were also similar to those in other studies (Sinclair et al., 2010; Vincent et al., 2006).

Caregivers noted difficulties with providing emotional and behavioral support for care recipients. Many times, the change in the care recipient's behavior was due to a fluctuation in blood glucose or from frustration related to a restricted diet. Surprisingly, there have been no studies that addressed providing emotional and behavioral support to care recipients in this context. The available literature primarily focused on the caregiver providing support related to depressive symptoms experienced by the care recipient (Brod, 1998; Hennessy et al., 1999). Though this latter topic is important, there is a knowledge gap related to emotional and behavioral concerns surrounding fluctuations in blood glucose and frustration from diet restrictions.

Caregivers also cited concerns related to providing an adequate diet, ensuring care compliance, and monitoring blood glucose. These findings were similar to those in other studies (Hennessy et al., 1999; Shilubane & Potgieter, 2007; Vincent et al., 2006). Vincent and colleagues (2006) found that caregivers did not have a clear understanding of how foods affected blood glucose. In their study of family caregivers of American Indians with diabetes, Hennessy and colleagues (1999) found that caregivers often struggled with noncompliance of care recipients in following their plan of care. Caregivers in this study, feeling unsupported by healthcare providers developed their own way to encourage care recipients to follow meal or exercise plans. This perceived lack of support added to already stressful situations. Findings suggested that family caregivers could benefit from working with dieticians to create meal plan strategies that encourage dietary adherence. The cultural context related to meal preparation and dietary preferences is important for family caregivers to consider in assisting with dietary needs

of care recipients. Goody and Drago (2009) discussed how a person's culture often defines the type of foods eaten by individuals and the meaning behind certain foods. For example, food is often used in symbolic ways and can play an important role in social events.

The least frequently mentioned category of concerns overall was the provision of instrumental care such as that related to finances, transportation, and respite care. This was surprising because 68% of the caregivers interviewed stated they had problems living on their limited financial resources. The caregivers who did have concerns related to instrumental care discussed problems related to buying medication, transporting the care recipient, and finding outside help for the care recipient while caregivers were at work. Shilubane and Potgieter (2007) reported similar findings in their study. Most caregivers in this latter study (71.9%) indicated that lack of money prevented care recipients from managing their diabetes appropriately. Additionally, Sinclair and colleagues (2010) found that family caregivers in their study needed help with respite care while caregivers were at work. African Americans in particular expressed more needs and concerns regarding instrumental care; however, most classified their income as being "comfortable." It is possible that transportation and respite issues were of more concern to African American caregivers in this sample; however, the sample size was too small to draw strong conclusions regarding these findings.

Caregivers also had personal needs related to their role of caregiving. Many had difficulty finding personal time and had their own health concerns. Findings in this respect were similar in other caregiver studies (Brod, 1998; Hennessy & John, 1995; Sinclair et al., 2010; Vincent et al., 2006). Some studies noted that family caregivers had higher rates of depression (Anafroglu et al., 2012), neglected their own needs in order to care for their family members (Brod, 1998), and neglected to engage in activities they enjoyed (Sinclair et al., 2010).

The findings in this study revealed, with two exceptions, few differences among American Indian, African American, and Caucasian participants. Consistent with the findings of Bakas and colleagues (2002), this study found that African American caregivers' needs and

concerns were mostly similar to that of their counterparts, although in the current study they expressed wishes for much more instrumental support. American Indian caregivers expressed one particular culturally related concern, namely, healthcare providers' perceptions of social gatherings such as Pow Wows. For example, the caregiver who expressed concern that her husband's stroke symptoms were misdiagnosed as a drunken stupor is concerning because those with type 2 diabetes are twice as likely to experience a stroke (Goldstein et al., 2001; Lloyd-Jones et al., 2010). However, assuming the perceptions of the participant were accurate, this situation would reflect more on the health providers' behavior than on cultural factors per se.

One possible explanation for the similarities of needs and concerns among American Indian, African American, and Caucasian caregivers is the phenomenon of acculturation. In particular, most American Indians who do not live on reservations have probably become acculturated to the Western culture.

### **Limitations**

The small convenience sample for this study may not be representative of the national population of American Indian, African American, and Caucasian caregivers. For example, American Indians living on reservations may well have different needs. Further, lack of differences among cultural groups may be related to the use of an existing framework that did not probe for cultural variations such as cultural beliefs and practices related to diabetes management. Results could have been strengthened by collecting more detailed information including health insurance coverage, caregiver perception of the patient's health status and co-morbidities experienced by patients. Some may consider telephone interviewing as a limitation in qualitative research; however, Pettinari and Jessopp (2001) pointed out that "your ears become your eyes" in a telephonic intervention and that interveners often develop different skills to "compensate for the absence of visibility" (p. 668). Additionally, telephone interviews increase access to diverse participants with limited resources. Despite these limitations, this study provides valuable insight into the needs and concerns of these Midwest caregivers and has implications for health practices.

### **Implications for Practice**

Changes in health care have resulted in early hospital release of patients; in turn, family caregivers are given less time to learn how to deliver in-home care. Using a common framework is an effective way to look at the needs of family caregivers, including those across cultures. The needs and concerns framework (see Table 4) derived from Bakas et al. (2002) and Welch et al. (2013) and adapted to caregivers of type 2 diabetes was supported by the findings in this study and provides a way for healthcare providers in this context to systematically assess family caregiver needs. These needs may include those that fall outside of the healthcare providers' scope of practice, such as respite care or financial concerns, and may require referral to a social worker. Though few cultural differences were noted in this sample, healthcare providers are encouraged to take culture into consideration when assessing the needs and concerns of caregivers.

### **Implications for Future Research**

Identifying the needs and concerns of family caregivers of persons with type 2 diabetes is prerequisite to designing future intervention studies for this population. The needs and concerns framework used in this study has been supported by studies focused on stroke, hemodialysis, and now type 2 diabetes. For example, the framework has been used to develop a telephone intervention program for stroke caregivers that has preliminary evidence of efficacy (Bakas et al., 2009a) and satisfaction (Bakas et al., 2009b) and is currently being tested in a larger randomized controlled clinical trial. The current framework, adapted for caregivers of adults with type 2 diabetes, also may be used in future studies to develop an assessment checklist. This checklist could be used to develop an intervention similar to the Telephone Assessment and Skill-Building Kit (TASK) intervention (Bakas et al., 2009a; Bakas et al., 2009b) while ensuring that the intervention is culturally sensitive and targeted specifically to caregivers of those with type 2 diabetes. Findings from this study provide information that may be useful to the future

development of interventions designed to support family caregivers of persons with type 2 diabetes.

## Chapter 4

This chapter presents the results of the manuscript, “The Diabetes Caregiver and Support Scale: Development and Psychometric Testing.”

Lisa J. Scarton, PhD(c), RN  
Jonas Scholar and PhD Student  
Indiana University School of Nursing  
1111 Middle Drive, NU 413  
Indianapolis, IN 46202  
Office: 812-345-0523  
Fax: 317-274-2996

Tamilyn Bakas, PhD, RN, FAHA, FAAN  
Professor and Jane E. Procter Endowed Chair  
University of Cincinnati College of Nursing  
3110 Vine Street, PO Box 210038  
Cincinnati, OH 45219-2068

Wendy R. Miller, PhD, RN, CCRN  
Assistant Professor  
Indiana University School of Nursing  
1033 E. Third Street  
Bloomington, IN 47405

Susan M. McLennon, PhD RN  
Science of Nursing Care  
Indiana University School of Nursing  
1111 Middle Drive, NU 413  
Indianapolis, IN 46202

Lesa L. Huber, PhD  
Associate Clinical Professor  
Indiana University School of Public Health-Bloomington  
Bloomington, Indiana

Margie A. Hull, MEd., MSN, ACNS-BC, CDE, RN  
Diabetes Clinical Nurse Specialist, Certified Diabetes Educator  
Eskenazi Health  
720 Eskenazi Avenue  
Indianapolis, IN 46202

## Chapter 4 Abstract

**Background:** The support that family caregivers provide to persons with type 2 diabetes can be influential in diabetes self-management; however, family caregivers often experience poor physical and mental health as a result of their caregiving role. Available tools for this population focus primarily on the help caregivers provide from the patient's perspective and are not diabetes-specific.

**Purpose:** To develop and psychometrically test the D-CASS, which measures how difficult or easy caregiver activity and supportive behaviors are for family caregivers of persons with type 2 diabetes.

**Methods:** Psychometric testing of the D-CASS with 101 family caregivers of persons with type 2 diabetes was conducted using item analysis, internal consistency reliability, test-retest reliability, criterion-related validity, and construct validity. Family caregivers were predominately female (82.2%), spouses (50.2%), and American Indian (17%), African American (24%), or White (55%).

**Results:** Evidence of internal consistency reliability ( $\alpha = .82$ ) was provided for the D-CASS, with item-total correlations of .39 to .63. Two-week test-retest reliability was supported by an intraclass correlation coefficient of 0.70. Criterion-related validity was supported with a single-item criterion measuring overall how easy or difficult it is for caregivers to provide care for their loved ones ( $r = .65, p < .01$ ). Unidimensionality was supported by factor analysis, loadings ranged from .45 to .70, with 32% of the variance explained by the first factor (eigenvalue = 4.02). Using three hierarchical multiple regressions, evidence of construct validity was obtained.

**Conclusion:** The 11-item D-CASS is a brief and easy-to-administer instrument that has evidence of reliability and validity in family caregivers of persons with type 2 diabetes. The D-CASS may play an important role in identifying priority areas of interventions and may be used as an outcome measure for caregiver research.



Approximately 21 million Americans have been diagnosed with diabetes (ADA, 2014). The leading cause of complications from diabetes includes stroke, kidney failure, and non-traumatic lower-limb amputations (ADA, 2014; CDC, 2014). Type 2 diabetes accounts for more than 90% of these cases (ADA, 2014) and requires individuals to make difficult lifestyle changes. Most of the lifestyle changes essential to managing this disease take place in the home environment. For this reason, family members play an important role in the management of diabetes, often providing necessary support and care to promote self-management of this disease (Strom & Egede, 2012; Trief et al., 2001). Family caregivers are defined broadly as any relative, partner, or friend who provides an extensive range of assistance and support to a person with a chronic condition such as type 2 diabetes (Family Caregiver Alliance, 2006). Studies have shown that family support can be influential in self-management of diabetes and on diabetes outcomes (Van Dam et al., 2005).

Despite the important role of caregivers in the context of type 2 diabetes, little research has been conducted with this population (Rintala et al., 2013; Scarion, Bakas, Poe et al, 2014). Available tools for this population focus primarily on the help caregivers provide from the patient's perspective. There are no tools that focus on the activities and support caregivers provide that are from their own perspective. Because of the key role of family members, such a tool is needed to study this population and to serve as an important outcome measure for future interventions.

Sinclair and colleagues (2010) conducted a study with 83 caregivers of persons diagnosed with diabetes. Of those caregivers, 53% said they felt overwhelmed by their caregiving activities and 39% felt the activities were a physical strain. Interventions are needed to support these family caregivers and to help decrease negative health effects (Rintala et al., 2013); however, an essential step in developing interventions is to understand and measure the difficulty of caregiving activities and supportive behaviors caregivers are faced with on a daily basis. Unfortunately, no instruments were found in the literature with documented evidence of

reliability and validity to help measure these diabetes-specific caregiving activities in this population. Therefore, the aim of this study was to develop and psychometrically test the D-CASS. This scale was specifically designed to measure the difficulty of caregiver activities and supportive behaviors for family caregivers of persons with type 2 diabetes. The research questions guiding this study were:

1. Does the D-CASS show evidence of internal consistency reliability and test-retest reliability?
2. Does the D-CASS show evidence of content validity?
3. Does the D-CASS show evidence of criterion-related validity?
4. Does the D-CASS show evidence of construct validity using factor analysis?
5. Does the D-CASS show evidence of construct validity guided by a conceptual model (see Figure 1) derived from Bakas, Champion et al. (2006) and Lazarus and Folkman (1984)?

### **Conceptual Definitions**

Caregiver activities and support are defined as activities and supportive behaviors that caregivers engage in to assist their loved ones with type 2 diabetes. The five main categories of caregiver activities and support were derived and adapted from previously identified needs and concerns of stroke caregivers (Bakas et al., 2002) and daily home hemodialysis caregivers (Welch et al., 2013) and were found to be consistent with the needs and concerns of family caregivers of persons with type 2 diabetes (Scarton, Bakas, Miller et al., 2014; Scarton, Bakas, Poe et al., 2014). The five categories include:

1. Information and resources support (e.g., information on warning signs of complications, knowledge of healthy meal plans or medications)
2. Emotional and behavioral support (e.g., encouraging the care recipient, supporting the care recipient during times of anxiety, frustration, or depression)

3. Physical care (e.g., meal preparation, assisting with medication and blood glucose monitoring)
4. Instrumental care (e.g., finances, transportation)
5. Dealing with one's own personal responses to caregiving (e.g., new responsibilities, one's own emotions and health)

### **Conceptual Model**

Bakas and colleagues' caregiver conceptual model (Bakas, Champion et al., 2006), which is based on Lazarus and Folkman's theory of stress, appraisal, and coping (Lazarus & Folkman, 1984) guided the psychometric testing of the D-CASS. The premise of Lazarus' theory is that personal and environmental factors, which are mediated by threat appraisal, result in emotional and adaptational outcomes specific to a particular situation such as caregiving. Personal and environmental factors such as optimism or perceived difficulty of caregiver activities (i.e., D-CASS), respectively, influence how a caregiver appraises his or her ability to provide future care (i.e., threat), which then is associated with emotional and adaptational outcomes. Depressive symptoms represent emotional outcomes, whereas life changes and unhealthy days represent adaptational outcomes.

### **Background and Significance**

More research is needed in the area of family caregivers of persons with type 2 diabetes (Fisher et al., 1998; Rintala et al., 2013); however, connections are being developed between family caregiver support and patients' health behaviors and their psychological well-being (Martire & Schulz, 2007). A systematic review of persons with type 2 diabetes and their caregivers underscored the limited research that exists on caregivers (Rintala et al., 2013). Of those studies included in the review, only 13 of the 29 studies addressed the caregiver, with the majority of these focusing on the impact caregiver support had on diabetes self-management outcomes (e.g., improved A1C levels, weight loss; Rintala et al., 2013).

There is a paucity of studies that examines the perceived difficulty of caregiver activities and supportive behaviors. Findings from an integrative review (Scarton, Bakas, Miller et al., 2014) on the needs and concerns of family caregivers of persons with type 2 diabetes revealed that caregivers have a perceived lack of knowledge regarding how to help support care recipients in managing their diabetes, as well as how to support care recipients who are experiencing depressive symptoms. Caregivers also struggled with finding information and resources about type 2 diabetes and dealing with their own personal responses to their caregiving role. Better understanding of what activities caregivers perceive as being difficult is needed to identify the type of supportive intervention that would be most helpful.

A number of diabetes-specific tools are available to measure family support behaviors, including the DFBC-II (Glasgow & Toobert, 1988) and the MDQ (Talbot et al., 1996). The DFBC-II has evidence of reliability and validity in measuring family members' supportive versus unsupportive behaviors toward the person with diabetes, whereas the MDQ measures perceptions of the person with diabetes regarding social support, diabetes management, and positive versus misguided family support behaviors such as nagging (Talbot et al., 1996). These tools are helpful in understanding how family support behaviors affect self-management outcomes such as adherence for the person with type 2 diabetes; however, they are not useful in understanding how caregivers perceive the care activities and support behaviors they perform on a regular basis. For example, items on the MDQ ask questions such as, "To what extent does your spouse (or significant other) support you with your diabetes?" (Talbot et al., 1996).

There are a variety of tools that have been developed to measure caregiver activities in other chronic diseases such as cancer and stroke. The OCBS (Carey et al., 1991) was originally developed to measure time spent and task difficulty in caregivers of cancer survivors. This instrument has been psychometrically tested in caregivers of cancer and stroke survivors (Bakas et al., 2004). Although the OCBS is a useful assessment tool, a more sensitive diabetes-specific tool is needed to determine care activity difficulty for caregivers of persons with type 2 diabetes.

Another instrument that measures caregiver outcomes is the BCOS (Bakas & Champion, 1999). This instrument measures stroke-specific life changes experienced by caregivers of stroke survivors. Although this tool has been useful in measuring caregiver changes in social functioning, subjective well-being, and physical health, it does not measure caregivers' perception of difficulty or ease with caregiver activities or support.

Much of the current diabetes research focuses on how to improve diabetes self-management outcomes for persons with type 2 diabetes. Although it is now acknowledged that family caregivers play a vital role in this process, little attention has been directed toward the caregivers and how their caregiving activities may affect their own emotional and physical health. The proposed instrument, D-CASS, by accessing perceived difficulty or ease with caregiver activities and support, will provide an important scale that may serve as a future outcome measure in evaluating interventions to support family caregivers of persons with type 2 diabetes.

## **Methods**

### **Instrument Development**

The items in the D-CASS were developed using current diabetes literature (Scarton, Bakas, Miller et al., 2014) and the results of a qualitative study that explored the needs and concerns of family caregivers of persons with type 2 diabetes (Scarton, Bakas, Poe et al., 2014). Participants in this study consisted of 33 ethnically diverse family caregivers living in the Midwest. Telephone interviews using a semi-structured interview guide (see Appendix C) took place over a span of seven months. The five main categories, previously listed, for caregiver activities and support, were corroborated by the findings in this study. No additional categories emerged, which indicated that the categories were broad enough to be applicable to this population. The items in the D-CASS were generated from these five main categories. The initial questionnaire had 80 items that were generated using caregiver quotes along with 10 items that were generated based on current diabetes literature which led to a total of 90 items.

## **Content Validity**

Content validity was established with the help of six experts who evaluated the item pool (Lynn, 1986). The experts consisted of four doctorally prepared researchers (two with expertise in family caregiver research and two with expertise in diabetes research) and two master's level-prepared nurses (both are diabetes clinical nurse specialists). These experts were asked to match each of the items with one of the five categories then to rank the relevancy and clarity of each item as well as the comprehensiveness of the instrument (Grant & Davis, 1997). Experts rated each item on a 4-point scale ranging from 1 (*not relevant*) to 4 (*very relevant*). Additionally, experts were asked to provide comments for item revision and overall instrument improvement.

Using items rated by experts, content validity index of each item (I-CVI) as well as the content validity index for the overall scale (CVI) was computed. The I-CVI is the proportion of experts who assigned a rating of 3 (*moderately relevant, needing minor changes*) or 4 (*very relevant and succinct*) to each item. Lynn (1986) recommends using an I-CVI of .83 when six or more experts are used. The range of I-CVI for this instrument was .86–1.0 with all 90 items meeting the .83 cut-off. Twenty-one of the 90 items were rated by one of the experts as a 1 or 2.

The CVI for the entire instrument is the proportion of total items judged content valid by the experts (Lynn, 1986). The CVI was calculated using the percentage of the total I-CVIs, with .80 considered an acceptable CVI (Davis, 1992). The CVI for the entire instrument was 1.0 (90 out of 90 items were judged content valid by the experts).

Experts also were asked to match each of the items with one of the five nominated categories. Of the 90 items, 42 had been assigned to incorrect categories by two or more experts, indicating potential overlapping or complex concepts. Although these 42 items had acceptable I-CVI, 38 of the 42 items were removed from further analysis as a result of overlapping or complex concepts. The remaining four items were retained because of conceptual importance and were modified based on expert recommendations. There were 48 items that had both acceptable I-CVI

ratings and were placed in expected categories by at least five of the six experts. Each of these items was evaluated and decisions were made whether to retain or modify the item based on the expert's comments. Thirty-seven of the items were kept as written and one item was eliminated. The remaining 10 items were modified based on expert recommendations. Therefore, a total of 51 items, across five main categories, (information and support 11; emotional and behavioral 11; physical care 15; instrumental care 4; take care of oneself 10) were on the scale to be psychometrically evaluated. Findings from this study show evidence of content validity of the D-CASS in family caregivers of persons with type 2 diabetes.

### **Psychometric Testing of the D-CASS**

#### **Design and Sample for Pilot Testing**

Design: A cross-sectional, descriptive-correlational design.

Sample: A convenience sample of 101 family caregivers of persons with type 2 diabetes was attained for the pilot study (Clark & Watson, 1995). *Inclusion criteria* included that participants must be: (1) 18 years or older, (2) a primary unpaid caregiver of an adult with type 2 diabetes, and (3) able to read and converse in English. *Exclusion criteria* included: (1) caregiver does not consider himself or herself a caregiver, stating that the patient does not require support, or (2) care recipient resides in a nursing home or long-term care facility.

#### **Procedures**

Initial approval of the university institutional review board for the protection of human subjects was attained prior to the start of the study. All participants were given full information about the nature, purpose, voluntary participation, and possible risks and benefits of the study. Only authorized study personnel had access to the database, contact information, or linkages between study identification numbers and participants enrolled in the study. Participants were not identified in reports or manuscripts from the study. All paper forms and study materials were stored in locked file cabinets accessible only to authorized study personnel. All computers, servers, and electronic files used in the study were password protected, accessible only to

authorized study personnel. Authorized study personnel included the investigators and research staff involved in the study.

Recruitment/Data Collection: Recruitment strategies used.

(1) Study brochures were created and distributed and included detailed information about the study, a telephone number to call with questions, and a self-addressed postage-paid response card. Study brochures were placed at locations where individuals with type 2 diabetes were likely to visit such as local hospitals and diabetes centers. Study brochures also were available through Facebook®. Interested participants had the option to either click on a link provided on Facebook® that took them directly to the study information sheet and the questionnaire, or participants could call the telephone number provided on Facebook® for more information or to complete the questionnaire over the telephone.

(2) Study brochures were distributed at statewide American Indian Pow Wows. A separate table was provided at the event for individuals who were interested in completing the interview process during the event. Individuals also had the option to take the study brochure and response card and mail the self-addressed postage-paid response card at a later time.

(3) Study brochures also were used to recruit participants from a large hospital in the Midwest. Potential participants from this facility initially were identified by the diabetes clinical nurse specialist. The diabetes clinical nurse specialist distributed study brochures to patients with type 2 diabetes or their family caregivers. Individuals interested in participating in the study completed the self-addressed postage-paid response card and returned the response card to the diabetes clinical nurse specialist. Response cards returned to the diabetes clinical nurse specialist were forwarded to the research team.

(4) Individuals from a previous caregiver study who indicated they would like to be notified of future caregiver studies also were contacted. Participants who were interested in being a part of the study were mailed a study brochure.



All participants received a study information sheet that detailed the purpose of the study, study procedures, potential risks/benefits, and how confidentiality would be maintained during the study. Individuals who self-referred by returning the response card received the study information sheet by mail. The study information sheet was explained to interested family caregivers, if eligible, and if they provided verbal informed consent, the caregiver was enrolled. At the time of the interview, caregivers were asked if they were willing to participate in a second interview two weeks later. All data was collected over the telephone, face to face, or through a link provided on Facebook®, and information was recorded on paper forms and/or in Redcap®, a secure, web-based application designed to support data capture for research projects. No names or identifying information was linked with any of the paper forms. Those who were eligible and chose to participate received a \$20 gift card in appreciation for completing the questionnaires. Participants who chose to participate in the second interview received an additional \$10 gift card.

### **Instrumentation**

Demographic Questionnaire: Data regarding demographics for patient and caregiver including age, gender, race/ethnicity, education, type of housing, number of years with diabetes, number of years as a caregiver, employment status, and household income were collected from eligible participants and used to describe the sample. Descriptive statistics (e.g., frequencies, percent, means, standard deviations, and ranges) was used to describe the sample using SPSS® version 23.0. The Chronic Conditions Index (Cornoni-Huntley et al., 1986) is an 17 item scale used to measure chronic conditions such as high blood pressure, heart conditions, lung disease, cancer, and other conditions measured using a response scale of 1 (*yes*) or 2 (*no*). Diabetes-specific items were added to the index such as kidney problems, neuropathy, retinopathy, foot problems, and depression. Caregivers reported their own co-morbidities as well as the care recipient's co-morbidities. This instrument has evidence of face validity (Cornoni-Huntley et al., 1986) and has been used in other caregiver studies (Schulz et al., 1995).

To test for construct validity, measures for each of the constructs in the conceptual module (see Figure 1) were included in the study. The LOT-R was used to measure caregiver optimism (Scheier et al., 1994). The scale consists of six scored items. Respondents indicated the degree of agreement using a 5-point Likert scale with summed scores ranging from 0 (*strongly disagree*) to 4 (*strongly agree*) with higher scores indicating greater optimism. The LOT-R has been used in various settings including with family caregivers and has shown evidence of reliability and validity (Bakas, Champion et al., 2006; Scheier et al., 1994). The D-CASS is a new instrument that measured the perceived difficulty of caregiver activities and supportive behaviors for family caregivers using a 7-point response scale ranging from -3 (*extremely difficult*) to +3 (*extremely easy*). Items were recoded from 1 to 7 to provide positive numbers for analysis with summed lower scores indicating more caregiver activity and support difficulty. The ACS was used to measure perceived threat related to the caregiver's role (Carey et al., 1991). The 12 items are rated on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree*. Individual item scores are summed for a total score with higher scores reflecting higher levels of threat. Internal consistency reliability has been reported in studies of family caregivers of stroke patients (Bakas & Burgener, 2002).

The PHQ-8 is an 8-item questionnaire that was used to measure depressive symptoms experienced by caregivers (Kroenke & Spitzer, 2002; Kroenke et al., 2001; Kroenke, Strine, Spitzer, Williams, Berry, & Mokdad, 2009). Item responses are scored on a 4-point scale ranging from *not at all* to *nearly every day* with summed scores ranging from 0 (*no depression*) to 24 (*all symptoms occurring daily*). The PHQ-8 has established reliability and validity in the primary care population (Kroenke & Spitzer, 2002; Kroenke et al., 2001). The BCOS is a 15-item scale used to measure life changes as a result of providing care (Bakas, Champion et al., 2006). The 15 items are scored on a 7-point scale ranging from -3 (*changed for the worse*) to +3 (*changed for the best*). Items were recoded from 1 to 7 to provide positive numbers for analysis with summed lower scores indicating more caregiving-related negative life changes. Evidence of reliability and

validity has been shown in family caregivers of stroke patients (Bakas, Champion et al., 2006; Bakas & Champion, 1999). The Unhealthy Days, a 4-item questionnaire, was used to measure health-related quality of life. Unhealthy days were calculated by summing responses to questions two and three with a total score ranging from 0 days to 30 days with higher numbers indicating more unhealthy days. Validity and reliability have been reported for this instrument (CDC, 2000; Hennessy et al., 1994).

### **Data Analysis**

**Internal consistency reliability.** Cronbach alpha was used to show internal consistency reliability. An internal consistency reliability of .70 is satisfactory for new scales (DeVellis, 2012). Inter-item correlations were assessed to determine how well the items relate to one another. Items with an average inter-item correlation between .30 and .70 were retained (Ferketich, 1991). Items that fell below .30 were examined for low correlation. Items with low correlation were deleted if doing so did not decrease Cronbach's coefficient. Items that have inter-item correlation above .70 were examined for redundancy. Items that were highly correlated and were not likely to affect the validity of the scale were deleted. Item-to-total correlations and item analysis also were computed to assess for good variability in relation to the means and floor and ceiling affect.

**Test-retest reliability.** Test-retest reliability was used to assess the stability of the instrument. The D-CASS was administered to a subsample of participants who agreed to be interviewed twice, approximately two weeks apart. Intra-class correlation (ICC) was used to examine within-person variation and test-to-test variation (Yen & Lo, 2002). An ICC score of .61 or greater, indicating substantial agreement between the two scores, was considered satisfactory for this study (Landis & Koch, 1977).

**Criterion-related validity.** Due to a lack of an established instrument that measures similar constructs as the D-CASS, evidence of criterion-related validity was assessed through correlations using a single-item criterion measuring how easy or difficult it is for caregivers to

provide care for their loved ones overall. Criterion-related validity was assessed by using Pearson  $r$  correlation coefficients between the overall D-CASS measure and the single-item criterion.

**Construct validity.** Factor analysis and testing the model relationships was used to provide evidence of construct validity. The Bartlett test of sphericity and the Kaiser-Meyer-Olkin (KMO) Index were used to support the use of factor analysis (Munro, 2005). Exploratory factor analysis using principal axis factoring was used to assess dimensionality of the scale, and varimax rotation was used to increase factor interpretability (Waltz, Strickland, & Lenz, 2010). The eigenvalue (values less than 1) and scree test (factors below the *elbow* or where the slope of the curve distinctly levels out) was used to determine the number of factors to extract from the scale (Cattell, 1966; DeVellis, 2012). Testing of the model relationships was done by using hierarchical multiple regression to access for further evidence of construct validity.

## Results

### Sample Characteristics

Sample characteristics for the participants are summarized in Table 5. A total of 101 caregivers participated in the study. Among them, 17% were American Indian, 24% were African American, 55% were White, and .05% reported another race. The mean age of the participants was 51.03 ( $SD$  17.6) years. The majority of caregivers were female (82.2%), spouses (50.2%), adult children (18.8%), friend (5.0%), and other (25.7%). Many of the caregivers reported they had just enough income to make ends meet (45.5%) while 13.9% did not have enough income to make ends meet. The average number of years providing care was 8.24 with a range of 8 months to 33 years. Care recipients lived with type 2 diabetes for an average of 11.2 years with a range of 8 months to 40 years. The caregiver and care recipient had similar years of education (13.67 and 12.9, respectively). Three significant differences were noted across the three groups: relationship to the care recipient, age of the caregiver, and gender of the care recipient. White caregivers were significantly more likely to care for their spouse compared to African Americans and American Indians who were significantly more likely to care for other family members  $\chi^2 = (2, N = 101) =$

11.75,  $p = .003$ . White caregivers were also significantly more likely to be older compared to African American and American Indian caregivers ( $F(3,96) = 3.07, p = .031$ ). Lastly, White care recipients were significantly more likely to be male than African American or American Indian care recipients  $\chi^2 = (2, N = 101) = 10.58, p = .007$ .

Table 5

*Sample Characteristics*

Caregiver	American Indian <i>n</i> = 17 (17%)		African American <i>n</i> = 24 (24%)		Caucasian <i>n</i> = 55 (54%)		Statistics	
	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>f</i> (%)	<i>M</i> ( <i>SD</i> ) Range	<i>df</i>	<i>F</i> ( <i>df</i> )
Age		46.88 (17.22) 20–74		47.21(15.32) 24–76		55.42(17.74) 20–85		<i>F</i> (3,96) = 3.07 <i>p</i> = .031
Gender								
Male	3(17.6)		4(16.7)		9(16.4)		.015 <sup>a</sup>	
Female	14(82.4)		20(83.3)		46(83.6)		(2) <i>p</i> = .992	
Years Educ.		12.82(1.29) 11–15		14.08(2.08) 10–18		13.53(2.69) 7–21		<i>F</i> (3,96) = 1.531 <i>p</i> = .211
Income								
Comfortable	5(29.4)		9(37.5)		24(43.6)		1.528 <sup>a</sup> (4)	
Just enough to make ends meet	9(52.9)		11(45.8)		25(45.5)		<i>p</i> = .822	
Not enough to make ends meet	3(17.6)		4(16.7)		6(10.9)			
Relationship								
Spouse	7(41.2)		6(25)		36(65.5)		11.747 <sup>b</sup> (2)	
							<i>p</i> = .003	
							phi = .350	

Son or daughter	3(17.6)		8(33.3)		7(12.7)		
Other relative	1(5.9)		2(8.3)		3(5.5)		
Friend	1(5.9)		2(8.3)		2(3.6)		
Other	5(29.4)		6(25)		7(12.7)		
Years of caregiving		7.88(3.82) 2–15		7.01(7.00) .17–30		9.00(8.24) .08–33	$F(3,96) = .447$ $p = .720$
Care Recipient		American Indian $n = 17$ (17%)		African American $n = 24$ (24%)		Caucasian $n = 55$ (54%)	Statistics
Age		59.43(11.03) 41–85		60.78(12.5) 29–85		62.24(13.28) 19–83	$F(3,100) = 580$ $p = .630$
Gender							
Male	10(47.6)		10(43.5)		42(76.4)		10.058 (2) $p = .007$ $\phi = .319$
Female	11(52.4)		13(56.5)		13(23.6)		
Years Educ.		12.86(2.29) 8–16		11.83(3.38) 0–18		13.31(2.28) 8–20	$F(3,100) = 2.659$ $p = .053$
Years with type 2 diabetes		12.88(8.85) .50–40		11.96(8.28) .17–30		10.07(7.66) .08–30	$F(3,100) = .886$ $p = .452$

Note. Expected<sup>a</sup> is less than 5. Relationship<sup>b</sup> for Chi Square was run as spouse verses non-spouse.

## Measures

Scale means, variances, and Cronbach's alphas ranging from .75–.94 are listed in Table 6. Six of the scales showed significant nonnormality ( $p < .001$ ) after square root and log transformation were computed for the variables, as recommended by Tabachnick and Fidell (2013). However, the residual plot suggests multivariate normality, and the tests used have been found to be robust under the application of non-normally distributed data (Schmider, Ziegler, Danay, Beyer, & Buhner, 2010).

Table 6

### *Descriptive Statistics for Measures*

Measure	No. of items	<i>n</i>	<i>M</i> ( <i>SD</i> )	(Possible Range) Actual Range	Cronbach's Alpha
D-CASS	11	101	44.1(12.3)	(11–77) 20–70	.82
LOT-R	6	100	15.3(3.9)	(0–24) 5–24	.75
ACS	12	98	32.4(9.0)	(12–60) 13–60	.92
PHQ-8	8	98	4.1(4.1)	(0–24) 0–17	.82
BCOS	15	98	63.1(14.5)	(15–105) 32–105	.94
Unhealthy Days	2	98	8.3(10.8)	(0–30) 0–30	NA
CCI <sup>a</sup>	17	98	2.2(1.8)	(0–17) 0–8	NA
CCI <sup>b</sup>	17	98	4.2(2.4)	(0–17) 0–10	NA

<sup>a</sup>Chronic Conditions Index CG Index. <sup>b</sup>Chronic Conditions Index CR Index.

## Item Analysis

Item analysis for the 51-item D-CASS involved deletion of 18 items with inter-item correlations below .30 or above .70, indicating low correlation or item redundancy, respectively (Ferketich, 1991). Other items deleted were items with high ceilings (18 items) and low factor loadings (3 items). Item statistics are shown in Table 7 with item means ranging from 3.41 (*counting carbohydrates when preparing meals*) to 4.54 (*listen to the person with diabetes when he or she experiences depressive symptoms*). Item means indicated that counting carbohydrates when preparing meals and the caregiver dealing with their own feelings were most difficult, while listening to the person with diabetes when he or she experiences depressive symptoms and



helping the person stabilize his or her blood sugar were the easiest. Corrected item-total correlations were acceptable and ranged from .39 to .63. The ceiling and floor effects both ranged from 5% to 20.8%.

Table 7

*Item Statistics and Factor Loadings for the Final D-CASS Scale*

D-CASS Items	<i>M(SD)</i>	% Ceiling	% Floor	Corrected Item-to-Total Correlation	Alpha If Item Deleted	Factor Loadings
1. Listen to the person with diabetes when he or she experiences depressive symptoms (sadness)	4.54(1.781)	16.8	5.0	.42	.81	.45
2. Avoid nagging	3.96(1.969)	11.9	13.9	.39	.82	.45
3. Prepare a range of meals that appeal to the person with diabetes	4.04(1.902)	13.9	9.9	.40	.82	.48
4. Count carbohydrates when preparing meals for the person with diabetes	3.41(1.716)	5.9	17.8	.42	.81	.50
5. Help the person stabilize his or her blood sugar (keep it from going really high or low)	4.48(1.973)	20.8	7.9	.50	.81	.54
6. Exercise with your loved one to help encourage physical activity	3.76(2.094)	12.9	20.8	.53	.80	.57

Table continues

7. Deal with your feelings (fear, worry) related to your loved one having diabetes associated complications (low blood sugar, kidney disease)	3.49(1.665)	5.0	10.9	.54	.80	.62
8. Balance your life now that you have caregiving responsibilities	3.93(1.883)	10.9	11.9	.63	.79	.70
9. Take care of your own health needs	4.21(1.796)	10.9	9.9	.53	.80	.62
10. Keep your energy level up while caring for the person with diabetes	4.34(1.818)	16.8	5.0	.51	.81	.62
11. Take time to relax	3.99(1.916)	14.9	9.9	.52	.81	.62

---

### **Internal Consistency Reliability**

Internal consistency reliability was supported for the 11-item D-CASS (Table 7) with a Cronbach's  $\alpha$  coefficient of .82 indicating high internal consistency reliability ( $N = 101$ ). A subsample of 46 participants completed the D-CASS two-weeks later, with a Cronbach  $\alpha$  of .84. The ICC was .70 suggesting substantial agreement (Landis & Koch, 1977).

### **Criterion-related Validity**

Criterion-related validity was supported by the 11-item D-CASS correlation with a single-item criterion measuring overall how easy or difficult it is for caregivers to provide care for their loved ones ( $r = .65, p < .01$ ).

### **Construct Validity Using Factor Analysis**

The Bartlett's test of sphericity ( $P = .000$ ) and the Kaiser-Meyer-Olkin index (KMO value = .80) was used to support the use of factor analysis (Munro, 2005). Tinsley and Tinsley (1987) recommend 3–5 participants per item for scale development. For the 11-item scale, 101 participants exceeded this recommendation. Exploratory factor analysis with principal axis factoring with varimax rotation was used because theoretically factors were presumed to be unrelated and varimax rotation will increase factor interpretability (Waltz et al., 2010). Factor analysis loadings are shown in Table 7. Exploratory factor analysis using an unrotated one-factor solution supported unidimensionality of the D-CASS with factor loadings ranging from .45 to .70 with 32% of the variance explained by the first factor (eigenvalue = 4.02). Using the eigenvalue rule of 1.0 two factors were suggested for further analysis. Exploratory factor analysis using principal axis factoring varimax rotation did not produce any additional interpretable factors. Additionally, examination of the scree plots favored a one-factor solution. The unidimensional one-factor solution provided evidence of construct validity for the total 11 item D-CASS score.

### **Construct Validity Guided by a Conceptual Model**

To further test for construct validity hierarchical multiple regression was conducted guided by the conceptual model in Figure 1. Prior to conducting hierarchical multiple regression, relevant assumptions were tested. Review of the residual and scatter plots indicated the assumptions of normality, linearity, and homoscedasticity were met (Tabachnick & Fidell, 2013). The assumption of singularity also was met as the independent variables were not a combination of other independent variables. Lastly, the assumption of multicollinearity was met as the collinearity statistics (tolerance and variance inflation factor) did not exceed the recommended values, .10 and 10, respectively (Tabachnick & Fidell, 2013). Due to missing data, 98 out of 101 participants were entered into the analysis. This meet the requirements for testing regression,  $98 \geq 50 + 8(6) = 98$  (Tabachnick & Fidell, 2013).

Details of the three hierarchical multiple regression equations are displayed in Tables 8–10. The demographic variable, years of education, was entered in step 1 of the regression equation with depressive symptoms as the dependent variable (Table 8) accounting for 6.1% of the variance [ $F(1, 96) = 6.27, p < .05$ ]. Optimism and caregiving activity and support difficulty or ease were added in step 2 with the model accounting for an additional 25% of the variance [ $F(3, 94) = 14.12, p < .001$ ]. Threat appraisal was added in step 3 accounting for an additional 3% of the variance [ $F(4, 93) = 12.07, p < .001$ ]. Overall, the model constructs in step 3 accounted for 34% of variance (31% adjusted) for depressive symptoms. Years of education, optimism, and threat appraisal were significant individual predictors of depressive symptoms in the final model accounting for 5%, 8.9%, and 2.9% of unique variance, respectively, in depressive symptoms. Caregiving activities and support was a significant individual predictor only in step 2 with 2.5% unique variance, but once appraisal was added in step 3, it was no longer a significant individual predictor.

Table 8

*Hierarchical Multiple Regression PHQ-8*

Independent Variable	<i>B</i>	Beta	<i>t</i>	Bivariate <i>r</i>	Unique <i>r</i> <sup>2</sup>
Years of education	.38	.25	2.50*	.25**	.050
Step 1 <i>R</i> = .25, <i>R</i> <sup>2</sup> = .061; Adjusted <i>R</i> <sup>2</sup> = .052; <i>F</i> Change = 6.27*; <i>R</i> <sup>2</sup> Change = .061, <i>F</i> (1,96)=6.27*					
Years of education	.41	.27	3.12**	.25**	.050
LOT-R	-.36	-.34	-3.76***	-.41***	.089
D-CASS	-.09	-.28	-3.15**	-.38***	.025
Step 2 <i>R</i> = .56, <i>R</i> <sup>2</sup> = .31; Adjusted <i>R</i> <sup>2</sup> = .29; <i>F</i> Change = 17.11***; <i>R</i> <sup>2</sup> Change = .251, <i>F</i> (3,94)=14.12***					
Years of education	.35	.23	2.66**	.25**	.050
LOT-R	-.35	-.32	-3.56**	-.41***	.089
D-CASS	-.06	-.19	-1.87	-.38***	.025
ACS	.09	.21	2.05*	.41***	.029
Step 3 <i>R</i> = .59, <i>R</i> <sup>2</sup> = .34; Adjusted <i>R</i> <sup>2</sup> = .31; <i>F</i> Change = 4.21*; <i>R</i> <sup>2</sup> Change = .03 <i>F</i> (4,93) = 12.07***					

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

While screening for possible inclusion of independent variables for the regression model, African American participants scored significantly higher for life changes than American Indian and White caregivers. The *dummy coded* demographic variable, race (African American versus non-African American), was entered in step 1 of the regression equation with life changes as the dependent variable (Table 9) accounting for 10% of the variance [*F*(1, 96) = 10.05, *p* < .01]. Optimism and caregiving activity and support difficulty or ease were added in step 2 accounting for an additional 26% of the variance [*F*(3, 94) = 17.56, *p* < .001]. Threat appraisal was entered in step 3 and accounted for an additional 7% of variance [*F*(4, 93) = 17.79, *p* < .001]. Depressive symptoms in step 4 accounted for an additional 3% of variance [*F*(5, 92) = 15.66, *p* < .001]. Overall, the model constructs in step 4 accounted for 46% of the variance (43% adjusted) for life changes. African American race, caregiving activity and support difficulty or ease, threat

appraisal, and depressive symptoms were significant individual predictors of life changes in the final model accounting for 7.8%, 4.9%, and 2.6% of unique variance, respectively, in life changes.

Table 9

*Hierarchical Multiple Regression BCOS*

Independent Variable	<i>B</i>	Beta	<i>t</i>	Bivariate <i>r</i>	Unique <i>r</i> <sup>2</sup>
African American	10.3	.31	3.17**	.31**	.022
Step 1 <i>R</i> = .31, <i>R</i> <sup>2</sup> = .10; Adjusted <i>R</i> <sup>2</sup> = .09; <i>F</i> Change = 10.05**; <i>R</i> <sup>2</sup> Change = .10, <i>F</i> (1,96) = 10.05**					
African American	9.6	.29	3.46**	.31**	.022
LOT-R	-.002	-.001	-.01	.17*	.006
D-CASS	.60	.52	5.95***	.53***	.078
Step 2 <i>R</i> = .60, <i>R</i> <sup>2</sup> = .36; Adjusted <i>R</i> <sup>2</sup> = .34; <i>F</i> Change = 19.39***; <i>R</i> <sup>2</sup> Change = .26, <i>F</i> (3,94) = 17.56***					
African American	10.2	.30	3.87***	.31**	.022
LOT-R	-.12	-.03	-.384	.17*	.006
D-CASS	.43	.37	3.96***	.53***	.078
ACS	-.51	-.32	-3.50**	-.48***	.049
Step 3 <i>R</i> = .66, <i>R</i> <sup>2</sup> = .43; Adjusted <i>R</i> <sup>2</sup> = .41; <i>F</i> Change = 12.22**; <i>R</i> <sup>2</sup> Change = .07, <i>F</i> (4,93) = 17.79***					
African American	9.8	.29	3.77***	.31**	.022
LOT-R	-.33	-.09	-1.03	.17*	.006
D-CASS	.39	.33	3.64***	.53***	.078
ACS	-.43	.27	-2.88**	-.48***	.049
PHQ-8	-.69	-.19	-2.11*	-.42***	.026
Step 4 <i>R</i> = .68, <i>R</i> <sup>2</sup> = .46; Adjusted <i>R</i> <sup>2</sup> = .43; <i>F</i> Change = 4.46*; <i>R</i> <sup>2</sup> Change = .03, <i>F</i> (5,92) = 15.66***					

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

The demographic variable, income, was entered in step 1 of the regression equation with unhealthy days as the dependent variable (see Table 10) accounting for 8% of the variance [*F*(1, 96) = 7.87, *p* < .01]. Optimism and caregiving activity and support difficulty or ease were entered in step 2 accounting for an additional 21% of the variance [*F*(3, 94) = 12.81, *p* < .001]. Threat

appraisal was entered in step 3 accounting for an additional 2% of variance [ $F(4, 93) = 10.34$ ,  $p < .001$ ]. Depressive symptoms in step 4 accounted for an additional 9% of variance [ $F(5, 92) = 12.43$ ,  $p < .001$ ]. Overall, the model constructs in step 4 accounted for 40% of the variance (37% adjusted) for unhealthy days. Optimism and depressive symptoms were significant individual predictors of unhealthy days in the final model accounting for 2.8% and 9.5% of unique variance, respectively, in unhealthy days. Caregiving activity and support difficulty or ease was a significant independent predictor in steps 2 and 3 accounting for 2.2% of unique variance in unhealthy days; however, once depressive symptoms were added in step 4, it was no longer significant, likely as a result of shared variance.

Table 10

*Hierarchical Multiple Regression Unhealthy Days*

Independent Variable	B	Beta	t	Bivariate r	Unique r <sup>2</sup>
Income	4.4	.28	2.81**	.28**	.004
Step 1 $R = .28$ , $R^2 = .08$ ; Adjusted $R^2 = .07$ ; $F$ Change = 7.87**; $R^2$ Change = .08, $F(1,96) = 7.87$ **					
Income	1.1	.07	.746	.28**	.004
LOT-R	-.88	-.31	-3.33**	-.43***	.028
D-CASS	-.27	-.32	-3.35**	-.43***	.022
Step 2 $R = .54$ , $R^2 = .29$ ; Adjusted $R^2 = .27$ ; $F$ Change = 14.20***; $R^2$ Change = .21, $F(3,94) = 12.81$ ***					
Income	1.1	.07	.733	.28**	.004
LOT-R	-.84	-.30	-3.19**	-.43***	.028
D-CASS	-.21	-.24	-2.32*	-.43***	.022
ACS	.18	.12	1.54	.36***	.002
Step 3 $R = .56$ , $R^2 = .31$ ; Adjusted $R^2 = .28$ ; $F$ Change = 2.36; $R^2$ Change = .02, $F(4,93) = 10.34$ ***					
Income	1.1	.07	.811	.28**	.004
LOT-R	-.53	-.19	-2.06*	-.43***	.028
D-CASS	-.16	-.18	-1.84	-.43***	.022
ACS	.07	.06	.598	.36***	.002
PHQ-8	.97	.37	3.83***	.55***	.095
Step 4 $R = .64$ , $R^2 = .40$ ; Adjusted $R^2 = .37$ ; $F$ Change = 14.70***; $R^2$ Change = .09, $F(5,92) = 12.43$ ***					

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .



## Discussion

Family caregivers play a vital role in diabetes self-management and often provide the needed support and care to individuals with type 2 diabetes (Strom & Egede, 2012; Trief et al., 2001); however, much of the existing diabetes research focuses on how to improve diabetes self-management outcomes for persons with type 2 diabetes with little attention focused on the caregivers and how their caregiving activities and support may affect their own emotional and physical health. Additionally, existing measures for this population focus primarily on the help caregivers provide from the patient's perspective. Because of the important role family caregivers play, a tool was needed that focuses on the activities and support caregivers provide from their own perspective. Findings from this study provided evidence of reliability and validity for the 11-item D-CASS, which measures the difficulty or ease of caregiver activities and supportive behaviors for family caregivers of persons with type 2 diabetes.

Of the 90 items developed, 51 were judged as content valid by six experts. The creation of an item pool that is three to four times larger than the final scale is recommended to help ensure against poor internal consistency reliability (DeVellis, 2012). The final 11-item D-CASS showed evidence of internal consistency reliability. Similar to the MDQ that reported a Cronbach alpha range of .70–.90, the D-CASS had a Cronbach alpha of .82. The D-CASS is unique in that it measures perceived difficulty or ease of caregiving activities and support from the caregiver's perspective. In contrast, the MDQ was designed to measure social support, diabetes management, and positive versus misguided family support behaviors from the patient's perceptions (Talbot et al., 1996). Because family caregivers have an important role in diabetes self-management, having a tool that measures the difficulty or ease of activity and support behaviors is a necessary step in identifying supportive intervention for these caregivers.

Item analysis revealed important findings. Missing data were minimal; however, some of the items had high ceiling effects. Three of the items with the highest ceiling effects were *helping the person stabilize his or her blood sugar*, *listening to the person with diabetes when he or she*

*experiences depressive symptoms, and the caregiver keeping his or her energy level up while caring for the person with diabetes.* One possible reason for high ceiling effects may be that care recipients in this sample had well-controlled blood sugars which in turn may prevent or slow potential complications. Maintaining tight diabetes control has been found to consistently decrease diabetes-related complications and improve outcomes in persons with type 2 diabetes. (Clement, Bhattacharyya, & Conway, 2009; King, Peacock, & Donnelly, 1999). Another reason may be that caregivers in this sample might have already integrated caregiving activities into their daily lives. For example, some of the caregivers might have a system in place for helping to ensure they are able to keep their own energy level up while providing care.

It is also important to look at the D-CASS at an item level. Findings revealed that caregivers found certain aspects of providing care to be difficult as evidenced by high floor effects in items such as counting carbohydrates when preparing meals. Caregivers also found it difficult to deal with their own feelings such as fear or worry related to their loved one having diabetes and associated complications. These findings are similar to those found in a large multinational survey study designed to examine experiences of individuals with type 1 and type 2 diabetes, their family members, and health care providers (Burns et al., 2013). The findings of this large study reinforce the need for caregivers to be included in diabetes education. Providing specific education for family caregivers may help reduce the difficulty of these activities. For example, registered dietitians could teach caregivers how to effectively count carbohydrates using food labels or provide caregivers with a variety of healthy recipes. Additionally, diabetes clinical nurse specialists could offer psychosocial support by providing education to family members related to preventing or managing diabetes-related complications. Supporting family members by providing education could help validate their concerns and offer solutions that may decrease feelings of fear or worry and could, in turn, further support the care recipient (Burns et al., 2013; Sinclair et al., 2010).

Criterion-related validity was supported by a significant, highly correlated D-CASS association with a single item asking overall how easy or difficult it is for caregivers to provide care for their loved one ( $r = .65, p < .01$ ). The single item range was 1–7 with lower numbers indicating more difficulty providing care as a whole while higher numbers indicated less difficulty overall. The mean for this item was 4.8, falling close to the natural midpoint of 4.0.

Evidence of construct validity for the D-CASS was provided through exploratory factor analysis. An item is considered unidimensional if it measures a single construct (Netemeyer, Bearden, & Sharma, 2003). Principal axis factoring using a one-factor solution accounted for 32% of the variance on the first factor. Inspection of the scree plot confirmed a one-factor solution. However, a two-factor solution also was run since the eigenvalue for factor two was 1.28. Items that loaded on the two factors did not make conceptual sense, and several items had high loadings on both factors indicating conceptual overlap and providing further support of unidimensionality of the scale. Having a unidimensional scale is common in the caregiving literature (Bakas, Champion et al., 2006; Ballesteros, González-Faile, Muñoz-Hermoso, Dominquez-Panchón, & Martín-Carrasco, 2012; Lewin et al., 2005). For example, Bakas, Champion and colleagues' (2006) scale that measures life changes resulting from providing care to stroke survivors was unidimensional. The D-CASS as a unidimensional scale provides information on the ease or difficulty of caregiving activity and support behaviors and allows for the summing of the total score.

Additional support for construct validity of the scale was provided through testing of relationships using a conceptual model derived from Bakas, Champion and colleagues (2006) and based on Lazarus and Folkman's theory of stress, appraisal and coping (1984). Three separate hierarchical regression equations were used. The dependent variable depressive symptoms was explained by 34% of the model constructs with optimism ( $r^2 = 8.9\%$ ), years of education ( $r^2 = 5\%$ ), and threat appraisal ( $r^2 = 2.9\%$ ) being significant individual predictors. The literature as well as the conceptual model (see Figure 1) supports the correlation between caregiver optimism

and depressive symptoms (Carter, & Acton, 2006). For example, Carter and Acton (2006) had similar findings in their study of family caregivers of cancer patients. Findings indicated a significant moderate negative correlation between caregiver optimism and depressive symptoms. Caregivers who reported being more optimistic also reported fewer depressive symptoms (Carter & Acton, 2006). Being a family caregiver can be stressful, and it is possible that personal factors such as optimism may decrease depressive symptoms.

Caregiving activities and support was a significant individual predictor of depressive symptoms only in step 2 of the regression equation with 2.5% unique variance. Once appraisal was added in step 3, caregiving activity and support was no longer a significant individual predictor, suggesting that appraisal is likely a mediator, supporting Lazarus and Folkman's theory of stress, appraisal, and coping (1984). This finding is consistent with other caregiver studies of individuals with chronic illnesses (Bakas, Champion et al., 2006; Haley, Levine, Brown, & Bartolucci, 1987; Nausier et al., 2011; Pot, Deeg, van Dyck, & Jonker, 1998). Haley and colleagues (1987) conducted a study of family caregivers of persons with Alzheimer's disease and found that higher levels of caregiver well-being was linked to more benign appraisals of stress (Haley et al., 1987). Threat appraisal might be amenable to stress management interventions such as cognitive behavioral therapy to reduce depressive symptoms, which has been shown to reduce stress and depression in the general population by helping individuals to identify and modify dysfunctional thinking and beliefs to decrease undesired emotions and behaviors (Butler, Chapman, Forman, & Beck, 2006). While years of education and optimism also were significant individual predictors of depressive symptoms, developing an intervention targeting caregiver activities and support might also be useful, with the D-CASS potentially being a more sensitive outcome measure. More research is warranted in this area.

In the second regression equation the outcome variable, life changes, was explained by 46% of the model constructs. Caregiving activity and support difficulty or ease ( $r^2 = 7.8\%$ ), threat appraisal ( $r^2 = 4.9\%$ ), and being African American ( $r^2 = 2.2\%$ ) were significant individual

predictors of life changes. Caregiving activity and support difficulty was significantly correlated with life changes suggesting that interventions to improve activities and support difficulty may help to improve how caregivers view life changes as a result of providing care.

Threat appraisal was also a predictor of life changes. This finding was consistent with Bakas, Champion and colleagues' (2006) study of family caregivers of stroke survivors in which threat appraisal had a moderate negative correlation with life changes and was a significant individual predictor of life changes. Lastly, being African American was an individual predictor of life changes. Individual experiences with the role of caregiving tend to differ considerably among cultural, racial, and ethnic groups (Pharr, Francis, Terry, & Clark, 2014). Findings from a qualitative study revealed that caregiving was seen by some cultures and ethnic groups as an expected part of life that one did not question (Pharr et al., 2014). Additionally, a meta-analysis conducted on ethnic differences for family caregivers revealed that African American caregivers often experienced lower levels of caregiver stress compared to non-Hispanic White caregivers (Pinquart & Sörensen, 2005). There are many factors that may contribute to this difference including African American caregivers being more likely to use positive appraisal to cope with high levels of stress, being more intrinsically motivated to care for family members, and having greater access to informal support (Pinquart & Sörensen, 2005). These findings may give insight into why African American caregivers in this study had higher scores on life changes compared to American Indian and White caregivers. These findings indicate that interventions should be culturally tailored to address racial and ethnic differences among caregivers.

The outcome variable, unhealthy days, was explained by 40% of the model constructs with depressive symptoms ( $r^2 = 9.5\%$ ) and income ( $r^2 = .4\%$ ) being significant individual predictors. The correlation between unhealthy days, income, and depressive symptoms in this study is consistent with the literature (Nauser et al., 2011; Pinquart & Sörensen, 2007; Schulz & Sherwood, 2008). It is well established that family caregivers in general experience higher levels

of stress and have poorer physical health than non-caregivers (Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlan, 2003). A meta-analysis revealed that depressive symptoms as well as lower socioeconomic status were related to worse physical health among family caregivers (Pinquart & Sörensen, 2007). Findings from another study (Schulz & Sherwood, 2008) suggest the progression of negative health effects take place when caregivers experience depressive symptoms associated with their caregiving responsibilities which is then followed by impaired health habits and eventually leads to compromised health outcomes. The correlation of depressive symptoms and unhealthy days speaks to the potential benefits of developing an intervention that uses the D-CASS as a tool to help identify activities and behaviors that are difficult for caregivers. Targeting those items in an intervention may help to alleviate the stress that may lead to depressive symptoms and unhealthy days.

The three hierarchical multiple regression equations support construct validity for the D-CASS. Years of education, optimism, and threat appraisal were significant individual predictors of depressive symptoms. Caregiving activity and support difficulty or ease as measured by the D-CASS were significant individual predictors of depressive symptoms before appraisal was added into the equation as a mediator. Being African American, caregiving activity and support difficulty or ease (D-CASS), threat appraisal, and depressive symptoms were significant individual predictors of life changes. Lastly, optimism and depressive symptoms were significant individual predictors of unhealthy days, while caregiving activities and support difficulty or ease (D-CASS) was a significant independent predictor before depressive symptoms accounted for shared variance. These findings provide support for construct validity for the D-CASS through model testing.

### **Limitations**

This study has a number of limitations. The findings of this study are limited by the use of a convenience sample. Additionally, the cross-sectional design did not allow for causal inferences. Although effort was made to recruit participants from underrepresented groups,

generalizability is limited due to more than half the participants being White. The study could be strengthened by using a longitudinal design that would allow for the ability to establish causality.

### **Conclusion**

The 11-item D-CASS is a brief scale that is easy to administer and measures diabetes-specific perceived difficulty or ease of caregiver activities and support. The 11-item D-CASS shows evidence of internal consistency reliability, test-retest reliability, criterion-related validity, and construct validity. There is a clear need for more research to support family caregivers of persons with type 2 diabetes. The D-CASS provides a way to measure which activities and support behaviors are easy or difficult for caregivers and may help to identify priority areas for intervention development. Moving forward, future research should include the development and testing of an intervention that supports family caregivers of persons with type 2 diabetes. The D-CASS may play an important role in identifying priority areas of interventions for these caregivers. Additionally, the D-CASS may also be used as an outcome measure to evaluate these new interventions.

## Chapter 5

The number of people living with diabetes is increasing in epidemic proportions with diabetes affecting 29.1 million people in the U.S. (ADA, 2014). A neglected focus in literature is that of family caregivers of persons with type 2 diabetes. Family caregivers who provide care for individuals with chronic diseases often experience challenges that impact their physical and emotional well-being as well as their social well-being (Awadalla et al., 2006; Hennessy & John, 1995; Sinclair et al., 2010). Caregivers need support to help reduce caregiver burden and to help increase confidence in providing effective care to their loved ones. Additionally, increasing the caregivers' confidence may also indirectly reduce caregiver stress by increasing their sense of certainty (Reinhard, Given, Petlick, & Bemis, 2008). However, there are few interventions available to support these caregivers (Rintala et al., 2013).

The initial step in developing interventions for this population is the ability to understand and measure the difficulty or ease with which caregivers are able to perform activities and supportive behaviors. There are no instruments currently available with documented evidence of reliability and validity to help measure diabetes-specific caregiving activities. This is unfortunate because family caregivers play a vital role in promoting and supporting diabetes self-management of family members. Developing a methodologically sound tool is necessary to better understand priority areas for intervention development as well as to serve as an outcome measure to evaluate the interventions for family caregivers of persons with type 2 diabetes.

The overall purpose of this dissertation was to develop and test a tool that measured the perceived difficulty or ease of caregiver activities and supportive behaviors. This led to the main study and focus of the dissertation—the development and psychometric testing of the D-CASS (see Appendix A). To convey the results of the primary study (Scarton, Bakas, Miller et al., 2014), the dissertation was assembled using the compilation of three distinct manuscripts. The first manuscript (see Chapter 2) provided a look at the existing literature through an integrative review that focused on what was known regarding the needs and concerns of family caregivers of



persons with type 2 diabetes (Scarton, Bakas, Miller et al., 2014). The lack of information in this area led to the second manuscript (see Chapter 3) that explored common needs and concerns identified by family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes (Scarton, Bakas, Poe et al., 2014). The final manuscript (see Chapter 4), and the main focus of this dissertation, used findings from the qualitative study as well as the diabetes literature to develop and psychometrically test the D-CASS. This final chapter will synthesize the findings from the three manuscripts, discuss the strengths and limitations of the research, and identify future research.

### **Summary Chapter 2**

The first manuscript, “Needs and Concerns of Family Caregivers of Persons with Type 2 Diabetes: An Integrative Review of Cross-cultural Literature with Implications for the American Indian Population,” presented an extensive review of the literature while identifying existing knowledge and provided recommendations for future research (Scarton, Bakas, Miller et al., 2014). Although the body of literature addressing needs and concerns of family caregivers of persons with type 2 diabetes was very limited, studies in this integrative review illuminated several areas of need. For example, caregivers revealed concerns surrounding their general lack of diabetes knowledge as well as wanting more information on warning signs of complications and managing diabetes-related complications (Scarton, Bakas, Miller et al., 2014). Additionally, caregivers had needs related to supporting the care recipient who had depressive or behavioral symptoms. Some caregivers felt that healthcare providers did not address issues surrounding these emotional and behavioral concerns (Scarton, Bakas, Miller et al., 2014). Lastly, caregivers struggled with managing their own health and well-being including social well-being (Scarton, Bakas, Miller et al., 2014).

This integrative review offers important insight into the needs of caregivers, specifically caregivers of individuals with type 2 diabetes. Findings support the need for further research in examining the particular needs of these caregivers. Additionally, once a better understanding is

gained, from the caregivers' perspective of their needs, future research should focus on developing additional tools and supportive interventions for these family caregivers.

### **Summary Chapter 3**

Findings from the integrative review led to the second manuscript, "Needs and Concerns of Family Caregivers of American Indians, African Americans, and Caucasians with Type 2 Diabetes," a qualitative study that explored common needs and concerns identified by family caregivers of American Indians ( $n = 14$ ), African Americans ( $n = 11$ ), and Caucasians ( $n = 8$ ) with type 2 diabetes (Scarton, Bakas, Poe et al., 2014). This study used semi-structured interviews containing open-ended questions (see Appendix C) to examine the needs and concerns of these caregivers. Qualitative content analysis was used to interpret the meaning of the textual data and transcripts were coded into themes based on five pre-determined categories. These pre-determined categories were derived and adapted from previously identified needs and concerns of stroke caregivers (Bakas et al., 2002; Bakas et al., 2009a) and daily home hemodialysis caregivers (Welch et al., 2013). The categories included providing information and resources about type 2 diabetes, managing emotions and behaviors of the care recipient, providing physical care, providing instrumental care, and dealing with personal response to caregiving. No additional themes emerged outside of these five categories indicating the framework was broad enough for this population. The exploratory nature of the study resulted in several important findings in all five categories such as the significant needs caregivers have for general information on type 2 diabetes, concerns surrounding how to support the care recipient who is experiencing emotional and behavioral changes, and concerns with finding time to engage in activities caregivers enjoy as well as taking care of their own health and well-being (Scarton, Bakas, Poe et al., 2014). In this particular sample caregivers in all three groups (American Indian, African American, and Caucasian) held similar concerns related to supporting the care recipient.

This qualitative study provided the framework to develop a new instrument that would capture caregivers' needs and concerns in all five areas. Findings from this qualitative study

supported the use of the framework for caregivers of persons with type 2 diabetes. Conducting this qualitative study provided insight into the needs and concerns of family caregivers of persons with type 2 diabetes, a prerequisite for developing a supportive intervention. However, there were no tools available to measure which activities and supportive behaviors caregivers find difficult or easy. In the context of future research, the implications of the study findings suggested a need to develop a tool that would measure the difficulty or ease in caregiving activities and supportive behaviors, and this led to the third, and final, part of this research.

#### **Summary Chapter 4**

Findings from the diabetes literature and the qualitative study were used to develop a diabetes-specific instrument designed to measure the difficulty or ease of caregiver activities and supportive behaviors for family caregivers of persons with type 2 diabetes. The purpose of this study, “The Diabetes Caregiver and Support Scale: Development and Psychometric Testing,” was to develop and psychometrically test the D-CASS. Available measures were helpful in understanding how family support behaviors affect self-management outcomes from the patient’s perspective but were not useful in understanding how caregivers perceive the care activities and support behaviors they perform on a regular basis. This study used a cross-sectional, descriptive-correlational design. Psychometric properties for the D-CASS were assessed using methods to determine internal consistency reliability, test-retest reliability, criterion-related validity, and construct validity using factor analysis and model testing guided by the conceptual model derived from Lazarus’ theory of stress, appraisal, and coping (1984) and Bakas and colleagues’ model (Bakas, Champion et al., 2006) applied to family caregiving.

This cross-sectional, descriptive-correlational study (see Chapter 4) provided evidence of reliability and validity for a diabetes-specific instrument that measures how difficult or easy caregiving activity and support behaviors were for family caregivers of persons with type 2 diabetes. Evidence of internal consistency reliability ( $\alpha = .82$ ) and two-week test-retest reliability (ICC = .70) was supported for the D-CASS. Criterion-related validity was established with a

single-item criterion measuring overall how easy or difficult it is for caregivers to provide care for their loved ones ( $r = .65, p < .01$ ). Unidimensionality was supported by factor analysis, loadings ranged from .45–.70, with 32% of the variance explained by the first factor (eigenvalue = 4.02). The 11-item D-CASS is a brief and easy-to-administer scale that will provide insight into activities and support behaviors caregivers find difficult or easy; therefore, the D-CASS may potentially serve as a tool to help identify priority areas in intervention development. This is important because interventions should be closely linked with outcome measures. Because the D-CASS measures caregiver activities and support behaviors from the caregiver's perspective, this tool is unique and caregiver-centered, thus allowing it to function as an outcome measure that can be used to evaluate future interventions designed to support family caregivers of persons with type 2 diabetes.

### **Strengths**

Overall, this dissertation study has several strengths. First, an established conceptual framework, derived from Bakas and colleagues' caregiver needs and concerns framework (Bakas et al., 2002), was used to organize the findings of the integrative review (see Chapter 2). Using a guiding theoretical framework provides focus and clear boundaries for the integrative review process (Whittemore & Knafl, 2005). Additionally, this same framework was used in the qualitative study (see Chapter 3) that explored the needs and concerns of family caregivers of persons with type 2 diabetes and was used to code key needs and concerns common to these family caregivers. A second framework derived from Bakas and colleagues' caregiver conceptual model (Bakas, Champion et al., 2006) and based on Lazarus and Folkman's theory of stress, appraisal, and coping (1984), guided the psychometric testing of the D-CASS (see Chapter 4) and was specifically used to evaluate construct validity.

Another strength of the qualitative and psychometric studies was the diverse sample that included African American and American Indian participants. The inclusion of racially and ethnically diverse populations in research is crucial for addressing health disparities such as

diabetes. Although diabetes affects all racial and ethnic groups, it is especially prevalent in the American Indian, African American, and Hispanic American populations (CDC, 2014).

Recruitment of minority participants can be challenging due to many barriers such as mistrust of scientific investigators (Yancey, Ortega, & Kumanyika, 2006). The lack of adequate recruitment of minority participants can lead to underrepresentation of minorities in research and hinders the ability to eliminate such health disparities.

### **Limitations**

This dissertation study also had some limitations. First, there was a paucity of existing research on the needs and concerns of family caregivers of persons with type 2 diabetes, and the studies that were included in the integrative review (see Chapter 2) used small sample sizes that may limit generalizability. Second, the current studies used convenience sampling that may not be representative of American Indian, African American, and White participants. Few differences were noted across cultures in both studies, which may be due to acculturation. Acculturation refers to ethnic minorities, such as American Indians, who adopt an alternative culture instead of retaining their indigenous culture (Kim & Abreu, 2001; Landrine & Klonoff, 2004). American Indians who continue to practice traditional ways and who live on a reservation may have very different needs and concerns compared to an individual who has assimilated to Western ways. Lastly, the study to psychometrically test the D-CASS (see Chapter 4) used a cross-sectional design that did not allow for causal inferences. The study may have benefited from a longitudinal design.

### **Future Research**

Several opportunities exist for future research in the area of family caregivers of persons with type 2 diabetes. First, more studies need to be conducted on how cultural factors may affect caregiving outcomes. Although it is recognized that racial and ethnic differences affect caregiving experiences, it is still unclear how culture impacts caregiving (Aranda, 1997; Pharr et al., 2014). Second, with the use of the D-CASS, a culturally-tailored intervention can be developed to help

support these caregivers. The D-CASS can help identify specific caregiving areas to target. Additionally, future research should include adequate minority representation to ensure that findings are applicable to diverse populations and to help decrease health disparities such as diabetes (Yancey et al., 2006).

### **Conclusion**

Family caregivers are an important part of diabetes self-management. Limited literature exists on the needs and concerns of these caregivers. This dissertation laid the ground work to develop and psychometrically test an instrument to measure activities and support behaviors of family caregivers of persons with type 2 diabetes. The qualitative study (see Chapter 3) provided an opportunity to explore the needs and concerns of family caregivers of persons with type 2 diabetes and these findings contributed to the development of the D-CASS (see Chapter 4), an instrument with evidence of validity and reliability used to measure caregiver activity and support behaviors. This tool can be used to identify target areas in which to develop future interventions to support caregivers. The D-CASS also may be used as an outcome measure for caregiver research in the context of type 2 diabetes.

## Appendix A

### Diabetes Caregiver Activity and Support Scale (D-CASS)

This survey is designed to measure how difficult it is for you to provide care or support for your family or friend who has type 2 diabetes. For each activity or support item circle one number indicating the degree of difficulty or ease of the item. The numbers indicating the degree of difficulty or ease range from **-3 meaning it is extremely difficult** to **+3 meaning extremely easy**. The number **0 means it is neither easy nor difficult**.

No, I don't do this activity	Yes, I do this activity (if so, then rate)	Extremely difficult			Neither difficult or easy			Extremely easy
N	Y →	-3	-2	-1	0	+1	+2	+3

1. Listen to the person with diabetes when he or she experiences depressive symptoms (sadness)	-3	-2	-1	0	+1	+2	+3
2. Avoid nagging	-3	-2	-1	0	+1	+2	+3
3. Prepare a range of meals that appeal to the person with diabetes	-3	-2	-1	0	+1	+2	+3
4. Count carbohydrates when preparing meals for the person with diabetes	-3	-2	-1	0	+1	+2	+3
5. Help the person stabilize his or her blood sugar (keep it from going really high or low)	-3	-2	-1	0	+1	+2	+3
6. Exercise with your loved one to help encourage physical activity	-3	-2	-1	0	+1	+2	+3
7. Deal with your feelings (fear, worry) related to your loved one having diabetes associated complications (low blood sugar, kidney disease)	-3	-2	-1	0	+1	+2	+3
8. Balance your life now that you have caregiving responsibilities	-3	-2	-1	0	+1	+2	+3
9. Take care of your own health needs	-3	-2	-1	0	+1	+2	+3
10. Keep your energy level up while caring for the person with diabetes	-3	-2	-1	0	+1	+2	+3
11. Take time to relax	-3	-2	-1	0	+1	+2	+3

## Appendix B

### Demographic Questions

This group of questions will provide us with important information about you and the care that you provide. Please answer the following questions.

1. What is your age? \_\_\_\_\_
2. What is the patient's age? \_\_\_\_\_
3. What is your gender? \_\_\_\_\_ Male \_\_\_\_\_ Female
4. What is the patient's gender? \_\_\_\_\_ Male \_\_\_\_\_ Female
5. What is your race?  
\_\_\_\_\_ American Indian or Alaska Native  
\_\_\_\_\_ Asian  
\_\_\_\_\_ Black or African American  
\_\_\_\_\_ Native Hawaiian or other Pacific Islander  
\_\_\_\_\_ White  
\_\_\_\_\_ Multi-race: Please specify \_\_\_\_\_  
\_\_\_\_\_ Other or Unknown: Please specify \_\_\_\_\_
6. What is your ethnicity? \_\_\_\_\_ Hispanic or Latino \_\_\_\_\_ Not Hispanic or Latino
7. What is the patient's race?  
\_\_\_\_\_ American Indian or Alaska Native  
\_\_\_\_\_ Asian  
\_\_\_\_\_ Black or African American  
\_\_\_\_\_ Native Hawaiian or other Pacific Islander  
\_\_\_\_\_ White  
\_\_\_\_\_ Multi-race: Please specify \_\_\_\_\_  
\_\_\_\_\_ Other or Unknown: Please specify \_\_\_\_\_



8. What is the patient's ethnicity? \_\_\_\_\_ Hispanic or Latino \_\_\_\_\_ Not Hispanic or Latino
9. How many years of education have you had including grade school, middle school, high school (12 years), technical or business school, or college? \_\_\_\_\_ Years
10. How many years of education has the patient had including grade school, middle school, high school (12 years), technical or business school, or college? \_\_\_\_\_ Years
11. What is your relationship with the patient?
- \_\_\_\_\_ Spouse
- \_\_\_\_\_ Son or Daughter
- \_\_\_\_\_ Son or Daughter In-law
- \_\_\_\_\_ Other relative: Please specify \_\_\_\_\_
- \_\_\_\_\_ Friend
- \_\_\_\_\_ Other: Please specify \_\_\_\_\_
12. Where is the patient currently living?
- \_\_\_\_\_ House
- \_\_\_\_\_ Apartment
- \_\_\_\_\_ Assisted living facility
- \_\_\_\_\_ Other: \_\_\_\_\_
13. Do you currently live in the same home as the patient? \_\_\_\_\_ Yes \_\_\_\_\_ No
14. How long has the patient had type 2 diabetes? \_\_\_\_\_ Years \_\_\_\_\_ Months \_\_\_\_\_ Day
15. How long have you been providing care or support for the patient? \_\_\_\_\_ Years \_\_\_\_\_ Months \_\_\_\_\_ Days
16. How many days per week do you help or provide support the patient?
- \_\_\_\_\_ daily, 7 days per week
- \_\_\_\_\_ 6 days per week
- \_\_\_\_\_ 5 days per week
- \_\_\_\_\_ 4 days per week

- 3 days per week
- 2 days per week
- 1 days per week
- less than one day per week

17. Are there other family members living at home with you that also need your care (for example: children, spouse, parents, others)?

Yes: Please specify \_\_\_\_\_  No

18. What is your current employment status?

- Employed full-time
- Employed part-time
- Homemaker
- Retired
- Unemployed
- Disabled
- Other: Please specify \_\_\_\_\_

19. Did you have to quit a job or take early retirement in order to provide care for the patient?

Yes  No

20. Considering your household income from all sources (today), would you say that you are:

- Comfortable
- Just have enough to make ends meet
- Do NOT have enough to make ends meet

## Appendix C

### Telephone Interview Questionnaire Guide

1. Tell me about a typical day of providing care for your (relative/friend) with type 2 diabetes.
2. What have you been most concerned about or had problems with since your (relative/friend) was diagnosed with type 2 diabetes?
3. What have you found helpful in dealing with those concerns or problems?
4. What diabetes education do you need to help your (relative/friend) who has type 2 diabetes?
5. Tell me about how you help manage your (relative/friend)'s diet.
6. Tell me about how you help manage your (relative/friend)'s diabetes medication.
7. Tell me about how you help manage your (relative/friend)'s activity or exercise.
8. Tell me about how you help manage your (relative/friend)'s emotions and behaviors.
9. Tell me about how you manage your own life while helping your (relative/friend).
10. Tell me about how you seek medical care for your (relative/friend)'s type 2 diabetes.  
(Probes: What makes it difficult to seek care for your relative/friend? What makes it easy? How comfortable do you feel about talking with healthcare professionals?)
11. What advice would you give to other family caregivers of persons with type 2 diabetes?
12. If we were to develop a program to help family caregivers like yourself, what would be most helpful? (Probe: What would be most helpful to you now as a caregiver?)

## Appendix D

### Institutional Review Board Exemption and Approval



INDIANA UNIVERSITY

OFFICE OF THE VICE PRESIDENT FOR RESEARCH  
Office of Research Compliance

To: Tamilyn Bakas NURSING

Lisa Scarton NURSING

From: Human Subjects Office

Office of Research Compliance – Indiana University

Date: June 29, 2015

RE: NOTICE OF EXEMPTION - NEW PROTOCOL

Protocol Title: Activities and Support Provided by Family Caregivers of Persons with Type 2 Diabetes

Study #: 1506080617

Funding Agency/Sponsor: None

Status: Exemption Granted | Exempt

Study Approval Date: June 29, 2015

The Indiana University Institutional Review Board (IRB) EXE000001 | Exempt recently reviewed the above-referenced protocol. In compliance with 46 C.F.R. § 46.109 (d), this letter serves as written notification of the IRB's determination.

The study is accepted under 45 C.F.R. § 46.101 (b), paragraph(s) (2) Category 2: Surveys/Interviews/Standardized Educational Tests/Observation of Public Behavior Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior if: i) information obtained is recorded in such a manner that human subjects cannot be identified, directly or through identifiers linked to the subjects; or ii) any disclosure of the human subjects responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects financial standing, employability or reputation.

Acceptance of this study is based on your agreement to abide by the policies and procedures of the Indiana University Human Research Protection Program and does not replace any other

approvals that may be required. Relevant policies and procedures governing Human Subject Research can be found at: [http://researchadmin.iu.edu/HumanSubjects/hs\\_guidance.html](http://researchadmin.iu.edu/HumanSubjects/hs_guidance.html).

The Exempt determination is valid indefinitely unless changes in the project may impact the study design as originally submitted. Please check with the Human Subjects Office to determine if any additional review may be needed.

You should retain a copy of this letter and all associated approved study documents for your records. Please refer to the assigned study number and exact study title in future correspondence with our office. Additional information is available on our website at <http://researchadmin.iu.edu/HumanSubjects/>.

If your source of funding changes, you must submit an amendment to update your study documents immediately.

If you have any questions or require further information, please contact the Human Subjects Office via email at [irb@iu.edu](mailto:irb@iu.edu) or via phone at (317)274-8289 (Indianapolis) or (812) 856-4242 (Bloomington).

You are invited, as part of ORA's ongoing program of quality improvement, to participate in a short survey to assess your experience and satisfaction with the IRB related to this approval. We estimate it will take you approximately 5 minutes to complete the survey. The survey is housed on a Microsoft SharePoint secure site which requires CAS authentication. This survey is being administered by REEP; please contact us at [reep@iu.edu](mailto:reep@iu.edu) if you have any questions or require additional information. Simply click on the link below, or cut and paste the entire URL into your browser to access the survey: [https://www.sharepoint.iu.edu/sites/iu-ora/survey/Lists/Compliance/IRB\\_Survey/NewForm.aspx](https://www.sharepoint.iu.edu/sites/iu-ora/survey/Lists/Compliance/IRB_Survey/NewForm.aspx). /enclosures



**INDIANA UNIVERSITY**  
**OFFICE OF RESEARCH ADMINISTRATION**

**To:** TAMILYN BAKAS  
NURSING

**From:** IU Human Subjects Office  
Office of Research Administration – Indiana University

**Date:** October 31, 2012

**RE: EXEMPTION GRANTED**

**Protocol Title:** Access to Healthcare and Type 2 Diabetes and Heart Failure Self-Management Practices of American Indians and their Family Caregivers living in Indiana

**Protocol #:** 1210009874

**Funding Agency/Sponsor:** INDIANA MINORITY HEALTH COALITION

**IRB:** IRB-01, IRB00000220

---

Your study named above was accepted on October 31, 2012 as meeting the criteria of exempt research as described in the Federal regulations at 45 CFR 46.101(b), paragraph(s) (2) . This approval does not replace any departmental or other approvals that may be required.

As the principal investigator (or faculty sponsor in the case of a student protocol) of this study, you assume the following responsibilities:

**Amendments:** Any proposed changes to the research study must be reported to the IRB prior to implementation. To request approval, please complete an Amendment form and submit it, along with any revised study documents, to [irb@iu.edu](mailto:irb@iu.edu). Only after approval has been granted by the IRB can these changes be implemented.

**Completion:** Although a continuing review is not required for an exempt study, you are required to notify the IRB when this project is completed. In some cases, you will receive a request for current project status from our office. If we are unsuccessful at in our attempts to confirm the status of the project, we will consider the project closed. It is your responsibility to inform us of any address changes to ensure our records are kept current.

Per federal regulations, there is no requirement for the use of an informed consent document or study information sheet for exempt research, although one may be used if it is felt to be appropriate for the research being conducted. As such, these documents are returned without an IRB-approval stamp. Please note that if your submission included an informed consent statement or a study information sheet, the IRB requires the investigational team to use these documents.

You should retain a copy of this letter and any associated approved study documents for your records. Please refer to the project title and number in future correspondence with our office. Additional information is available on our website at <http://researchadmin.iu.edu/HumanSubjects/index.html>.

If you have any questions, please contact our office at the below address.

Thank you.



**INDIANA UNIVERSITY**  
**OFFICE OF RESEARCH ADMINISTRATION**

To: Tamilyn Bakas

From: IU Human Subjects Office

Office of Research Administration – Indiana University

Date: January 24, 2013

RE: NOTICE OF EXPEDITED APPROVAL

Protocol Title: Needs and Concerns of Family Caregivers of Persons with Type 2 Diabetes

Protocol #: 1301010329

Funding Agency/Sponsor: INDIANA UNIVERSITY HEALTH

IRB: IRB-01, IRB00000220

Expiration Date: January 21, 2015

The above-referenced protocol was reviewed by the Institutional Review Board (IRB-01). The protocol meets the requirements for expedited review pursuant to §46.110, Category (7). The protocol is approved for a period of January 22, 2013 through January 21, 2015. This approval does not replace any departmental or other approvals that may be required.

If you submitted and/or are required to provide participants with an informed consent document, study information sheet, or other documentation, a copy of the enclosed approved stamped document is enclosed and must be used.

As the principal investigator (or faculty sponsor in the case of a student protocol) of this study, you assume the following responsibilities:

**CONTINUING REVIEW:** Federal regulations require that all research be reviewed at least annually. You may receive a “Continuation Renewal Reminder” approximately two months prior to the expiration date; however, it is the Principal Investigator’s responsibility to obtain review and continued approval *before* the expiration date. If continued approval is not received by the expiration date, the study will automatically expire, requiring all research activities, including enrollment of new subjects, interaction and intervention with current participants, and analysis of identified data to cease.

**AMENDMENTS:** Any proposed changes to the research study must be reported to the IRB prior to implementation. Only after approval has been granted by the IRB can these changes be



implemented. An amendment form can be obtained at:  
[http://researchadmin.iu.edu/HumanSubjects/hs\\_forms.html](http://researchadmin.iu.edu/HumanSubjects/hs_forms.html).

**UNANTICIPATED PROBLEMS AND NONCOMPLIANCE:** Unanticipated problems and noncompliance must be reported to the IRB according to the policy described in the Unanticipated Problems and Noncompliance SOP, which can be found at

[http://researchadmin.iu.edu/HumanSubjects/hs\\_policies.html](http://researchadmin.iu.edu/HumanSubjects/hs_policies.html). NOTE: If the study involves gene therapy and an event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).

**ADVERTISEMENTS:** Only IRB-approved advertisements may be used to recruit participants for the study. If you submitted an advertisement with your study submission, an approved stamped copy is provided with the approval. To request approval of an advertisement in the future, please submit an amendment, explaining the mode of communication and information to be contained in the advertisement.

**COMPLETION:** Prompt notification must be made to the IRB when the study is completed (i.e. there is no further subject enrollment, no further interaction or intervention with current participants, including follow-up, and no further analysis of identified data). To notify the IRB of study closure, please obtain a close-out form at  
[http://researchadmin.iu.edu/HumanSubjects/hs\\_forms.html](http://researchadmin.iu.edu/HumanSubjects/hs_forms.html).

**LEAVING THE INSTITUTION:** The IRB must be notified of the disposition of the study when the principal investigator (or faculty sponsor in the case of a student project) leaves the institution.

**VULNERABLE POPULATION:** Please note that there are special requirements for the inclusion of prisoners in research. You may not enroll or otherwise include an individual who is or becomes a prisoner while enrolled in the research. For additional information on the requirements for including prisoners in research, please refer to  
[http://researchadmin.iu.edu/HumanSubjects/hs\\_policies.html](http://researchadmin.iu.edu/HumanSubjects/hs_policies.html).

Note: SOPs exist covering a variety of topics that may be relevant to the conduct of your research. For more information on the relevant policies and procedures, go to  
[http://researchadmin.iu.edu/HumanSubjects/hs\\_policies.html](http://researchadmin.iu.edu/HumanSubjects/hs_policies.html).

You should retain a copy of this letter and any associated approved study documents (e.g. informed consent or information sheet) for your records. Please refer to the project title and number in future correspondence with our office. Additional information is available on our website at <http://researchadmin.iu.edu/HumanSubjects/index.html>. Please contact our office if you have questions or need further assistance.

Thank you.

## References

- Ali, S., Stone, M. A., Peters, J. L., Davies, M. J., & Khunti, K. (2006). The prevalence of co-morbid depression in adults with type 2 diabetes: A systematic review and meta-analysis. *Diabetic Medicine*, *23*, 1165–1173.
- American Diabetes Association. (2013). *Statistical update*. Retrieved from <http://www.diabetes.org/diabetes-basics/diabetes-statistics>
- American Diabetes Association. (2014). *National diabetes statistics report*. Retrieved from <http://www.diabetes.org/diabetes-basics/statistics>
- Anaforoglu, I., Ramazanogullari, I., Algun, E., & Kutanis, R. (2012). Depression, anxiety and quality of life of family caregivers of patients with type 2 diabetes. *Medical Principles & Practice*, *21*(4), 360–365.
- Aranda, M. P. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *Gerontologist*, *37*(3), 342–354.
- Awadalla, A. W., Ohaeri, J. U., Al-Awadi, S. A., & Tawfiq, A. M. (2006). Diabetes mellitus patients' family caregivers' subjective quality of life. *Journal of the National Medical Association*, *98*(5), 727–736.
- Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., & Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing*, *36*(2), 95–106.
- Bakas, T., Austin, J. K., Okonkwo, K. F., Lewis, R. R., & Chadwick, L. C. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing*, *34*(5), 242–251.
- Bakas, T., & Burgener, S. C. (2002). Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors. *Topics in Stroke Rehabilitation*, *9*(1), 34–45.

- Bakas, T., & Champion, V. (1999). Development and psychometric testing of the Bakas Caregiving Outcomes Scale. *Nursing Research*, 48(5), 250–259.
- Bakas, T., Champion, V., Perkins, S. M., Farran, C. J., & Williams, L. S. (2006). Psychometric testing of the revised 15-item Bakas Caregiving Outcome Scale. *Nursing Research*, 55(5), 346–355.
- Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009a). Content validity and satisfaction with a stroke caregiver intervention program. *Journal of Nursing Scholarship*, 41(4), 368–375.
- Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009b). Stroke caregiver outcomes, from the Telephone Assessment and Skill-building Kit (TASK). *Top Stroke Rehabilitation*, 16(2), 105–121.
- Bakas, T., Pressler, S. J., Johnson, E. A., Nauser, J. A., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research*, 55(3), 180–188.
- Ballesteros, J., González-Fraile, E., Muñoz-Hermoso, P., Domínguez-Panchón, A. I., Martín-Carrasco, M. (2012). Unidimensional 12-item Zarit Caregiver Burden Interview for the assessment of dementia caregivers' burden obtained by item response theory. *Value Health*, 15(8), 1141–1147.
- Bernal, G., Bonilla, J., & Bellido, C. (1995). Ecological validity and cultural sensitivity for outcome research: Issues for the cultural adaptation and development of psychosocial treatments with Hispanics. *Journal of Abnormal Psychology*, 5(23), 67–81.
- Brod, M. (1998). Quality of life issues in patients with diabetes and lower extremity ulcers: Patients and care givers. *Quality of Life Research*, 7(4), 365–372.
- Burns, K. K., Nicolucci, A., Holt, R. I. G., Willaing, I., Hermanns, N., Kalra, S., Wens, J., . . . Peyrot, M. (2013). Research: Educational and psychological issues diabetes attitudes, wishes and needs second study (DAWN2): Cross-national benchmarking indicators for family members living with people with diabetes. *Diabetic Medicine*, 30(7), 778–788.

- Butler, A. C., Chapman, J. E., Forman, E. M., & Beck, A. T. (2006). The empirical status of cognitive-behavioral therapy: A review of meta-analyses. *Clinical Psychology Review*, 26(1), 17–31.
- Carey, P. J., Oberst, M. T., McCubbin, M. A., & Hughes, S. H. (1991). Appraisal and caregiving burden in family members caring for patient receiving chemotherapy. *Oncology Nursing Forum*, 18(8), 1341–1348.
- Carter, P. A., & Acton, G. J. (2006). Personality and coping: Predictors of depression and sleep problems among caregivers of individuals who have cancer. *Journal of Gerontological Nursing*, 32(2), 45–53.
- Carver, C. S., Scheier, M. F., & Segerstrom, S. C. (2010). Optimism. *Clinical Psychology Review*, 30(7), 879–889.
- Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research*, 1(2), 245–276.
- Centers for Disease Control and Prevention. (2000). *Measuring healthy days*. Atlanta, GA: Author.
- Centers for Disease Control and Prevention. (2011). *National diabetes fact sheet: National estimates and general information on diabetes and pre-diabetes in the United States*. Atlanta, GA: Author.
- Centers for Disease Control and Prevention. (2014). *National diabetes statistics report estimates of diabetes and its burden in the United States*. Atlanta, GA: Author.
- Chow, E. A., Foster, H., Gonzalez, V., & McIver, L. (2012). The disparate impact of diabetes on racial/ethnic minority populations. *Diabetes Advocacy*, 30(3), 130–133.
- Ciechanowski, P., Katon, W., & Russo, J. (2000). Depression and diabetes: Impact of depressive symptoms on adherence, function, and costs. *Archives of Internal Medicine*, 160, 3278–3285.

- Clark, L. A., & Watson, D. (1995). Constructing validity: Basic issues in scale development. *Psychological Assessment, 7*(3), 309–319.
- Clement, M., Bhattacharyya, O., & Conway, J. R. (2009). Is tight glycemic control in type 2 diabetes really worthwhile? YES. *The College of Family Physicians of Canada, 55*(6), 580–582.
- Collins, L. G., & Swartz, K. (2011). Caregiver care. *American Family Physician, 83*, 1309–1317.
- Cornoni-Huntley, J., Brock, D. B., Ostfeld, A. M., Taylor, J. O., & Wallace, R. B. (1986). *Established populations for epidemiologic studies of the elderly resource data book* (No NIH Pub No. 86-2443). Washington, DC: United States Department of Health and Human Services.
- Crowder, S. J., & Broome, M. E. (2013). A framework to evaluate the cultural appropriateness of intervention research. *Western Journal of Nursing Research, 34*, 1002–1022.
- Davis, L. (1992). Instrument review: Getting the most from your panel of experts. *Applied Nursing Research, 5*(4), 104–107.
- DeVellis, F. F. (2012). *Scale development: Theory and application* (3rd ed.). Thousand Oaks, CA: Sage.
- Family Caregiver Alliance. (2006). *Caregiver assessment: Principles, guidelines, and strategies for change*. Report from a National Consensus Development Conference, Vol. 1. San Francisco, CA.
- Feinstein, A. R. (1970). The pre-therapeutic classification of co-morbidity in chronic disease. *Journal of Chronic Diseases, 23*(7), 455–468.
- Ferketich, S. (1991). Focus on psychometrics: Aspects of item analysis. *Research in Nursing and Health, 14*(2), 165–168.
- Fisher, L., Chesla, C. A., Bartz, R. J., Gilliss, C., Skaff, J. A., Sabogal, F., . . . Lutz, C. P. (1998). The family and type 2 diabetes: A framework for intervention. *The Diabetes Educator, 24*(5), 599–607.

- Glasgow, R. E., & Toobert, D. J. (1988). Social environment and regimen adherence among type II diabetic patients. *Diabetes Care*, *11*(5), 377–386.
- Goins, R. T., Spencer, S. M., McGuire, L. C., Goldberg, J., Wen, Y., & Henderson, J. A. (2011). Adult caregiving among American Indians: The role of cultural factors. *Gerontologist*, *51*, 310–320.
- Goldstein, L. B., Adams, R., Becker, K., Furberg, C. D., Gorelick, P. B., Hademenos, G., . . . del Zoppo, G. J. (2001). Primary prevention of ischemic stroke: A statement for healthcare professionals from the Stroke Council of the American Heart Association. *Circulation*, *103*, 163–182.
- Goody, C. M., & Drago, L. (2009). Using cultural competence constructs to understand food practices and provide diabetes care and education. *Diabetes Spectrum*, *22*(1), 43–47.
- Grant, J. S., & Davis, L. L. (1997). Focus on quantitative methods: Selection and use of content experts for instrument development. *Research in Nursing and Health*, *20*(3), 269–274.
- Haley, W. E., Levine, E. G., Brown, S. I., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, *2*(4), 323–330.
- Hennessy, C. H., & John, R. (1995). The interpretation of burden among Pueblo Indian caregivers. *Journal of Aging Studies*, *9*(3), 215–229.
- Hennessy, C. H., & John, R. (1996). American Indian family caregivers' perception of burden and needed support services. *Journal of Applied Gerontology*, *15*, 275–293.
- Hennessy, C. H., John, R., & Anderson, L. A. (1999). Diabetes education needs of family members caring for American Indian elders. *The Diabetes Educator*, *25*, 747–754.
- Hennessy, C. H., Moriarty, D. G., Zack, M. M., Scherr, P. A., & Brackbill, R. (1994). Measuring health-related quality of life for public health surveillance. *Public Health Reports*, *109*(5), 665–672.

- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288.
- Kelly, K., Reinhard, S., & Brooks-Danso, A. (2008). Executive summary: Professional partners supporting family caregivers. *American Journal of Nursing, 108*(9) 6–12.
- Kim, B., & Abreu, J. (2001). Acculturation measurement: Theory, current instruments, and future directions. In J. G. Ponterotto, J. M. Casas, L. A. Suzuki, & C. M. Alexander (Eds.), *Handbook of multicultural counseling* (2nd ed., pp. 394–424). Thousand Oaks, CA, Sage.
- King, P., Peacock, I., & Donnelly, R. (1999). The UK Prospective Diabetes Study (UKPDS): Clinical and therapeutic implications for type 2 diabetes. *British Pharmacological Society, 48*(5), 643–648.
- Kroenke, K., & Spitzer, R. L. (2002). The PHQ-9: A new depression diagnostic and severity measure. *Psychiatric Annals, 32*(9), 509–515.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*, 606–613.
- Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B. W., Berry, J. T., & Mokdad, A. H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders, 114*(1–3), 163–173.
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometric, 33*(1), 159–174.
- Landrine, H., & Klonoff, E. A. (2004). Culture change and ethnic-minority health behavior: An operant theory of acculturation. *Journal of Behavioral Medicine, 27*(6), 527–552.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.
- Lewin, A. B., Geffken, G. R., Heidgerken, A. D., Duke, D. C., Novoa, W., Williams, L. B., & Storch, E. A. (2005). The diabetes family behavior checklist: A psychometric evaluation, *Journal of Clinical Psychology in Medical Settings, 12*(14), 315–322.

- Lim, J., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes*, 2, 1–9.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lloyd-Jones, D., Adams, R. J., Brown, T. M., Carnethon, M., Dai, S., De Simone, G., . . . Wylie-Rosett, J. (2010). Heart disease and stroke statistics—2010 update: A report from the American Heart Association. *Circulation*, 121, e46–e215.
- Look AHEAD Research Group. (2007). Reduction in weight and cardiovascular disease risk factors in individuals with type 2 diabetes: One-year results of the Look AHEAD trial. *Diabetes Care*, 30(6), 1374–1384.
- Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research*, 35(6), 382–385.
- Martire, L. M., & Schulz, R. (2007). Involving family in psychosocial interventions for chronic illness. *Current Directions in Psychological Science*, 16(2), 90–94.
- Mukwato, K. P., Mweemba, P., Makukula, M. K., & Makoleka, M. M. (2010). Stress and coping mechanisms among breast cancer patients and family caregivers: A review of literature. *Medical Journal of Zambia*, 37(1), 40–45.
- Munro, B. H. (2005). *Statistical methods for health care research* (5th ed.). Philadelphia, PA: Lippincott, Williams, & Wilkins.
- National Alliance for Caregiving (NAC) & AARP. (2009). *Caregiving in the U.S. 2009*. Bethesda, MD: Authors.
- Nausser, J. A., Bakas, T., & Welch, J. L. (2011). A new instrument to measure quality of life of heart failure family caregivers. *The Journal of Cardiovascular Nursing*, 26(1), 53–64.
- Netemeyer, R. G., Bearden, W. O., & Sharma, S. (2003). *Scaling procedures: Issues and applications*. Thousand Oaks, CA: Sage.



- O'Connell, J. M., Wilson, C., Manson, S. M., & Acton, K. J. (2012). The costs of treating American Indian adults with diabetes within the Indian Health Service. *American Journal of Health, 102*(2), 301–308.
- Paddison, C. (2010). Family support and conflict among adults with type 2 diabetes. *European Diabetes Nursing, 7*(1), 29–33.
- Pettinari, C., & Jessopp, L. (2001). 'Your ears become your eyes': Managing the absence of visibility in NHS direct. *Journal of Advanced Nursing, 36*(5), 668–675.
- Pharr, J. R., Francis, C. D., Terry, C., & Clark, M. C. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *International Scholarly Research Notices, Public Health, 2014*, Article ID 689826, 1–8.  
doi:10.1155/2014/689826
- Pinquart, M., & Sörensen, S. (2003). Predictors of caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences, 58B*(2), 112–128.
- Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90–106.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences, 62B*(2), 126–137.
- Pot, A. M., Deeg, D. J. H., van Dyck, R., & Jonker, C. (1998). Psychological distress of caregivers: The mediator effect of caregiving appraisal. *Patient Education and Counseling, 34*(1), 43–51.
- Pressler, S. J., Gradus-Pizlo, I., Chubinski, S. D., Smith, G., Wheeler, S., Sloan, R., & Jung, M. (2013). Family caregivers of patients with heart failure: A longitudinal study. *The Journal of Cardiovascular Nursing, 28*(5), 417–428.
- Reinhard, S. S., Given, B., Petlick, N. H., & Bemis, A. (2008). *Patient safety and quality: An evidence-based handbook for nurses*. Rockville, MD: Agency for Healthcare Research and Quality.

- Rintala, T. M., Jaatinen, P., Paavilainen, E., & Astedt-Kurki, P. (2013). Interrelation between adult persons with diabetes and their family: A systematic review of literature. *Journal of Family Medicine, 19*(1), 3–28.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and Health, 18*(2), 179–183.
- Scarton, L. J., Bakas, T., Miller, W. R., Poe, G. D., & Huber, L. L. (2014). Needs and concerns of family caregivers of persons with type 2 diabetes: An integrative review of cross-cultural literature with implications for the American Indian population. *The Diabetes Educator, 40*(4), 444–452.
- Scarton, L. J., Bakas, T., Poe, G. D., Hull, M. A., Ongwela, L. A., & Miller, W. R. (2014). Needs and concerns of family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes. *Clinical Nursing Research, 1–18*, doi:10.1177/1054773814562879
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology, 67*(6), 1063–1078.
- Schmider, E., Ziegler, M., Danay, E., Beyer, L., & Buhner, M. (2010). Is it really robust? Reinvestigating the robustness of ANOVA against violations of the normal distribution assumption. *Methodology, 6*(4), 147–151.
- Schram, M. T., Baan, C. A., & Pouwer, F. (2009). Depression and quality of life in patients with diabetes: A systematic review from the European depression in diabetes (EDID) research consortium. *Current Diabetes Reviews, 5*, 112–119.
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*(6), 771–791.

- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9), 23–27.
- Shilubane, H. H., & Potgieter, E. (2007). Patients' and family members' knowledge and views regarding diabetes mellitus and its treatment. *Curationis, 30*(2), 58–65.
- Sinclair, A. J., Armes, D. G., Randhawa, G., & Bayer, A. J. (2010). Care delivery caring for older adults with diabetes mellitus: Characteristics of carers and their prime roles and responsibilities. *Diabetic Medicine, 27*(9), 1055–1059.
- Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. *Current Diabetes Report, 12*(6), 769–781.
- Strong, C. (1984). Stress and caring for elderly relatives: Interpretations and coping strategies in an American Indian and White sample. *Gerontologist, 24*, 241–246.
- Sullivan, B. J., Marcuccilli, L., Sloan, R., Gradus-Pizlo, I., Bakas, T., Jung, M., & Pressler, S. J. (2015). Competence, compassion, and care of the self: Family caregiving needs and concerns in heart failure. *Journal of Cardiovascular Nursing*. Advance online publication. PMID: 25658185
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed.). Boston, MA: Pearson Education.
- Talbot, F., Nouwen, A., Gingras, J., Gosselin, M., & Audet, J. (1996). The assessment of diabetes-related cognitive and social factors: The multidimensional diabetes questionnaire. *Journal of Behavioral Medicine, 20*(3), 291–312.
- Tinsley, H. E. A., & Tinsley, D. J. (1987). Uses of factor analysis in counseling psychology research. *Journal of Counseling Psychology, 34*(4), 414–424.
- Tremont, G. (2011). Family caregiving in dementia. *Medicine and Health/Rhode Island, 9*, 36–38.

- Trief, P. M., Himes, C. L., Orendorff, R., & Weinstock, R. S. (2001). The marital relationships and psychosocial adaptation and glycemic control of individuals with diabetes. *Diabetes Care*, 24(8), 1384–1388.
- Van Dam, H. A., van der Horst, F. G., Knoops, L., Ryckman, R. M., Crebolder, H., van den Borne, B. H. W. (2005). Social support in diabetes: A systematic review of controlled intervention studies. *Patient Education and Counseling*, 59(1), 1–12.
- Vincent, D., Clark, L., Zimmer, L. M., & Sanchez, J. (2006). Using focus groups to develop culturally competent diabetes self-management program for Mexican Americans. *The Diabetes Educator*, 32(1), 89–97.
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous for one's physical health? A meta-analysis. *Psychological Bulletin*, 129(6), 946–972
- Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2010). *Measurement in nursing and health research* (4th ed.). New York, NY: Springer.
- Welch, J. L., Thomas-Hawkins, C., Bakas, T., McLennon, S. M., Byers, D. M., Monetti, C. J., & Decker, B. S. (2013). Needs, concerns, strategies, and advice of daily home hemodialysis caregivers. *Clinical Nursing Research*, 23(6), 664–663.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Methodological Issues in Nursing Research*, 52(5), 546–553.
- Yancey, A. K., Ortega, A. N., & Kumanyika, S. K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health*, 27, 1–28.
- Yen, M., & Lo, L. H. (2002). Examining test-retest reliability: An intra-class correlation approach. *Nursing Research*, 51(1), 59–62.

## CURRICULUM VITAE

**Lisa J. Scarton**

### **EDUCATION**

PhD Indiana University, Indianapolis, IN 2016  
BSN Indiana University, Bloomington, IN 2006

### **GRANTS AND FELLOWSHIPS AWARDED**

William and Doris Rodie Scholarship Award \$2,000 2015  
Indiana University School of Nursing  
100th Anniversary Scholars \$60,000 2014–2016  
Pre-doctoral Fellowship, Indiana University, School of Nursing  
Jonas Nurse Leaders Scholars \$60,000 2012–2014  
Pre-doctoral Fellowship, Indiana University, School of Nursing  
Nursing Research Incentive Funds \$1,500 2012  
Indiana Minority Health Coalition \$20,000 2012–2013  
Access to Healthcare  
Hudson and Holland Minority Scholar \$18,000 2003–2006  
Undergraduate Scholarship for Nursing School  
Choctaw Scholar \$1,600 2004–2005  
Choctaw Nation of Oklahoma Higher Education

### **TEACHING EXPERIENCE**

Teaching Assistant, Fall Semester 2013  
*Introduction to the Discipline of Nursing*, B232 (3 credits) Enrollment: 50 students  
Teaching Assistant, Summer Semester 2015  
*Measurement and Data Analysis*, R505 (3 credits) Enrollment: 60 students  
Guest Lecturer, Fall Semester 2015  
*Clinical Care I: Biophysical Processes*, H356 Enrollment: 60 students

### **PROFESSIONAL HEALTHCARE EXPERIENCE**

Nurse Intervener November 2011–May 2014  
*Telephone Assessment and Skill-building: Intervention for Stroke Caregivers (TASK II)*  
NIH R01 NR010388 (Dr. Tamilyn Bakas, PI), Indiana University School of Nursing,  
Indianapolis, IN  
Graduate Research Assistant July 2012–December 2013  
Indiana University School of Nursing (Dr. Tamilyn Bakas), Indianapolis, IN  
Clinical Nurse Manager August 2008–May 2012  
IU Health Morgan Hospital, Medical-Surgical Unit, Martinsville, IN

Charge Nurse September 2006–August 2008  
IU Health Morgan Hospital, (Formerly Morgan Hospital and Medical Center), Medical-Surgical  
Unit, Martinsville, IN

Registered Nurse May 2006–September 2006  
Bloomington Hospital, Medical-Surgical Unit, Bloomington, IN

#### **LICENSES/ CERTIFICATIONS**

Indiana Registered Nurse License 2006–present  
American Heart Association CPR Certificate 2006–present

#### **PROFESSIONAL ORGANIZATIONS**

American Diabetes Association Pro 2015–present  
Native Research Network 2013–present  
Midwest Nursing Research Society 2013–present  
American Indian Center of Indiana 2011–present  
Sigma Theta Tau International 2011–present  
Indiana Organization of Nurse Executives 2009–present  
Native American Faculty and Staff Council 2012–2013

#### **PROFESSIONAL HONORS AND AWARDS**

William and Doris Rodie Award 2015–2016  
School of Nursing, Indiana University  
100<sup>th</sup> Anniversary Scholar 2014–2016  
School of Nursing, Indiana University  
Jonas Nurse Leaders Scholar Award 2012–2014  
School of Nursing, Indiana University  
Emily Holmquist Award 2012–2013  
School of Nursing, Indiana University  
Hudson and Holland Minority Scholar 2003–2006  
Undergraduate Scholarship

#### **PROFESSIONAL DEVELOPMENT**

Office of Faculty Affairs and Professional Development August 6, 2014  
*Scientific Writing from the Reader's Perspective*

IUPUI Center for Teaching and Learning August 24, 2014  
*Educational Training for Teaching Associates*

## PROFESSIONAL SERVICE

American Indian Center of Indiana Board Member	2012–2013
American Indian Center of Indiana Board Chair	2013–2014
Indiana Action Coalition Safety Subcommittee Member	2012–2014
Native American Faculty and Staff Council Vice President	2012–2013
<i>Clinical Nursing Research Journal</i> Manuscript Reviewer	2014–present
<i>Journal of Cardiovascular Nursing</i> Manuscript Reviewer	2014–present
<i>Rehabilitation Nursing</i> Manuscript Reviewer	2014–present

## PRESENTATIONS

**Scarton, L.,** Bakas, T., Miller, W., Poe, D., & Huber, L. *Needs and Concerns of Family Caregivers of Persons with Type 2 Diabetes: An Integrated Review of Cross-cultural Literature with Implications for the American Indian Population.* Native Health Research Conference, Phoenix, AZ, June 1–5, 2014.

**Scarton, L.,** Miller, W., Poe, D., Hull, M., Ongwela, L., & Bakas, T. *Needs and Concerns of Family Caregivers of American Indians, African Americans, and Caucasians with Type 2 Diabetes.* Poster presentation. Midwestern Nursing Research Society, St. Louis, MO, March 27–30, 2014.

**Scarton, L.** *Needs, Concerns, Task Difficulty, and Life Changes Among Family Caregivers of Persons with Type 2 Diabetes.* Eskenazi Health, Indianapolis, IN, February 4, 2014.

**Scarton, L.,** Poe, D., & Bakas T. *Access to Healthcare and Type 2 Diabetic Self-management Practices of American Indians and their Family Caregivers Living in Indiana.* Cardiovascular and Diabetes Coalition of Indiana Quarterly Meeting, December 11, 2013.

**Scarton, L.** *Leadership Project for the Jonas Scholarship.* Jonas Scholars Leadership Conference, Washington, DC, October 29, 2013.

**Scarton, L.,** Bakas T., & Poe, D. *Access to Healthcare and Type 2 Diabetic Self-management Practices of American Indians and Their Family Caregivers Living in Indiana.* Health Disparities Research Summit, Indianapolis, IN, June 19, 2013.

## PUBLICATIONS

**Scarton, L.,** & de Groot, M. (2015). Psychosocial aspects of diabetes in American Indians/Alaska Natives: A systematic literature review. *Health Education and Behavior.* (In press).

McLennon, S. M., Hancock, R. D., Redelman, K., **Scarton, L.,** Riley, E., Sweeney, B., Habermann, B., Jessup, N. M., & Bakas, T. (2015). Comparing treatment fidelity between study

arms of a randomized controlled clinical trial for stroke family caregivers. *Clinical Rehabilitation*. doi:10.1177/0269215515585134

**Scarton, L.**, Bakas, T., Poe, D., Hull, M., Ongwela, L., & Miller, W. (2014). Needs and concerns of family caregivers of American Indians, African Americans, and Caucasians with type 2 diabetes. *Clinical Nursing Research*. doi:10.1177/1054773814562879

**Scarton, L.**, Bakas, T., Miller, W., Poe, D., & Huber, L. (2014) Needs and concerns of family caregivers of persons with type 2 diabetes: An integrated review of cross-cultural literature with implications for the American Indian population. *The Diabetes Educator*, 40(4), 444–452.

Bakas, T., & **Scarton, L.** (2014). Stroke and the family. In J. Stein, R. Harvey, R. Macko, C. Winstein, R. Zorowitz, & G. Wittenberg (Eds.), *Stroke recovery and rehabilitation* (2nd ed.). Woodbridge, CT: Demos Publishing.