INCORPORATING COMORBIDITY, VALUES AND PREFERENCES INTO CLINICAL CARE GUIDELINES DESIGNED FOR OLDER ADULTS LIVING WITH TYPE 2 DIABETES
The dissertation of Elizabeth A. Beverly has been reviewed and approved* by the following:

Linda A. Wray  
Associate Professor of Biobehavioral Health  
Dissertation Advisor  
Chair of Committee

Roger J. McCarter  
Professor of Biobehavioral Health

Patricia Bartholow Koch  
Professor in Biobehavioral Health

Sheila G. West  
Associate Professor of Biobehavioral Health

Janice Penrod  
Associate Professor of Nursing

Collins O. Airhihenbuwa  
Professor of Biobehavioral Health  
Department Head, Department of Biobehavioral Health

*Signatures are on file in the Graduate School
Abstract

The prevalence of type 2 diabetes, coupled with the life-altering and potentially life-threatening secondary outcomes of disease progression, support the need to better understand how older adults live with and manage diabetes. Most clinical care guidelines for older adults are disease-focused and do not provide guidance for prioritizing multiple health conditions that are common in older adults. Nor do most guidelines make explicit provision for addressing older adults’ values and preferences for care when they differ from guideline recommendations. Considering the rapidly increasing number of older adults with diabetes and the enormous public health burden of diabetes, the development and implementation of more appropriate guidelines are critical needs. Toward this goal, the purpose of this research was to illuminate the context of type 2 diabetes in the older population, in particular, how older adults prioritize attention to their comorbidity, values and preferences.

The present research integrated a multi-method approach (focus groups, Q-sorting techniques) to explore the influence of comorbidities as well as values and preferences for diabetes care in older adults living with type 2 diabetes. The first study employed focus group methods to assess the perceived challenges to diabetes self-management in older adults living with multiple concurrent chronic conditions. The most common challenges to clinical management included Healthcare, Medical costs and insurance, and Conflicting treatment regimens. Complications, Physical disability and limitations, Acute illness, and Stress were the most frequently cited challenges to active self-management. The second study employed focus group methods and Q-sorting techniques to define, identify, and rank the values and preferences older adults express for their diabetes care. Findings revealed that older adults expressed Individual and Shared values for care in addition to diverse Treatment, Interpersonal and
Practice preferences for care. In sum, contemporary issues, such as clinical heterogeneity and diverse values and preferences, challenge the health community to provide comprehensive care to older adults living with diabetes. The findings of this research support the need to assess the impact of comorbidity in diabetes self-management with respect to clinical outcomes. Moreover, the findings underscore the importance of understanding the diverse values and preferences older adults express in their diabetes care. As the prevalence of diabetes burgeons in our aging population, a concerted effort to address comorbidity and values and preferences for care is vital to maximize successful management and, ultimately, to improve both the length and quality of life experienced by older adults.
# Table of Contents

List of Tables ............................................................................................................. viii

List of Figures ............................................................................................................ ix

Acknowledgements ................................................................................................... x

Chapter 1: Introduction .............................................................................................. 1

Type 2 Diabetes ......................................................................................................... 1
Guidelines for Treatment ........................................................................................ 3
Age, Sex, and Race-Ethnicity ................................................................................... 4
Comorbidity, Values, and Preferences ...................................................................... 7
Conceptual Framework .............................................................................................. 10
Study 1 ...................................................................................................................... 13
Study 2 ...................................................................................................................... 13
Summary .................................................................................................................... 14

Chapter 2: Methodology ............................................................................................ 15

Focus Groups ............................................................................................................ 16
Q-sorting Techniques ................................................................................................ 17
Setting/Sampling ....................................................................................................... 17
Eligibility Criteria ..................................................................................................... 20
Procedures ................................................................................................................. 20
  Focus Group Discussion Guides ................................................................... 20
  Moderating the Focus Groups ....................................................................... 21
  Q-sort Interviews ........................................................................................... 22
  Other Considerations ..................................................................................... 22
Data Analysis ............................................................................................................. 23
Rigor .......................................................................................................................... 25

Chapter 3: Manuscript 1: Challenges to Diabetes Self-Management in Older Adults Living
  with Multiple Health Conditions ............................................................................... 27

Abstract ...................................................................................................................... 27
Introduction ................................................................................................................ 27
Methodology .............................................................................................................. 29
  Design .............................................................................................................. 29
  Procedure ..................................................................................................... 30
  Data Analysis ............................................................................................... 31
Results ......................................................................................................................... 32
  Defining the Categories ................................................................................. 33
  Challenges to Clinical Management .............................................................. 33
  Challenges to Active Self-Management .......................................................... 37
# Table of Contents

Discussion .................................................................................................................. 40  
Limitations ..................................................................................................... 42  
Implications .................................................................................................... 43  

Chapter 4: Manuscript 2: The Experience of Comorbidity in Older Adults Living with Type 2 Diabetes ................................................................. 44  
Abstract ...................................................................................................................... 44  
Introduction ................................................................................................................ 44  
Methodology .............................................................................................................. 46  
  Design ............................................................................................................. 46  
  Procedure ........................................................................................................ 48  
  Data Analysis .................................................................................................. 49  
Results ......................................................................................................................... 50  
  Theme 1 ........................................................................................................... 51  
  Theme 2 ........................................................................................................... 53  
  Theme 3 ........................................................................................................... 55  
Discussion ................................................................................................................... 56  
  Limitations ........................................................................................................ 58  
  Implications for nurses .................................................................................... 59  

Chapter 5: Manuscript 3: Values and Preferences in the Clinical Management of Type 2 Diabetes ................................................................. 61  
Abstract ...................................................................................................................... 61  
Introduction ............................................................................................................... 61  
Methodology .............................................................................................................. 63  
  Design ............................................................................................................. 63  
  Procedure ........................................................................................................ 65  
  Data Analysis .................................................................................................. 66  
Results ........................................................................................................................ 67  
  Distinction between Values and Preferences ................................................. 68  
  Values for Care ............................................................................................... 69  
  Preferences for Care ........................................................................................ 72  
Discussion ................................................................................................................... 75  
  Limitations ........................................................................................................ 77  
  Implications ........................................................................................................ 78  

Chapter 6: Discussion and Implications ................................................................. 80  
Clinical Recommendations .................................................................................... 83  
Practice Implications ........................................................................................... 84  
Policy Implications ................................................................................................. 87  
Strengths and Limitations ................................................................................... 88  
Future Directions ................................................................................................. 90  

References ................................................................................................................... 92
Appendix A: Advertisements ................................................................. 108
Appendix B: Recruitment Letters ....................................................... 111
Appendix C: Scripts for Screening Potential Participants .................. 115
Appendix D: Screening Questionnaires .............................................. 120
Appendix E: Interview Guides ............................................................ 123
Appendix F: Consent Forms ............................................................... 132
List of Tables

Table 2.1 Sociodemographic and health characteristics of participants with diabetes ..... 32
Table 2.2 Chronic health conditions reported by two or more participants ...................... 33
Table 3.1 Sociodemographic and health characteristics of participants with diabetes ..... 50
Table 3.2 Chronic health conditions reported by two or more participants ....................... 51
Table 4.1 Sociodemographic and health characteristics of participants with diabetes ..... 67
Table 4.2 Self-reported values for diabetes care and Q-sort rankings ............................... 68
Table 4.3 Self-reported preferences for diabetes care and Q-sort rankings ....................... 69
List of Figures

Figure 1.1 Conceptual Framework Presenting an Ecological Model of Type 2 Diabetes in Older Adults .............................................................................................................................. 12

Figure 5.1 Individualizing Diabetes Care in Older Adults with Type 2 Diabetes ............ 85
Acknowledgements

I would like to acknowledge the many people who have made this work possible. First, I would like to extend my thanks and gratitude to Dr. Linda Wray, my dissertation advisor and committee chair. I am eternally grateful for your invaluable support, unending patience, and friendship throughout my four years. Words cannot express how much I appreciate the time and effort you gave at every step of this journey. I could not have done this alone and I greatly appreciate all of your encouragement.

I would also like to thank Dr. Roger McCarter, Dr. Patricia Koch, Dr. Sheila West, and Dr. Janice Penrod, supportive members of my dissertation and comprehensive exam committees. Thank you for your willingness to share your expertise and thoughtful insight in all aspects of this research. I am privileged to have had you as committee members.

I would also like to thank my parents, Thomas and Karen Beverly, for teaching me to value education and supporting me in all my endeavors. Thank you for all of the emotional (and financial) support you have provided me over the years. To my brothers Justin, Andrew, and David – you see, I have been working these past four years!

Allison, you are the sister I always wanted. I can honestly say that I have spent the best years of my life in graduate school, and I owe that to you. Thank you for always knowing what to say, for always taking the time to listen, and for always making me laugh. Chair races, chocolate runs, and movie nights with pokey sticks will all go down in BWF history. You are the best friend a girl could ask for.

To the love of my life, Mike, I thank you from the bottom of my heart. You taught me that all of the really exciting things in life require more courage than we currently possess, a deep breath, and a leap of faith. That what can be imagined can be achieved. Thank you for always believing in me. You are my blessing in life and I am overwhelmed and overjoyed to spend every day of the rest of my life with you. 143!

I must also thank all of the faculty, staff, and students in the Department of Biobehavioral Health and Gerontology Center who served as friends and mentors. Thank you to Shannon, Lisa, Tamika, Mindy, Amy, Lauren, Andrea, Ruthann, Ann, Melissa, Ching-Ju, and Oralia. Your kindness has not gone unnoticed.

My deepest appreciation goes to all of the participants in this research, to whom this dissertation is dedicated. Thank you for giving me the opportunity to learn from your experiences. Without you, this research will be impossible. Thank you.

Finally, this dissertation could not have been completed without support from the National Institute on Aging Predoctoral Training Grant (T32 AG00048), the Social Science Research Institute Level 2 Grant, the Pennsylvania State University Graduate Alumni Association Dissertation Award, and the Ed and Helen Hintz Award for Outstanding Graduate Work in the Department of Biobehavioral Health.
Chapter 1

Introduction

Diabetes, and its related complications, is one of the most significant and growing chronic health problems in the United States (Wray, Ofstedal, Langa, & Blaum, 2005). Type 2 diabetes is marked by the body’s inability to make insulin as well as the body’s inability to effectively use the insulin it produces (Centers for Disease Control and Prevention (CDC), 2005). Roughly 20 percent of all adults aged 60 and older (approximately 10 million) have diabetes, the vast majority type 2 diabetes (CDC, 2005). Although type 2 diabetes increasingly affects younger adults, adults aged 60 and older continue to comprise the largest proportion of individuals with diabetes in the U.S. Considering the rapidly increasing number of adults with diabetes and the enormous public health burden of diabetes, the development and implementation of more appropriate interventions is a critical need.

The prevalence rates of type 2 diabetes have skyrocketed in the past few decades, due in part to rapidly increasing rates of obesity and physical inactivity in all age groups. The projection of diabetes burden in the United States through 2050 is likely to increase by 165% with the biggest percent increase in individuals aged 75 years and older (336%) (Boyle et al., 2001). As the prevalence of diabetes continues to expand, associated healthcare expenditures will also likely increase. The American Diabetes Association (ADA) has estimated the cost of diabetes to be at least $132 billion (ADA, 2003a). Of this amount, $92 billion was due to direct medical expenditures and $40 billion was due to disability, work loss and premature mortality. While prevention of diabetes is the ultimate goal, more effective management for older adults already diagnosed with diabetes is also imperative to reduce mounting healthcare costs and the risks for
future complications. [Note: For purposes of this dissertation “older adults” pertains to adults age 60 years and older].

Diabetes management requires adults to assume responsibility for multiple lifestyle and medical surveillance self-care behaviors to achieve and sustain optimal glycemic control. Lifestyle behaviors include adhering to healthful diets and increased physical activity; and medical surveillance behaviors include taking needed medications and maintaining proper foot care. The importance of behavioral adherence has been emphasized in the medical literature; yet, less than one in eight adults over age 20 who are living with diabetes follow the guidelines for optimal management (Lutfey & Wishner, 1999; Saydah, Fradkin, Cowie, 2004). Adults also need to accept diabetes on an emotional level. Dealing with diabetes on a daily basis can be a psychological burden; adults may have negative experiences with insulin injections, needle sticks, physician visits, and anxiety caused by the self-monitoring of blood glucose. Given the behavioral and psychological demands of diabetes, a deeper exploration of the psychosocial factors is relevant to all aspects of diabetes management. Understanding more fully how adults with diabetes live with and attempt to manage diabetes, is crucial for developing more appropriate behavioral interventions.

In the following sections, I provide: a review of the current guidelines for treatment; an overview of the literature on age, sex, and race-ethnicity differences in diabetes; prior research revealing the importance of comorbidity, values, and preferences in diabetes care; a conceptual framework; a brief overview of the research studies and corresponding papers; and a summary of the significance of this research.
Guidelines for Treatment

Despite current approaches to diabetes care, this disease is frequently under-diagnosed and subsequently under-treated (CDC, 2005). Moreover, evidence-based knowledge of type 2 diabetes in the older population is not readily available and further research is needed (Wahl et al., 1998). Several guidelines have addressed the care of older adults with type 2 diabetes (ADA, 2008; Olsen & Norris, 2004; Brown, Mangione, Saliba, & Sarkisian, 2003; European Diabetes Policy Group, 1999; World Health Organization (WHO), 1999); however, there is no consensus for glycemic goals that can be applied to all older adults.

Currently, the diagnostic criteria for type 2 diabetes in older individuals are the same as for all adults. Guidelines from the WHO (1999) and the ADA (1997, 2003b) employ a fasting plasma glucose level >126 mg/dL, a random plasma glucose >200 mg/dL and a post-challenge plasma glucose level >200 mg/dL, with abnormal values confirmed via subsequent tests. Isolated postprandial hyperglycemia (2-hour postprandial – after a meal – glucose level >140 mg/dL) is more common in older individuals (DECODE Study Group, 1999). Therefore, using fasting plasma glucose levels alone may miss the diagnosis of type 2 diabetes. Furthermore, physiologic changes associated with aging may alter the clinical presentation of diabetes and make its diagnosis problematic. For example, symptoms of hyperglycemia such as polyuria, polydipsia and polyphagia may not be present (Meneilly & Tessier, 2001). In addition, glucosuria (excretion of glucose in the urine) may not be detected due to the increased renal threshold for glucose associated with older age (Meneilly, 2000). More often than not, the presenting symptoms of hypoglycemia in older adults are neuroglycopenic (confusion, delirium, dizziness) rather than adrenergic (palpitation, sweating, tremors), contributing to delayed diagnoses and the presence of diabetes-related complications (Sinclair, 2006; ADA, 2008).
The treatment of type 2 diabetes in the older population presents unique challenges. Goals for treatment include sustained glycemic control, prevention and treatment of microvascular (e.g., retinopathy, nephropathy, neuropathy) and macrovascular complications (e.g., cardiovascular disease, cerebrovascular disease, peripheral vascular disease), increased self-management knowledge, and improved general health status and quality of life (Brown et al., 2003). Healthy, well-functioning older adults may benefit greatly from intensive glycemic control and the prevention or delay of diabetes-related complications. Appropriately, older adults with intact physical and mental abilities should aim for the ADA goal of Hemoglobin A1c (HbA1c) less than 7% (ADA, 2008; Brown et al., 2003). However, not all older adults may benefit from intensive glycemic goals. The potential benefits of strict adherence to glycemic goals should be balanced against the risks, like hypoglycemia and complexity of the treatment regimen (ADA, 2008). In view of that, older adults with comparatively lower functional status, comorbidity (the presence of one or more diseases or disorders in addition to a primary disease or disorder,) frailty, and an increased risk of hypoglycemia or drug side effects should aim for the American Geriatric Society (AGS) goal of HbA1c less than 8% (Brown et al., 2003). Life expectancies are also highly variable in this segment of the population. Accordingly, quality of life considerations should take priority in setting glycemic goals for older individuals with diabetes (Blaum, Ofstedal, Langa, & Wray, 2003). In sum, healthcare providers must consider the heterogeneity of older adults when establishing treatment goals.

Age, Sex, and Race-Ethnicity

Previous research has documented that diabetes status differs markedly by age, sex, and race/ethnicity in U.S. adults. Epidemiologic studies indicate that the prevalence of diabetes increases with age for both women and men (King, Aubert, & Herman, 1998; Boyle et al., 2001;
Wray et al. 2004, 2005, 2006; Rizvi, 2007). For older adults, diabetes is associated with a higher relative risk of death as well as an increased incidence of admission to an institution, which may be reflective of the disabling nature of diabetes-related complications (Jarrett, McCartney, & Keen, 1982; Tsuji, Whalen, & Finucane, 1995; Rockwood, Awalt, MacKnight, & McDowell, 2001). Further, older adults are susceptible to a higher frequency of medical comorbidities, frailty, depression, and socioeconomic issues (Amato et al., 1996; Stuck, Walthert, Nikolaus, Bula, Hohmann, & Beck, 1999; Anderson, Freedland, Clouse, & Lustman, 2001; Franks & Fiscella, 2002; Sinclair, 2006; Wray et al., 2006; Rizvi, 2007). Various community-based studies have also shown impaired cognitive function in older adults with diabetes (e.g., see Elias et al., 1997; Gregg et al., 2000). Impaired cognitive function may interfere with treatment adherence, contributing to poorer glycemic control because of inconsistent diet and medication use and increased risk of hypoglycemia if patients forget that they have taken their medication and repeat the dose (Sinclair, 2006). Thus, thoroughness in the assessment and treatment of diabetes is an essential quality that is needed in managing older adults with diabetes.

Previous research has also suggested that women are disproportionately affected by diabetes and its related complications (Harris, 1998). Older women with diabetes may manage diabetes with fewer economic and social resources in addition to increased risks for cardiovascular complications, compared to men (Robbins, Vaccarino, Zhang, & Kasl, 2001; Sabolsi, Solomon, & Manson, 2001; Rathmann et al., 2005; Wray et al., 2006). Data from the Behavioral Risk Factor Surveillance System (BRFSS) show socioeconomic status (SES) of women with diabetes is markedly lower than that of women without diabetes, which may compromise their ability to access care or receive adequate clinical and preventive services (Fiscella, Franks, Gold, & Clancy, 2000; CDC, 2001). Further, important distinctions have also
been made regarding the patterns of glucose regulation, morbidity and mortality, metabolic syndrome, depression and osteoporosis, as well as the impact of lifestyle modifications and medication therapies (e.g., see Legato et al., 2006; Szalat & Raz, 2007). Lastly, marked gender differences have also been identified in the family caregiving literature (e.g., Franks, Wendorf, Gonzalez, & Ketterer, 2004; Katz, Kabeto, & Langa, 2000): Later in life, both men and women primarily receive support from women (i.e., wives, adult daughters). Because women provide the majority of support to family members and serve as gatekeepers for family health, they may provide more effective support to their spouses or partners with diabetes than vice versa. For that reason, women may better judge when their spouses or partners need assistance and may better modulate their efforts accordingly, with men receiving greater benefit of that assistance. Thus, potential gender differences observed in diabetes self-management may be related to the spouses’ or partners’ support or control of the person with diabetes health behavior. Understanding the key role other types of support play in optimizing diabetes management may be all the more important given recent evidence that adults with diabetes, particularly women with diabetes, are disproportionately likely to be unmarried, compared to those without diabetes (Sabolsi, Solomon, & Manson, 2001). Clearly, additional research is needed to fully appreciate gender differences in the types and quality of support.

Finally, a wealth of epidemiological data documents disproportionately higher rates, earlier onset, and greater severity of diabetes as well as diabetes-related complications in African American and Hispanic American adults, compared to non-Hispanic white adults (e.g., Ferraro & Farmer, 1996; Harris, Klein, Cowie et al., 1998; Crimmins, Hayward, & Seeman, 2004; CDC, 2005; Wray et al., 2006). While the process of urbanization/westernization is associated with a progressive increase in the prevalence of type 2 diabetes across all ethnic groups, the prevalence
of diabetes appears to differ among various ethnic groups (Abate & Chandalia, 2003). At every age group, African Americans have highest incidences of diabetes, with over 20% of adults age 60 to 74 years old living with the disease (CDC, 2005). Overall, rates of type 2 diabetes are growing faster in ethnic minorities (i.e., African-American, Hispanic American, Native American, Pacific Islander, and some Asian American), and consequently these groups are experiencing much higher rates of morbidity and mortality, in some instances by as much as 50 percent more than the total population (Carter, Pugh, & Monterrosa, 1996; Mokdad et al., 2001; CDC, 2005). Understanding the mechanisms underlying these disparities is challenging due to the interaction of personal and environmental factors that contribute to health (House & Williams, 2000). Acquiring knowledge and understanding in diabetes care for racial/ethnic differences enhances diabetes care for the vulnerable directly and, often, indirectly by influencing attitudes (avoiding racism) to care. Thus, research designed to systematically examine racial-ethnic disparities, as well as age and sex differences, may be particularly important in treating an increasingly diverse population of adults living with diabetes.

Comorbidity, Values, and Preferences

Clinical (e.g., comorbidity, complications) and functional (e.g., impairment or disability) heterogeneity challenge the health community to provide comprehensive care to older adults living with diabetes. Recently the ADA (2008) and the American Geriatrics Society (AGS; Brown et al. 2003) acknowledged the complexities of caring for older adults and formally recommended that their care be individualized depending on the clinical and functional characteristics of the older adult. Individualization of care refers to care that addresses the needs, interests, lifestyle, values, and preferences of the patient. For diabetes, individualized care must also take into account life expectancy, personalized goals for treatment, willingness and ability to
comply with proposed treatment regimen, financial resources and home care situation (Halter, 1998; Rizvi, 2007). To provide the highest quality of care, the clinical management of diabetes must understand and explicate the experience of diabetes from the point of view of the older adults directly affected.

Two critical yet understudied domains in the individualization of diabetes care include comorbidity and values and preferences. Clinicians are increasingly confronted with diseases, impairments and conditions that complicate the management of type 2 diabetes. Prior research has found higher rates of comorbid illness, functional disability, and premature death in older adults living with type 2 diabetes (Kenny, Rubenstein, Martin, & Tinetti, 2001; Shekelle, MacLean, Morton, & Wenger, 2001; National Diabetes Education Program (NDEP), 2004; Diabetes Control Program (DCP), 2005; University of Michigan Health System (UMHS), 2006). Yet few guidelines are tailored to older adults with diabetes, due to the limited clinical trial data for older, frail diabetics (U.K. Prospective Diabetes Study (UKPDS) Group, 1998a; UKPDS Group, 1998b; Huang, Meigs, & Singer, 2001) and the heterogeneity, both clinically and functionally, of the older population (Walter & Covinsky, 2001; Blaum, 2002; Gill, 2002). For that reason, the individualization of care requires an understanding of the challenges of living with multiple health conditions from the patient perspective.

Furthermore, the individualization of care must take into account an older adult’s values for care and his/her preferences for how to achieve them (Huang, Gorawara-Bhat, & Chin, 2005). Values represent an enduring belief that a specific behavior or ideal is personally or socially preferable (Rokeach, 1973). Preferences represent choices or priorities derived from such values. Older adults express a variety of values and preferences for care that may strongly impact their treatment goals. Older adults express a variety of values and preferences for diabetes
care that strongly impact their treatment goals. For some older individuals, maintaining functional independence in activities of daily living and minimizing the financial, physical, and psychological burden of diabetes care may take precedence over aggressive medical management (Durso, 2006). Others may prefer intense medical management and long-term preventive care strategies (Durso, 2006). Diabetes care would benefit greatly from guidelines that address the values and preferences of the older adult. Further, diabetes care would benefit from investigations that target if and how the expression of values and preferences contributes to optimal management, and whether they differ by age, gender, or race-ethnicity. All in all, older adults’ values and preferences for care provide an important context for identifying appropriate treatment goals and plans for diabetes care. Clinical care guidelines should recognize this context, prioritize the important risks to older adults with diabetes, and provide guidance for applying its recommendations based on that adult’s personal values and preferences.

In sum, contemporary issues, like comorbidity and values and preferences, challenge the health community to provide comprehensive care to older adults living with diabetes. It is critical to recognize the impact of comorbidity in self-management with respect to clinical outcomes. Moreover, it is necessary for the research community to more aggressively address the psychosocial needs, like values and preferences, of older adults. As the prevalence of diabetes grows rapidly among our aging population, the healthcare community must strengthen clinical guidelines to maximize successful care and, ultimately, improve both the length and quality of life experienced by older adults. Toward this goal, the purpose of this dissertation was to illuminate the context of type 2 diabetes in the older population, with prioritization of comorbidity and values and preferences for care.
This dissertation reports the findings of two research studies designed to explore the influence of comorbidity, values and preferences in the management of type 2 diabetes in older adults. Descriptions of the conceptual framework, Study I, Study II, and the corresponding papers are provided below.

Conceptual Framework

The focus of this dissertation is on the lived experiences of older adults diagnosed with type 2 diabetes. Although genetics, age, ethnicity, and lifestyle contribute to the development of type 2 diabetes, this study recognizes that diabetes status is greatly influenced by multiple facets of the physical and social environments. Thus, proposed associations among the complexities and interdependencies between intrapersonal (i.e., individual, biological, and psychological); interpersonal (i.e., family, peers and other social contacts); community setting (system, group, and community); and societal (i.e., culture and policy) determinants of type 2 diabetes are considered using a broader Ecological Systems Perspective (see Bronfenbrenner, 1979; Bronfenbrenner, 1986; Bronfenbrenner, 1988). Ecological Systems Perspective states that an individual’s beliefs and behaviors can be explained and described accurately only by understanding the individual’s environment (Bronfenbrenner, 1986). The Ecological Systems Perspective is concerned with the context in which an individual lives and the interactions between the individual, other individuals, and society.

This research is informed by the Ecological Systems Perspective in its examination of comorbidity, values, and preferences among older adults living with type 2 diabetes in the larger community and societal settings. This dissertation argues that individual diabetes status cannot be effectively explained without consideration of the context in which the older adult is embedded. In the case of an older adult with diabetes, the immediate context includes the family,
peers, and other social contacts. Relationships with family, friends, and other social contacts play an influential role in the health behaviors of adults (McLeroy, Bibeau, Steckler, & Glanz, 1988); and specific to diabetes, social support has been associated with improved glycemic control, regimen adherence, and emotional well-being (e.g., Brown & Hedges, 1994; Tillotson & Smith, 1996; Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997, Trief, Himes, Orendorff, & Weinstock, 2001; Trief, Ploutz-Snyder, Britton, & Weinstock, 2004; Beverly, Penrod, & Wray, 2007; Beverly, Miller, & Wray, 2008; Beverly & Wray, 2008). Concurrently, the immediate context is embedded in larger environmental contexts including the community and societal settings. For example, individual factors particular to the older adult, such as comorbidity, values, and preferences, may interact with familial and societal factors (e.g., media) to influence diabetes status (Beverly, Wray, & Miller, 2008). A growing amount of literature suggests that characteristics of the community, such as neighborhoods, businesses, and recreational facilities, are associated with the health and health behaviors of adults (Kaplan, Everson, & Lynch, 2000). Furthermore, public policy has the ability to influence health and health behaviors via regulatory channels at the local, state, and national levels. By and large, this conceptual framework offers a structure for understanding the multidimensional complexities of type 2 diabetes in the older population which, in turn, may assist in the identification and translation of comorbidities, values, and preferences into clinical practice.

Figure 1.1 presents a conceptual model for the integration of multiple perspectives for understanding the factors influencing the diabetes experience in older adults. The conceptual framework illustrates the study’s proposed relationships among individual and environmental factors for older adults living with diabetes: (1) intrapersonal factors (microsystem); (2) interpersonal factors (mesosystem); (3) community settings (exosystem); and (4) societal factors
The intrapersonal factors (e.g., biological and psychosocial) include comorbidities as well as values and preferences for diabetes care. The utility of this model is to highlight the necessity of addressing characteristics of the older adult as well as the familial and societal contexts in which the older adult is embedded in order to understand and explicate the experience of type 2 diabetes.

In sum, addressing the social and environmental context is key to understanding the contemporary issues of diabetes prevention and management. Further research is needed to identify additional factors (e.g., comorbidity, values, and preference) that influence diabetes management so that clinicians and policy makers can develop more effective tools to encourage greater adherence to and maintenance of optimal management behaviors and, in turn, enhanced health outcomes.
Study I

Study I, *Incorporating Comorbidity into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes*, aimed to collect and analyze focus group data on older adults living with diabetes in Central Pennsylvania about comorbidity and its impact on type 2 diabetes management. The study’s overarching goal was to illuminate the role of comorbidity in the treatment of type 2 diabetes with the purpose of providing more effective supports for older adults with multiple health conditions. Focus group methods were employed to: (1) assess the perceived challenges to diabetes self-management in older adults living with multiple concurrent chronic conditions, and (2) describe the experiences of living with comorbidity. Techniques for content analysis and thematic analysis were used to assess, categorize, and interpret the data. Findings from the study and implications of those findings are provided in the following papers: (1) Challenges to Diabetes Self-Management in Older Adults Living with Multiple Health Conditions and; (2) The Experience of Comorbidity in Older Adults Living with Type 2 Diabetes.

Study II

Study II, *Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes*, aimed: (1) to collect and analyze focus group data on older adults living with diabetes in Central Pennsylvania about their values and preferences for diabetes care, and (2) to prioritize those values and preferences. The study’s overarching goal was to illuminate the role of values and preferences in the treatment of type 2 diabetes with the purpose of improving coordination and consistency of care for older adults living with this chronic condition. Focus group methods and Q-sorting techniques were employed to define, identify, and rank values and preferences older adults express for their diabetes care. Techniques
for content analysis were used to assess, categorize and interpret the data. Findings from the study and implications of those findings are provided in the following paper: (3) Values and Preferences in the Clinical Management of Type 2 Diabetes.

Summary

The prevalence of diabetes, coupled with these life-altering (and potentially life-threatening) secondary outcomes of disease progression, support the need to better understand how older adults live with and manage diabetes. Most clinical care guidelines for older adults are disease-focused and do not provide guidance for prioritizing multiple health conditions that are common in older adults (Durso, 2006). Nor do most guidelines make explicit provision for addressing an adult’s healthcare values and preferences when they differ from guideline recommendations (Huang, Gorawara-Bhat, & Chin, 2004; Durso, 2006). Considering the rapidly increasing number of individuals with diabetes and the enormous public health burden of diabetes, the development and implementation of more appropriate guidelines are critical needs. The following chapter presents a detailed description of the methodology. The subsequent three papers provide insights that draw on the experiences of older adults living with type 2 diabetes. The format for each paper corresponds to the requirements of the journal to which each was submitted. Finally, the discussion and implications chapter provides recommendations to improve the standards of care for older adults living with diabetes.
Chapter 2
Methodology

Qualitative research is a field of inquiry used to gain insight into people's attitudes, behaviors, values, concerns, motivations, aspirations, culture or lifestyles (Morse & Field, 1995). It is a process of understanding social or human phenomena based on distinct methodological traditions of inquiry. Overall, qualitative research aims to understand the world in which we live and why things are the way they are. When using a qualitative approach, researchers explore reality from an emic perspective, or the perspective of the participants in their natural settings. Accordingly, qualitative research is primarily concerned with developing descriptive accounts of observed phenomena as they occur in real life for the generation of a model or theory (Morse & Field, 1995).

Qualitative research has been widely used in the social sciences (e.g., anthropology, political science) and more recently in healthcare research. Different disciplinary perspectives have contributed to distinct qualitative methods. For example, the focus on cultural patterns in anthropology underlies the methods of ethnography (i.e., study of culture and cultural processes) and ethnoscientific (i.e., method of developing precise and operationalized descriptions of cultural concepts). Selecting the most appropriate method depends on what the researcher wishes to know, what the expected outcomes of the research will be, the constraints of the setting, the participants, and to a lesser extent, the resources available to the researcher. For the purposes of this dissertation, focus group and Q-sort methodologies were selected to: (1) assess the challenges of comorbidity in older adults living with type 2 diabetes; (2) describe the experiences of comorbidity in older adults living with type 2 diabetes; and (3) define and identify the values and preferences older adults express for diabetes care. The following sections describe the
procedures employed to seek and receive approval to conduct these studies from the Institutional Review Board of the Pennsylvania State University, including the methodology, setting/sampling, eligibility criteria, data collection procedures, data analysis, and rigor associated with the studies.

**METHODOLOGY**

**Focus Groups**

Focus groups are a form of qualitative research that originated in business and were used to obtain attitudes towards a product, concept, advertisement, idea, or packaging (Krueger, 1994). The premise of focus group research is that attitudes, perceptions, beliefs, and expectations are not developed in isolation but rather through interaction with others (Krueger, 1994; 2000; Morgan, 1997). Thus, in focus groups, questions are asked in an interactive group setting where participants are free to talk with other group members. In health promotion research, focus groups are particularly useful tools that can: (1) help educators develop more effective targeted educational messages and programs to provide specific knowledge and skills; (2) guide the design of research questions and analytic models using larger-scale quantitative data; and (3) inform the interpretation of broader existing quantitative research findings (Krueger, 1994; 2000; Morgan, 1997).

In Studies I and II, focus groups were selected for their ability to uncover and explain challenges and experiences related to comorbidity and values and preferences for diabetes care, which may not have been expected, anticipated or even surfaced during general quantitative surveys or questionnaires. With focus groups, challenges and experiences can be examined in-depth, as opposed to quantitative surveys or questionnaires which may be confined by their structure and timing. Focus group discussions have the advantage of raising key issues that
matter to participants so that researchers are better able to develop and test interventions with greater confidence than otherwise might be the case.

**Q-sorting Technique**

The Q-sorting technique is a general methodology for gathering and processing collected information. The aim is to sample a range and diversity of views expressed, not to make assertions of the participants expressing them (Cross, 2005). Q-sorting consists of a modified rank-ordering procedure in which items are placed in an order unique to the point of view of the individual performing the procedure (Brown, 1980). For the purposes of Study II, Q-sorting techniques were applied to facilitate the ranking or prioritizing of the values and preferences identified during the focus group discussions (Stephenson, 1953). In other words, the Q-sorting technique was used to determine the relative ranking of values and preferences by the participants.

**Setting/Sampling**

In order to maximize the phenomenon of interest, intensity sampling (a form of purposive sampling) was used to draw the sample of older adults living with diabetes. The purpose of qualitative research is to understand a phenomenon and generate ideas for hypothesis testing rather than to test hypotheses (Patton, 1990). Consistent with the philosophical underpinnings of qualitative research, intensity sampling identified participants who were able to richly describe the experiences of type 2 diabetes. Intensity sampling techniques are useful in learning more about how a group (i.e., people with type 2 diabetes) thinks and experiences a given phenomenon (Fetterman, 1998). Such purposeful sampling is different from statistically driven research which relies on randomness to generalize findings from a small sample to a larger population. The logic of qualitative sampling rests not on generalizability or representativeness, but on the notion of
saturation, that is, the point at which no new information is obtained. Therefore, sample size is not a criterion for evaluating the rigor of the sampling strategy but, rather, for evaluating the adequacy and the comprehensiveness of the findings. A good size for a focus group is between five to ten participants per session (Krueger, 1994; 2000; Morgan, 1997). Focus groups with more than ten participants may become unwieldy and counterproductive. However, a focus group can still take place if fewer than five participants attend. In both Studies I and II, a focus group consisted of only three participants who still provided very valuable information.

Recruitment efforts were focused on the Pennsylvania State University Diabetes Database as well as through advertisements in diabetes support group meetings, public service announcements, and flyers in community buildings (see Appendix A). The Pennsylvania State University Diabetes Database provides researchers of approved diabetes studies with the contact information of volunteers who have previously indicated an interest and desire to participate in future research. For Studies I and II, letters were mailed to adults who were age 60 and older living in Central Pennsylvania to explain the purpose of the studies and to request consent to contact them about participating in the study (see Appendix B). An email address and telephone number was included for potential participants to call to receive additional information about the studies. Those interested in participating in the studies were screened for eligibility via a telephone screening interview after providing oral consent (see Appendices C and D). Next, focus groups were scheduled according to participant preferences for dates and locations. Participant preferences included both clinical sites (professional sector) and community sites (popular sector). Clinical sites consisted of geriatric outpatient clinics associated with local hospitals and major health science centers. Community sites consisted of recreational centers, senior centers, and churches. All sites were reserved prior to the scheduled dates. Participants
were reminded of the date and location of their focus groups by postcard and telephone in the week prior to the scheduled date. The research protocols for Studies I and II were approved by the Pennsylvania State University Institutional Review Board prior to the initiation of the studies.

For Study I, a purposeful sample of 35 participants age 60 years and older was selected according to: (1) their ability to participate in the study; (2) their experience living with type 2 diabetes; and (3) their experience living with one or more comorbid conditions. The purpose was to seek out participants who had different experiences with type 2 diabetes and comorbid health conditions so that a comprehensive description of challenges to diabetes self-management was obtained. For example, older adults varied by age, sex, race and ethnicity, marital status, occupational status, education, and health status. Thirty-five participants were adequate to obtain comprehensive descriptions of type 2 diabetes and comorbidity.

For Study II, a purposeful sample of 48 participants age 60 years and older was selected according to: (1) their ability to participate in the study; and (2) their experience living with type 2 diabetes. The purpose was to seek out participants who had different experiences with type 2 diabetes so that a comprehensive description of values and preferences for diabetes care was obtained. In Study II, older adults also varied by age, sex, race and ethnicity, marital status, occupational status, education, and health status. Forty-eight participants were adequate to obtain comprehensive descriptions of values and preferences for diabetes care. Following the focus groups, older adults were asked to participate in a subsequent one-on-one interview to determine the relative ranking of values and preferences. Thirty of the 48 participants participated in the Q-sort interviews.
Eligibility Criteria

For Study I, eligibility was determined on the basis of five criteria: (1) adults age 60 years and older; (2) physician diagnosis of type 2 diabetes at least one year previously; (3) physician diagnosis of one or more comorbid conditions at least one year previously; (4) community-dwelling; and (5) adults with a high understanding of the English language and vocabulary. Participants were excluded if they were experiencing a physician diagnosis of Alzheimer’s disease or dementia. Eligibility criteria were the same for Study II with the exception of requiring a physician diagnosis of one or more comorbid conditions.

Procedures

Focus group discussion guides

The discussion guide, which contain the questions asked of participants during the focus groups, usually consists of an introduction (i.e., icebreaker), a series of open-ended questions moving from broad to more specific, and a conclusion to elicit final thoughts. When developing the discussion guide, two factors were considered. First, it was necessary to identify who the studies wanted to obtain information from. Second, it was necessary to identify what type of information the studies wanted to obtain. With this dissertation, Study I was interested in exploring the experiences of comorbidity in older adults living with type 2 diabetes, not only the challenges of comorbidity but also the beliefs, perceptions, expectations, and attitudes of comorbidity. Questions pertaining to the quality of diabetes care were also explored. Study II was interested in defining and identifying the diverse values and preferences older adults express for their diabetes care. In addition, questions pertaining to the quality of diabetes care were explored.
The structured discussion guides for Studies I and II were devised (see Appendix E), field tested for flow and clarity of the discussion questions, then used by the trained moderator and co-moderator to promote consistency across the groups. The moderator used directive probes to elicit additional information and clarify ambiguous comments; the co-moderator wrote field notes to capture key points in and observations about the discussion. All focus groups followed the same discussion guide. A question such as "What are your preferences for diabetes care?" could receive different responses depending on the values of the participants. By using a general discussion guide, comparisons were made between the responses of the various groups.

*Moderating the focus groups*

The purpose of conducting focus groups is to gather information about how much the group knows and feels about the particular issue being discussed. The focus group is not a forum to inform participants of an issue or to convince them of any point of view. For this reason, it is critical to utilize an experienced focus group moderator to conduct the sessions.

Because moderating the focus groups is a challenging process, an experienced moderator has the ability to draw information from the participants. The moderator must be able to keep control of the focus group, and if participants get off topic the moderator must be able to pull the group back together. The moderator must also be able to keep the discussion informal so as to encourage all participants to speak what is on their minds. Not all participants will like the topic being discussed; accordingly, participants should be allowed to voice their opinions. Therefore, the moderator must maintain a neutral position throughout the focus groups to facilitate any and all negative reports in the process. Finally, the moderator should confer with the co-moderator to determine if further issues need to be explored. If the co-moderator has additional questions, the moderator may ask those questions at the end of the focus group session. The focus group
session will last approximately 60 to 120 minutes. The participants of the focus group will dictate the length of the session based on their willingness to participate and the amount of information discussed.

Q-sort interviews

In subsequent one-on-one interviews with a subset of the Study II focus group participants (30 of the 48 participants), adults were asked to rank-order the values and preferences that were expressed during the focus groups (see Appendix E). [Note: Q-sorting of values was performed separately from the Q-sorting of preferences.] Sixteen values and sixteen preferences were provided on notecards. Participants were instructed to read through the values and preferences to get an impression of the range of values and preferences to allow the mind to settle into the situation. Next, participants were asked to sort the values and preferences according to those that were most important to them. Values were placed in seven piles ranked from most important to least important. The seven piles followed a roughly normal distribution, with one value or preference at each of the extremes (most important and least important), four items in the middle or neutral pile, and the others in between. The piles were labeled +3 to -3 to reflect their degree of importance. To clarify their degree of importance, values and preferences were then numbered 1 to 16 to demonstrate the relative rankings. The placement of values and preference was recorded and counted to demonstrate their relative importance.

Other considerations

The research team must determine what equipment is needed to obtain detailed information from the focus groups. The degree of detail required for the study will determine whether to audiotape, videotape, or take notes. For the purposes of this dissertation, all focus group sessions were audio-recorded and transcribed verbatim. [Note: Q-sort interviews were not
The advantage of audiotaping is it allows the research team to denote of the time of important comments made during each focus group. The researchers are then able to locate these comments and record the exact information. In addition to the audiotaping, the moderator and co-moderator composed detailed field notes to record group responses and non-verbal behavior. The moderator and co-moderator gauged consensus in the group on each question by counting head nods and asking for agreement.

Other items which were considered included informed consent forms and compensation for the participants. Informed consent forms were required for participation in the focus groups and Q-sort interviews; forms were approved by the Pennsylvania State University Institutional Review Board (see Appendix F). Participants were given an opportunity to review the consent form prior to participating in the focus groups and/or Q-sort interviews. Upon arrival, participants were provided two copies of the informed consent form. They were instructed to sign both forms, retain one, and return the second copy. Both consent forms were signed by the researcher prior to distributing them. All participants signed the consent form prior to initiating the focus groups and/or Q-sort interviews. After the completion of the focus groups and Q-sort interviews, participants received payment for participation. Compensation for participating in the focus groups for Studies I and II included a diabetes self-management book (retail: $19.99) or $20.00. Compensation for participating in the Q-sort interview included $20.00.

**Data Analysis**

Data analysis steps overlapped to protect against bias in interpreting the focus group data: (1) audiotapes were transcribed verbatim; (2) key concepts, notable quotes, and misconceptions were compiled from the transcribed records, using coding sheets; (3) one investigator and the research assistant independently coded the data, and the inter-rater reliability established; (4)
other investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining transcript data; and (5) categories and themes were independently summarized by the first investigator and research assistant and discrepancies reviewed and resolved by the other investigators.

For Study I, qualitative data were analyzed using techniques for content analysis (Morse & Field, 1996) and thematic analysis (Morgan, 1997; Krueger, 1994; 2000). Content analysis was used to assess, categorize, and interpret the focus group data. Transcripts were analyzed line-by-line to develop a categorical schema of the challenges of comorbidity perceived by the older participants living with type 2 diabetes. Specifically, discussions were summarized immediately following each of the focus groups; codes were developed using the research questions as guides; and the codes of new transcripts were compared to existing codes following each focus group to more fully develop the properties of the overarching categories. This process continued until saturation was reached; that is, until no new codes or categories emerged, and the research team, consisting of a gerontologist, doctoral student and research assistant, reached consensus that coding additional transcripts would only repeat themes. Thematic analysis involved the search for and identification of common threads that extended throughout the focus groups. Themes represented abstract concepts indicated by the data, linking substantial portions of the focus group discussions together. Quotes were used to demonstrate the abstract concepts and illustrate their meaning. It is important to note that the thematic analysis is an interpretation of the researchers based on their experience, skills, and ability to garner insightful and rich detail from the participants. No negative cases or reports were discarded in either process.

For Study II, techniques for content analysis were used to assess, categorize and interpret the focus group data (Morse & Field, 1996). Transcripts were analyzed line-by-line to develop a
categorical schema of the diverse values and preferences expressed by these older participants living with type 2 diabetes. Specifically, discussions were summarized immediately following each of the focus groups; codes were developed using the research questions as guides; and the codes of new transcripts were compared to existing codes following each focus group to more fully develop the properties of the overarching categories. Descriptive statements were formed and quotes were sorted appropriately under the newly-developed categories. This process continued until saturation was reached; that is, until no new codes or categories emerged, and the research team, consisting of a gerontologist, doctoral student and research assistant, reached consensus that coding additional transcripts would only repeat themes. No negative cases or reports were discarded in the process. For the Q-sort data, the values and preference were ranked from 1 to 16 to demonstrate their relative importance.

**Rigor**

Rigor in qualitative research is evaluated via credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) (Lincoln & Guba, 1985). Credibility refers to the accuracy of the information obtained in a study. Credibility of the data was supported in three ways: (1) one investigator and the research assistant independently coded the data to check for inter-rater agreement; (2) other investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining transcript data; and (3) categorizations were independently summarized by the first investigator and research assistant and discrepancies were reviewed and resolved by the other investigator. Transferability refers to the extent to which study findings are transferable (rather than generalizable) to other contexts (Leininger, 1991). The purpose of this dissertation was to elicit in-depth knowledge of the phenomenon studied, and not knowledge that can be generalized. However, the attitudes,
beliefs, perceptions, and expectations of older adults living with type 2 diabetes may be transferable to others in similar contexts. For purposes of this study, transferability was supported via thick (or rich) descriptions and verbatim quotations included in the data. Dependability refers to the consistency of the data. In the study, dependability of the data was achieved via an audit trail to track data collection and analysis. Lastly, confirmability refers to the objectivity or the degree to which the findings can be confirmed or corroborated by others. In the proposed study, confirmability was established with the use of the inquiry audit.
Challenges to Diabetes Self-Management in Older Adults Living with Multiple Health Conditions

ABSTRACT

Purpose: To provide the highest quality of care for older adults living with multiple health conditions, the clinical management of diabetes must address the challenges of living with multiple health conditions from the patient perspective. Toward this goal, the purpose of this research was to assess the perceived challenges to diabetes self-management in older adults living with comorbidity. Methods: With this in mind, the study collected and analyzed focus group data on 35 older adults living with type 2 diabetes and other health conditions. The group dynamic was structured to stimulate participants with diabetes to examine the influence of multiple health conditions on daily self-management with others who were in similar situations. Results: The most common challenges to clinical management included Healthcare, Medical costs and insurance, and Conflicting treatment regimens. Complications, Physical disability and limitations, Acute illness, and Stress were the most frequently cited challenges to active self-management. Conclusions: Contemporary issues, like clinical heterogeneity, challenge the health community to provide comprehensive care to older adults living with diabetes. Our findings support the need to assess the impact of comorbidity in diabetes self-management with respect to clinical outcomes. As the prevalence of diabetes grows rapidly among our aging population, the healthcare community must strengthen clinical guidelines to maximize successful care and, ultimately, improve both the length and quality of life experienced by older adults.

INTRODUCTION

Adults aged 60 and older comprise the largest proportion of individuals with diabetes. Older adults with diabetes have higher rates of comorbid illness, functional disability and
premature death (Kenny et al., 2001; Shekelle et al., 2001; NDEP, 2004; DCP, 2005; UMHS, 2006). Few guidelines are tailored to older adults with diabetes, due to the limited clinical trial data for older, frail diabetics (UKPDS Group, 1998a; UKPDS, 1998b; Huang, Meigs, & Singer, 2001) and the heterogeneity, both clinically and functionally, of the older population (Walter & Covinsky, 2001; Blaum, 2002; Gill, 2002). Therefore, to address the problem of diabetes management in older adults and better design interventions to decrease morbidity, individualized goal-setting in diabetes care for older adults has been recommended (ADA, 2008; Brown et al., 2003).

Diabetes management goals include sustained glycemic control; prevention and treatment of microvascular and macrovascular complications; increased self-management knowledge; and improved general health status and quality of life (Brown et al., 2003). In the case of older adults, these goals may be complicated by their clinical and functional heterogeneity. For example, maintaining functional independence in activities of daily living and minimizing the financial, physical and psychological burden of diabetes care may take precedence over aggressive medical management (Huang, Gorawara-Bhat, & Chin, 2004; Durso, 2006). Therefore, individualized goal-setting in diabetes care would benefit from guidelines that address the clinical and functional status as well as the healthcare preferences of the older adult.

In sum, type 2 diabetes and comorbidity represent substantial health problems to the aging population and to the healthcare providers treating them. Research on the medical management of older adults with more than one chronic condition, and in particular the diabetes management of older adults with more than one comorbid condition, is scarce. Considering the rapidly increasing number of individuals with diabetes and the enormous public health burden of diabetes, the development and implementation of more appropriate guidelines are critical needs.
Therefore, to provide the highest quality of care for older adults living with comorbidity, the clinical management of diabetes must understand the challenges of living with multiple health conditions from the patient perspective. Toward this goal, the purpose of this research was to assess the challenges of comorbidity in older adults living with type 2 diabetes.

**METHODOLOGY**

**Design**

Focus group methods were used in this study to assess the perceived challenges to diabetes self-management in older adults living with multiple concurrent chronic conditions. The group dynamic was structured to stimulate participants with diabetes to examine the influence of multiple health conditions on needs for care with others who were in similar situations. Emphasis in this study was placed on real experiences to capture the impact of comorbidity in the daily management of type 2 diabetes. The group process promoted a sharing among participants that generated a deeper examination and discussion of related issues, thus promoting greater depth in the findings. The research protocol was approved by the Pennsylvania State University Institutional Review Board prior to the initiation of the study.

In order to maximize the phenomenon of interest, intensity sampling (a form of purposive sampling) was used to identify and select older adults living with diabetes and other health conditions. Potential participants were screened by telephone for eligibility and other sociodemographic information (e.g., birth date, age, gender, race-ethnicity, comorbidity status, marital status, participant education, occupational status, year of diabetes diagnosis). The primary inclusion criteria for focus group participation were mentally alert community-dwelling adults, aged 60 or older, who reported a physician diagnosis of type 2 diabetes and the presence of at least one other chronic health condition. Participants were excluded if they were diagnosed
by a physician with Alzheimer’s disease or dementia. Recruitment efforts were focused on the Pennsylvania State University Diabetes Database as well as through advertisements in diabetes support group meetings, public service announcements, and flyers in community buildings.

In qualitative studies, the size of the sample is determined by the quality of data. Recruitment, data collection, and analysis are reiterative, occurring simultaneously. Two criteria are used to evaluate sampling: adequacy and appropriateness (Morse, 1994). Adequacy addresses the volume of the data, or, in other words, there are adequate data to support the emergent insights. Appropriateness refers to the quality of that data; that is, the data provide the descriptive and interpretive depth required to clearly delineate the theoretical derivation. Using these criteria, data are collected until saturation is reached; that is when no new information is generated from the participants and the derived theoretical scheme accounts for the reported experiences or insights.

In this study, recruitment efforts were suspended when 35 participants were successfully enrolled. Group members varied by age (60 and older), gender, race/ethnicity, education and occupation; however, all group members lived in Pennsylvania and shared the experience of living with type 2 diabetes and other chronic health conditions.

Procedure

Eight 90-minute focus groups, each consisting of three to eight participants, were conducted according to patient preferences and included clinical sites (professional sector) but more often, community sites (popular sector). Clinical sites consisted of geriatric outpatient clinics associated with local hospitals and major health science centers. Community sites consisted of recreational centers and churches. A structured discussion guide was devised, field tested for flow and clarity of the discussion questions, then used by trained moderators and co-
moderators to promote consistency across the groups. Moderators were instructed in the use of directive probes to elicit additional information and clarify ambiguous comments; co-moderators wrote field notes to capture key points in and observations about the discussion. All focus group sessions were audio-recorded and transcribed verbatim. All names and identifiers were removed from the text to protect participant confidentiality (for example, “Dr. Jones from Philadelphia” would be replaced by Dr. [Endocrinologist] from [medical center].”) These clean transcripts (i.e., transcripts purged from identifiers) were used in analysis. In addition to the audiotaping, the moderator and co-moderator composed detailed field notes to record group responses and non-verbal behavior (e.g., head nods, facial expressions).

Data Analysis

Techniques for content analysis were used to assess, categorize and interpret the data (Morse & Field, 1996). Transcripts were analyzed line-by-line to develop a categorical schema of the challenges of comorbidity perceived by these older participants living with type 2 diabetes. Specifically, discussions were summarized immediately following each of the focus groups; codes were developed using the research questions as guides; and the codes of new transcripts were compared to existing codes following each focus group to more fully develop the properties of the overarching categories. This process continued until saturation was reached; that is, until no new codes or categories emerged, and the research team, consisting of a gerontologist, doctoral student and research assistant, reached consensus that coding additional transcripts would only repeat themes. No negative cases or reports were discarded in the process.

Credibility of the data was supported in three ways: (1) one investigator and the research assistant independently coded the data to check for inter-rater agreement; (2) other investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining
transcript data; and (3) categorizations were independently summarized by the first investigator and research assistant and discrepancies were reviewed and resolved by the other investigator. Dependability of the data interpretations was supported with an audit trail to track the decision making process.

RESULTS

Table 2.1 provides general demographic and health characteristics of the 35 participants who participated in the study’s focus groups, based on the data obtained during eligibility screening. Participants ranged in age from 60 through 88 years (mean age 75 years), 57% were women and 94% were Caucasian (6% African American). The older adults in the study had a range of three to nine (mean of 5.6) chronic health conditions, including their diabetes (see Table 2.2). Socioeconomic data were not collected; because of the location of the pilot study (Central Pennsylvania), it was understood that the sample would be predominantly middle to upper class.

| Table 2.1: Sociodemographic and health characteristics of participants with diabetes |
|---------------------------------|------------------|
| Age (years)                     | 74.9 (60.0-88.0) |
| Female (percent)                | 57.1             |
| Caucasian (percent)             | 94.0             |
| Median education                | High School      |
| Married (percent)               | 68.6             |
| Retired (percent)               | 88.6             |
| Mean number of health conditions including diabetes | 5.6 (3.0-9.0) |
| Years with diabetes             | 15.0 (2.0-50.0)  |
| Hemoglobin A1c (percent)        | 7.1 (5.6-8.2)    |
| Prescribed oral hypoglycemic medication(s) (percent) | 42.9 |
| Prescribed insulin injection(s) (percent) | 48.6 |
| Body Mass Index (kg/m²)         | 30.1 (19.8-48.8) |

Note. The items HbA1c, body mass index, prescribed oral hypoglycemic medication(s), and prescribed insulin injection(s) are based on self-reported measures of adherence
### Table 2.2: Chronic health conditions reported by two or more participants

<table>
<thead>
<tr>
<th>Conditions</th>
<th>% Reporting Condition (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>66% (23)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>54% (19)</td>
</tr>
<tr>
<td>Retinopathy</td>
<td>43% (15)</td>
</tr>
<tr>
<td>High cholesterol (hypercholesterolemia)</td>
<td>34% (12)</td>
</tr>
<tr>
<td>Obesity (morbid)</td>
<td>29% (10)</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>23% (8)</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>23% (8)</td>
</tr>
<tr>
<td>Cardiac arrhythmia</td>
<td>17% (6)</td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>17% (6)</td>
</tr>
<tr>
<td>Depression</td>
<td>14% (5)</td>
</tr>
<tr>
<td>Post-myocardial infarction</td>
<td>14% (5)</td>
</tr>
<tr>
<td>Asthma</td>
<td>11% (4)</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>9% (3)</td>
</tr>
<tr>
<td>Presbycusis (hearing loss)</td>
<td>9% (3)</td>
</tr>
<tr>
<td>Stroke</td>
<td>9% (3)</td>
</tr>
<tr>
<td>COPD</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Leukemia</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Nephropathy</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>6% (2)</td>
</tr>
</tbody>
</table>

Note. Chronic conditions based on self-report data

### Defining the Categories

Through the discussions in the focus groups, older adults were able to reflect on the impact of comorbidity in the daily management of type 2 diabetes. The core categories used by the older adults to describe their perceived challenges were characterized by: Challenges to clinical management and Challenges to active self-management. Subcategories for Challenges to clinical management included Healthcare, Medical costs and insurance, and Conflicting treatment regimens; subcategories for Challenges to active self-management included Complications, Physical disability and limitations, Acute illness, and Stress.

1. Challenges to clinical management

1.1 Healthcare

Challenges related to healthcare included poor communication with physicians (46%), generalized treatment plans (40%), lack of diabetes knowledge (31%) and limited physician-
patient consultations (29%). Many participants felt their physicians were not willing to individualize treatment plans to address their clinical and functional status as well as their healthcare preferences. In addition, many felt that their physicians did not spend adequate time discussing the relationship between diabetes and other health conditions:

This managed medicine, they only give you 15 minutes or you have to pay for another office visit. It’s unbelievable. In 2005, when I was in the hospital I lost the use of my legs for a week. I wanted to talk to the doctor more so it had to go into another 15 minutes. So Medicare was charged for another office visit. That’s what I don’t like. Sometimes you have to talk to your doctor, especially if you have multiple health concerns [an 83 year old woman with 4 health conditions].

Participants also reported difficulty managing their diabetes when in the hospital receiving treatment for comorbid conditions:

For the most part, my diabetes is controlled except for the last 20 days when I was in the hospital. In the hospital it was wildly out of control. They didn’t let me keep my schedule. I take Lantus which is a long term insulin. You normally inject it once a day and the level goes up but there’s no peak. It stays that way around the clock for about 24 hours until you take another shot. I’m taking 20 units of Lantus. In the hospital the doctor said, ‘The sugar is doing something. We’re going to give you another shot of Lantus at 12 hours.’ He didn’t understand what Lantus does. That was absolutely clear, he didn’t know [Participant 29, a 79 year old man with 6 health conditions].

However, not all participants reported an uncoordinated system of care:

My primary physician knows who I go to for what. And he asks that they send him a report so that he keeps track of me. Especially when I had the infection in the foot, he
was constantly getting copies of the lab work and x-rays to keep up on it so he could question me as well as the foot surgeon [Participant 20, a 68 year old man with 5 health conditions].

1.2 Medical costs and insurance

High medical costs and lack of insurance coverage were often cited as challenges to managing multiple health conditions. Some participants (29%) felt they were forced to make changes to their medication regimen due to the financial constraints of too many medications: “I flat cut four medicines out. I took away two medicines which are for my pain, one for my kidney stones, which I have on a regular basis, and the other for shrinking my prostate” [Participant 4, a 68 year old man with 8 health conditions]. Other participants (57%) felt they had to sacrifice the best available treatments as a result of lack of insurance coverage: “I hit the ‘donut hole’ in the fall. In November I ran out of my pill for bone density – Fosamax – and I didn’t reorder it until January 1st because the price tripled!” [Participant 3, a 68 year old man with 4 health conditions]

Another patient described her frustration with her insurance plan by saying:

I have macular degeneration and that’s a pain in the ‘you know where!’ [laughing] I have to sit and read with a magnifying glass and it burns me up to no end! I was on an experimental drug that stopped the hemorrhaging. But one day the doctor said, “Well I’m not going to give you this anymore because it’s a $1000 a shot. Your insurance won’t cover it so I’ll give you something else.” Well the something else didn’t do a thing and my eyes are getting worse [Participants 33, an 84 year old woman with 8 health conditions].
1.3 Conflicting treatment regimens

Challenges to self-management included conflicting medication regimens (29%), dietary plans (26%) and exercise recommendations (54%). Participants relied on their physicians to provide appropriate treatment regimens to meet the needs of multiple health conditions. However, many participants cited conflicting treatment regimens for their comorbid conditions: “With this problem, it’s like a conflict between my diabetes and this other thing [Duhring’s disease]. It’s so hard trying to manage your diabetes along with other health problems” [Participant 5, an 81 year old woman with 8 health conditions]. Consequently, many were frustrated at not knowing how to resolve these conflicts:

When I found out about my diabetes, I went on a diet immediately and started reading labels in the grocery store. I’d spend hours in the store. That was a very frustrating process. You’d find a product that was low in sugar, low in cholesterol, low in fat but it had a ton of salt in it. You almost figure the best thing to do is buy a package of styrofoam cups and eat those. That’s the safest thing. So it’s one of those questions I have, when you have to balance this, against this, against this, what is the best thing to do? You’re not supposed to have all that salt because of the high blood pressure. You don’t want the carbs because of diabetes. You don’t want the fat because of high cholesterol. What should I do? [Participant 30, a man with 9 health conditions].

Other participants stated how their conflicting treatment regimens contributed to diabetes-related complications: “I was concerned about strokes and I had one. I was not on medication. I could not take an aspirin as usually a doctor would prescribe to prevent it because I had had an ulcer. So that was a no-no” [Participant 23, a 79 year old woman with 6 health conditions].
2. Challenges to active self-management

2.1 Complications

The threat of complications was a constant in the back of the participants’ minds. Participants verbalized fear in part because of the “horror stories” they heard from people with long-term health complications related to diabetes: “My other concern besides losing a limb is the blindness. It scares the hell out of me. I think I’d rather lose a leg or a foot” [Participant 24, a 67 year old man with 6 health conditions]. Despite this fear, many participants (46%) stated that the threat of complications motivated them to pay attention to their diabetes management:

I was concerned and I still am concerned. I became concerned not when I was diagnosed but when I began reading about it and its complications. It’s partly what motivated me to stay under control with it. The things that it can cause are really dreadful things to have, whether you’re young or whether you’re old. You can lose your eyesight, your feet and your mobility [Participant 27, an 83 year old man with 7 health conditions].

Another patient shared:

My neuropathy makes me pay attention to my diabetes more. I still have this thought in my mind that it is reversible to some extent – and I think it’s iffy – but as long as I keep my blood sugar down maybe the pain will go away. Because it’s very painful [Participant 4, a 68 year old man with 8 health conditions].

For participants who had already been diagnosed with complications, their experiences represented the harsh realities of poor glycemic control:

About two and a half years ago, I got an infection in my left foot. And because of my diabetes I came pretty close to losing my big toe. That was the waker-upper. Then I really
took hold of it. It took having a complication to get me to manage it [Participant 20, a 68 year old man with 5 health conditions].

2.2 Physical limitations and disability

Physical limitations and disability were commonly cited as challenges to diabetes self-management. Challenges included difficulty adhering to the multiple lifestyle and medical surveillance self-care behaviors to achieve and sustain optimal glycemic control. Many participants (46%) stressed the difficulty of participating in regular exercise as a result of their physical limitations and disability:

The problems I’ve had with control were when I was physically unable to exercise. I broke three ribs and I spent three months where I just could not exercise. I recovered from that and then had appendicitis and I was knocked down from that for almost a year. By then, I was getting anemic so I didn’t exercise for maybe a year and a half. I found that to be a great disadvantage. [Participant 27, an 83 year old man with 7 health conditions].

Pain, injury, immobility and vision problems were frequently mentioned as reasons for precluding exercise participation: “Well I can’t walk. That’s all there is to it. They [doctors] say, ‘Just walk up and down the street.’ But I can’t! I have too much pain in my legs.” [Participant 8, an 81 year old woman with 7 health conditions]. Participants also discussed difficulty in taking needed medications (31%) and maintaining proper foot care (26%):

I think sometimes if you’re sitting and you’re in severe pain you sort of don’t get up when you should to take your shot. So you’re a little late or whatever. And that’s usually at night. Pain seems to grow at night. I take insulin twice a day, usually when I get up in the morning and 9 o’clock at night. And sometimes I don’t want to get up at 9 o’clock
because I’m hurting so darn much. I mean I do take my insulin but maybe not when I should [Participant 13, a 74 year old man with 3 health conditions].

2.3 Acute illness

While participants were asked questions regarding the challenges of managing multiple chronic health conditions, many suggested that acute illness had a greater impact on their management than their chronic conditions:

I think because of the chronic nature of diabetes once you get something that’s more acute, diabetes fades into the background. Quite frankly I don’t think I’m going to die of diabetes. I think diabetes is going to outlive me. But yeah it goes into the background [Participant 16, a 76 year old man with 5 health conditions].

Most participants (63%) felt that the sudden onset coupled with various systemic symptoms (e.g., fever, nausea, pain) contributed to the overwhelming experience of acute illness:

Now I have an experience, I had pneumonia in the fall and for two weeks I wanted to eat nothing but white bread with a little butter on it. So my management with my diabetes went as they say ‘to hell and a handbasket’ for a couple of weeks. And then I tried slowly to get back to a better diet, but I couldn’t do it immediately. It affected my management drastically [Participant 2, a 66 year old woman with 4 health conditions].

2.4 Stress

Managing multiple chronic health conditions 24 hours a day, 365 days per year for the rest of the participants’ lives was a considerable challenge. Participants living with diabetes described how they endured the complications of the disease, as well as the needle sticks, restricted diet, hypoglycemic events, medical expenses and overall anxiety about the future as
they strove to exert some control over their body. Nearly all participants (94%) experienced stress throughout the course of their disease:

It [diabetes] becomes a way of life, you don’t even think about it. To that extent, it’s the way you live your life. So if there is a major stressor that comes on, that stressor takes the forefront of your energy. Because I’m sure we’ve all had major stressors while we’ve had diabetes – they may not have been life threatening – but major stressors. You’re still living your routine, but it’s the mental distress part of it that becomes more difficult because that’s where your focus is. And stress management is an important part of diabetes [Participant 25, a 65 year old woman with 4 health conditions].

**DISCUSSION**

Prevention of type 2 diabetes is the ultimate goal; nevertheless, enabling older adults to manage their diabetes is also critical to reduce the risks for future complications. Self-management requires adhering to multiple lifestyle and medical surveillance self-care behaviors to achieve and sustain optimal glycemic control, behaviors that are inherently modifiable. Lifestyle behaviors include adhering to healthful diets and increased physical activity; and medical surveillance behaviors include taking needed medications and maintaining proper foot care. Yet, less than one in eight adults over age 20 who are living with diabetes follow the guidelines for optimal management (Saydah, Fradkin, & Cowie, 2004). Moreover, older adults with multiple concurrent chronic conditions must integrate self-management behaviors for potentially interacting conditions to achieve desired outcomes. Thus, understanding more fully how comorbidity impacts the daily self-management of type 2 diabetes is critical for developing more appropriate behavioral interventions.
Focus group discussions revealed a number of important challenges to diabetes self-management for the 35 participants living with comorbidity. Participants cited challenges to their clinical management (*Healthcare, Medical costs and insurance, and Conflicting treatment regimens*) and active self-management (*Complications, Physical disability and limitations, Acute illness, and Stress*). Our research represents one of the first evaluations of the challenges older participants face in the self-care management of type 2 diabetes and multiple concurrent chronic conditions. Prior research on comorbidity has documented its influences on outcome measures in several domains of healthcare, including disability, length of hospital stay, hospital readmission, and mortality (Guralnik, LaCroix, & Evertt, 1989; Mulrow, Gerety, Cornell, Lawrence, & Kanten, 1994; Poses, McClish, Smith, Bekes, & Scott, 1996; Rochon et al., 1996; Incalzi, 1997; Fuchs et al., 1998; Librero, Peiro, & Ordinana, 1999). Our findings are unique in that they assessed challenges both within and outside of the healthcare system. Moreover, our findings provide insight into what older adults need from the healthcare community to achieve optimal diabetes management. This is particularly important research since most older adults with one chronic health condition have one or more concurrent conditions (Hoffman, Rice, & Sung, 1996; Jackson, 1999).

Comments provided by the participants reveal important practice implications for diabetes care guidelines. Quality care models aim to improve patient involvement in treatment via education and individualized goal-setting so as to improve adherence to self-care regimens. Treatment adherence has been shown to reduce disability and mortality, improve quality of life, and reduce medical costs (Horwitz et al., 1990; Gallagher, Viscoli, & Horwitz, 1993; Horwitz & Horwitz, 1993). Thus, interventions designed to promote self-care management are a high priority. This study represents an incremental step toward achieving higher quality care for older
participants living with diabetes and comorbidity. Findings from this study aim to guide the
development of interventions designed at promoting patient self-management of type 2 diabetes
and comorbidity. In sum, the difficulty associated with managing multiple concurrent chronic
conditions should prompt clinicians to more aggressively address the healthcare needs of older
participants living with diabetes. Comprehensive diabetes care guidelines are needed to educate
older adults about more effective ways to prioritize the management of multiple health
conditions. The more the healthcare community knows about comorbidity, the better prepared
clinicians will be to provide individualized treatment plans that take into account the clinical and
functional status of older adults.

Limitations

Study limitations include the homogeneity of the study sample with regard to race
(predominantly Caucasian) and residential status (community dwelling). Thus, the small, non-
randomly selected convenience sample may have limited the ability to generalize the findings to
a larger population. The cultural and social variations regarding comorbidity and self-care
management among varied ethno-cultural groups have not been addressed and warrant further
study. Finally, the use of self-reported diagnoses may have introduced error. Older participants
may have confused symptoms and minor ailments with more significant diseases. As well, older
participants may have forgotten to report important health diagnoses.

Notwithstanding these limitations, our study highlighted the complex and varied
challenges facing older adults living with type 2 diabetes and other concurrent chronic health
conditions. Qualitative research is an excellent way to garner preliminary information concerning
the key role comorbidity plays in the daily self-management of type 2 diabetes. This information
can be used to develop more refined measures and instruments for collecting data on comorbidity and, in turn, more effective interventions for older adults living with diabetes.

**Implications**

Contemporary issues, like clinical heterogeneity, challenge the health community to provide comprehensive care to older adults living with diabetes. The ADA (2008) and the AGS (Brown et al., 2003) recently acknowledged the complexities of caring for older adults, recommending that diabetes treatment goals be individualized depending on clinical status and preferences for care. Our findings support the need to assess the impact of comorbidity in diabetes self-management with respect to clinical outcomes. Recognizing and acknowledging participants' perceived challenges to comorbidity may provide a systematic way to include older participants in the evaluation and treatment process, thereby enhancing therapeutic alliance. Opportunities abound for meaningful interactions between clinicians and older adults to bolster successful coping in chronic disease management. Such interactions enable older adults to meet their individual and social needs by encouraging them to select and initiate behaviors to achieve optimal glycemic control. Clinicians should encourage older adults with multiple concurrent chronic conditions to identify and engage in self-care behaviors within their existing repertoire that can serve to buffer the effects of comorbidity on perceived health and quality of life. As the prevalence of diabetes grows rapidly among our aging population, the healthcare community must strengthen clinical guidelines to maximize successful care and, ultimately, improve both the length and quality of life experienced by older adults.
Chapter 4

The Experience of Comorbidity in Older Adults Living with Type 2 Diabetes

ABSTRACT

Clinicians involved in the primary care of older adults are increasingly confronted by the presence of one or more diseases or disorders in addition to a primary disease. Prior research has found significant comorbidity in older adults with type 2 diabetes. To provide the highest quality of care for older adults living with multiple health conditions, the clinical management of diabetes must understand the experiences of living with comorbidity from the patient perspective. The study collected and analyzed focus group data on 35 older adults living with type 2 diabetes and other health conditions. Analyses revealed three core themes describing the influence of comorbidity on type 2 diabetes management: Too much to handle, They don’t understand, and Help us before it’s too late. Our study highlighted the complex and varied challenges facing older adults living with type 2 diabetes and other concurrent chronic health conditions.

INTRODUCTION

Health conditions are common in older adults, and multiple health conditions are to be expected (Fillenbaum, Pieper, Cohen, Cornoni-Huntley, & Guralnik, 2000). Clinicians involved in the primary care of older adults are increasingly being confronted by the presence of one or more diseases or disorders in addition to a primary disease. Prior research has found significant comorbidity in older adults with type 2 diabetes, in particular risk for cardiovascular disease, cerebrovascular disease, and diabetic retinopathy (Fillenbaum et al., 2000; Liebl et al., 2002). It is not uncommon for older adults to have three or more distinct diseases requiring attention. Despite this considerable medical and public health burden, minimal empirical research on
comorbidity has entered the literature. In fact, the majority of clinical research overtly excludes older adults with significant comorbidity. Consequently, there is relatively little evidence for the medical management of older adults with more than one chronic condition, and in particular, diabetes management of older adults with more than one comorbid condition.

According to 2002 death certificates, type 2 diabetes was the sixth leading cause of death and a major contributor to other serious health complications (Centers for Disease Control and Prevention (CDC), 2005). Treatment of the older population must consider nonglycemic risk factors that contribute to standard microvascular and macrovascular complications as well as common geriatric syndromes. Microvascular and macrovascular complications are largely responsible for increased morbidity and mortality in individuals with diabetes. The incidence and progression of diabetic microvascular complications (e.g., retinopathy, nephropathy, neuropathy) increases with the duration of the disease, disproportionately affecting older adults with diabetes (Adler et al., 1997; Aiello et al., 1998; Stratton et al., 2000; Rein et al., 2006; Bethel, Sloan, Belsky, & Feinglos, 2007; Rizvi, 2007). Similarly, macrovascular complications (e.g., cardiovascular disease, cerebrovascular disease, peripheral vascular disease) are more common among older adults with diabetes and are a major cause of excess mortality (Croxson, Price, & Burden, 1994; Kuusisto, Mykkänen, Pyörälä, & Laakso, 1994; Standl et al., 1996; Haffner, Lehto, Rönnemaa, Pyörälä, & Laakso, 1998; Wei, Gaskill, Haffner, & Stern, 1998). Older adults are also at greater risk for several geriatric syndromes, including depression, cognitive impairment, injurious falls, neuropathic pain, and urinary incontinence (Newman & Hassan, 1999; Dealberto, Seeman, McAvay, & Berkman, 1997; DCP, 2005; NDEP, 2004; Piven, 2001; Shekelle et al., 2001; Cummings et al., 1995; UMHS, 2006; American Geriatrics Society, British Geriatrics Society, and American Academy of Orthopedic Surgeons Panel on Falls Prevention,
In addition, high rates of comorbid illness may require older adults to take multiple medications, leading to drug side effects and drug-drug/drug-disease interactions (Brown et al., 2003). All things considered, a multifactorial approach to screening and treating specific complications should be undertaken. The overall goals of treatment should aim toward optimizing function and reducing the burden of morbidity and mortality in this older segment of the population.

The prevalence of diabetes, coupled with these life-altering (and potentially life-threatening) secondary outcomes of disease progression, support the need to better understand how older adults live with and attempt to manage diabetes. Most clinical care guidelines for older adults are disease-focused and do not provide guidance for prioritizing multiple concurrent chronic conditions that are common in older adults (Huang, Gorawara-Bhat, Chin, 2005; Durso, 2006). To provide the highest quality of care for older adults living with multiple health conditions, the clinical management of diabetes must understand the beliefs, perceptions, expectations, and attitudes of comorbidity from the patient perspective. Toward this goal, the purpose of this research was to describe the experiences of comorbidity in older adults living with type 2 diabetes.

**METHODOLOGY**

**Design**

Focus group methods were used in this study to describe the experiences of comorbidity in older adults living with type 2 diabetes. The group dynamic was structured to stimulate participants with diabetes to examine the influence of multiple health conditions on their diabetes self-management with others who were in similar situations. Emphasis in this study was placed on real experiences to capture the impact of comorbidity in the daily management of type 2
diabetes. The group process promoted a sharing among participants that generated a deeper examination and discussion of related issues, thus promoting greater depth in the findings. The research protocol was approved by the University Institutional Review Board prior to the initiation of the study.

In order to maximize the phenomenon of interest, intensity sampling (a form of purposive sampling) was used to identify and select older adults living with diabetes and other health conditions. Potential participants were screened by telephone for eligibility and other sociodemographic information (e.g., birth date, age, gender, race-ethnicity, comorbidity status, marital status, participant education, occupational status, year of diabetes diagnosis). The primary inclusion criteria for focus group participation were mentally alert community-dwelling adults, aged 60 or older, who reported a physician diagnosis of type 2 diabetes and the presence of at least one other chronic health condition. Participants were excluded if they were diagnosed by a physician with Alzheimer’s disease or dementia. Recruitment efforts were focused on the University Diabetes Database as well as through advertisements in diabetes support group meetings, public service announcements, and flyers in community buildings.

In qualitative studies, the size of the sample is determined by the quality of data. Recruitment, data collection, and analysis are reiterative, occurring simultaneously. Two criteria are used to evaluate sampling: adequacy and appropriateness (Morse, 1994). Adequacy addresses the volume of the data, or, in other words, there are adequate data to support the emergent insights. Appropriateness refers to the quality of that data; that is, the data provide the descriptive and interpretive depth required to clearly delineate the theoretical derivation. Using these criteria, data are collected until saturation is reached; that is when no new information is generated from
the participants and the derived theoretical scheme accounts for the reported experiences or insights.

In this study, recruitment efforts were suspended when 35 participants were successfully enrolled. Group members varied by age (60 and older), gender, race/ethnicity, education and retirement; however, all group members lived in Pennsylvania and shared the experience of living with type 2 diabetes and other chronic health conditions.

**Procedure**

Eight 90-minute focus groups, each consisting of three to eight participants, were conducted according to participant preferences and included clinical sites (professional sector) but more often, community sites (popular sector). Clinical sites consisted of geriatric outpatient clinics associated with local hospitals and health science centers. Community sites consisted of recreational centers and churches. A structured discussion guide was devised, field tested for flow and clarity of the discussion questions, then used by trained moderators and co-moderators to promote consistency across the groups. A series of eight open-ended questions elicited participant views on: (1) challenges experienced in caring for their multiple health conditions; (2) psychosocial concerns related to their self-management; (3) experiences in setting priorities for their care; and (4) preferences for receiving their care. Moderators were instructed in the use of directive probes to elicit additional information and clarify ambiguous comments; co-moderators wrote field notes to capture key points in and observations about the discussion. Participants were asked general open-ended questions to introduce the focus of the discussion groups (e.g., How did you first learn that you have diabetes?), and at the conclusion to elicit final thoughts and allow participants to reflect upon aforementioned comments (e.g., After listening to all of the things we talked about today, do you have any recommendations for improving your
diabetes care?) All focus group sessions were audio-recorded and transcribed verbatim. All names and identifiers were removed from the text to protect participant confidentiality (for example, “Dr. Jones from Philadelphia” would be replaced by Dr. [Endocrinologist] from [medical center].”) These clean transcripts (i.e., transcripts purged from identifiers) were used in analysis.

Data Analysis

Qualitative data were analyzed using techniques described by Morgan (1997) and Krueger (1994; 2000). Specifically, the discussion was summarized immediately following each of the focus groups; codes were developed for relevant themes, using the research questions as guides; and the codes of new transcripts were compared to existing codes following each focus group to more fully develop the properties of the overarching categories. This process continued until saturation was reached; that is, until no new codes or categories emerged, and the research team, consisting of a gerontologist, doctoral student and research assistant, reached consensus that coding additional transcripts would only repeat themes. No negative cases or reports were discarded in the process.

Credibility of the data was supported in three ways: (1) one investigator and the research assistant independently coded the data to check for inter-rater agreement; (2) other investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining transcript data; and (3) categorizations were independently summarized by the first investigator and research assistant and discrepancies were reviewed and resolved by the other investigator. Dependability of the data interpretations was supported with an audit trail to track the decision making process.
RESULTS

Table 3.1 provides general demographic and health characteristics of the 35 patients who participated in the study’s focus groups, based on the data obtained during eligibility screening. Patients ranged in age from 60 through 88 years (mean age 75 years), 57% were women and 94% were Caucasian (6% African American). The older adults in the study had a range of three to nine (mean of 5.6) chronic health conditions, including their diabetes (see Table 3.2). Socioeconomic data were not collected; because of the location of the pilot study (central Pennsylvania), it was understood that the sample would be predominantly middle to upper class.

| Table 3.1: Sociodemographic and health characteristics of participants with diabetes |
|---|---|
| Age (years) | 74.9 (60.0-88.0) |
| Female (percent) | 57.1 |
| Caucasian (percent) | 94.0 |
| Median education | High School |
| Married (percent) | 68.6 |
| Retired (percent) | 88.6 |
| Mean number of health conditions including diabetes | 5.6 (3.0-9.0) |
| Years with diabetes | 15.0 (2.0-50.0) |
| Hemoglobin A1c (percent) | 7.1 (5.6-8.2) |
| Prescribed oral hypoglycemic medication(s) (percent) | 42.9 |
| Prescribed insulin injection(s) (percent) | 48.6 |
| Body Mass Index (kg/m$^2$) | 30.1 (19.8-48.8) |

Note. The items HbA1c, body mass index, prescribed oral hypoglycemic medication(s), and prescribed insulin injection(s) are based on self-reported measures of adherence.

Defining the Themes

Through the discussions in the focus groups, older adults were able to reflect on their experiences of living with multiple health conditions. As the focus groups progressed, we were able to capture the influence of comorbidity in the self-management of type 2 diabetes. The core themes used by the older adults to describe their experiences were characterized by: Too much to handle, They don’t understand, and Help us before it’s too late.
<table>
<thead>
<tr>
<th>Conditions</th>
<th>% Reporting Condition (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>66% (23)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>54% (19)</td>
</tr>
<tr>
<td>Retinopathy</td>
<td>43% (15)</td>
</tr>
<tr>
<td>High cholesterol (hypercholesterolemia)</td>
<td>34% (12)</td>
</tr>
<tr>
<td>Obesity (morbid)</td>
<td>29% (10)</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>23% (8)</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>23% (8)</td>
</tr>
<tr>
<td>Cardiac arrhythmia</td>
<td>17% (6)</td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>17% (6)</td>
</tr>
<tr>
<td>Depression</td>
<td>14% (5)</td>
</tr>
<tr>
<td>Post-myocardial infarction</td>
<td>14% (5)</td>
</tr>
<tr>
<td>Asthma</td>
<td>11% (4)</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>9% (3)</td>
</tr>
<tr>
<td>Presbycusis (hearing loss)</td>
<td>9% (3)</td>
</tr>
<tr>
<td>Stroke</td>
<td>9% (3)</td>
</tr>
<tr>
<td>COPD</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Leukemia</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Nephropathy</td>
<td>6% (2)</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>6% (2)</td>
</tr>
</tbody>
</table>

**Note.** Chronic conditions based on self-report data

**Theme 1: Too much to handle**

Optimal health outcomes for older adults living with multiple health conditions depend heavily on medical management. For the 35 older adults participating in the focus groups, 32 reported difficulty adhering to a healthful diet, increased physical activity and/or medical surveillance behaviors, such as taking needed medications and maintaining proper foot care, as a result of their other health conditions. Walter, a 74 year old man with 4 health conditions, stated:

After you have three or four complications then you have a juggling act. You can reach a point where you have one health condition or maybe two that you can manage. But if you have three, four, or five conditions and you have to take medications throughout the day for your various conditions, some medications can be taken with food and some can’t, and you have arthritis so you can’t exercise. I think there is a point where it becomes too much.
Participants also had to integrate self-management behaviors for potentially interacting conditions to achieve desired outcomes. Many spoke of struggling to manage their diabetes amidst their interacting conditions, as evidenced in the following exchanges:

Donald, a 68 year old man with 8 health conditions: I’ve had kidney stones about 30 times and every time I get an attack I don’t worry at all about my diet or anything else until I get done treating it to get the pain to go away.

Richard, a 76 year old man with 6 health conditions: But you can’t let your blood sugars go to hell!

Donald: Let’s put it this way, when you get to the morphine stage you don’t care about your blood sugar. You just want your pain to go away!

Shirley, a 66 year old woman with 4 health conditions: And when you can’t eat anything at all.

Donald: Yeah because you’re going to throw up because of the pain!

Shirley: That’s right.

Donald: I don’t give a single thought to my blood sugar when that happens.

While participants acknowledged the importance of medical management for their multiple health conditions, many perceived some conditions as more serious than others. The majority of participants (20 of 35) admitted to prioritizing another health condition over their diabetes. As Betty, an 81 year old woman with 8 health conditions, expressed: “I think of everything, the atrial fibrillation is the highest priority. I’ve been hospitalized three times and been in the emergency room a few times because of it. So I think my diabetes is secondary.” Similarly, Henry, a 74 year old man with 5 health conditions, described his experience with a competing health condition: “Being diagnosed with cancer is a lot more life threatening than
diabetes. I focus on the cancer more than the diabetes.” Thus, the challenge of managing multiple
complex self-care regimens may have limited the participants’ abilities to deal with comorbidity
in their daily life. Participants may have found it too difficult to manage all of their conditions,
leading them to selectively attend to conditions based on their perceived severity. This finding
was articulated best by Charlie, a 68 year old man with 5 health conditions:

I think most of us forget how to prioritize and put things in their proper sequence. Take
‘d’ and put it all the way up to ‘a’ without thinking of any of the ramifications of ‘a, b,
and c’ that you don’t pay attention to. I think a lot of us don’t know how to prioritize.
[pause] It’s just as difficult for one person as it is the next to manage things, especially if
you have physical disabilities or health disabilities. Nothing’s easy anymore in this world.

Theme 2: They don’t understand

A prominent theme evident across all focus groups was a perceived lack of understanding
from the health community as it related to the self-management of older adults living with
multiple health conditions. Many participants (18 of 35) perceived a general unwillingness from
their clinicians to individualize treatment plans that would address their comorbid conditions. As
Emily, a 64 year old woman with 5 health conditions, expressed: “My experience has been, you
walk into an endocrinologist’s office and everyone is treated pretty much the same.” Another
participant, Jack, a 69 year old man with 4 health conditions, shared: “Well I guess I can’t expect
my doctor to be knowledgeable of every disease. They see a lot of diabetics and they have a
pretty good experience base but they can’t spend a whole lot of time on that.” Some participants
(14 of 35) also felt that health community did not appreciate the growing problem of type 2
diabetes and comorbidity in the aging population:
The doctors need to be a little more sympathetic to the fact that diabetes is an epidemic in the USA now. Twenty years ago I thought I might have a blood sugar problem but I couldn’t get anybody interested. They couldn’t diagnose all the things happening to me. And then 20 years later I have diabetes. But they might have been able to discover this back then if they were educated and looking for it and if there was some sort of testing they could do. Maybe they could have caught it before my nerve damage was done. [Donald, a 68 year old man with 8 health conditions]

The lack of understanding from the health community led some participants (11 of 35) to attribute this perception to age discrimination. Two women verbalized their frustration with the provision of care in the following dialogue:

Helen, an 87 year old woman with 4 health conditions: Sometimes I find that when doctors are treating someone my age they say, “Well you’re not forty – you’re closer to death so we won’t treat you as aggressively as we would treat someone else.”

Betty, an 81 year old woman with 8 health conditions: Yeah, it’s very upsetting. They’re always telling me that I’m doing great and yet I know how I’m feeling. I’ll be 82 in July; I think I ought to know my own body by then. [laughing] And I know that I don’t feel as good as they say I do. I think doctors discriminate against older people in that respect. They say that you’re okay and you’re not.

What is more, participants felt that their health care providers did not address their needs or preferences for care. Many described experiences with poor communication and limited support from their clinicians. Gladys, an 84 year old woman with 8 health conditions, shared her difficulties with care:
In the beginning of October I was told that I had had two heart attacks. Every time the doctor came to see me he kept telling me that I was going to die. He said, “Now you had two heart attacks and pretty soon, you’re just in a waiting position, you’ll be getting another heart attack and that’s going to take you.” That was horrible thing to hear! I finally waited till I couldn’t take it anymore. I said to him, “You know, I think God isn’t ready for me yet in heaven. He thinks there’s something that I can still accomplish during my lifetime. And until God decides he wants me, nobody else is going to take me down!”

*Theme 3: Help us before it’s too late*

Participants showed that living with multiple health conditions could have a negative impact on diabetes self-management, exemplified by feelings of helplessness. Feeling like their management was too much to handle, coupled with a belief that the health community didn’t understand, left participants longing for comfort and support. Doris, a 68 year old woman with 4 health conditions, described feeling alone and unworthy in her unending struggle to manage diabetes:

I don’t know if it’s because of my other problems, but to me as soon as the doctors find that you have diabetes they don’t want to take care of you. If I have a cut on my finger, they don’t want to take care of it because I’m diabetic. It seems like as soon as they find out you’re diabetic whatever your problem is they don’t want to take care of it because you’re diabetic. That’s the way I feel about it. They told me that there was surgery for spinal stenosis but they won’t do the surgery because I’m diabetic. It makes me feel terrible. It feels like I’m never going to have anything done for me because I am diabetic. None of the doctors will want to take care of my problems. I think they’re worried about complications and malpractice. But they aren’t looking out for my best interests.
As participants faced multiple health conditions, they reported that their lives had become overwhelming, casting great uncertainty towards their future. The ominous perception of the time that remained was a constant in the back of the minds of the participating older adults. At the risk of losing control over their bodies, many participants broached the topic of physician-assisted dying. Seven participants yearned to control their own end-of-life care. Julia, a 72 year old woman with 6 health conditions, shared:

I want to be allowed to die. When it gets to a certain point, I’d like to be able to take a pill and go. And I’m serious. I’m not committing suicide now. When you get to a point where things are tough and they can’t do anything for you, I think they should be able to give you a pill.

Moreover, several participants (9 of 35) felt that they had become hostages in their aging bodies. No longer in control of their health, participants were at “the mercy of their diseases.” Longing to bring an end to her pain and torment, Mary, an 83 year old woman with 4 health conditions, put into words: “I’ve got arthritis in my back and from my waist down. My biggest problem is my legs. So I say, ‘The sooner I go, the better I feel because I really don’t care anymore.” For these older adults, feeling helpless made self-management seem too difficult and too much trouble. Perhaps Emma, a 78 year old woman with 3 health conditions, said it best: “I just hope and pray they can do something to help us and make it easier for us before it’s too late.”

**DISCUSSION**

Type 2 diabetes and comorbidity represent substantial health problems to the aging population. Since persons with diabetes can be expected to live more than a decade after diagnosis, clinicians must understand how comorbidity influences the challenges faced by this
population: Do older people with diabetes and other comorbidities perceive some conditions as more serious than others and thus selectively attend to behavior change recommendations? What impact does the complex management of multiple chronic health conditions have on the quality of life of older adults? Understanding if diagnoses “compete” with each other or disrupt the day-to-day pattern of life may shed light on how individual or joint decisions are made regarding diabetes management and overall life satisfaction.

Our research represents one of the first studies designed to describe the experiences of comorbidity in older adults living with type 2 diabetes. Analyses revealed three core themes describing the influence of comorbidity on type 2 diabetes management: Too much to handle, They don’t understand, and Help us before it’s too late. The 35 participating older adults reported difficulty adhering to the required lifestyle and medical surveillance behaviors for their potentially interacting conditions. To deal with the difficulties of comorbidity, participants prioritized their health conditions and selectively attended to the management behaviors of those conditions based on severity. What is more, participants felt that the health community did not adequately address their needs and preferences for care. Thus, the challenges experienced in caring for their multiple health conditions left participants feeling helpless in their efforts to manage diabetes. These findings provide a greater understanding of the perceived challenges to diabetes self-management in older adults living with multiple concurrent chronic conditions.

Our research was informed by the Shifting Perspectives Model of Chronic Illness (Paterson, 2001; Thorne et al., 2002). This model depicts chronic illness as a continually shifting process in which an individual makes sense of the illness experience. The shifting process reflects two dynamic perspectives, illness in the foreground and wellness in the foreground. These two perspectives represent the values, beliefs, expectations, and feelings of an individual’s
illness experience. Thus, it is the perception of the illness, not the illness itself, which determines how an individual with chronic illness interprets and responds to the illness. According to the model, shifting from one foreground to the other occurs when an individual perceives a threat (e.g., new symptoms, poor test results) to his or her illness. The great majority of participants in this study shared a perception of illness (or illnesses) in the foreground. Participants appeared to focus on the burden, suffering, and loss that was associated with managing diabetes and comorbidity. Our findings suggest that comorbidity may be a perceived threat resulting in a shift to illness in the foreground. Additional research is needed to determine if either specific or a particular combination of comorbid conditions contribute to a shift in perspective.

Limitations

Study limitations include the homogeneity of the study sample with regard to race (predominantly Caucasian) and residential status (community dwelling). Thus, the small, non-randomly selected convenience sample may have limited the ability to generalize the findings to a larger population. The cultural and social variations regarding comorbidity and self-care management among varied ethno-cultural groups have not been addressed and warrant further study. Finally, the use of self-reported diagnoses may have introduced error. Older patients may have confused symptoms and minor ailments with more significant diseases. As well, older patients may have forgotten to report important health diagnoses.

Notwithstanding these limitations, our study highlighted the complex and varied challenges facing older adults living with type 2 diabetes and other concurrent chronic health conditions. Qualitative research is an excellent way to garner preliminary information concerning the key role comorbidity plays in the daily self-management of type 2 diabetes. This information
can be used to develop more refined measures and instruments for collecting data on comorbidity and, in turn, more effective interventions for older adults living with diabetes.

**Implications for nurses**

The findings of this study underscore the importance of understanding the experience of comorbidity as it relates to the self-management, quality of life, and productive life of older adults living with diabetes. Nurses and other clinicians should allocate the time to understand how older adults with multiple health conditions live with and set priorities for their diabetes management. Nurses are well positioned to recognize the cues of older adults struggling to manage their diabetes amidst other health conditions. Moreover, older adults who feel helpless in their management may be at particular risk for developing depression, given that older adults with diabetes are at a higher risk for depression compared to the general population (ADA, 2008; Brown et al., 2003). Nurses need to be aware of the signs and symptoms of depression in older adults living with diabetes. Nurses should seize the opportunity to assist older adults living with comorbidity to follow their treatment regimens to improve diabetes outcomes.

The role of healthcare providers is to assist older adults living with comorbidity to identify and understand the perspectives of their illnesses. As our study demonstrates, nurses and other healthcare providers must be committed to listening to what older adults have to say about how multiple health conditions impact their diabetes management. The Shifting Perspectives Model of Chronic Illness emphasizes the individuation of the experience of chronic illness. Older adults vary in their clinical and functional status and thus vary in their attention to self-management. Understanding the variation directs clinicians to support older adults in either perspective. Furthermore, this theoretical perspective lends itself to research designs that allow older adults with comorbidity to move between foregrounds. Clinical investigations should
examine the impact of comorbidity on the type of foreground that dominates and the shift between foregrounds. Future research would benefit from studies designed to explore the process by which older adults with comorbidity balance their capabilities with environmental demands to optimize diabetes self-management. Qualitative longitudinal research, within and across cases, would allow researchers to discern convergence and divergence of cases over time. Longitudinal analysis could shed light on the movement between illness in the foreground and wellness in the foreground for older adults living with multiple chronic conditions. Such research may provide explanations for variations in attention to diabetes management. This information could then be used to design interventions to promote strategies that mediate the effects of chronic conditions so as to bring about a shift to wellness in the foreground.
Chapter 5

Values and Preferences in the Clinical Management of Type 2 Diabetes

ABSTRACT

Purpose: Individualized diabetes care has been recommended to address the problem of diabetes management in older adults and better design interventions to decrease morbidity. Methods: With this in mind, the study: (1) collected and analyzed focus group data on 48 older adults with diabetes regarding their values and preferences for diabetes care; and (2) employed the Q-sorting technique to prioritize those values and preferences. Results: Findings revealed that older adults expressed Individual and Shared values for care in addition to diverse Treatment, Interpersonal and Practice preferences for care. Participants prioritized Health, Collaboration, Quality of Life and Independence in their values for care, and Honesty, Listening Skills, Treatment to maintain current health and Aggressive treatment to prevent complications in their preferences for care. Conclusions: Comments provided by the participants revealed important practice implications for diabetes care during older age. The findings of this study underscore the importance of understanding the diverse values and preferences older adults express for diabetes care. Knowledge of values is critical for understanding their influence on preferences for care and, in turn, diabetes management. The diabetes healthcare team should incorporate individual values and preferences for care when prioritizing and balancing individualized clinical recommendations for older adults living with diabetes.

INTRODUCTION

Diabetes, and its related complications, is one of the most significant and growing chronic health problems in the United States (Wray et al., 2005). Roughly 20 percent of all adults aged 60 and older have diabetes, the vast majority being type 2 diabetes (CDC, 2005). Although
type 2 diabetes increasingly affects younger individuals, adults aged 60 and older continue to comprise the largest proportion of individuals with diabetes in the U.S. Despite the large numbers of older adults with diabetes, how to care for this group remains unclear due to the limited clinical trial data for older, frail adults (UKPDS Group, 1998a; UKPDS, 1998b; Huang, Meigs, & Singer, 2001) and the heterogeneity, both clinically and functionally, of the older population (Walter & Covinsky, 2001; Blaum, 2002; Gill, 2002). For healthy, well-functioning older adults, treatment goals developed for the general population may be appropriate to prevent or delay the onset of diabetes-related complications. In contrast, older adults with low functional status, comorbidity, frailty, an increased risk of hypoglycemia or drug side effects may not benefit from the standard population goals set for intensive glycemic control. Therefore, the potential benefits of strict adherence to glycemic goals must be weighed against the potential risks, like hypoglycemia and complexity of the treatment regimen, for older adults living with diabetes. Given the rapidly increasing number of older adults with diabetes and the enormous public health burden of diabetes, clinicians must consider the heterogeneity of older adults when establishing treatment goals.

The ADA and the AGS recently acknowledged the challenges of caring for older adults with diabetes and formally recommended that their care be individualized depending on the clinical and functional characteristics of the older patient (ADA, 2008; Brown et al., 2003). Individualized care must take into account life expectancy, personalized goals for treatment, willingness and ability to comply with proposed treatment regimen, financial resources and home care situation (Halter, 1998; Rizvi, 2007). A crucial aspect in the individualization of care may be the consideration of older adults’ values and preferences for diabetes care (Huang, Gorawara-Bhat, Chin, 2005; Durso, 2006). Values represent an enduring belief that a specific
behavior or ideal is personally or socially preferable (Rokeach, 1973). Preferences represent choices or priorities derived from such values. Older adults express a variety of values and preferences for care that may strongly impact their treatment goals. For some, maintaining functional independence in activities of daily living and minimizing the financial, physical and psychological burden of diabetes care may take precedence over aggressive medical management (Durso, 2006). Others may prefer intense medical management and long-term preventive care strategies (Durso, 2006). Given these differences, older adults’ values and preferences for care provide an important context for identifying appropriate treatment goals and plans for diabetes care. Clinical care guidelines should recognize this context, prioritize the important risks to older adults with diabetes, and provide guidance for applying its recommendations based on that adult’s personal values and preferences. Toward this goal, the purpose of this research was to explore values and preferences in the treatment of type 2 diabetes with the aim of improving coordination and consistency of care for older adults living with this chronic condition.

**METHODOLOGY**

**Design**

The study integrated a two-method approach (focus groups, Q-sorting techniques) to explore values and preferences for care in older adults living with type 2 diabetes. Focus group methods were used in this study to define and identify the values and preferences older adults express for their diabetes care. The group dynamic was structured to stimulate participants with diabetes to examine their values and preferences on needs for care with others who were in similar situations. Emphasis in this study was placed on real (lived) experiences to capture the diverse values and preferences older adults hold in the management of type 2 diabetes. The
group process promoted a sharing among participants that generated a deeper examination and discussion of related issues, thus promoting greater depth in the findings. In subsequent interviews with a subset of those adults, Q-sorting techniques were applied to facilitate the ranking or prioritizing of the values and preferences identified during the focus group discussions (Stephenson, 1953). The Q-sorting technique is a general methodology for gathering and processing collected information. The aim is to sample a range and diversity of views expressed, not to make assertions of the participants expressing them (Cross, 2005). For the purposes of this study, the Q-sorting technique was used to determine the relative ranking of values and preferences by the participants.

In order to maximize the phenomenon of interest, intensity sampling (a form of purposive sampling) was used to identify and select 48 older adults living with diabetes. Potential participants were screened by telephone for eligibility and other sociodemographic information (e.g., birth date, age, gender, race-ethnicity, comorbidity status, marital status, participant education, occupational status, year of diabetes diagnosis). The primary inclusion criteria for participation were mentally alert community-dwelling adults, aged 60 or older, who reported a physician diagnosis of type 2 diabetes. Participants were excluded if they were diagnosed by a physician with Alzheimer’s disease or dementia. Recruitment efforts were focused on the Pennsylvania State University Diabetes Database as well as through advertisements in diabetes support group meetings, public service announcements, and flyers in community buildings. The research protocol was approved by the Pennsylvania State University Institutional Review Board prior to the initiation of the study.
Procedure

Eight 90-minute focus groups, each consisting of three to seven participants, were conducted according to participant preferences (site locations and times) and included various community sites (recreational centers, senior centers and churches). A structured discussion guide was devised, field tested for flow and clarity of the discussion questions, then used by trained moderators and co-moderators to promote consistency across the groups. A series of nine open-ended questions elicited participant views on: (1) values and preferences for diabetes care; (2) experiences with clinicians addressing values and preferences for care; and (3) recommendations for improving clinical care. Moderators were instructed in the use of directive probes to elicit additional information and clarify ambiguous comments; co-moderators wrote field notes to capture key points in and observations about the discussion. Participants were asked general open-ended questions to introduce the focus of the discussion groups (e.g., How did you first learn that you have diabetes?), and at the conclusion to elicit final thoughts and allow participants to reflect upon aforementioned comments (e.g., After listening to all of the things we talked about today, what would you like to be different?) All focus group sessions were audio-recorded and transcribed verbatim. All names and identifiers were removed from the text to protect participant confidentiality (for example, “Dr. Jones from Philadelphia” would be replaced by Dr. [Endocrinologist] from [medical center].”) These clean transcripts (i.e., transcripts purged from identifiers) were used in analysis.

In subsequent one-on-one interviews with 30 of the 48 focus group participants, adults were asked to rank-order the values and preferences that were expressed during the focus groups [Note: Q-sorting of values was performed separately from the Q-sorting of preferences]. Sixteen values and sixteen preferences were provided on notecards. Participants were instructed to read
through the values and preferences to get an impression of the range of values and preferences to allow the mind to settle into the situation. Next, participants were asked to sort the values and preferences according to those that were most important to them. Values were placed in seven piles ranked from most important to least important. The seven piles followed a roughly normal distribution, with one value or preference at each of the extremes (most important and least important), four items in the middle or neutral pile, and the others in between. The piles were labeled +3 to -3 to reflect their degree of importance. To clarify their degree importance, values and preferences were then numbered 1 to 16 to demonstrate the relative rankings. The placement of values and preference was recorded and counted to demonstrate their relative importance.

Data Analysis

Techniques for content analysis were used to assess, categorize and interpret the focus group data (Morse & Field, 1996). Transcripts were analyzed line-by-line to develop a categorical schema of the diverse values and preferences expressed by these older participants living with type 2 diabetes. Specifically, discussions were summarized immediately following each of the focus groups; codes were developed using the research questions as guides; and the codes of new transcripts were compared to existing codes following each focus group to more fully develop the properties of the overarching categories. Descriptive statements were formed and quotes were sorted appropriately under the newly-developed categories. This process continued until saturation was reached; that is, until no new codes or categories emerged, and the research team, consisting of a gerontologist, doctoral student and research assistant, reached consensus that coding additional transcripts would only repeat themes. No negative cases or reports were discarded in the process.
Credibility of the data was supported in three ways: (1) one investigator and the research assistant independently coded the data to check for inter-rater agreement; (2) other investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining transcript data; and (3) categorizations were independently summarized by the first investigator and research assistant and discrepancies were reviewed and resolved by the other investigator. Dependability of the data interpretations was supported with an audit trail to track the decision making process.

RESULTS

In this study, recruitment efforts were suspended when 48 participants were successfully enrolled. Table 4.1 provides general demographic and health characteristics of the participants who participated in the study’s focus groups, based on the data obtained during eligibility screening. Participants ranged in age from 60 through 85 years (mean age 73 years), 62.5% were women and 81.3% were Caucasian (8.3% African American; 8.3% Middle Eastern, 2.1% Hispanic). Socioeconomic data were not collected; because of the location of the pilot study (Central Pennsylvania), it was understood that the sample would be predominantly middle to upper class.

| Table 4.1: Sociodemographic and health characteristics of participants with diabetes |
|-------------------------------|-----------------------------|
| Age (years)                   | 73.1 (60.0-85.0)            |
| Female (percent)              | 62.5                        |
| Caucasian (percent)           | 81.3                        |
| Median education              | High school                 |
| Married (percent)             | 56.3                        |
| Retired (percent)             | 87.5                        |
| Comorbid conditions (percent) | 97.9                        |
| Years with diabetes           | 11.9 (1.0-42.0)             |
| Hemoglobin A1c (percent)      | 7.1 (5.9-9.6)               |
| Prescribed oral hypoglycemic medication(s) (percent) | 52.1                       |
| Prescribed insulin injection(s) (percent) | 37.5                       |
| Body Mass Index (kg/m²)       | 32.5 (20.5-51.2)            |

Note. The items HbA1c, body mass index, prescribed oral hypoglycemic medication(s), and prescribed insulin injection(s) are based on self-reported measures of adherence.


Distinction between Values and Preferences

During the focus groups, participants were asked to define what values and preferences for care meant to them. Participants defined values (see Table 4.2) as what they believed to be most important in their diabetes care. For some, values represented a preferred state of being (e.g., happiness, autonomy); for others, values represented a desired health outcome:

Don’t you think the biggest value is what you want for an outcome? My daughter-in-law has diabetes. She’s not worried about neuropathy or what’s going to happen when she’s 70. She had trouble with a pregnancy. It’s a more immediate problem. So her value was “what do I have to do to have a stable family at the age of 35.” As opposed to us, who are getting up there in age a little – we’re just after comfort and a little more peace.

[Participant 17, a 68 year old man]

<table>
<thead>
<tr>
<th>Table 4.2: Self-reported values for diabetes care and Q-sort rankings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Values</strong></td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>Individual values</td>
</tr>
<tr>
<td>Autonomy</td>
</tr>
<tr>
<td>Gratitude</td>
</tr>
<tr>
<td>Happiness</td>
</tr>
<tr>
<td>Health</td>
</tr>
<tr>
<td>Independence</td>
</tr>
<tr>
<td>Individualization</td>
</tr>
<tr>
<td>Longevity</td>
</tr>
<tr>
<td>Peace</td>
</tr>
<tr>
<td>Quality of life</td>
</tr>
<tr>
<td>Spirituality</td>
</tr>
<tr>
<td>Shared values</td>
</tr>
<tr>
<td>Collaboration</td>
</tr>
<tr>
<td>Family</td>
</tr>
<tr>
<td>Knowledge and education</td>
</tr>
<tr>
<td>Support</td>
</tr>
<tr>
<td>Trust</td>
</tr>
<tr>
<td>Understanding</td>
</tr>
</tbody>
</table>

Participants defined preferences (see Table 4.3) as choices or priorities derived from their values for care. One man expressed his desire to live a long life and his preferences for how to achieve this value:
I said to my doctor, “I’m going to give you an assignment. I’m 76 and if I’m lucky I’ve got another 10 years. I want you to manage my diabetes.” He said, “What does that mean?” I said, “I want life. So keep me mobile. Keep me active. I don’t want to take too much stuff in terms of medicine. I don’t want to be insulin dependent. I’m not sure I want to use syringes. I’d rather live my life the way I want to live it. I’m going to have French fries every now and then. I’m going to go to have my hamburger at least once a week. And I’m going to live with it. Those are my preferences.” [Participant 20, a 76 year old man]

Table 4.3: Self-reported preferences for diabetes care and Q-sort rankings

<table>
<thead>
<tr>
<th>Preferences</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment preferences</td>
<td></td>
</tr>
<tr>
<td>Aggressive treatment to prevent complications</td>
<td>4</td>
</tr>
<tr>
<td>End-of-life decision making</td>
<td>16</td>
</tr>
<tr>
<td>Innovation and research</td>
<td>9</td>
</tr>
<tr>
<td>Minimal medication usage</td>
<td>7</td>
</tr>
<tr>
<td>Proven effective treatments</td>
<td>12</td>
</tr>
<tr>
<td>Specialists</td>
<td>11</td>
</tr>
<tr>
<td>Treatment alternatives to insulin</td>
<td>14</td>
</tr>
<tr>
<td>Treatment to maintain current health</td>
<td>3</td>
</tr>
<tr>
<td>Interpersonal preferences</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>5</td>
</tr>
<tr>
<td>Honesty</td>
<td>1</td>
</tr>
<tr>
<td>Listening skills</td>
<td>2</td>
</tr>
<tr>
<td>Willingness to comply with recommendations</td>
<td>6</td>
</tr>
<tr>
<td>Practice preferences</td>
<td></td>
</tr>
<tr>
<td>Affordability</td>
<td>8</td>
</tr>
<tr>
<td>Convenience</td>
<td>13</td>
</tr>
<tr>
<td>Organization and cleanliness</td>
<td>15</td>
</tr>
<tr>
<td>Time</td>
<td>10</td>
</tr>
</tbody>
</table>

Values for Care

Individual values

Individual values were conceived of as guiding principles which helped to steer older adults in the selection of self-management behaviors and desired health outcomes. Individual values ranged from Autonomy to Gratitude to Spirituality. For the older adults participating in
the focus groups, *Health* was prioritized above all other values. Two participants conveyed the importance of *Health* in the following dialogue:

Participant 7, a 74 year old man: I value health. Anybody who has good health has the world.

Participant 8, a 60 year old woman: Yeah, I think the older you get the more value you place in it.

Participant 7: I would rather have that than all the money in the world. No pain, no more needles. To me that would be it.

When it came to managing their diabetes, participants described feeling somewhat defeated as a result of their exhausting routine to stave off potential complications. It was not surprising that while their treatments tended to focus on preventing these long-term complications, participants were preoccupied with the daily experiences of living with this chronic condition. Many spoke of the importance of *Quality of Life* and *Independence* in their values for care. These values were articulated best by the following quote:

My values are to stay mobile and independent. And feel half decent. If I was sitting around in pain all the time, there’s no value in life when it gets to a certain point. My mother-in-law, she sits in a wheelchair hating every second she’s alive. She’d be better off not being alive. She’s 95 and has mild dementia. She doesn’t like being in a nursing home. My dad was the same way. He got to the point where he couldn’t see and he couldn’t hear. He had macular degeneration and he had that bad knee and was in a wheelchair. He had no external inputs. And my mother-in-law has no external inputs. When you close in on yourself all you can think about is yourself. And all you can think
about is, “I’m miserable.” It’s happened to both of them. I don’t want to live like that.

[Participant 17, a 68 year old man]

*Shared values*

Participants identified six values for care that reflected the influence of significant others (spouse, family, and friends) community and culture: Collaboration, Family, Knowledge and education, Support, Trust and Understanding. Discussions revealed a distinct need for increased knowledge and education in the community in addition to a collective understanding of diabetes. To make sense of what was going on with their diabetes, participants looked to their providers and the greater health community to help shape their values for care. Participants prioritized the value of a collaborative partnership in their care. Moreover, many stressed the need for a trusting relationship between themselves and their providers:

Isn’t this like the primary elections coming up? How many people can you listen to about the value of a particular candidate? With your diabetes advice, who can be your trusted advisor that you stick with? I can’t listen to everybody. I have to go to one person. I need someone to help me understand what’s going on so I can participate in my own therapies. I need someone I can talk to when there are things that I don’t understand. [Participant 17, a 76 year old man]

Participants also valued the support of significant others in their efforts to manage diabetes and emphasized the importance of involving family in their care. Participants felt that they could not manage their diabetes without the support of others. As one man exclaimed:

Good Lord if it was not for my wife, I do not know where I would be! She takes care of me. And if anything happens to her I’ll be in a very, very different position in terms of
my healthcare and health maintenance. She is the one that keeps me healthy.

[Participant 28, a 69 year old man]

For these older adults, significant others, community and culture provided a foundation for the expression of their values for care: “I am influenced by conversations that I have, books that I read, and programs that I see. I’m influenced by a lot of things including people in my life.”

[Participant 33, a 61 year old woman] Another participant shared how his family is a part of his care:

I don’t know if this is usual or not but my wife and I see the doctor at the same time. We both go in and have two appointments side by side. We’re both there when the doctor is talking to me about my diabetes and I’m there when he’s talking to her about her health. So she hears what he’s telling me and I hear what he’s telling her and it works out fantastic. [Participant 46, a 73 year old man]

Preferences for Care

Treatment preferences

Participants acknowledged several preferences in the treatment of their diabetes, ranging from Innovation and research to Specialists to Treatment alternatives to insulin. Among these preferences, participants prioritized Treatment to maintain current health and Aggressive treatment to prevent complications as most salient in their care. For some, maintaining their current health and functional capabilities took precedence over aggressive medical management (e.g., strict adherence to glycemic goals). Others preferred aggressive treatment to prevent or delay the onset of diabetes-related complications. One woman explained her preference to do whatever it takes to maintain her health:
If it’s to maintain my health – and it’s not a life support situation – but to maintain my current health I would do anything. If my doctor said this is what you have to do and he’s researched it, yes I would do anything. [Participant 8, a 60 year old woman]

Despite being ranked last, end-of-life decision making was frequently mentioned in the focus groups discussions. Participants voiced that it was their choice whether or not to continue with their treatments; and it was their choice whether or not to be resuscitated:

I’ve heard of the “sleep of peace.” I look at that and I’ve thought about that. To me I want the sleep of peace. My knee won’t hurt anymore. I won’t be hooked up to a dialysis machine. I’m not going to go blind. So if I can’t have these things that I consider very basic, I will reevaluate. [Participant 34, a 76 year old man]

As a final point, comorbidity may be an important factor in the expression of treatment preferences as well as the relative importance of those preferences for care. For that reason, providers need to consider the clinical and functional characteristics of the older adult when addressing values and preferences for care:

I have more than just diabetes to be concerned about. Diabetes is the one I’m probably most aware of, but if something else goes out of whack it doesn’t matter what happens to the diabetes. So I think probably when I try to rank values and preferences it will really be in the context of my total healthcare. [Participant 19, 69 year old man]

Interpersonal preferences

Interpersonal preferences referred to the interactions between participants and their providers, and included Communication, Honesty, Listening skills and Willingness to comply with recommendations. Honesty was ranked highest among preferences for care. Participants felt
Honesty was an essential component in developing the right treatment plan to successfully manage their diabetes:

I’ve had a doctor for a good number of years and I trust him because he’s demonstrated his ability, his concern and his honesty. He’ll say, “You know, we could try this or we could try that. But I think this will work best.” He gives me an opinion. And he stresses that I’m the only who’s ultimately got to do or not do. [Participant 19, a 68 year old man]

Relationally, some participants reported on their willingness to comply with any and all recommendations provided by their clinicians. Whether or not participants complied with prescribed treatment recommendations, all participants recognized the importance of open communication and listening skills. In the discussions, women were more likely to prioritize Communication and Listening skills:

I want a healthcare provider who will listen to me and what my concerns are. If I say I’m concerned about the number of low readings I’m having, I want someone to respond to that. If I say I’m having an uncomfortable reaction to a medicine and I don’t like that reaction, I want someone who will respond to that. I want someone who understands that this is an individual circumstance rather than giving me platitudes of what generally works. [Participant 3, a 78 year old woman]

Practice preferences

Participants, in particular women, also discussed their preferences for Affordability, Convenience, Organization and cleanliness, and Time in the medical practices they visited for care. Of these practice preferences, participants prioritized affordable care and time spent with their clinicians. As one woman explained, “Something that’s really important to me is cost. I can retire next year but I can’t afford medical insurance so I won’t retire.” [Participant 29, a 60 year
old woman] Similarly, another woman shared her preference for time, “I want a doctor who cares about me. I want someone who will invest the time to care about me as a person.” [Participant 41, a 65 year old woman] Many participants discussed the importance of convenience in traveling to and from the medical practice as well as the overall organization and cleanliness of the office space:

I want a clean, sanitary office. I want a practice that’s going to value my time as well as the physician’s. I want an office that is set up for my convenience as well as the doctor’s. I want an office that has a changing curtain if I need to take my clothes off. It makes a huge difference in maintaining your dignity. [Participant 12, a 65 year old woman]

**DISCUSSION**

Exploring the values and preferences of older adults is a logical step in developing an approach to effectively individualize diabetes care. To support older adults in their efforts to manage diabetes, clinicians require an understanding of the diverse values for care and preferences for how to achieve them that are expressed by these older adults. Although the ADA (2008) and the AGS (Brown et al., 2003) urge clinicians to base their recommendations for managing diabetes on individuals’ personal values and preferences, we know little about those values and preferences—what they are, what underlies them, and how they influence diabetes-related health outcomes. Our research represents one of the first studies designed to define and identify the values and preferences older adults express for diabetes care. Values were defined as a preferred state of being or a desired health outcome for their diabetes care; preferences were defined as choices or priorities derived from their values for care. Older adults expressed *Individual* and *Shared* values for care in addition to diverse *Treatment*, *Interpersonal* and *Practice* preferences for care. Participants prioritized *Health*, *Collaboration*, *Quality of Life* and
Independence in their values for care, and Honesty, Listening Skills, Treatment to maintain current health and Aggressive treatment to prevent complications in their preferences for care. The relative rankings from the Q-sorting interviews provide guidance to which values and preferences may be most salient in the individualization of diabetes care. Finally, our study may have demonstrated potential gender differences in the expression of interpersonal preferences as well as practice preference in their diabetes care. Additional research is needed to fully appreciate gender differences in the preferences older adults express in their diabetes care.

In addition to the cognitive factors just described, a number of external factors appeared to be associated with the self-reported values and preferences for care. Older adults often have had a lifetime of experiences with diabetes as well as healthcare and significant others that are powerful determinants of their values and preferences for care (Huang, Gorawara-Bhat, & Chin, 2005). Although the diabetes healthcare team is important in individualization of care for older adults, significant others, community and culture may play equally important roles in shaping values and preferences for diabetes care. Further research is needed to examine external factors that may influence values and preferences so that clinicians and policy makers can develop more effective tools to encourage greater adherence to and maintenance of optimal management behaviors and, in turn, enhanced health outcomes.

Our study demonstrates the importance of understanding individual values and preferences in older adults living with diabetes. While clinicians oversee the screening, diagnostic and therapeutic actions of diabetes management, quality care must also recognize and reflect a patient-centered approach. Patient-centered care responds to individual values and preferences and allows opportunities for individuals to be involved in their care (Institute of Medicine, 2001). A patient-centered approach provides care that is respectful of and responsive
to individual values and preferences so as to ensure patient values and preferences guide clinical management (Institute of Medicine, 2001; Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). It is essential for clinicians to recommend interventions that reflect patient-importance as well as clinical-relevance (Guyatt, Montori, Devereaux, Schünemann, & Bhandari, 2004). Furthermore, patient-centered care must incorporate problem-solving skills to achieve treatment goals and provide ongoing monitoring and support for goal attainment (Fisher, Brownson, O'Toole, Shetty, Anwuri, & Glasgow, 2005). If older adults are informed throughout the decision process, their decisions may be more likely to align with their values and preferences and, in turn, to improve adherence to individualized care plans.

In sum, comments provided by the participants revealed important practice implications for diabetes care during older age. The findings of this study underscore the importance of understanding the diverse values and preferences older adults express for diabetes care. Knowledge of values is critical for understanding their influence on preferences for care and, in turn, diabetes outcomes. The diabetes healthcare team should incorporate individual values and preferences for care when prioritizing and balancing individualized clinical recommendations for older adults living with diabetes (Huang, Gorawara-Bhat, Chin, 2005). As the prevalence of diabetes burgeons in our aging population, a concerted effort to address individual values and preferences for diabetes care is vital to maximize successful management and, ultimately, to improve both the length and quality of life experienced by older adults.

Limitations

The findings should be considered in light of the study’s limitations. This exploratory study was designed to explore the diverse values and preferences older adults express for diabetes care. The study population was drawn from community-dwelling sample of older adults
living in Central Pennsylvania; values and preferences may be distinct from older adults living in residential versus institutional settings. The sample was also predominantly Caucasian, and the perspective of other ethnic groups may be different. Nonetheless, the sample characteristics generally reflect the demographic make-up of older adults living in Central Pennsylvania. In addition, the small, non-randomly selected convenience sample may have limited the ability to generalize the findings to a larger population. Lastly, only the perspectives of the older adults with diabetes were focused on in this study. Providers’ perspectives on values and preferences for older adults with diabetes are not known.

Notwithstanding these limitations, our study highlighted the diverse values and preferences older adults express for their diabetes care. Qualitative research is an excellent way to garner preliminary information concerning the key role values and preferences play in the clinical management of type 2 diabetes. This information can be used to develop more refined measures and instruments for addressing diabetes care needs and, in turn, improve the management for older adults living with diabetes.

**IMPLICATIONS**

The findings from this study provide reason for clinicians, educators and interventionists to consider values and preferences in the management of type 2 diabetes. By using a patient-centered approach that fosters collaboration in the clinical management of diabetes, clinicians can help ensure that older adults make informed decisions about their self-care and assume responsibility for their glycemic control. To achieve quality in medical decision-making, older adults must be informed and feel confident that their decisions match the values and preferences they deem to be important. No one treatment plan can be right for all older adults; thus, the decisions that will best treat the older population will depend on their own values and
preferences for care. Furthermore, older adults should be encouraged to provide feedback to the diabetes care team to make sure individual expectations are being met. Overall, providers must be committed to translating practice guidelines into a patient-centered care plan for older adults with diabetes. Providers must recommend treatment goals according to the impact medical treatments and preventive care strategies are likely to have on older adults’ overall health while explicitly acknowledging their values and preferences for care.
Chapter 6
Discussion and Implications

The significance of this study lies in the growing problem of type 2 diabetes in older adults in the United States. Type 2 diabetes and its related complications prove costly and most often have a deleterious impact on the physical and psychosocial well-being of older individuals. Moreover, the burden of this disease is expected to intensify in the future as the prevalence increases due to the aging of the population. From a health promotion perspective, the rise in diabetes is a major public health priority, especially in the older segment of the population. Despite this public health concern, research on the complex needs of older adults with type 2 diabetes is lacking. For that reason, research designed to understand and explicate the experience of type 2 diabetes from the point of view of the adults directly affected can help improve care for the older population.

The purpose of this research was to illuminate the context of type 2 diabetes in the older population, and in particular, how older adults prioritize attention to their comorbidity, values and preferences. The research integrated a multi-method approach (focus groups, Q-sorting techniques) to explore the influence of comorbidities as well as values and preferences for diabetes care in older adults living with type 2 diabetes. Study I employed focus group methods to describe and assess the perceived challenges to diabetes self-management in older adults living with multiple concurrent chronic conditions. The most common challenges to clinical management included Healthcare, Medical costs and insurance, and Conflicting treatment regimens. Complications, Physical disability and limitations, Acute illness, and Stress were the most frequently cited challenges to active self-management. Thematic analysis revealed three core themes describing the experiences of comorbidity in older adults living with type 2 diabetes:
Too much to handle, They don’t understand, and Help us before it’s too late. These findings highlight the complex and varied challenges of diabetes self-management in older adults living with type 2 diabetes and other concurrent chronic health conditions, and support the need to assess the impact of comorbidity in diabetes care with respect to clinical outcomes.

The second study employed focus group methods and Q-sorting techniques to define, identify and rank the values and preferences older adults express for their diabetes care. Findings revealed that older adults expressed Individual and Shared values for care in addition to diverse Treatment, Interpersonal and Practice preferences for care. Participants prioritized Health, Collaboration, Quality of Life and Independence in their values for care, and Honesty, Listening Skills, Treatment to maintain current health and Aggressive treatment to prevent complications in their preferences for care. These findings underscore the importance of understanding the diverse values and preferences older adults express for diabetes care. Knowledge of values is critical for understanding their influence on preferences for care and, in turn, diabetes outcomes. Clinicians, educators and interventionists must consider values and preferences in the management of type 2 diabetes. Clinicians should incorporate individual values and preferences for care when prioritizing and balancing individualized treatment recommendations for older adults living with diabetes. To provide the highest quality of care, a concerted effort to address individual values and preferences for diabetes care is vital to maximize successful management and, ultimately, to improve both the length and quality of life experienced by older adults.

This dissertation is unique in that it examined the influence of comorbidities as well as values and preferences for diabetes care in older adults living with type 2 diabetes from the Ecological Systems Perspective. The Ecological Systems Perspective represents the coalescing of research and theory from developmental psychology, sociology, social work, and education.
This emerging perspective emphasizes the interconnections of individual, interpersonal, community, and societal factors and the bidirectionality of the effects between the individual and the surrounding environment. When diabetes care is examined from an ecological perspective, no one individual or factor can be identified as the cause of a problem. An ecological perspective focuses on the individual, his or her diabetes, and the effect of diabetes on the environment, and vice versa. While the older adult and his or her diabetes care team have a profound influence on adherence to management recommendations, the environment (e.g., family, community, culture) also influences adherence. Thus, when treating diabetes in older adults, researchers and healthcare providers need to consider not only the older adult but also the multiple contributing factors from the environment. Comorbidity and values and preferences represent key factors which may lead to older adults behaving in particular ways to suit their environment. For example, older adults may use the value of Family to guide their behaviors so that they feel less alone in their efforts to manage diabetes. The Ecological Systems Perspective addresses the complexities and interdependencies between comorbidity, values, and preferences by way of the biological, psychological, societal, and cultural determinants of health. This meta approach offers potential to direct efforts to expand the scope of research and, in turn, improve diabetes care.

In sum, contemporary issues, like clinical heterogeneity and diverse values and preferences, challenge the health community to provide comprehensive care to older adults living with diabetes. It is critical to recognize the impact of comorbidity in self-management with respect to clinical outcomes. Moreover, it is necessary for the research community to more aggressively address the psychosocial needs, like values and preferences, of older adults. As the prevalence of diabetes grows rapidly among our aging population, the healthcare community
must strengthen clinical guidelines to maximize successful care and, ultimately, improve both the length and quality of life experienced by older adults. The following sections describe the clinical recommendations, practice recommendations, policy implications, strengths and limitations of the studies on comorbidity, values and preferences, as well as future directions for research on these topics.

**Clinical Recommendations**

Improvements in the clinical care of older adults with diabetes must begin with a statement of purpose. Clinicians must be committed to respecting older adults’ wants, needs and preferences, while providing the proper education and support to assist older adults in making informed decisions about their care. Two specific aims for improvement include the following:

1. **Incorporating comorbidity into clinical care**

Research on the clinical management of older adults with more than one chronic condition, and in particular the diabetes management of older adults with more than one comorbid condition, is scarce. Most clinical care guidelines for older adults are disease-focused and do not provide guidance for prioritizing multiple concurrent chronic conditions that are common in older adults. Ideally, they should provide guidance to clinicians for prioritizing medical treatments and preventive care by ranking these according to the impact the interventions are likely to have on older adults’ overall health while explicitly acknowledging their coexisting chronic health conditions. Clinicians are responsible for providing individualized treatment – healthful diet, physical activity, medication – that addresses the medical and emotional needs of the older adult.

Furthermore, diabetes care is a continuous process. Older adults and their clinicians should engage in ongoing discussions about what care is best for them and why. Discussing
perceived challenges to comorbidity may provide a systematic way to include older participants in the evaluation and treatment process, thereby enhancing therapeutic alliance. Over time, the treatment process should become an open dialogue continually redefining and attending to the ever-changing needs of older adults.

2. *Incorporating values and preferences into clinical care*

Improving clinician’s awareness of how older adults define values and preferences for care represents an incremental step towards the individualization of care. By invoking the values and preferences of older adults, clinicians can facilitate their involvement in developing and implementing individualized care plans. An initial open-ended discussion regarding the overall values and preferences for care may be an effective way to understand an older adult’s treatment goals and help clinicians frame future discussions in the older adult’s own language. Future research should address how clinicians communicate with older adults concerning the prioritization of values and preferences for diabetes care.

**Practice Implications**

Recent diabetes guidelines recommend the individualization of treatment goals for adults age 60 and older (ADA, 2008; Brown et al., 2003). The diagram in Figure 5.1 illustrates the key concepts introduced in these guidelines, with special consideration of the findings from Study I and Study II. The approach outlined in Figure 5.1 begins with the clinical assessment of an older adult’s general health status. Prior research has cited that clinical characteristics play a crucial role in determining whether or not an older adult should strive for treatment goals developed for the general population (Brown et al., 2003). Older adults with diabetes complications, life-limiting comorbid conditions, and substantial cognitive or functional impairment are less likely to benefit from intensive glycemic control (ADA, 2008; Brown et al., 2003). For that reason, the
adverse effects of hypoglycemia may take priority over risk reduction for microvascular complications. Findings from Study I advise clinicians to also consider the number of comorbid conditions as well as the type and severity of conditions. In addition, clinicians must be aware of older adults’ perceived challenges to clinical management (e.g., poor communication with providers, limited consultations, conflicting treatment regimens) and active self-management (e.g., diabetes complications, acute illness, stress). Clinicians must identify perceived challenges, implement systematic approaches to meet patient needs with available resources, and be alert to shifting priorities so that there is continual reassessment of patient needs.

Equally important is the consideration of individual values and preferences for diabetes care. Findings from Study II reveal the diverse values and preferences older adults express for
their diabetes care. Clinicians must be able to meet the most common types of needs as well as have the capability to respond to individual values and preferences for care. What is more, clinicians must be able to elicit older adults’ values and preferences regarding their satisfaction with treatment plans and overall well-being with comorbid health conditions. Because an older adult’s well-being is greatly influenced by the daily demands of adhering to multiple lifestyle and medical surveillance behaviors, clinicians must be aware of the perceived impact of specific treatment plans in addition to the impact of comorbid conditions. Lastly, to improve patient centered care, clinicians should also address social influences, which may help them provide guidance for prioritizing treatment and preventive care while acknowledging the individual’s values and preferences for care.

Following the initial assessment, diabetes treatment goals and overall health goals should be tailored to the older adult. It is critical for clinicians to be aware of an older adult’s coexisting health conditions as well as the older adult’s cognitive or functional status. What is more, clinicians must be able to elicit individual values and preferences to facilitate collaborative decision-making in the individualization of care. Once individual treatment goals are established, clinicians will need to prioritize the various components of diabetes care depending on the older adult’s initial assessment.

Prioritization of care refers to the concept that treatment plans may vary from patient to patient. Accordingly, plans will need to balance the potential benefits with the potential risks and relative ease of implementing a specific therapy. For example, healthy, well-functioning older adults may benefit greatly from intensive glycemic control and the prevention or delay of diabetes-related complications. On the other hand, older adults with low functional status, comorbidity, frailty, and an increased risk of hypoglycemia or drug side effects may not benefit
from strict adherence to glycemic goals. While management of glucose is important, quality of life considerations should take priority in setting glycemic goals for older individuals with diabetes. In the final step of the process, clinicians will administer the actual treatment plan, which should be based on the initial patient assessment and the establishment of individualized treatment goals.

Policy Implications

The findings of this research have important policy implications for older adults living with diabetes. Current practices designed to measure or enhance quality of care do not make explicit provision for addressing the clinical heterogeneity of older adults or the values and preferences older adults express for care. Policies that fail to incorporate comorbidity, values and preferences run the risk of providing overly aggressive care to older adults even when it may not be clinically beneficial, cost-effective, or even desired. While recent guidelines have acknowledged the heterogeneity of the older population and recommended that their care be individualized, practical and patient-centered guidelines must address this complexity by going beyond recommending interventions that target disease-specific conditions. Guidelines must address the challenges to self-management in older adults living with comorbidity. Moreover, guidelines must address the diversity of values and preferences that older adults express for their diabetes care. To provide appropriate care to the older population, clinicians require more comprehensive information on the experience of type 2 diabetes as well as the impact of comorbidity, values, and preferences as they relate to clinical care.

The overarching goal of this research was to incorporate comorbidity, values and preferences into clinical care guidelines designed for older adults living with diabetes with the aim of improving coordination and consistency of care for older adults living with this chronic
condition. This research will further contribute to the scarce amount of literature focusing on the impact of comorbidity, values and preferences as it relates to the self-management, quality of life, and productive life of older adults. The findings of this research may also help to improve the standards of care for older adults living with diabetes. [Note. Additional research is needed to determine whether incorporating comorbidity, values, and preferences improves clinical care and/or health outcomes.]

**Strengths and Limitations of Studies**

The overarching goal of the dissertation was to illuminate the context of type 2 diabetes in the older population, in particular, how older adults prioritize attention to comorbidity, values, and preferences. This research represents two of the first studies designed to explore the impact of comorbidity in self-management as well as the diverse values and preferences older adults express for diabetes care. Because of the exploratory nature of this research, qualitative methods were employed to gain a deeper understanding of the diabetes experience. Qualitative research is an excellent way to garner preliminary information concerning the key roles comorbidity, values, and preferences play in the clinical management of type 2 diabetes. Specifically, focus group methods are particularly useful tools that can: (1) help educators develop more effective targeted educational messages and programs to provide specific knowledge and skills; (2) guide the design of research questions and analytic models using larger-scale quantitative data; and (3) inform the interpretation of broader existing quantitative research findings. Further, Q-sorting techniques are excellent tools for gathering and processing the information collected in the focus group discussions. By conducting a mixed method approach, this dissertation has the advantage of providing a coherent, well-explained analysis of two critical, yet understudied, domains in the individualization of diabetes care.
Finally, optimal diabetes management involves adhering to a complex set of individual behaviors that are strongly influenced by comorbidity and values and preferences for care. This dissertation utilized the expertise of a multidisciplinary team of researchers to examine the influence of comorbidity, values, and preferences for care in optimal diabetes management and to collect preliminary data as the basis for future research proposals.

Limitations of the study must also be acknowledged. Limitations include the relative homogeneity of the study samples with regard to race (predominantly Caucasian) and residential status (community dwelling). Nonetheless, the sample characteristics generally reflect the demographic make-up of older adults living in Central Pennsylvania. Thus, the small, non-randomly selected convenience samples may have limited the ability to generalize the findings to a larger population. The cultural and social variations regarding comorbidity, values, and preferences among varied ethno-cultural groups have not been addressed and warrant further study. Previously documented disparities with respect to morbidity and mortality of women, different ethnic groups, and those of lower SES also warrant further investigation. Additionally, the use of self-reported diagnoses may have introduced error. Older patients may have confused symptoms and minor ailments with more significant diseases. As well, older patients may have forgotten to report important health diagnoses. Time since diabetes diagnosis and relationship with the same healthcare provider may have also influenced older adults’ perceptions of comorbidity as well as values and preferences for care. For example, older adults recently diagnosed with diabetes may perceive greater challenges to clinical and active self-management. In addition, older adults with a longstanding relationship with their provider may report fewer challenges due to the trust and confidence gained over time. Lastly, emphasis in this study was placed on real experiences to capture the impact of comorbidity in the daily management of type
2 diabetes as well as the diverse values and preferences older adults express for diabetes care. Perspectives regarding primary care versus specialty care were not explored and require further investigation to determine their influence on comorbidity, values and preferences. Further, providers’ perspectives on the influence of comorbidity in diabetes management as well as the role of values and preferences in clinical care were not explored.

**Future Directions**

Future research would benefit from research designed to explore the process by which older adults with comorbidity balance their capabilities with environmental demands to optimize diabetes self-management. We will use the data collected in Study I to provide the basis for the preliminary studies section of an R21 research proposal aimed at collecting similar data on comorbidity from a diverse sample of older adults living with diabetes. Using Grounded Theory methods developed by Glaser (1978, 1992), the proposal will explore the process of managing type 2 diabetes in the context of comorbidity. A Grounded Theory design will shed light on the movement between illness in the foreground and wellness in the foreground (Shifting Perspectives Model of Chronic Illness; Paterson, 2001; Thorne et al., 2002) for older adults living with multiple chronic conditions. Such research may provide explanations for variations in attention to diabetes self-management behaviors. This information could then be used to design interventions to promote strategies that mediate the deleterious effects of chronic illness so as to bring about a shift to wellness in the foreground.

Future research would also benefit from research designed to examine the relationship of values and preferences to diabetes-related health outcomes. We will use the data collected in Study II to construct a survey designed to assess the values and preferences older adults express for diabetes care (in both English and Spanish as appropriate for Mexican American adults).
Subsequently, we will conduct a pretest of the survey via telephone interviews (min N=100) lasting approximately 15-20 minutes in length. The pretest is necessary to assess the utility of the survey in the field and to identify problems with its construction. Preliminary survey data will provide the basis for the preliminary studies section of the George Bennett Postdoctoral Grant to be submitted to The Foundation for Informed Medical Decision Making, a nonprofit organization located in Boston, Massachusetts dedicated to promoting informed medical decision making. This research proposal will be aimed at collecting similar data from a larger state-representative sample of adults living with diabetes in older age. The focus of the postdoctoral research proposal will be to assess the conditions under which the values and preferences for diabetes care are likely to predict diabetes management behaviors. This proposal will highlight the agreements and contradictions among individual values, preferences and behaviors, and thereby provide recommendations for more effective interventions designed to restore consistency. It is pertinent to investigate the extent to which diabetes management is in agreement with the values and preferences placed on diabetes care by individuals relative to other values and preferences in their system. Accordingly, explaining how older adults make decisions around prioritizing treatment plans and how healthcare providers might incorporate values and preferences in the care plans they develop will require direction from intermediate level behavior change theories, such as the concept of Decisional Balance in the Transtheoretical Model. Additional research is also needed to explore provider perspectives as well as the feasibility and practicality of a clinical tool for values and preferences. The overarching goal of this proposal will be to develop more refined measures and clinical instruments for assessing older adults’ values and preferences related to diabetes care.
REFERENCES


Appendix A

Advertisements
Research volunteers are being sought to participate in a study on diabetes and other health conditions. This research study is conducted by members of the Penn State Institute for Diabetes and Obesity at The Pennsylvania State University.

You may be eligible to receive $20 or a diabetes self-management book (Retail: $19.99) by participating in our study on diabetes if:

- You have been diagnosed with type 2 diabetes at least one year previously.
- You have been diagnosed with one or more other health conditions at least one year previously.
- You are at least age 60 and live in Central Pennsylvania.

Research volunteers will participate in a focus group interview. If you want to participate in this study, please call us at (814) 863-XXXX. We look forward to hearing from you!!
Help us study values and preferences for diabetes care!

Research volunteers are being sought to participate in a study on values and preferences for diabetes care. This research study is conducted by members of the Penn State Institute for Diabetes and Obesity at The Pennsylvania State University.

You may be eligible to receive $20 or a diabetes self-management book (Retail: $19.99) by participating in our study on diabetes if:

• You have been diagnosed with type 2 diabetes at least one year previously.
• You identify yourself as primarily white, African American, or Mexican American.
• You are at least age 60 and live in Central Pennsylvania.

Research volunteers will participate in a focus group interview. If you want to participate in this study, please call us at (814) 863-XXXX. We look forward to hearing from you!!

This research study is being conducted by Ms. Elizabeth Beverly, NIA Pre-Doctoral Fellow in Biobehavioral Health, PSU and has been approved by the Institutional Review Board (IRB) of the Pennsylvania State University.
Appendix B

Recruitment Letters
Dear [insert name],

My name is Elizabeth Beverly and I am a graduate student at Penn State University. I am conducting a new study on diabetes complications and the effect of these complications (and/or other health conditions) on type 2 diabetes management. I was given your contact information from the Penn State Institute for Diabetes and Obesity. According to their records you are a volunteer in the Penn State Diabetes Database and have expressed an interest in participating in future diabetes-related studies.

This new study is focusing on the impact of multiple health conditions on the management of type 2 diabetes. You will be asked to share your opinions about how you manage diabetes in one discussion group. Example questions you will be asked include: "Can you tell me about your experiences with other health conditions?" and "How have these other health conditions affected your diabetes?" During the discussion group, you will meet other people who are living with diabetes. Again, there are no right or wrong answers to any of the questions asked during the discussion group. I simply want to learn how you take care of your diabetes and the challenges you face while managing it. I have conducted a lot of these groups, and people always tell us they have fun and enjoy meeting other people with diabetes. I hope you will too! The discussion group will last about 90 minutes.

The discussion group will be conducted on campus and will last about 60 minutes. After participating in the discussion group, you will receive $20.00 or a recently published diabetes self-management book. This is my way of thanking you for your time.

If you are interested in participating in this new study, please feel free to contact me at XXX@psu.edu or (814) 863-XXXX. Participation in this study is entirely optional and if you do not want to participate I will remove your name from the list.

I hope that you will be able to participate in this new study. Thank you!

Sincerely,

Elizabeth A. Beverly, MS
Dear [insert name],

My name is Elizabeth Beverly from The Pennsylvania State University, Department of Biobehavioral Health and I am writing to invite you to participate in a research study on type 2 diabetes care. My colleagues and I at Penn State University and the Penn State Institute for Diabetes and Obesity are looking for research volunteers to participate in a research study on the values and preferences older adults express for their diabetes care. For example, some adults may prefer maintaining functional independence in activities of daily living and minimizing the financial, physical and psychological burden of diabetes care may take precedence over aggressive medical management. Others may prefer intense medical management and long-term preventive care strategies. Although we know more and more all the time about treatment goals and plans for diabetes care, we need to learn even more so we can develop better education programs for older adults living with diabetes. Your help is crucial to our developing those programs!

We were given your name from the Penn State Diabetes Database. According to his records you are a volunteer in the Penn State Diabetes Registry and have expressed an interest in participating in future diabetes-related studies. You may be eligible to participate in our study on diabetes if you have been diagnosed with type 2 diabetes at least one year previously; you identify yourself as primarily white, African American, or Mexican American; and you are at least age 60 and live in Central Pennsylvania. The research study has been approved by Penn State’s Institutional Review Board (IRB).

If you decide to participate in this study, you will be asked to participate in a discussion group. During the discussion group, you will meet other people who are living with diabetes. You will be asked to share your opinions about different values and preferences for diabetes care. Again, there are no right or wrong answers to any of the questions asked during the discussion group. We simply want to learn about your values and preferences for diabetes care. We have conducted a lot of these groups, and people always tell us they have fun and enjoy meeting other people with diabetes. We hope you will too! The discussion group will last about 90 minutes. After participating in the discussion group, you will receive $20.00 or a recently published diabetes self-management book. This is our way of thanking you for your time.
Since we are working with a limited number of people, the success and quality of our data is based on the cooperation of the people who attend. Your participation and willingness to share thoughts with us would be greatly appreciated!

Participation in this research study is completely voluntary. You can choose to be in the study or not. If you have any questions and would like to participate in this study, please feel free to contact me at XXX@psu.edu or 814-863-XXXX. We hope you will help us learn more about values and preferences for diabetes care!

Thank you very much!

Sincerely,

Elizabeth Beverly, M.S.
Appendix C

Scripts for Screening Potential Participants
Incorporating Comorbidity into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Contacting potential participants

1. Introduce yourself.

“Hello, my name is ___________, and I am working with Dr. Linda Wray in the Department of Biobehavioral Health at Penn State University. We are conducting a research study on type 2 diabetes and multiple health conditions. I am calling to see if you would be interested in participating in this research study. Would you mind if I told you a little more about the study?”

2. If yes, then describe the research study.

“We are recruiting adults living in Central Pennsylvania, in which the adults are at least age 60, diagnosed by a physician with type 2 diabetes for at least one year, and diagnosed with at least one other health condition for one year. We are interested in learning how adults with multiple health conditions manage type 2 diabetes in addition to their other health conditions. If you are eligible to participate in this research study you will attend a focus group discussion with other adults living with type 2 diabetes and other health conditions. Compensation for participating in this research study will be $20.00 or a book entitled Diabetes Self-Management Answer Book: 501 Tips and Secrets to Keep You Healthy (retail $19.99) as our thank you. The book is over 400 pages in length and includes 501 expert, easy-to-understand health tips you can trust from some of the nation’s leading experts on diabetes.

Do you think you would be interested in participating in this research study?”

3. If no, say “Ok, thank you for your time.”

If yes, say “Great, I just have a few more questions for you.” Ask the following questions.

- Ask the questions on the screening questionnaire

4. Eligibility

If ineligible: “Unfortunately, you don’t meet our eligibility criteria for participating in this particular study, but we appreciate your taking the time to inquire about it.”

If eligible: “You meet our eligibility criteria for participating in this study. At this time I would like to ask you for your mailing address to send you a letter with information about the study and a consent form. Do you have a preference for a focus group day or time?”

5. Close out the phone call.

“Okay, well that’s all I need from you. We will be sending you information about the focus group discussion. Thank you for your time.”
6. **After hanging up:**

- Make sure you have the participant’s information written down, and highlight whether or not they are interested in participating.
- Make sure all the answers to the above questions are recorded.
Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Contacting potential participants

1. Introduce yourself.

“Hello, my name is ___________, and I am working with Dr. Linda Wray in the Department of Biobehavioral Health at Penn State University. Research volunteers are being sought to participate in a research study on values and preferences for diabetes care. This research study is affiliated with Penn State University through involvement from The Penn State Institute on Diabetes and Obesity. I am calling to see if you would be interested in participating in this research study. Would you mind if I told you a little more about the study?”

2. If yes, then describe the research study.

“We are recruiting adults living in Central Pennsylvania who are age 60 and older, diagnosed by a physician with type 2 diabetes for at least one year. We are interested in the different values and preferences adults express for their diabetes care. If you are eligible to participate in this research study you will attend a focus group discussion with other adults living with type 2 diabetes and other health conditions. Compensation for participating in this research study will be $20.00 as our thank you.

Do you think you would be interested in participating in this research study?”

Would you like my phone number? If yes, say “Great, please feel free to contact Elizabeth Beverly at 814-863-XXXX.”

3. If no, say “Ok, thank you for your time.”

Would you like my phone number? If yes, say “Great, please feel free to contact Elizabeth Beverly at 814-863-XXXX.”

If yes, say “Great, I just have a few more questions for you.” Ask the following questions.

- Ask the questions on the screening questionnaire

4. Eligibility

I would like to ask you a few questions to determine if you are eligible for participating in this particular study.

- How old are you? __________ If < 60, then ineligible.
- How long have you known you have diabetes? ___________ If < 1 year, then ineligible.
• Are you under a doctor’s care for diabetes? ______ yes ______ no If no, then ineligible.

• Have you been diagnosed with Alzheimer’s disease or dementia in the past year? ______ yes ______ no If yes, then ineligible.

• Do you consider yourself primarily white or Caucasian, Black or African American, Latino or Hispanic, Asian American, or other?
  a) White/Caucasian
  b) Hispanic/Latino
  c) Black/African American
  d) American Indian
  e) Asian American
  f) Other ___________________
  g) Don’t know
  h) Refused

*If ineligible: “Unfortunately, you don’t meet our eligibility criteria for participating in this particular study, but we appreciate your taking the time to inquire about it.”*

*If eligible: “You meet our eligibility criteria for participating in this study. At this time I would like to ask you for your mailing address to send you a letter with information about the study and a consent form. Do you have a preference for a focus group day or time? I would also like to give you the name and contact information for the principal investigator of the study. Her name is Elizabeth Beverly and her phone number is 814-863-XXXX.”*

5. **Close out the phone call.**

“Okay, well that’s all I need from you. We will be sending you information about the focus group discussion. Thank you for your time.”

6. **After hanging up:**

• Make sure you have the participant’s information written down, and highlight whether or not they are interested in participating.
• Make sure all the answers to the above questions are recorded.
Appendix D

Screening Questionnaires
Incorporating Comorbidity into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

ID # ___________________

Name __________________________________________________________

How old are you? __________

How long have you known you have diabetes? ____________

Are you under a doctor’s care for diabetes? ____ yes ____ no

Have you been diagnosed with Alzheimer’s or dementia in the past year? _____ yes _____ no

Have you even been diagnosed with other health conditions? _____ yes _____ no

What other health conditions have you been diagnosed with? ____________________________
_____________________________________________________________________________

What is your most recent Hemoglobin A1c? _______________

Are you on any medication for your diabetes? ___ yes ___ no If yes, is it insulin? ___ yes ___ no

What is your current weight? _______________ Height? ________________

What is your highest level of education? _______________

Are you retired? ______________

Are you married? ______________ If yes, how long have you been married? __________

Do you consider yourself primarily:

a) White/Caucasian
b) Hispanic/Latino
c) Black/African American
d) American Indian
e) Asian or Pacific Islander
f) Middle Eastern
g) Other
h) Don’t know
i) Refused
Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

ID # ___________________

Name __________________________________________________________

How old are you? __________

How long have you known you have diabetes? ____________

Are you under a doctor’s care for diabetes? ____ yes ____ no

Have you been diagnosed with Alzheimer’s or dementia in the past year? _____ yes _____ no

Have you even been diagnosed with other health conditions? _____ yes _____ no

What other health conditions have you been diagnosed with? ____________________________
_____________________________________________________________________________

What is your most recent Hemoglobin A1c? _______________

Are you on any medication for your diabetes? ___ yes ___ no If yes, is it insulin? ___ yes ___ no

What is your current weight? _______________ Height? ________________

What is your highest level of education? _______________

Are you retired? ______________

Are you married? ______________ If yes, how long have you been married? __________

Do you consider yourself primarily:

j) White/Caucasian
k) Hispanic/Latino
l) Black/African American
m) American Indian
n) Asian or Pacific Islander
o) Middle Eastern
p) Other
q) Don’t know
r) Refused
Appendix E

Interview Guides
Incorporating Comorbidity into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Focus Group Discussion Guide:

Background and Introduction:

Moderator: "Good morning/afternoon/evening and welcome to our session. Thanks so much for taking time from your busy schedules to join our discussion. My name is (moderator's name).

As I told you in the phone calls inviting you to participate, all of you have something in common, specifically that you have type 2 diabetes in addition to other health conditions. We know adults with diabetes face many challenges in managing their diabetes, and that they want to lead healthy, productive lives. Your views about these health challenges are important to us because other people with diabetes may have similar views. Your opinions and guidance may help us develop more effective education programs for couples living with diabetes.

Today we’ll be asking about your own experiences and opinions about managing diabetes in addition to your other health conditions. Remember, there are no right or wrong answers, just differing points of view. Please feel free to share your point of view even if it differs from what others have said. We want to hear from everyone here today.

Before we begin, let me give you some information about the study and some ground rules. First off, everything said here is strictly confidential. As they say in the Las Vegas commercials on TV, what happens here stays here! We won’t share your personal information with people outside the study. Additionally, if you speak about the contents of the focus group outside the group, it is expected that you will not tell others what individual participants said. In our later reports summarizing the ideas expressed in these meetings, we will never attach your names to specific comments or information. This is a research project only, and there are no sales involved. So, please speak up and let us hear from you!

Second, we're recording the sessions because we don't want to miss any of your comments. So, please speak clearly and loudly when you speak and let only one person speak at a time. If several of you are talking at the same time, we may miss some or all of what you said. If at any time you want us to turn off the recorder because of something particularly private you want to share or for some other reason, please let us know. Keep in mind that we're just as interested in negative comments as positive comments. In fact, sometimes the negative comments are the most helpful! Finally, in compliance with Federal regulations the tapes will be destroyed in the year 2011, three years after the study has been completed.

We’ve done a lot of these groups in past projects. Participants always tell us they have fun at these sessions and we hope you will too! Are there any questions before we break into two groups?
Great! Now that we’re settled, I want to remind you if you need to get up to stretch your legs, get something more to drink, or use the restroom down the hall, please feel free to do so. We certainly want you to feel comfortable during the session!

OK, let's begin. Let's start by finding out some more about each other. Why don’t you introduce yourself to the person to your right and name one of your favorite hobbies and a little known fact about you? That means you have to talk with the person to your right and left. Then we’ll ask each of you to introduce the person to your right to the rest of us.

Now that we know a little bit about each other, I’ll ask a few broad questions about when you were first diagnosed with diabetes and how the diagnosis has affected your daily life. Then I’ll present a couple of hypothetical situations to you and ask how you would deal with them."  

**Interview Guide**

How did you first learn that you have diabetes?

- How serious did you think the diagnosis was at the time? Why did you think that?
- How did the news make you feel? What was your biggest concern then?

Who manages the diabetes that you’re living with? In other words, who takes control of your diabetes management?

What were your expectations of your diabetes management?

- What were your expectations about how diabetes would affect your life?
- What were your expectations about how diabetes would affect your relationship with your family and friends?
- How were your expectations met?

What kinds of treatments are you using to manage your diabetes?

- Medications/supplements
- Diet/nutrition
- Exercise
- Other

Can you tell me about your experiences with other health conditions?

- Signs/symptoms
- Complications
- Other

How have these other health conditions affected your diabetes?

- Self-management
• Quality of life
• Productive life
• Other

Has this changed how you carry out your usual activities? How so?

• Limitations in functional ability
• Impairments

What kind of strategies do you use to accommodate these changes?

• Supportive and assistive devices
• Social support networks

What are your preferences for diabetes care? How do they coincide with your other health conditions?

What is the chief concern about your diabetes? Your other health conditions?

Summary:

After listening to all of you today, we would like to summarize the key points of our discussion.

(Summarize main points from above)

Does this summary sound complete?

Do you have any changes or additions?

Have we missed anything?

As we mentioned at the beginning of this meeting, we’re conducting this discussion group to help us prepare more effective education programs for people with diabetes. What advice do you have for us as we begin this process? Do you have any final thoughts?

Thanks again for your participation! Your discussions were extremely helpful! It was a pleasure spending some time with you.

If you’re interested, we’ll be happy to send you a summary of what we’ve learned once we compile all of the information from these and other focus groups later this year. You can sign-up for that report as you leave here. Don’t forget to pick up with your compensation ($20 or the diabetes self-management book – retail $19.99) as our thank-you for all your help.

Take care and keep in touch! You’ve been great!!
Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Focus Group Discussion Guide:

Background and Introduction:

*Moderator:* "Good morning/afternoon/evening and welcome to our session. Thanks so much for taking time from your busy schedules to join our discussion. My name is (moderator's name). Assisting us are (co-moderators’ names).

As I told you in the phone calls inviting you to participate, all of you have something in common, specifically that you have type 2 diabetes. We know adults with diabetes face many challenges in managing their diabetes, and that they want to lead healthy, productive lives. Your views about these health challenges are important to us because other people with diabetes may have similar views. Your opinions and guidance may help us develop more effective education programs for adults living with diabetes.

Today we’ll be asking about your own values and preferences for diabetes care. Remember, there are no right or wrong answers, just differing points of view. Please feel free to share your point of view even if it differs from what others have said. We want to hear from everyone here today.

Before we begin, let me give you some information about the study and some ground rules. First off, everything said here is strictly confidential. As they say in the Las Vegas commercials on TV, what happens here stays here! We won’t share your personal information with people outside the study. Additionally, if you speak about the contents of the focus group outside the group, it is expected that you will not tell others what individual participants said. In our later reports summarizing the ideas expressed in these meetings, we will never attach your names to specific comments or information. This is a research project only, and there are no sales involved. So, please speak up and let us hear from you!

Second, we're recording the sessions because we don't want to miss any of your comments. So, please speak clearly and loudly when you speak and let only one person speak at a time. If several of you are talking at the same time, we may miss some or all of what you said. If at any time you want us to turn off the recorder because of something particularly private you want to share or for some other reason, please let us know. Keep in mind that we're just as interested in negative comments as positive comments. In fact, sometimes the negative comments are the most helpful!

Finally, in compliance with Federal regulations the tapes will be destroyed in the year 2011, three years after the study has been completed.

We’ve done a lot of these groups in past projects. Participants always tell us they have fun at these sessions and we hope you will too! Are there any questions before we start?
Great! Now that we’re settled, I want to remind you if you need to get up to stretch your legs, get something more to drink, or use the restroom down the hall, please feel free to do so. We certainly want you to feel comfortable during the session!

OK, let’s begin. Let’s start by finding out some more about each other. Why don’t you introduce yourself to the person to your right and name one of your favorite hobbies and a little known fact about you? That means you have to talk with the person to your right and left. Then we’ll ask each of you to introduce the person to your right to the rest of us.

Now that we know a little bit about each other, I’ll ask a few broad questions about when you were first diagnosed with diabetes and how the diagnosis has affected your daily life.

**Interview Guide**

Can you tell me how you discovered that you have type 2 diabetes (e.g., signs and symptoms)?

- What types of treatment are you using to manage your diabetes (medication, diet, physical activity, etc.)?
- How has your diabetes changed since you were diagnosed (HbA1c, complications, etc.)?

When I say what are your values for diabetes care, what does this mean to you?

What are your values for diabetes care? How do they coincide with other aspects of your life?

- Family
- Friends
- Religion or spirituality
- Culture or community

When I say what are your preferences for diabetes care, what does this mean to you?

What are your preferences for diabetes care? How do they coincide with other aspects of your life?

- Family
- Friends
- Religion or spirituality
- Culture or community

What is the chief concern about your diabetes? Your diabetes care?

How would you rate your diabetes (medical) care?

Do you feel that your doctors (diabetes healthcare team) address your values and preferences for care? How so?
What would you like to be different?

**Summary:**

After listening to all of you today, we would like to summarize the key points of our discussion.

*(Summarize main points from above)*

Does this summary sound complete?

Do you have any changes or additions?

Have we missed anything?

As we mentioned at the beginning of this meeting, we’re conducting this discussion group to help us improve the medical care for people with diabetes. What advice do you have for us as we begin this process? Do you have any final thoughts?

Thanks again for your participation! Your discussions were extremely helpful! It was a pleasure spending some time with you.

If you’re interested, we’ll be happy to send you a summary of what we’ve learned once we compile all of the information from these and other focus groups later this year. You can sign-up for that report as you leave here. Don’t forget to pick up your compensation ($20.00) as our thank-you for all your help.

Take care and keep in touch! You’ve been great!!
Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Q-sort Interview Guide

Introduction

*Interviewer:* "Good morning/afternoon/evening and welcome to our session. Thanks so much for taking time from your busy schedule to participate in this interview. My name is (interviewer's name), you may remember me from the focus group discussion.

As we talked about at the end of the focus group, we are interested in the significance of these values and preferences for your diabetes management. We know adults with diabetes variety of values and preferences for diabetes care that strongly impact their treatment. Your views about which values and preferences are more important that others may help us develop more effective treatment programs for adults living with diabetes.

Today we will be asking you to rank-order the values and preferences for diabetes care that were discussed during the focus groups. Remember, there are no right or wrong answers, just differing points of view. You may recognize some of the values and preferences from your focus group discussion; however, some of these values and preferences may be new to you. We would like you to sort the different values and preferences, listed individually on these notecards [show the participant the notecards] from most important to least important.

First, we would like you to sort these values according to those that are most important to you. We would like you to sort these values by placing them in 5 piles ranked from most important (top) to least important (bottom). [The 5 piles follow a roughly normal distribution, with 2 items at each of the extremes (most important and least important), 4 items in the middle or neutral pile, and the others in between]. The piles are labeled +2 to -2 to reflect their degree of importance, as shown in this diagram [show diagram, see attached].

- Please sort the values according to those with which are most important (+2) to those with which are least important (-2).

Second, we would like you to sort the preferences according to those that are most important to you. You will be following the instructions you used to sort the values.

- Please sort the preferences according to those with which are most important (+2) to those with which are least important (-2).

Summary

Do you have any changes you would like to make?
As we mentioned at the focus group, we’re conducting this interview to help us improve the medical care for people with diabetes. Do you have any final thoughts or comments about values and preferences for diabetes care?

Thanks again for your participation! Your comments were extremely helpful! It was a pleasure spending some time with you.
Appendix F

Consent Forms
INFORMED CONSENT FORM FOR SOCIAL SCIENCE RESEARCH
The Pennsylvania State University

Title of Project: Incorporating Comorbidities into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Principal Investigator: Elizabeth A. Beverly, MS
NIA Pre-Doctoral Fellow
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-867-XXXX
eab203@psu.edu

Faculty Advisor: Linda A. Wray, PhD
Assistant Professor
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-865- XXXX
law30@psu.edu

Purpose of the Study: The purpose of this study is to understand how adults with multiple health conditions manage type 2 diabetes in addition to their other health conditions.

Procedures to be Followed: You will be asked to participate in a discussion group about your experiences with multiple health conditions. You will meet other people with diabetes during the discussion group. You will be asked to share your opinions about managing diabetes during the discussion group.

Benefits to You: Most people find the discussion group enjoyable and fun. You will meet other people with diabetes. You will learn how they manage diabetes from day-to-day. You may learn more about how to manage the foods you eat, your exercise, and your blood sugar as a result of participating in the discussion.

Potential Benefits to Society: The information received from your participation in this study will help researchers develop better education programs for people with diabetes. The researchers will understand what living with multiple health conditions means to persons with diabetes and how the management of multiple health conditions relates to decision-making, and, in turn, to the management of diabetes. Better management of diabetes can lower your risks and other adults’ risks for complications associated with diabetes like heart disease.

Time Duration of the Procedures and Study: The discussion group you will attend will last approximately 90 minutes.
Statement of Confidentiality: Your participation in this research is entirely confidential. All of the information you give to the investigators will be identified by a code number rather than by name. Your name will never be placed on any material. Because it will be difficult to write down everything that is said during the discussion group, and the investigators don’t want to miss any important points, the discussion group will be audio taped to be sure they get all the information. Your name will not be recorded on the audio tape. The audio tapes will be transcribed by a professional transcriptionist. The PI and her academic advisor will have access to the audio recordings. Additionally, in compliance with Federal regulations the tapes will be destroyed in the year 2011, three years after the study has been completed. All of the information given to the investigators will be kept in a locked office that only the principal investigator and faculty advisor have access to. Lastly, if you speak about the contents of the focus group outside the group, it is expected that you will not tell others what individual participants said.

You may stop your participation in the study at any time. For example, you may refuse to answer any of the questions during the discussion group. In the event they publish articles about this research, they will not disclose any personally identifying information.

Right to Ask Questions: If you have questions about this research or your participation in this study, you may contact Elizabeth Beverly at 814-867- XXXX or XXX@psu.edu.

Compensation: You will receive $20 or a diabetes management book (retail $19.99) for participating in the study’s discussion group. This is our way of thanking you for your time and participation.

Voluntary Participation: Your participation in this study is voluntary, and you may withdraw from this study at any time by notifying the investigator. You do not have to answer any questions in the discussion group you do not want to answer.

You must be 60 years of age or older to consent to participate in this research study. If you consent to participate in this research study and to the terms above, please sign your name and indicate the date below.

You may keep a copy of this consent form for your records.

__________________________________________________________________________
Participant Signature Date

The undersigned verifies that the above informed consent procedure has been followed.

__________________________________________________________________________
Investigator Signature Date
INFORMED CONSENT FORM FOR SOCIAL SCIENCE RESEARCH
The Pennsylvania State University

Title of Project: Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Principal Investigator: Elizabeth A. Beverly, MS
NIA Pre-Doctoral Fellow
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-863- XXXX
eab203@psu.edu

Faculty Advisor: Linda A. Wray, PhD
Assistant Professor
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-865- XXXX
law30@psu.edu

Other Investigators: Carla K. Miller, PhD
Associate Professor of Human Nutrition
The Ohio State University
CMiller@ehe.osu.edu

Janice Penrod
Associate Professor of Nursing
The Pennsylvania State University
jlp198@psu.edu

Duane Alwin
McCourtney Professor of Sociology and Demography
The Pennsylvania State University
dfa2@psu.edu

Rhonda Belue
Assistant Professor of Health Policy Administration
The Pennsylvania State University
rzb10@psu.edu

Oralia A. Garcia Dominic
Doctoral candidate in Biobehavioral Health
The Pennsylvania State University
oag102@psu.edu
Purpose of the Study: The purpose of this research study is to understand the diverse values and preferences for diabetes care in older adults living with type 2 diabetes.

Procedures to be Followed: You will be asked to participate in a discussion group about your values and preferences for diabetes care. You will meet other people with diabetes during the discussion group. You will be asked to share your values and preferences for care during the discussion group. Upon completion of the focus group, there exists a possibility that you may be contacted at a later date to participate in an individual interview.

Risks and Discomforts: There are no potential risks in participating in this research beyond those experienced in everyday life. Some of the questions in the focus groups interviews are personal. You can refuse to answer any questions you do not want to answer.

Benefits to You: Most people find the discussion group enjoyable and fun. You will meet other people with diabetes. You will learn how they manage diabetes from day-to-day. You may learn more about how to achieve your diabetes management goals as a result of participating in the discussion.

Potential Benefits to Society: The information received from your participation in this study will help researchers improve the medical care for people living with diabetes. The researchers will identify a variety of values and preferences for diabetes care that strongly impact treatment goals. A better understanding of the values and preferences older adults express for diabetes care will improve the coordination and consistency of care for older adults living with this chronic condition.

Time Duration of the Procedures and Study: The discussion group you will attend will last approximately 90 minutes.

Right to Ask Questions: Please contact Elizabeth Beverly at 814-863-XXXX with questions, complaints or concerns about the research. You can also call this number if you feel this study has harmed you. If you have questions about your rights as a research participant, you can contact the Office for Research Protections at 814-865- XXXX.

Compensation: You will receive $20 or a diabetes management book (retail $19.99) for participating in the study’s discussion group. This is our way of thanking you for your time and participation.

Statement of Confidentiality: Your participation in this research is entirely confidential. All of the information you give to the investigators during the focus group will be identified by a code number rather than by name. Your name will not appear on the audio tapes.

Because it will be difficult to write down everything that is said during the discussion group, and the investigators don’t want to miss any important points, the discussion group will be audio taped to be sure they get all the information. Your name will not be recorded on the audio tape. The audio tapes will be transcribed by a professional transcriptionist. The PI and her academic advisor will have access to the audio recordings. Additionally, the tapes will be destroyed in the
year 2011, three years after the study has been completed. All of the information given to the investigators will be kept in a locked office that only the principal investigator and faculty advisor will have access.

Lastly, if you speak about the contents of the focus group outside the group, it is expected that you will not tell others what individual participants said. During the group discussion we recognize that when speaking to each other you might address one another by first name. When the audiotapes are transcribed, all names and identifiers will be removed from the text to protect participant confidentiality.

You may stop your participation in the study at any time. For example, you may refuse to answer any of the questions during the discussion group. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared. The following may review and copy records related to this research: The Office of Human Research Protections in the U.S. Department of Health and Human Services, the Social Science Institutional Review Board and the PSU Office for Research Protections.

**Voluntary Participation:** Your participation in this study is voluntary, and you may withdraw from this study at any time by notifying the investigator. You do not have to answer any questions in the discussion group you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 60 years of age or older to consent to participate in this research study.

You give permission to be audiotaped during the focus group activity.

If you consent to participate in this research study and to the terms above, please sign your name and indicate the date below.

You may keep a copy of this consent form for your records.

<table>
<thead>
<tr>
<th>Participant Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Investigator Signature</th>
<th>Date</th>
</tr>
</thead>
</table>
INFORMED CONSENT FORM FOR SOCIAL SCIENCE RESEARCH
The Pennsylvania State University

Title of Project: Incorporating Values and Preferences into Clinical Care Guidelines Designed for Older Adults Living with Type 2 Diabetes

Principal Investigator: Elizabeth A. Beverly, MS
NIA Pre-Doctoral Fellow
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-863- XXXX
eab203@psu.edu

Faculty Advisor: Linda A. Wray, PhD
Assistant Professor
Department of Biobehavioral Health
315 East Health and Human Development
University Park, PA 16802
814-865- XXXX
law30@psu.edu

Other Investigators: Carla K. Miller, PhD
Associate Professor of Human Nutrition
The Ohio State University
CMiller@ehe.osu.edu

Janice Penrod
Associate Professor of Nursing
The Pennsylvania State University
jlp198@psu.edu

Duane Alwin
McCourtney Professor of Sociology and Demography
The Pennsylvania State University
dfa2@psu.edu

Rhonda Belue
Assistant Professor of Health Policy Administration
The Pennsylvania State University
rzb10@psu.edu

Oralia A. Garcia Dominic
Doctoral candidate in Biobehavioral Health
The Pennsylvania State University
oag102@psu.edu
Purpose of the Study: The purpose of this research study is to understand the diverse values and preferences for diabetes care in older adults living with type 2 diabetes.

Procedures to be Followed: Following your participation in the focus group interview, you will be asked to participate in an individual interview about your values and preferences for diabetes care. You will be asked to rank or prioritize the importance of a list of values and preferences identified during your participation in the focus group interview.

Risks and Discomforts: There are no potential risks in participating in this research beyond those experienced in everyday life. Some of the questions in the Q-sort interviews are personal. You can refuse to answer any questions you do not want to answer.

Benefits to You: Most people find the interview enjoyable and fun. You may learn more about how to achieve your diabetes management goals as a result of participating in the interview.

Potential Benefits to Society: The information received from your participation in this study will help researchers improve the medical care for people living with diabetes. A better understanding of the values and preferences older adults express for diabetes care will improve the coordination and consistency of care for older adults living with this chronic condition.

Time Duration of the Procedures and Study: The interview you are being asked to take part will last approximately 60 minutes.

Statement of Confidentiality: Your participation in this research is entirely confidential. All of the information you give to the investigators will be identified by a code number rather than by name. Your name will never be placed on any material. All of the information given to the investigators will be kept in a locked office that only the principal investigator and her advisor have access to.

You may stop your participation in the study at any time. For example, you may refuse to rank or prioritize some of the values and preferences during the interview. In the event they publish articles about this research, they will not disclose any personally identifying information.

The following may review and copy records related to this research: The Office of Human Research Protections in the U.S. Department of Health and Human Services, the Social Science Institutional Review Board and the PSU Office for Research Protections.

Right to Ask Questions: Please contact Elizabeth Beverly at 814-863- XXXX with questions, complaints or concerns about the research. You can also call this number if you feel this study has harmed you. If you have questions about your rights as a research participant, you can contact the Office for Research Protections at 814-865- XXXX.

Compensation: You will receive $20.00 for participating in the study’s interview. This is our way of thanking you for your time and participation.
Voluntary Participation: Your participation in this study is voluntary, and you may withdraw from this study at any time by notifying the investigator. You do not have to answer any questions in the interview you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 60 years of age or older to consent to participate in this research study. If you consent to participate in this research study and to the terms above, please sign your name and indicate the date below.

You may keep a copy of this consent form for your records.

Participant Signature    Date

Investigator Signature    Date
Vita

Elizabeth Ann Beverly

Department of Biobehavioral Health
The Pennsylvania State University
315 East Health and Human Development
University Park, Pennsylvania 16802-6509

EDUCATION

• Ph.D., Biobehavioral Health, 2008
  The Pennsylvania State University, State College, PA
  Research mentor: Dr. Linda A. Wray

• M.S., Biobehavioral Health, 2006
  The Pennsylvania State University, State College, PA
  Research mentor: Dr. Linda A. Wray

• B.S., Biobehavioral Health, 2003 (Honors with Highest Distinction)
  The Pennsylvania State University, State College, PA
  Research mentor: Dr. Frank Ahern

PEER-REVIEWED PUBLICATIONS


• Beverly, E.A., Miller, C.K., & Wray, L.A. Spousal Support and Food-Related Behavior Change in Middle-Aged and Older Adults Living with Type 2 Diabetes. Forthcoming in the journal of Health Education & Behavior.