

ABSTRACT

Title of dissertation: EXPANDING THE CONCEPTUAL
FRAMEWORK OF HEALTH LITERACY TO
IMPROVE LONG-TERM SERVICES AND
SUPPORTS

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Low health literacy is a significant and growing public health problem. It is estimated that 90 million individuals in the U.S. have low health literacy, which is associated with poor health outcomes. Individuals with low health literacy skills may not be able to obtain health information, communicate with health care providers, or make optimal health care decisions. People from all backgrounds can have low health literacy levels, however, the rates are higher in certain groups such as older adults, Medicaid beneficiaries, and minority populations. Due to our rapidly aging and increasingly diverse U.S. population, the problems associated with low health literacy may increase over the next few decades.

Studies have examined the relationship between an individual's health literacy level and their own health outcomes. However, few have focused on how the health

literacy level of *others*, such as caregivers and health care professionals, impacts the health outcomes of care recipients. It is important to understand this relationship in terms of elders who depend on others, such as caregivers and family members, for their care. This series of three studies addresses this critical gap in health literacy research.

The first two studies examine the need for a health literacy component of a training program for care teams for individuals with dementia in participant-directed programs. The first is an ethnographic pilot study of caregivers in West Virginia's Personal Options Program, and the second is a mixed- methods study of "Decision-Making Partner" preparedness in Arkansas' IndependentChoices Program. The third study examines the effect of the emergency department referral process on repeated utilization of community health centers by low-income, uninsured adults and Medicaid Beneficiaries, as well as the role of Patient Navigators as mediators within the framework of health literacy.

This research provides evidence that the health literacy level of others, including caregivers, decision-making partners, and health care providers significantly impacts the ability of older adults to access health services and supports, communicate with healthcare providers, navigate the healthcare system, and manage chronic diseases. Therefore, addressing health literacy is essential for increasing health-related knowledge, improving health outcomes, and decreasing health disparities in long-term care.

**EXPANDING THE CONCEPTUAL FRAMEWORK OF HEALTH
LITERACY TO IMPROVE LONG-TERM SERVICES AND SUPPORTS**

by

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Chapter1: Expanding the Conceptual Framework of Health Literacy to Improve Long-Term Services and Supports

Introduction

The relationship between an individual's health literacy level and their health outcomes has received increasing attention over the last decade. Low health literacy is associated with negative health outcomes such as the poor management of chronic illnesses, and increased morbidity and mortality (Vernon et al., 2007). However, little is known about how the health literacy level of *others*, including caregivers and health care professionals, impacts the health outcomes of care recipients. There is a gap in the literature assessing how low health literacy and the lack of cultural competency within organizations may lead to poor health outcomes for individuals, and may contribute to population health disparities (Baur, 2010). The three articles in this dissertation address these critical gaps in health literacy research and add to the evolving definition and expanding conceptual framework of health literacy.

This introductory chapter gives a brief overview of the myriad of definitions and multiple measures of health literacy. It explains the need for a multi-dimensional framework to understand the impact of low health literacy and the necessity of targeting areas for improvement interventions. This first chapter also summarizes my multi-level research in the field of health literacy. Chapters two and three focus on individual-level health literacy (health literacy of caregivers and “decision-making partners”) as it pertains to long-term home care for elders with dementia in the United States. Chapter four focuses on health literacy at the organizational level. Finally, in

chapter five, I summarize my findings, and discuss research imperatives and policy implications of low health literacy based on these findings.

What is Health Literacy?

Health literacy is defined by the Patient Protection and Affordable Care Act of 2010 (PPACA) as “*the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions*” (Center for Health Literacy Promotion, 2013). This is just one of many definitions of “health literacy,” as the term means different things to different audiences (Berkman et al., 2010). Health literacy is often viewed as an individual-level concept, with a person’s health outcomes being dependent on their own health literacy levels. However, research suggests that health outcomes also depend on an individual’s interactions with healthcare providers and experiences within the healthcare system, as well as their ability to navigate the health system (Bernhardt et al., 2005; Benjamin, 2010). Thus, definitions of health literacy have evolved to include healthcare professionals, groups and committees, and health care systems (Berkman et al., 2010). Berkman et al. (2010) suggest that “different definitions may be needed depending on one’s goals;” and my research reinforces this concept.

Measuring Health Literacy

Just as there is no consensus on the definition of health literacy, there is no single instrument to measure health literacy levels (Berkman et al., 2010). Two of the most

widely used measurement instruments are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) which both use an individual's reading skills as a measure of their health literacy level (Berkman et al., 2010). Both of these instruments also have shorter validated versions and Spanish versions available. Other health literacy measurement instruments use word recognition, quantitative ability (numeracy), and various interactive tools to determine health literacy levels. For example, the Newest Vital Sign (NVS) uses a nutrition label accompanied by six questions about the label (Weiss, 2005), and the "Talking Touchscreen" is a computer-based instrument used to evaluate health literacy level (Yost et al., 2010). People are often said to be "health literate" if they can perform certain skills such as seek health information, communicate about health information with others, or apply this information to health situations to achieve better health outcomes (Berkman et al., 2010). Therefore, some researchers use a skills-based approach to evaluate health literacy (McCormack et al., 2010).

Individual Health Literacy

In the first National Assessment of Adult Health Literacy (2003) it was determined that approximately 14% of Americans had health literacy levels that were considered "Below Basic" (Glassman, 2013; National Center for Education Statistics, 2013). These individuals may not be able to fill out medical forms, understand or follow medical instructions, or effectively communicate with health care professionals (Vernon et al., 2007). It is estimated that as many as 90 million adults in the United

States today have health literacy levels that are Basic or Below Basic levels (Institute of Medicine (IOM), 2004; Agency for Healthcare Research and Quality (AHRQ, 2011).

Although individuals of all backgrounds and educational levels may lack health literacy skills (Lindquist et al. 2011), certain groups, such as adults who have not completed high school, individuals living below the poverty level, Medicaid beneficiaries, immigrant and minority populations, and older adults (age 65+) have higher rates of low health literacy (Health Resources and Services Administration (HRSA), nd.; U.S. Department of Health & Human Services, 2013). Almost half (49%) of the individuals without a high school education had health literacy levels that were considered below basic, compared with 15% of people with a high school education and 3% of those with a Bachelor's degree (Glassman, 2013). Approximately a third of Medicaid beneficiaries (30%) had below basic health literacy levels compared with 7% of individuals with employer provided health insurance (Glassman, 2013). More Hispanics (41%) had "below basic" health literacy levels compared with Blacks (24%) and Whites (9%) (Vernon et al., 2007). Nearly 60% of older individuals in the U.S. have low health literacy. These elders may have difficulty accessing information about their medical conditions or understanding their treatment options (Safeer et al., 2005).

What Does Low Health Literacy Mean for Elders?

By the year 2030, twenty percent of Americans will be age 65 and older (approximately 73 million individuals), and it is estimated that this number will

increase to 89 million by the year 2050 (Administration on Aging, 2013). There will also be significant changes in the racial and ethnic composition of our elderly population over the next 40 years (Vincent & Velkoff, 2010). The U.S. Census Bureau reports that as many as 55.4 million people currently identify themselves as speaking a language other than English at home and approximately 40% of these individuals (many of them older individuals) have very limited English speaking skills (Federal Emergency Management Agency, 2011). Thus, the problems associated with low health literacy are expected to increase over the next few decades unless we take steps to improve health literacy levels. Low health literacy is an important issue that must be addressed as we formulate policies to eliminate health disparities, and evaluate programs aimed at improving the long-term care system for our rapidly growing and increasingly diverse, elderly U.S. population.

Caregiver and Care Team Health Literacy

Many elders have disabilities or chronic health conditions that require ongoing medical care (National Conference of State Legislatures & American Association of Retired People [AARP] Public Policy Institute, 2011), and greater numbers of these older individuals rely on unpaid family members or other caregivers to help care for them at home (IOM, 2008). Although elders may depend on their family members and others (representatives or “decision-making partners”(DMPs) to help them with medical decisions, with navigating the health care system, and for personal care needs, the individuals they depend on may have limited health literacy skills that prevent them from adequately carrying out their role. Many caregivers are not able to access information about medical conditions or understand treatment options well

enough to make informed health care decisions for care recipients (Lindquist et al., 2011). Some health care professionals are not able to communicate with their patients well enough to coordinate care for them or transition care (Baur, 2010). Thus, there may be greater disparities in the ability of certain elders to receive help managing chronic conditions or access services and supports which will allow them to remain at home and within their communities. The lack of health literacy skills among caregivers and health care professionals may result in a poor of continuity of care, increased morbidity and mortality from chronic diseases for some older adults and increased nursing home placement for older individuals.

Health Literacy of Organizations and the Long-Term Care System

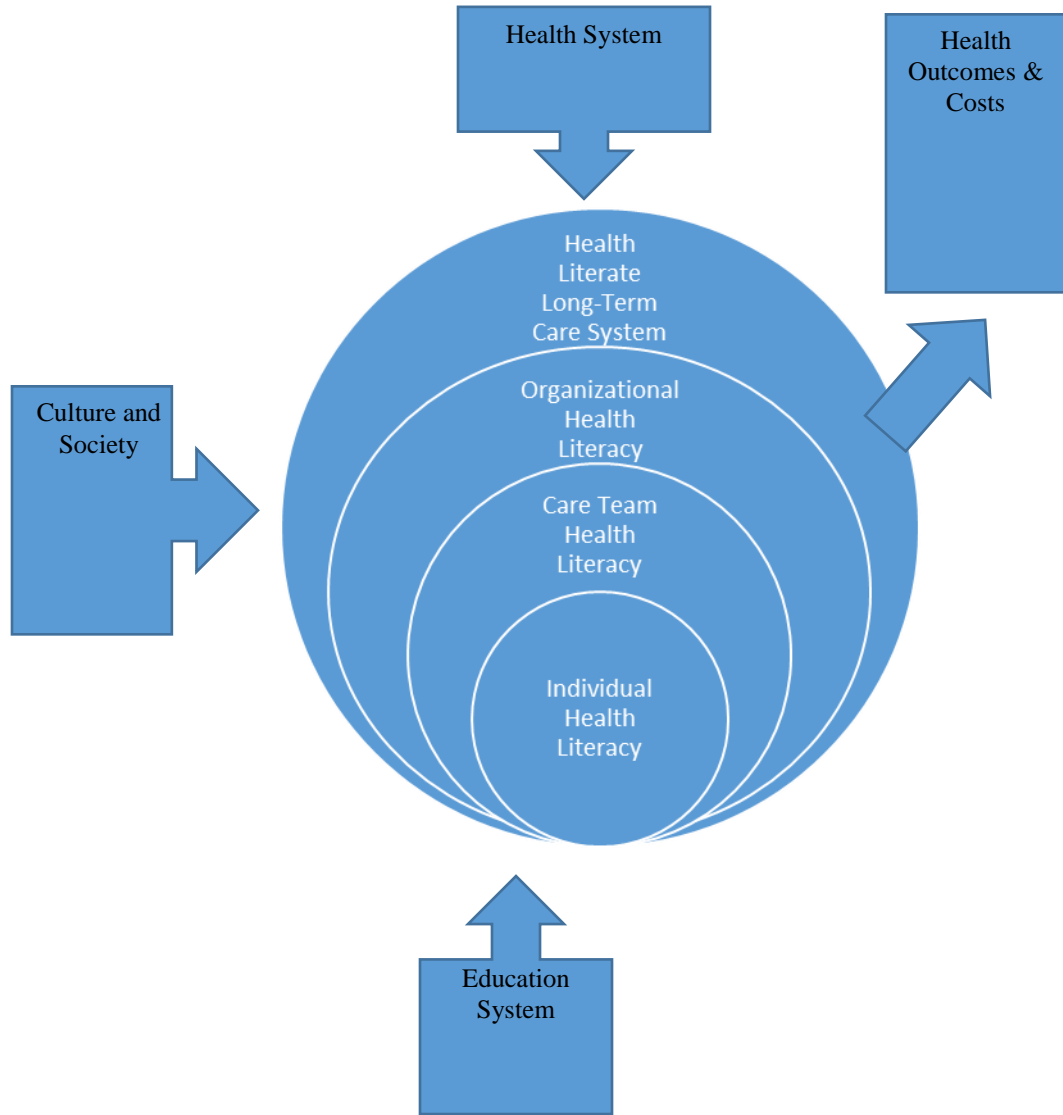
Although health literacy is often referred to as an individual-level construct, recent research has provided a broader definition of health literacy to include “organizational” and “public health literacy” (Berkman et al., 2010). Low health literacy within programs and organizations (including poor communication skills of health care professionals) can result in poor access to care or services for patients, medication errors, less compliance with screenings or preventive health care recommendations, inefficient use of health care services, and increased healthcare costs (AHRQ, 2011). Therefore, we must consider health literacy when examining the capability of organizations to provide programs and services. Several recent policy initiatives including the Patient Protection and Affordable Care Act (PPACA) (2010), the National Action Plan to Improve Health Literacy (U.S. Department of Health & Human Services, 2009), and the Plain Writing Act of 2010 (National Institutes of Health, 2013), address low health literacy and provide guidance for

improving health literacy, decreasing disparities in access to care and the quality of care, increasing patient communication, reducing medical errors, and decreasing healthcare costs (Glassman, 2012).

Framework for Health Literacy

Researchers have expanded the conceptual model of health literacy to a more ecological framework (Berkman et al., 2010). Within this framework, the health literacy of health care professionals, and the demands and complexity of the healthcare system are considered. The Institute of Medicine (IOM) (2004) suggests that a framework for health literacy must be multi-dimensional, and requires multi-level investigation. Therefore, in order to better understand health literacy, in the next four chapters of this dissertation, I report on my findings and conclusions about health literacy on an individual level, as a component of team care, as a critical part of the mission of health care organizations, and as a requirement for a successful long-term care system. I also examine three areas identified by the IOM Committee on Health Literacy, as being areas for interventions to improve health literacy: the health system, culture and society, and the educational system (IOM, 2004; Baur, 2010). A multi-dimensional health literacy framework, based on the IOM framework, and intervention areas can be seen in Figure 1.

Figure 1. Multi-Dimensional Framework for Health Literacy and Intervention Areas (Adapted from the Institute of Medicine model (2004))



Dissertation Summary

The first article (Chapter 2) of my dissertation introduces the concept of low health literacy skills in care teams (consisting of paid and unpaid caregivers and representatives of program participants) who provide care for individuals with Alzheimer's disease and related dementias in the West Virginia Personal Options

program (a "Cash and Counseling," participant-directed model of care). In a participant-directed program, participants determine for themselves what mix of services and supports work best for them. A Cash and Counseling model is a flexible participant-directed option that gives participants the option to manage a budget to obtain these services and supports. The second article (Chapter 3) focuses on the health literacy skills of family Decision Making Partners (DMPs) for individuals with dementia in Arkansas' IndependentChoices program (Arkansas's Cash and Counseling program). DMPs (or Representatives) represent program participants with dementia, and make care decisions with them, or for them when they are no longer able to do so on their own. Therefore the ability to obtain and use health information is extremely important for this population. In the third article (Chapter 4), I examine how the mode of emergency department patient referral to a community health center by health care professionals impacts the patient's subsequent visits to the center. Finally, in Chapter five, I conclude with an overview of health policies that address health literacy and cultural competency as well as areas for possible intervention, and how they may impact health outcomes for elders in the future.

The following are brief summaries of the three articles that comprise my dissertation work in health literacy:

Study 1

Identifying Training Needs of Care Teams for Older Individuals with Dementia in a Participant-Directed Personal Care Model: An Ethnographic Pilot Study

The first article in this series is based on a small ethnographic pilot study of care teams for five elderly participants with dementia in West Virginia's Personal

Options program. The purpose of the study, which was a joint effort with another researcher, was to describe how these elders and their caregivers fare in this participant-directed model of service and to develop a deeper understanding of their training needs. We wanted to gather information from various perspectives that could provide insight into the development of a care team training program. Therefore, in the study, we included participants in varying stages of dementia with different personal care arrangements, as well as their paid and unpaid caregivers.

Although our findings suggest that participants and their care teams fare well in the Cash and Counseling program, care teams indicate that they have multiple training needs including the need to know more about the Alzheimer's disease process. Care teams report that they do not always understand how Alzheimer's disease progresses or understand the behavioral changes that are associated with the disease. Therefore, they may have low health literacy in terms of dementia. Care teams express a need for training to ensure the safety of program participants and to develop techniques that will help them cope with the significant stress associated with caring for individuals with Alzheimer's disease and related dementias.

Evidence from this pilot study indicates that program representatives or family DMPs of elders with dementia in the Personal Options program have unique training needs and may be unprepared for their role. Representatives state that improved training may help them coordinate care, access information about dementia and other health conditions, and make more informed health care decisions. Therefore, one conclusion we made from this study was that future studies should examine the preparedness and dementia health literacy of *representatives*. Thus, this first article

introduces the overarching concept for my dissertation work (health literacy) as well as the population of interest for my second study (DMPs for elderly participants with dementia).

Study 2

Development and Use of a Health Literacy Skills Framework for Decision-Making Partners of Individuals with Dementia in a Participant-Directed Program

My second article is based on a secondary data analysis of a mixed-methods study of thirty DMPs for elderly participants with dementia in Arkansas' IndependentChoices program. The goal of that study, conducted by myself and three other researchers, was to examine the preparedness of DMPs to: represent the individual with dementia; ensure that they have the services and supports that they need; communicate their needs and desires; assure their safety; and manage their paid and unpaid caregivers. The objective of my analysis was to examine the data through the lens of health literacy by defining health literacy for DMPs and expanding on an existing health literacy skills framework to include dementia health literacy skills. I then used components of the expanded framework to evaluate the impact of DMP communication skills and perceived DMP preparedness to represent the care recipient with dementia, and their preparedness for the stress of their role. This study demonstrates that an existing health literacy skills framework can be expanded to include skills for the management of Alzheimer's disease and related dementias as well as coexisting chronic conditions. The development and use of such a framework

helped us better understand the impact of low dementia health literacy skills on health related outcomes for individuals with dementia,

In this study, some DMPs reported feeling stress due to the lack of communication (or poor communication) with program participants, caregivers, IndependentChoices staff or health care professional. Many of the DMPs reported they were not “very well prepared” to involve the participant in decision-making, or to represent their decisions and preferences. The results of this research suggest that enhancement of decision-making partner communication skills may increase their ability to obtain, process, and understand dementia health information and help them make more appropriate participant-directed health care choices for individuals with dementia and their caregivers.

Study 3

The first two articles in this dissertation focus on elders with dementia who are participants in Medicaid programs, and the health literacy skills of their caregivers and decision-making partners. The third article, however, focuses on the health literacy skills of very different populations; emergency department patients and health care professionals. This article continues the theme of health communication by examining the impact of the primary care referral process by providers and hospital navigators on emergency department utilization by adults over the age of eighteen. This article implies that low health literacy is not just a problem that impacts elderly individuals in poor rural areas in West Virginia and Arkansas, but may also impact adults living in a wealthy suburban area (Montgomery County, Maryland). Although

the mean age of the population in the third study is less than sixty five years old, these individuals are a part of our rapidly aging and culturally diverse population.

Article 3 (Chapter 4):

Effect of Primary Care Referral Process on Subsequent Emergency Department Visits and Utilization of Community Health Center Services by Low-Income, Uninsured Patients

My third article is based on the quantitative results of a large three-year study of the utilization of five hospital emergency departments by 10,000 low-income, uninsured patients in Montgomery County, Maryland. That study was conducted because of the increased use of emergency departments for non-emergent care, and because low-income, uninsured individuals within the County lacked primary care physicians and continuity of care. Research indicates that individuals that do not have a place to receive primary care have poorer management of chronic diseases, less screenings for cancer and other diseases, and they are more likely to use emergency departments when their medical condition worsens (Choudhry et al. 2007). Therefore, the goal of the study in Montgomery County study was to find ways to link emergency department patients to a “medical home” within a safety net clinic to reduce avoidable emergency department use and improve health outcomes.

My research includes a secondary data analysis that aims to identify factors that influence a patient’s repeated use of a safety net clinic. Specifically, I wanted to know what type of communication used to refer individuals to the clinics (by emergency department (ED) physicians and Patient Navigators) results in repeated clinic use. In the data analysis, I used a negative binomial count or “hurdle” model to

identify patient characteristics and factors that influence subsequent visits to community health centers. I found that age, gender, ethnicity and the emergency department in which the community health center referral was made, influenced subsequent clinic visits. The use of Patient Navigators was especially successful in helping Hispanic/Latino women age 40 and over find a “medical home”. This research suggests that cultural competency and the use of Patient Navigators may be important areas for interventions to increase patient health literacy.

Conclusion

Our aging population with its increasing diversity will present multiple challenges for the U.S. health care system. This report explains the challenges of low health literacy on an individual level, within organizations, and for the U.S. health care system. My dissertation addresses issues of low health literacy among caregivers and DMPs for elders with physical and cognitive disabilities. It also adds to the framework of health literacy skills and to the literature that explains the role of health care professionals as mediators of health literacy. Finding solutions to increase health literacy levels may improve health outcomes for older individuals, decrease disparities in access to long-term services and supports, improve the quality of health care, and help facilitate the appropriate use of health care services. Although this overarching view of health literacy pertains to individuals who are aging at home in the United States, much of the discussion and many of the conclusions in this dissertation can be applied to other long-term care settings.

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Chapter 2: A Pilot Study Identifying Training Needs of Care Teams for Older Individuals with Dementia in a Participant-Directed Personal Care Model

Abstract

Purpose Growing numbers of elders with dementia depend on family caregivers to assist them with daily living activities. However, a lack of preparedness for the caregiver role may lead family members to feel stress, provide poor quality care, or institutionalize the care recipient. Cash and Counseling, a participant-directed service option, offers participants and their caregivers flexibility and control over services, which can increase satisfaction and well-being. The purpose of this study is to describe how elders with dementia and their caregivers fare in this service model, and to develop a deeper understanding of training needs. **Methods** Two researchers conducted in-depth, in-home interviews with five care teams for elders with dementia in West Virginia's Personal Options program. Care teams included: an elder with dementia, a paid and unpaid worker, a participant representative, and a program consultant. The researchers coded interview transcripts to generate themes about care team training needs and to describe how the program worked for care team members. **Results** Families reported that the program helped them financially, and some family members stated that participants received better care than when they were in other caregiving situations. When asked about training needs, care teams reported needing:

information about dementia, skills for personal care and safety, as well as techniques for communicating, coping, and problem solving. Participant representatives, a key team member, play a critical role in helping individuals with dementia make care decisions and representing their care preferences. Yet, they do not currently receive specific training for this role. **Implications** Since some care team members have difficulty obtaining and understanding information about dementia as well as making appropriate health decisions, they may have low health literacy in terms of dementia care. Better training may improve the quality and coordination of care for individuals with dementia. Representatives may need special training to gain knowledge about participant-directed care, prepare caregivers, and plan for future care. However, we need more information about the preparedness, training needs, and health literacy level of representatives to inform development of a dementia training program that will enhance participant-directed services.

Key words: Dementia, Participant-Directed Services, Cash and Counseling model, Representatives, Training, Health Literacy

Introduction

Purpose and Background

There are approximately 5.4 million Americans living with Alzheimer's disease; a progressive and fatal brain disease that affects an individual's physical and cognitive functioning (Alzheimer's Association, 2012). The disease accounts for approximately 70% of all dementias which is a term used to describe a decline in mental ability severe enough to interfere with daily life (Alzheimer's Association,

2012). Individuals with Alzheimer's disease and related dementias often have significant behavioral changes, and lose their ability to communicate verbally and to carry out basic bodily functions (Alzheimer's Association, 2012).

The number of older individuals with Alzheimer's disease and related dementias in the U.S., and the cost and challenges of caring for these individuals continue to grow (Tilly, et al. 2011). Since the risk of dementia increases with age, the number of people with Alzheimer's disease and related dementias is expected to rise with our aging U.S. population (Alzheimer's Association, 2012). The estimated cost of caring for these elders today is approximately \$200 billion per year. However, by the year 2050, there may be as many as 16 million Americans living with Alzheimer's disease, with an estimated cost of \$1.1 trillion per year for their care (Alzheimer's Association, 2012). Caring for individuals with dementia is becoming more complex because of difficulties accessing support services and navigating our complicated health care system (Schultz & Martire, 2004; Egge, 2011).

Most individuals with dementia remain at home being cared for by unpaid and paid caregivers as their physical and cognitive abilities decline (Gould et al., 2009; Alzheimer's Association, 2012). In 2011, more than 15 million Americans provided 17.4 billion hours of unpaid care for individuals with dementia, helping them avoid institutionalization (Alzheimer's Association, 2012). However, the Alzheimer's Association (2012) reports that family members often receive little or no information about the physical difficulties of caring for someone with dementia or about the psychological strain of dealing with the behavioral changes that occur with Alzheimer's disease and related dementias (Alzheimer's Association, 2012). Many

caregivers are unprepared for the disease process and their own changing roles and responsibilities (Keady & Nolan, 2003). Thus, in terms of dementia care, family members may have low health literacy; defined as “*the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions*”(Center for Health Literacy Promotion, 2013).

Inadequate caregiver training and preparedness can have a significant impact on both caregivers and care recipients. Unprepared caregivers often feel stressed and overburdened (Egge, 2011; Feinberg, 2012). In fact, caregivers for individuals with dementia report greater levels of stress and more health problems than other caregivers, so retaining them is difficult (Gould et al., 2009; Tilly, et al. 2011). Poorly managed care, including a lack of care planning and coordination, may lead to increased care costs (Egge, 2011) and unnecessary hospitalizations for care recipients (Egge, 2011; Feinberg, 2012). Families without adequate support are more likely to place their relative in institutional care (Carpenter & Dave, 2004; Gaugler et al., 2005; Egge, 2011).

Individuals with Dementia and Participant-Directed Care

Due to increasing numbers of individuals with dementia, skyrocketing costs, and a lack of resources, policymakers have been searching for effective and efficient long-term services for this population. For example, the 2010 Patient Protection and Affordable Care Act (PPACA) addresses community living assistance services and supports (PPACA Detailed Summary, 2012). One potential solution is the expansion of participant-directed options (IOM, 2008; Tilly, 2011). Participant-directed

programs focus on long-term services and supports with an emphasis on the needs of families rather than agencies, and allow individuals with various types of disabilities to decide for themselves what type of services and supports work best for them (Mahoney, 2011). Some policymakers and others have concerns about the well-being of participants with dementia in a participant-directed setting (Tilly, 2007; San Antonio et al., 2010). However, research findings indicate that both older individuals with dementia and their caregivers have better outcomes in participant-directed programs than agency programs related to quality of life, independence, and satisfaction (Masters, 2006; Tilly et al., 2011).

Although participant-directed models may be beneficial, there is a need to provide and improve dementia-specific training. In a 2007 public policy report by the Alzheimer's association about participant-directed home and community services for adults with dementia in 11 states (Arkansas, Colorado, Florida, Maine, Massachusetts, New Jersey, Oregon, South Carolina, Vermont, Washington and Wisconsin), Tilly (2007) reported that Washington was the only state of the eleven that developed a dementia-specific training program for care providers in addition to program employees. Since that report was published, several states have developed training programs about dementia that include direct-care workers; many funded by the Administration on Aging through the Alzheimer's Disease Demonstration Grants to States (ADDGS) program (Alzheimer's Association, 2011). However, the content and the target audience for training programs are not consistent. Many training programs benefit paid employees or professional volunteers but do not offer support to unpaid family caregivers. For example, Maine's Best FriendsTM program only

helps train professional caregivers, and Oklahoma's ADDGS program provides training for respite volunteers (Alzheimer's Association, 2011).

The Administration on Aging developed a series of toolkits to assist states in developing training programs for home and community-based services for older individuals with dementia and their caregivers to help them provide culturally appropriate "dementia capable services" (Alzheimer's Association, 2011; U.S. Administration on Aging, nd). However, some states remain hesitant to provide training for caregivers because their services are only for program beneficiaries, or because the individual with dementia does not meet functional eligibility criteria (Tilly, et al. 2011). Many states are still struggling to develop a dementia-capable participant-directed, long-term services and support system (Tilly, 2011).

Cash and Counseling Model

"Cash and Counseling" is a participant-directed model that allows individuals to manage a budget so they can hire their own workers and buy goods and services to meet their individual needs (Benjamin and Fennell, 2007; Foster et al., 2007). Individuals in the program can have assistance from a representative to help conduct participant tasks and make financial decisions, an important program feature for individuals with dementia (Mahoney, et al. 2007; Tilly, 2007). The broad flexibility and control of care services offered in the Cash and Counseling model may increase the satisfaction and well-being of elderly individuals with dementia and their caregivers over traditional agency-directed models (Carlson et al., 2007; Simon-Rusinowitz et al., 2010; Mahoney, 2010). Due to the positive aspects of the Cash and

Counseling program for individuals with dementia, we want to develop a deeper understanding of care team training needs of this participant-directed care model.

Program Evaluation Methods

The use of various methods to evaluate the Cash and Counseling program has been an ongoing process. The original Cash and Counseling Demonstration and Evaluation (CCDE) was a controlled experiment in “home and community-based long-term care” (Doty et al, 2007). Analysis of this large-scale demonstration of volunteer Medicaid beneficiaries from Arkansas, Florida, and New Jersey was performed using a mixed-methods approach (Brown & Dale, 2007). Researchers from the University of Maryland, Baltimore County (UMBC) conducted a large ethnographic study of CCDE care teams to gain an in-depth understanding of the experiences of participants and caregivers (San Antonio et al., 2007). Although San Antonio et al. did not focus on individuals with dementia, people with dementia were included in their study. The insight gained from that and other Cash and Counseling studies (Eckert, 2001; San Antonio & Niles, 2005; Simon-Rusinowitz, 2005) guided this project and the development of the following research questions:

Research Questions

1. How do participants with dementia and their families fare in the Personal Options Program?
2. How do care teams in Personal Options describe their training needs?

These questions informed the research coding plan and provided structure for the data. However, the researchers expected that emerging themes would complete the coding matrix.

Methods

Data Source

Two researchers conducted a small ethnographic pilot study of participant care teams in West Virginia's Personal Options Medicaid program (West Virginia's "Cash and Counseling" program) in July, 2009. Each care team consisted of a program participant with dementia, a representative, a paid worker, unpaid caregivers for some teams, and a program consultant. Program consultants helped the research team identify participants with dementia. To gather information from various perspectives, the researchers included participants of different racial and ethnic backgrounds, in varying stages of dementia, and with different personal care and representation arrangements.

Data Collection

The research team used several sources to develop data collection questionnaires. The researchers developed questions about demographic information and satisfaction with the Personal Options program using questions from a West Virginia Personal Options mailed satisfaction survey that was conducted in June of 2008 (Public Partnership, LLC, 2008). The researchers obtained training and preparedness questions from a Cash and Counseling study by Foster et al. (2007).

The two researchers conducted in-home, semi-structured, open-ended, taped interviews with five elderly Medicaid Personal Options participants with dementia and their care teams. The researchers conducted simultaneous interviews with team members in separate rooms to ensure team member privacy. They then transcribed

interview tapes verbatim and processed them as a Word document. Detailed field notes taken by the researchers provided additional information for analysis.

Qualitative Data Analysis

Development and Use of Coding Matrix

As per the grounded theory method of Glaser and Strauss (1967), the research questions guided the development of a preliminary coding matrix and conceptual categories. The matrix included broad categories or themes related to participant and representative satisfaction and well-being. The researchers then added topics that could be included in a training and technical support curriculum, as well as perceptions of quality of care and unmet needs to the matrix.

The researchers analyzed interview transcripts using line by line comprehensive, collaborative coding. The researchers then identified major themes for each care team to further develop the coding matrix. Sub-categories for each theme were developed by the researchers by linking related ideas or identifying relationships. Finally, the researchers coded several interviews to compare differences between the two coders and to evaluate the need to expand the coding system based on emerging themes.

Participant Stories

The researchers composed a narrative story for each care team illustrating the significant impact of the participant-directed Personal Options program on the team. A large ethnographic study conducted for the CCDE by Eckert, et al (2001) served as

the model for the stories. The story writing process began using field notes and the interview transcripts. Each story wove together the voices and perspectives of the participant, caregiver, and representative about their experiences and training needs. The findings are supported by direct quotes taken from the extended versions of the stories. The researchers changed the names in the stories to provide confidentiality for care team members.

Findings

Description of Participants and Caregiving Situation

Although the researchers developed longer narrative stories for each of the five care teams, only a short description of each participant and their caregiving situation is included in this report.

Beatrice Kozen

Beatrice Kozen is an 89 year old, Caucasian woman with end stage Alzheimer's disease and other serious medical conditions. She is bedridden, unable to speak, and requires total care for all activities of daily living. Beatrice's daughter Nancy, who works in the medical field, is her paid caregiver. Nancy is single and lives with her mother as does Beatrice's son, Paul who also has a health condition. Mrs. Kozen's other daughter, Linda, is her mother's Personal Options Representative. Linda is a teacher and has summers off, so she stays with her sister to help care for their mother even though she is married and has a home an hour away. In addition to caring for their mother, the sisters care for Paul and for Linda's grandchildren. Mrs. Kozen's daughters have cared for her for about ten years, as her dementia progressed.

Carmen Gonzalez

Carmen Gonzalez is an 82 year old, Native American widow with moderate Alzheimer's disease. She lives with her daughter Maria and son-in-law Bob in rural West Virginia. Carmen had previously been in a nursing home; but Maria and Bob were concerned about the care she was receiving in the facility. They brought her to live with them, and with Bob's mother Jessie, who has physical disabilities. Maria is the caregiver for both elderly women, and Bob is Mrs. Gonzalez's representative in the Personal Options Program. In addition to Alzheimer's disease, Mrs. Gonzalez has multiple medical conditions, and is legally blind. As Mrs. Gonzalez's Alzheimer's disease progresses, her physical needs and behavioral issues make it more difficult to provide care for her and ensure her safety.

Victoria Hayes

Victoria Hayes is an 85 year old Mexican-American woman with moderate dementia who lives with her daughter, Karen, and son-in-law (Ben) in rural West Virginia. Four of Mrs. Hayes's children wanted to put her in a nursing home, but Karen, who is her mother's representative in the Personal Options program, was willing to care for her. Mrs. Hayes paid caregiver, Stan, was previously unknown to the family. Stan is in his mid 60's and has worked as a caregiver for other elderly individuals. However, he has medical problems that limit his ability to perform some routine caregiving tasks. Thus, some of Mrs. Hayes's personal care is left up to Karen. Because Stan is attentive to Mrs. Hayes, Karen is willing to do the extra work. Other family members, however, do not like the idea of a male caregiver for Mrs. Hayes.

They don't agree with many of Karen's decisions, yet they do not help with Mrs. Hayes's care.

Margaret Adams (Granny)

Margaret Adams (Granny) is a 92 year old Caucasian woman with mild dementia who lives with her daughter Edith in a mobile home on the outskirts of a large town in West Virginia. Granny is legally blind, hard of hearing, and uses a walker to get around the house. She has lived with her daughter, who is her only child, since her husband died many years ago. Edith is Granny's legal power of attorney and her paid caregiver in the Personal Options program. According to Edith, Granny's dementia has gotten progressively worse over the last year since a hospitalization for pneumonia. At times she does not recognize her daughter and she often yells at Edith. Granny has been sleeping a lot lately and she often refuses to eat.

Dolores "Ruby" Castor

Dolores "Ruby" Castor is a 90 year old Caucasian woman with mild dementia and multiple medical conditions. She lives by herself in a family enclave comprising three family homes, in rural West Virginia. Although she lives alone, Ruby receives assistance with housework and many daily living activities from her hired caregiver, Molly, who is a relative. Other members of her attentive family, including her daughters Pamela and Lauren, provide many hours of assistance. Ruby has difficulty walking, and recently had knee surgery. She continues, to do housework, which includes going up and down stairs. This greatly concerns her daughters, who fear for her safety. Ruby was talkative throughout the interview, but she often forgot facts

and names. Ruby's Personal Options Representative is her son-in-law, Kevin, who thinks of Ruby as his own mother.

Caregivers and Representatives

All of the program participants in this study required total or partial assistance with daily living activities. Personal Options staff determined the level of care needed, based upon the care recipient's stage of dementia and other medical conditions. The researchers were able to interview four program participants, five representatives, five paid caregivers, and four unpaid caregivers. Although three program consultants were interviewed, their interview transcripts were not used for this report.

The following are themes and subthemes for each research question along with representative quotations from care team members to support findings. A summary of findings can be found in Table 1 (Research Question 1) and Table 2 (Research Question 2).

Research Question 1: How do participants and their families fare in Personal Options?

Table 1. Summary of Findings for Research Question 1

Research Question 1		Summary of Findings
How do participants with dementia and their families fare in the Personal Options Program compared to other caregiving situations?	<u>Participants</u>	<u>Families</u>
	<ul style="list-style-type: none"> • Can remain at home • Are more comfortable • Have greater autonomy • Have a more consistent caregiver • Have more family interactions • Receive better care than other caregiving situations 	<ul style="list-style-type: none"> • Are helped financially • Have more peace of mind • Receive encouragement • Are able to honor wishes and fulfill commitments • Feel rewarded by caring for family member • Experience some stress due to caregiving

Participants

The interview data generally indicate that participants fare well in the Personal Options program. The following themes address participants' overall well-being:

Participants are comfortable and can remain at home: Care teams reported that the participant is comfortable, and can remain at home rather than be institutionalized. They viewed this as a positive outcome for the family. Care teams described situations pertaining to participant comfort. For example, Nancy, (the paid caregiver for Mrs. Kozen), discussed her efforts to keep her mother comfortable and dry “... *you might be turning her and she urinates three times... She goes through three pads in one turning....she never lays in urine*” “*Our goal is to keep her comfortable...*”

The participants have greater autonomy: Mrs. Castor, described being in charge and having control over daily housework “*I’m the one that decides what needs to be done!*” “Granny” is pleased with the help she receives from her daughter, however she is adamant that she will continue to do certain activities on her own for as long as she can. Despite these participants' advanced stage of Alzheimer's disease, care team members feel that they have a voice in directing their care because a trusted loved one is their representative who knows their wishes and desires. Mrs. Gonzalez's daughter spoke of her mother's personal autonomy: “*I go in some mornings to... get her up and she says “I’m tired, I’m not getting up”. “...so I just leave her alone for fifteen minutes and she usually gets up with no problem*”. (Maria, paid caregiver for Mrs. Gonzalez).

Participants have more consistent caregiver and more family interactions:

Being at home allows the participant to have more consistent caregivers and more meaningful family interactions than if they were in a nursing home. Mrs. Gonzalez's daughter Maria described the lengths she and Ben go to ensure that their mother has family interactions "*...anytime she wants to visit anybody or do anything, we always take her*" (Maria, paid caregiver for Mrs. Gonzalez). Care team members feel that participants have greater satisfaction and peace of mind being with family. Linda (representative for Mrs. Kozen) thinks that her mother functions at a higher level than other individuals in the advanced stage of Alzheimer's "*I would guarantee that at the level of Alzheimer's she is at, that she functions better than most in that level.*" Mrs. Castor's daughter, Pamela (unpaid caregiver for Mrs. Castor), believes that social interactions help her mother continue to perform the activities she enjoys "*The more she's around people...the better she is.*" "*She made bread two weeks in a row!*" Care teams reported that the presence of trusted, familiar, caregivers makes the participant less fearful for their personal safety especially when addressing intimate needs. Mrs. Adam's daughter Edith who is her caregiver, said "*she wouldn't want someone else to come in and take care of her*". Several family members said that strangers exacerbate the aggressive behavioral symptoms of Alzheimer's disease.

Participants receive better care: Some family members believe that participants receive better care from their families than they would if they were in other caregiving situations. Mrs. Castor had been in a nursing home rehabilitation unit following a hospitalization, and developed a urinary tract infection and dehydration. The family felt that this would not have happened if she had recovered at home.

Care teams described the extra steps family members take to provide care that helps prevent medical problems. For example, the Kozen family tries to be proactive in preventing skin irritation and bedsores so they buy supplies for their mother using their own money. Nancy (paid caregiver for Mrs. Kozen) explained, “*Sometimes insurance won’t pay for things until ... you have a problem...which you want to prevent the problem*”.

Family Members

Family members reported that they experience some physical and psychological stress caring for their loved one with dementia. At times, caregivers even neglect their own health because of their caregiving duties. Some teams reported that an unequal distribution of care among family members causes additional stress.

Caregivers experience physical and psychological stress: Even though the program is positive for the overall well-being of families, the constant care that is required for someone with dementia causes stress for some team members.

According to Nancy (paid caregiver for Mrs. Kozen), her mother needs round-the-clock care, including turning every few hours to prevent bedsores. Nancy sighed and said, “*I mean it’s exhausting... if I go out to cut the grass somebody needs to be here....*” “*I’m 59 years old now. I’m tired.*” Mrs. Gonzalez’s daughter also finds the round-the-clock care tiring. Maria described a typical day caring for her mother from early morning until evening. “*..., it takes twice as long for anything you do.*”

Families make many sacrifices to keep participants at home: According to care team members, in order to keep participants at home they make many personal sacrifices. The Kozen family described how much their elderly father did to care for his wife before he died: *“It was amazing what he was able to do at his age.”* (Linda, representative for Mrs. Kozen). Nancy (paid caregiver for Mrs. Kozen) gave up her full-time job and only works four days a month as a nurse in another state. She even neglects her own health while caring for her mother *“...I have gallstones... I refuse to have gallbladder surgery...”* *“I don’t spend money on myself...I think a whole lot if I buy a new pair of shoes...”*

An unequal distribution of care among family members causes stress. Even though some care team members make many sacrifices to keep their loved one at home, other family members do not share the caregiving duties. This causes unequal distribution of care and significant stress among some family members. Karen (paid caregiver for Mrs. Hayes) talked about family members who don’t agree with her caregiving decisions, yet they are not willing to help care for their mother. She said some of her siblings may take their mother out for the day but bring her back if her adult diaper needs to be changed. Linda (representative for Mrs. Kozen) reported that three of her seven siblings are not involved with their mother’s care and do not even visit her because they say *“it’s too painful to see Mom as she is.”*

Although care teams reported some negative consequences from constant caregiving, the program payments, flexibility, and assistance from the Personal Options counselors, decrease some stressors. Many team members find caregiving to

be rewarding, and they are grateful to be able to honor commitments to the participant and other family members.

The Personal Options program helps families financially. The Personal Options program helps families purchase items such as care supplies, gas for the car, utilities, and medical equipment. Thus, the program offers them peace of mind and reduces some financial stressors. Without the program, the Kozen family is unsure of where their mother would be. Linda (representative for Mrs. Kozen) said “...*as the years go by it is just financially devastating.*” Most of the families reported that they use their caregiver wages to buy items for the participant. Linda (representative for BK) described how her sister’s salary is spent “...*every penny goes right back into paying bills*”. Edith (paid caregiver for “Granny”) said that without her salary as a caregiver in the Personal Options program she would have to work and “*Granny would be left alone more and have to be cared for by someone she doesn’t know.*” Bob (representative for Mrs. Castor) said “*The best thing (about Personal Options) is just it gives us the extra money for the extra help*”.

Personal Options staff encourage families. Although the families are grateful for the financial help they get from the program, they find the encouragement they get from the Personal Options staff to be especially rewarding. Linda (Representative for Mrs. Kozen) said ...”*the encouragement that you get is very important. When Susan or Edward (Personal Options Counselors) have encouraged us...it’s really wonderful...!*” Her sister Nancy revealed that the Personal Options staff is always “*friendly, available, and glad to explain details*” (Nancy, paid caregiver for Mrs. Kozen)

Family can honor wishes and fulfill commitments. Because of the Personal Options program, families can fulfill their commitments and honor participants' wishes. For example, Mrs. Kozen's daughters had promised their father before he died that they would continue to care for their mother. Nancy said "*We made a commitment...!*" (Nancy, paid caregiver for Mrs. Kozen). Mrs. Gonzalez's daughter (paid caregiver for Mrs. Gonzalez) stated "*...she took care of me for all those years so now it's my turn!*"

Although many care team members find caring for their family member to be extremely rewarding, they do not think everyone is capable of caring for someone with dementia. Molly (paid caregiver for Mrs. Castor) summed up her feelings about caregiving as she said "*It can be rewarding but difficult*" "*...this job isn't for everyone...*" Bob, who is the representative for Mrs. Gonzalez, feels fortunate that he and his wife are able to care for both his mother-in-law and his own mother, "*The good Lord has really blessed us*" he stated. His wife Maria agreed "*I think it's a gift from God that, ... some people just have the patience and compassion to take care of somebody else*"

Research Question 2: How do care teams describe their training needs?

We identified several major themes for care team training needs as well as sub-categories within each theme (summarized in Table 2).

Table 2. Summary of Findings for Research Question 2

Research Question 2	Summary of Findings
How do care teams describe their training needs?	<p><u>Care teams need training/information in the following:</u></p> <ul style="list-style-type: none"> • Knowledge of Alzheimer’s disease (disease process, signs, symptoms, treatments, medications) <ul style="list-style-type: none"> ○ Addressing behavioral changes ○ Building skills for care needs ○ Training to improve participant safety ○ Training to communicate with participant including interpreting physical cues and body language) • Knowledge of other medical conditions • Training to communicate with: <ul style="list-style-type: none"> ○ participant ○ caregivers ○ health care professionals • Technical skills training for medical equipment and assistive devices • Knowledge of coping techniques • How to find respite care and other supports • Training to further understand the Personal Options program and participant-directed care • Representatives have unique training needs

Training in the knowledge of ADRD. Family members expressed a need to know more about the symptoms of Alzheimer’s disease, as well as how it is treated. Maria (paid caregiver for Mrs. Gonzalez) stated: *“I would have loved to have known more about Alzheimer’s disease ...what would have been done medically to try to treat it or slow it down...”* Pamela (unpaid caregiver for Mrs. Castor) said that caregivers need to *“understand dementia and how it really works.”* In addition to memory loss,

family members described some of the signs and symptoms of Alzheimer's disease and related dementias that their loved one experienced including personality changes, impaired judgment, disorientation, and a decrease in communication skills. Some family members noted that they would have liked to have known about these symptoms before they started.

How to address behavioral changes. One sub-theme in this category is training to deal effectively with behavioral issues. There is especially a need for knowledge of how to address difficult behaviors, wandering, and mood swings. Mrs. Kozen's daughters described their mother's early behavioral changes: *"...she just totally depended on Dad". She didn't want to ever be away from him". ... "She was very fearful...she cried"*

Some participants refuse care from family members or from health care professionals. Mrs. Hayes' daughter, Karen (representative for Mrs. Hayes), said that her mother won't even let her granddaughter touch her. Maria (paid caregiver for Mrs. Gonzalez) said that her mother not only refuses care from health care professionals, at times she displays aggressive behavior toward them. Maria stated *"...she won't let the hospice nurse touch her ..."* *"...she told the nurse she was going to hit her."*

Increased skills for personal care needs of participants with dementia. Care teams discussed the difficulty of caring for family members with dementia, and gave the researchers multiple examples of the training that is needed to provide safe, personal-care including: training to help caregivers transfer a person into a wheelchair, skills to make a bed with someone in it, and how to bathe someone with Alzheimer's disease. *"I will turn her by myself in the middle of the night and*

(sometimes) she'll have BM (bowel movement) smeared everywhere" (Nancy, paid caregiver for Mrs. Kozen). Families suggested that improved care skills may benefit both participants and caregivers.

Training about safety issues. Families expressed great concern about the safety of their loved one. They discussed the need for safety training and home modifications to keep participants from injuring themselves. Both Mrs. Castor's and Mrs. Gonzalez's family members were concerned about dehydration since both women like to spend time in their gardens on hot days. Families were especially concerned about the participant falling or wandering into an unsafe environment. Some care team members were concerned about the storage or administration of medications: *"... she'll put em under her tongue ...and then spit em out."* (Maria, paid caregiver for Mrs. Gonzalez). Bob said *"...if you (caregivers) get the medications messed up you can really get somebody into trouble"* (Bob, representative for Mrs. Gonzalez).

Training on how to communicate with participants with dementia. The interviews revealed that there is a need for families to receive special training on how to communicate with the participant, including how to interpret and use physical cues and body language. Family members want to know how to comfort and reassure participants. Maria (paid caregiver for Mrs. Gonzalez) explained how difficult it is to communicate with her mother...*" You have to tell her over and over and try to show her, you know, pat the chair ...here's where you sit mom."* Care teams are especially concerned about expressions and body language that convey pain and discomfort. For example, Mrs. Kozen who is unable to communicate verbally went several

months with an undiagnosed hip fracture and her daughter said: “... *she ...doesn't say “Oh my leg's hurting”*. The Kozen family, which includes a healthcare provider, was finally able to convince health care professionals that something was wrong with their mother because they described her facial expressions as she winced in pain.

Other major themes for training needs emerged from the data including: the need for knowledge about medical conditions in addition to dementia; how to communicate effectively with care team members and care professional; training in the use of assistive devices; training to develop coping techniques; and training specific to participant-direction and the Personal Options program. The researchers found that the representatives for individuals with dementia in this study may have unique training needs because of their role.

Knowledge of other medical conditions: Care team members described multiple medical conditions and functional limitations of their family member in addition to dementia for which they had requested information about from their doctors. Care teams have to monitor participants for complications associated with medical conditions, and administer treatments and medications appropriate for the medical problem. “...*I just check the skin color. Is she pale today? ... usually her blood pressure will be real low or something like that*” (Maria, paid caregiver for Mrs. Gonzalez). Caregivers must learn to take medical conditions into consideration when providing care for participants; for example, choosing foods to accommodate a diabetic diet. Edith (representative for “Granny”) described how she helps her

mother who is legally blind: *“When I fix her plate, I’ll set it down and show her now...the meats over here and the potatoes are over here ...”*

Training on how to communicate with care team members and health care professionals. Care team members feel that good communication is necessary in order to coordinate care. Molly stated *“We would call each other... If we’d run out of something or if Aunt Ruby wanted something particular...”* (Molly, paid caregiver for Mrs. Castor). Nancy (paid caregiver for Mrs. Kozen) feels that family communication is important to avoid misunderstandings: *“We decide as a family what needs to be done”*. Kevin (representative for Mrs. Castor) exclaimed *“Communication is a big, big thing!”* as he discussed care coordination. Mrs. Castor noted that listening is a part of good communication *“I think they (caregivers) have to listenbecause ...you can give them good advice”*.

Technical skills training. Care teams reported that training is needed for the use of assistive devices (such as wheelchairs, walkers and canes). Several team members reported that participants have difficulty with assistive devices because of poor eyesight or the progression of Alzheimer’s disease. Maria (paid caregiver for Mrs. Gonzalez) said of her mother’s walker *“it’s too confusing for her”*. Nancy (paid caregiver for Mrs. Kozen) feels that caregivers need training for simple assistive devices as well as more technical training such as how to use a Hoyer lift. She and others believe that training can help make care-giving easier.

Knowledge of coping technique. Care team members had different ways of coping with difficult situations and feel that training to develop additional techniques and problem solving skills will be helpful. Coping techniques that were identified by care

teams include: keeping a good sense of humor; relying on religion; sleeping when possible; talking with family or friends; walking away for a few minutes if you can; keeping a detailed log book; sticking to a routine; and, talking with program consultants.

“...when I have a bad day I just have to walk away and go outside, walk around the house, take deep breaths. Come back and try again”. (Maria, paid caregiver for Mrs. Gonzalez)

Finding respite care. Some team members report that finding respite care and being flexible enough to make contingency plans are essential for coping. *“... be sure and get away at least once a week”.* *“Even if I’m going to buy groceries...I can breathe.”* (Maria, paid caregiver for Mrs. Gonzalez). Maria’s husband, Bob agreed that respite care is essential. However, he is also concerned with Maria’s health; *“I love Carmen...but we made an agreement with each other ... we would devote these years of our life to that (caregiving) as long as it didn’t affect our health.”* (Bob, representative for Mrs. Gonzalez). Maria agreed *“.... Don’t ever let the door close on your other options because it could come a day that I don’t have a choice”.*

Training is needed to further understand the Personal Options Program and how to promote participant-directed care. Several aspects of the Personal Options program were confusing to certain care team members in this study. Linda (representative for Mrs. Kozen) described her confusion when the program was described to her: *“To me it was a bit complicated.”* Her sister, Nancy, agreed that the program could be difficult to understand at first, but the counselor helped her a great deal: *“....to be honest, Susan (counselor) has been a great help...”* (Nancy, paid

caregiver for Mrs. Kozen). Molly, who is the paid caregiver for Mrs. Castor thinks that the paperwork associated with the program can be overwhelming. As she discussed her timesheet, she said that each task has to be broken down into the number of minutes it took to perform: *“For the seven hours...each day...you had to break down in minutes. So it was 420 minutes per day”*.

Discussion

The purpose of this study was to collect care team views of the challenges and benefits of a Cash and Counseling option of care services for individuals with dementia. The researchers wanted to determine what training issues are important to families, and may increase program quality. The goal of the research was to utilize these data in designing appropriate training material to help eliminate barriers to this model of participant-directed services for elders with dementia.

Families Fare Well in the Personal Options Program but Have Multiple Training Needs

Families Fare Well in the Personal Options Program

The Alzheimer’s Association reports caregiving for elders with Alzheimer’s disease and related dementias to be stressful in any care option (Tilly, 2007). However, consistent with findings by Tilly, (2007), both individuals with dementia and their caregivers in this pilot study benefit from participation in a participant-directed program. Care teams report that participants are able to remain at home with a more consistent caregiver, have greater satisfaction and autonomy, and receive better care than they would in other caregiving situations. Families report less stress,

less financial strain and have greater flexibility and peace of mind about the care that their loved one receives.

Caregivers have Multiple Training Needs

The researchers found that care teams have multiple training and information needs including a need for knowledge of Alzheimer's disease and of other medical conditions. Caregivers indicate that they do not always understand the symptoms of Alzheimer's disease or how it progresses. Care teams express a need for training to address behavioral changes, develop coping techniques, and ensure the safety of participants. Some care team members did not have the capacity to obtain, communicate, process, or understand health information or services related to Alzheimer's disease, indicating that they have low health literacy in terms of dementia care. Improved training with a health literacy component may help caregivers in making more informed health care decisions.

Representatives Have Unique Training Needs

Representatives help individuals with Alzheimer's disease and related dementias bridge the gap between themselves and others as their physical and cognitive abilities diminish and their ability to verbally communicate decreases. Representatives have an increasingly important role in seeing that participant needs are met and care is provided as the participant desires. They must also ensure the safety of elders with dementia and work to coordinate care. However, several of the representatives in this study were unable to access information about dementia, and were unsure of their care decisions at times. All of the representatives in this pilot study had a dual role in that they performed caregiving and representative tasks for the participant. Thus,

representatives may have training needs that are different than other caregivers.

However, the difference in training needs between caregivers and representatives for individuals with dementia in a participant-directed program has not been examined.

These interviews revealed that representatives are able to represent the wishes of the participant because they are close family members who know the participants so well, yet they have the following unique training needs:

❖ **Representatives need training/information about the Alzheimer's disease**

process, and need to prepare caregivers for this process. Representatives must be able to show caregivers how to perform daily living activities while dealing with unwanted behavior, and at the same time, honor the participant's wishes.

The representatives in this study were especially concerned about participant safety, and teaching caregivers how to address wandering or medication mistakes.

❖ **Representatives need training in how to communicate with the participant,**

family members, and health care professionals and must teach these

communication skills to others. Representatives must understand the body language of the care recipient, and teach this information to caregivers.

Representatives must also know how to communicate with Personal Options staff members and health care professionals. As noted by Karen (representative for Mrs. Hayes), communication skills such as conflict resolution skills may be necessary to work out differences between care team or family members. Better communication with family members may enhance the ability of representatives to recruit family members to share caregiving tasks.

❖ **Representatives must learn to plan for the future.** Representatives must plan for the future keeping in mind their own well-being, as well as that of the participant and the caregiver. For example, several representatives expressed concern about the emotional effects on the family of placing the participant in a nursing home should their own health or the caregiver's health deteriorate. Representatives must determine what services will be needed and how to obtain these supports. The representatives in this study noted that effective planning requires organizational and decision-making skills as well as collaborative skills.

Implications and Future Studies

Better training may lead to better quality care for participants with dementia and greater satisfaction for both care recipients and caregivers. For example, information about safety for individuals with dementia may decrease emergency room visits and unnecessary hospitalizations reducing the skyrocketing cost of dementia care. Better communication may improve care coordination, the distribution of care, and family dynamics. With greater knowledge about the Alzheimer's disease process, care team members may be better able to manage unwanted behavioral symptoms and increase planning and preparedness for the future. Evidence from this pilot study suggests that program representatives have unique training needs and may be unprepared for their role. Representative training needs change over time as the physical and cognitive abilities of the program participant decrease. Thus, the researchers planned studies to

examine the changing needs of representatives as well as their dementia health literacy and preparedness.

Study Limitations and Strengths

One limitation of this study is its small sample size which may not accurately reflect how all participants with dementia and their families fare in the Personal Options program; or include every training need. However, since the researchers gathered information from all care team members, including the participant, they were able to evaluate training needs from various perspectives, which is a strength of the study. One of the greatest challenges of this study was interviewing older subjects with dementia and other physical disabilities. However, the communication skills needed to talk to individuals with dementia were learned by one researcher who worked for seven years in a nursing home Alzheimer's unit developing skills needed to talk with this population. Finally, to avoid potential bias in developing the coding matrix and in writing the narrative stories, the researchers started with a body of knowledge gained from previous research. This body of knowledge and the research questions guided the development of the coding matrix. To prevent bias in the stories, the researchers drew from multiple interviews with each team, field notes, and direct quotes that supported the narratives.

Conclusion

Due to our growing elderly population and the increase in Alzheimer's disease and related dementias, we must examine models of long-term care that promote quality,

flexibility, and participant-choice, allowing individuals with dementia to remain in their homes. The findings from this pilot study provide us with further evidence that a Cash and Counseling model of care works well for individuals with dementia and their families. However, care teams report that training is needed in multiple areas to make this home care option more dementia- friendly. A representative training program with a health literacy component may help improve health outcomes for elders with dementia and increase caregiver satisfaction. Training may also improve care quality and coordination, allowing for better distribution of care. Representatives have unique training needs that, if satisfied, will enable them to better support individuals with dementia and other members of the care team. The researchers expect that the findings from this study will lead to an expansion of this project to support the development of improved evidence-based participant-directed training programs.

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Chapter 3: The Relationship between Decision-Making Partner Communication Skills and Health Outcomes for Care Recipients with Dementia and their Care-Teams in a Participant-Directed Program

Abstract

Good communication skills are essential for helping “Decision-Making Partners” (DMPs) for elders with dementia feel “very well prepared” to represent the care recipient, and perform optimally in the DMP role. **Objectives:** The objectives of this study were to: 1) define health literacy for DMPs of elderly Medicaid recipients with dementia in a participant-directed program, 2) develop a health literacy skills framework for this population, and 3) use this framework to evaluate the impact of one health literacy skill (communication) on DMP self-reported preparedness to represent the care recipient, and preparedness for the stress of the DMP role. The findings from this study provide evidence for the development of a dementia training program with a health literacy component for DMPs, that will help them feel “very well prepared” for their role. **Methods:** I first defined health literacy for this population based on current definitions in the literature. I then developed a framework for dementia health-literacy skills by expanding an existing health literacy skills framework. Using components of the framework, I completed a secondary data analysis using preparedness data obtained from a telephone survey of thirty DMPs for individuals with Alzheimer’s disease and related dementias in the participant-directed Arkansas “IndependentChoices” program. I adopted a mixed-methods approach to the study, with the goal of using findings to inform training for DMPs in participant-directed programs and better serve people with dementia. Finally, I evaluated the

impact of the DMP's ability to communicate with the care team (which consists of program participants, caregivers, IndependentChoices staff, and health care professionals) on self-reported preparedness to represent the program participant, and preparedness for the stress of being a DMP. **Results:** Mean preparedness scores based on a likert scale (0= not prepared to 4= very well prepared) indicate that DMPs feel "pretty well prepared" for 11 of 14 self-reported measures of communication skills. However, less than half of the DMPs feel "very well prepared" for 7 measures of communication skills. DMPs gave examples of situations where a lack of communication or miscommunication between themselves and the care team may have led them to feel less than "very well prepared." **Conclusion:** The lack of adequate communication skills impacts the ability of DMPs to access information about dementia, communicate about this information, and to perform optimally in their role. To enhance participant-directed services, DMP training should include a health literacy component that includes communication skills. Future studies should examine the relationship between specific communication skills, such as negotiation skills and conflict resolution skills, and outcomes in terms of dementia in a participant-directed model, and examine other health literacy skills within the framework.

Key Words: Communication Skills, Decision-Making Partners, Dementia, Participant-Direction

Introduction

Family members and friends who assist individuals with dementia in making care decisions (called “decision-making partners” (DMPs) or “representatives”) play an important role advocating for the care recipient and ensuring that they receive care in the manner that they prefer (Whitlatch, 2008; Reinhard et al., 2011).

Representatives in participant-directed programs may also manage a flexible budget, and decide which services and supports meet the needs of the program participant when they are unable to perform these tasks themselves (National Resource Center for Participant-Directed Services, 2011). However, some representatives may have low *health literacy* defined in the Patient Protection and Affordable Care Act of 2010, Title V as “*the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions*” (Center for Health Literacy Promotion, 2013). Low health literacy (which includes poor communication skills) may impact the ability of representatives to access information about dementia, and use this information to make optimal health care decisions for elders with dementia in a participant-directed program.

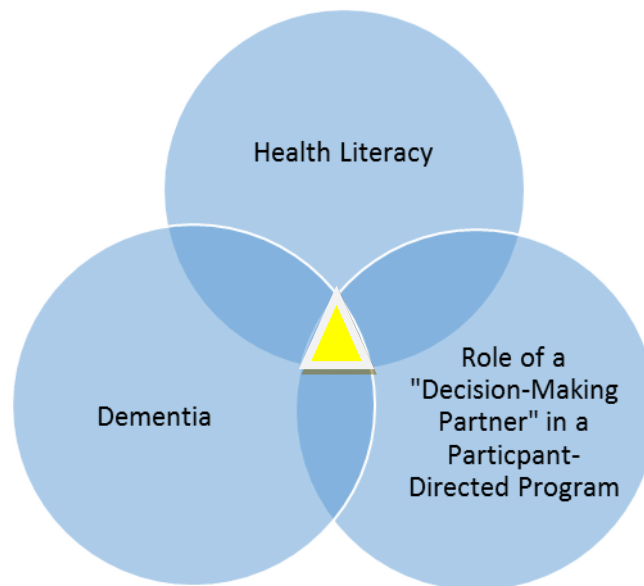
How this Study will add to Health Literacy Information

Previous studies have examined the impact of an individual’s level of health literacy on the management of their own chronic health conditions and health outcomes [including: diabetes (Schillinger et al., 2002), HIV/AIDS (Hicks et al., 2006), asthma (Mancuso & Rincon, 2006), cardiovascular and heart disease (Safeer et al., 2006; Morrow et al., 2006) and cancer (Amalraj et al., 2009); (Liechty, 2011)].

Research indicates that individuals with low health literacy have poorer health outcomes, and increased morbidity and mortality rates, than people with adequate health literacy levels (IOM, 2004; Liechty, 2011; Agency for Healthcare Research and Quality (AHRQ) 2011). A few studies, including Lindquist et al. (2011), Yin et al., 2007; and Sanders et al., (2007), have focused on the health literacy of caregivers and their care recipients' health outcomes. These studies report that caregivers with low health literacy may lack the skills to adequately manage the chronic disease of the care recipient. For example, in a study of caregivers for seniors, Lindquist et al. (2011) reported that as many as one-third of the caregivers have inadequate health literacy which may interfere with their ability to follow medication instructions.

To my knowledge, no studies have evaluated the impact of the health literacy skills of “decision-making partners” (DMPs) on health outcomes of care team members or on the ability to manage Alzheimer’s disease and related dementias (ADRD). Thus, there are large gaps in our knowledge of the health literacy of this population. The highlighted section of **Figure 1** shows the area of interest for this study; the intersection of health literacy, dementia, and the role of the DMP. This study contributes to the literature by exploring the meaning of health literacy for DMPs for elders with dementia in a participant-directed program.

Figure 1. The Intersection of Health Literacy, Dementia, and the Role of a Decision-Making Partner



Goals of this Study

The goals of this study were to:

1. Define health literacy for Decision-Making Partners for elderly Medicaid recipients with dementia in a participant-directed program.
2. Develop a framework of health literacy skills for this population.
3. Use the framework to evaluate the impact of one dementia health literacy skill (DMP communication skills) on the DMP's self-reported preparedness to represent the care recipient, and perceived preparedness for the stress of the DMP role.

Poor health literacy skills among DMPs can adversely affect the process of providing care for vulnerable individuals with dementia. The following case scenario of Mrs. Williams (a participant in IndependentChoices, an Arkansas participant-directed program) and her daughter Paulette (her DMP in the Program) demonstrates how inadequate DMP communication skills can impact the care team (Program participant, caregiver & DMP):

Case Scenario

Mary Williams is an 82 year widow with Alzheimer's disease who lives with her 51 year old daughter Paulette. Mrs. Williams is a participant in the Arkansas IndependentChoices program and Paulette is her mother's "Decision-making Partner" (DMP) in the Program. As a DMP, Paulette helps manage her mother's care services and her budget. She also helps her mother with personal care needs, and keeps track of the multiple medications that Mrs. Williams takes for her Alzheimer's disease, diabetes, and hypertension. At times, Mrs. Williams yells at Paulette because she doesn't want to take her medications. Paulette tries to reason with her mother, but she has a hard time communicating with her. Mrs. Williams' niece, Betty, is Mrs. Williams' paid caregiver in the program. Betty thinks "Aunt Mary" is "just stubborn at times" because she refuses to bathe or take her medications. Mrs. Williams and Betty often argue about her care. The lack of DMP communication skills leads to increased stress in the family. Paulette does not understand the Alzheimer's disease process or its associated behavioral issues. She

does not know how to adequately communicate with her mother, or know how to teach Betty how to care for her mother.

Background

Alzheimer's disease and Related Dementias

Alzheimer's disease poses a significant challenge for the aging population. There are approximately 5.4 million Americans, like Mrs. Williams, living with Alzheimer's disease; a progressive brain disease that significantly impacts both physical and cognitive functioning (Alzheimer's Association, 2012). Over the course of the disease, individuals with Alzheimer's disease and related dementias experience memory loss, behavioral changes, and have difficulty thinking, speaking, swallowing, and walking (Alzheimer's Association, 2012). There is no cure for Alzheimer's disease, and it is the sixth leading cause of death in the United States today (Alzheimer's Association, 2012; CDC, 2013). Since the risk of developing dementia increases with age, the number of individuals with dementia in the U.S. is expected to increase with our aging population (Alzheimer's Association, 2012; Tilly et al., 2011).

Family Caregivers

Most elders with dementia (70%) remain at home and rely on unpaid family and friends to help them with their care and decision-making tasks as their disease progresses (Masters, 2006). According to the Alzheimer's Association, in 2012,

fifteen million family caregivers of individuals with dementia provided over 17 billion hours of unpaid care worth approximately \$216 billion dollars (Alzheimer's Association, 2013). Family caregivers often assist individuals with dementia with activities of daily living (ADL) including bathing, using the bathroom, dressing, grooming, transferring, and eating. Families also help with instrumental activities of daily living (IADL) such as shopping, housecleaning, cooking, taking medications and managing finances (Tilly, 2011; Alzheimer's Association, 2012). Decision-making tasks that families often assist with include making medical decisions, and seeing that care is provided according to the values of the individual with dementia (Reinhard et al., 2011). Many family members, like Mrs. William's daughter Paulette, have multiple roles as both a DMP and a caregiver.

Although the services of unpaid family caregivers and paid workers help elders with dementia avoid placement in a nursing home or other facility, the physical and emotional burden of caregiving and decision-making often causes a great deal of stress for families (Tilly et al, 2011; Whitlatch, 2008). Providing care for someone with dementia can be difficult because of the extensive assistance they require with ADL and IADLs, or because their altered behaviors (such as Mrs. William's refusal to take her medications) impact compliance with treatments for dementia or coexisting chronic conditions, and personal care (Tilly et al. 2011). Individuals with dementia have been reported to have feelings of embarrassment and anxiety because of the assistance that they need (Judge et al. 2013). Family caregivers of individuals with dementia often report high levels of anxiety, depression, and exhaustion which may lead to their own social withdrawal and health problems (Alzheimer's

Association, 2013; Judge et al., 2013) or to institutionalization of the person with dementia (Egge, 2011).

Participant-Directed Services for Individuals with Dementia and the Role of the DMP

As many states address the dementia capabilities of their long-term services and supports (LTSS) system, there has been an expansion in the number of participant-directed- LTSS for individuals with dementia (Tilly et al, 2011). The goal of participant-directed services is to allow participants to select the providers and services that will best meet their needs allowing individuals with dementia to remain at home and within their community for as long as possible (Tilly et al., 2011). In the Cash and Counseling (C&C) program, one of the most flexible participant-directed models, participants receive a flexible budget to purchase goods and services and hire workers who may include family members (Masters, 2006; Simon-Rusinowitz et al., 2010). Participants can have, as part of their care team, an unpaid “representative” or DMP (usually a close friend or family member, like Paulette in our case scenario), who can help make care decisions and represent their care preferences (Tilly et al., 2011). DMPs for individuals with dementia in a C&C program play a critical role assisting participants with care decisions, and eventually performing program tasks for the participants as their physical and cognitive abilities decline.

Despite the essential role that they play, some DMPs may have low health literacy which affects their ability to represent the care recipient (Ruben & Simon-

Rusinowitz,in progress). These two investigators conducted an ethnographic pilot study aimed at identifying training needs of care teams for elders with dementia in West Virginia's Personal Options program (West Virginia's C&C Program),(Ruben & Simon-Rusinowitz, in progress). The researchers found that representatives in the study did not always understand the symptoms of Alzheimer's disease and related dementias or how the disease progresses. Some representatives reported they need information about dementia; indicating they may have low health literacy in terms of dementia. Some Representatives also reported that they were unprepared for certain aspects of their role. As a next step, the researchers planned a study (with two additional investigators) to evaluate DMP preparedness in the Arkansas IndependentChoices program (Simon-Rusinowitz et al, in progress).

In this current study, I performed a secondary analysis of the preparedness data obtained from the Arkansas DMP preparedness study. This study evaluates the impact of one DMP health literacy skill (communication ability) on self-reported preparedness to represent participants with dementia in a participant-directed program and preparedness for the stress of the DMP role. The findings from both studies will be used to inform the development of a dementia training program with a health literacy component for DMPs in participant-directed services.

Health Literacy

A brief description of the evolution of the relatively new field of health literacy is provided to help the reader understand the definition of health literacy for the study population, and the components of the conceptual framework of health literacy skills,.

Evolving Definition of Health Literacy

The definition of health literacy and understanding of its conceptual components have changed significantly over the last twenty years; from an individual-level construct to a systems-level construct (Berkman, Davis & McCormack, 2010; Paasche-Orlow et al, 2010). Early definitions of health literacy such as that by Selden, Zorn, Ratzen, & Parker (2000), Bernhardt, Brownfield, & Parker (2005), and the Institute of Medicine (IOM)(2004) considered it to be an individual-level construct and focused on an *individual's* ability to perform health-related tasks, make decisions about their own health, and function in a health-care environment (Berkman et al, 2010). The IOM definition was included in a report *Health Literacy: A Prescription to End Confusion* (IOM, 2004) and in Healthy People 2010 (U.S. Department of Health and Human Services, 2013).

Researchers continued to add constructs to the definition including factors that enhance the capacity for health literacy such as personal, cognitive, and social skills (Nutbeam, 2008) and the ability to communicate effectively (McCormack, 2010; Agency for Healthcare Research and Quality (AHRQ), 2011). As investigators added evidence to the field of health literacy, some researchers reported that health literacy “goes beyond the individual”-“health outcomes also depend on the skills and abilities of health care providers and others” (IOM, 2004). When developing provisions for health literacy in the 2010 Patient Protection and Affordable Care Act (PPACA) the degree to which an individual has the capacity to *communicate* was added to the Healthy People 2010 definition (CDC, 2011). Recent definitions have a more ecological framing; including the influences of family, the community, and the health

care system on health literacy. Some definitions of health literacy include group input and outcomes (public health literacy) (Berkman et al., 2010).

Berkman et al. (2010) assessed the status of the definition of “health literacy” and found that researchers have difficulty reaching a consensus because of the complex and dynamic nature of the constructs. According to the Center for Health Literacy Promotion (2013), the lack of agreement of a definition presents a significant challenge for health literacy research. Since there is no single definition of health literacy, Berkman et al., (2010) suggested it can be viewed in multiple ways depending on “one’s goals.” My goal is to better understand the impact of low health literacy skills of DMPs on the well-being of elders with dementia and their families in the Arkansas Independent Choices program. I defined health literacy for this study based on available definitions in the literature and specific to DMPs for individuals with dementia in a participant-directed C&C program. In this study health literacy is defined as:

“The degree to which “Decision-Making Partners” can obtain, process, understand, and communicate about dementia health information, services, and supports needed to make *informed* participant-directed health decisions for individuals with dementia and their caregivers”

Developing a Framework of Health Literacy Skills for this Study

Measuring Health Literacy

Just as there is no agreement on the definition of health literacy, there is no ideal measurement of health literacy (Baker, 2006). Instruments that measure health literacy often assess the ability to read, write or perform numeracy skills (McCormack, 2009; Baker, 2006). This is typically done in person by an individual who is trained to use measurement instruments such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) which are the two most commonly used instruments (McCormack, 2009; Baker, 2006). Additional measurement tools were developed that were deemed more culturally appropriate such as the Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50; based on REALM) (AHRQ, 2009). Weiss et al. (2005) developed a short screening test for low health literacy in English and Spanish for use in primary health care settings called the Newest Vital Sign (NVS). The NVS which uses a nutrition label accompanied by six questions, correlates with TOFHLA scores and takes only three minutes to administer orally. Some researchers (Davis, et al., 1993; DeWalt & Pignone, 2005) reported that certain demographic measures (sex, age race/ ethnicity and years of schooling) are highly correlated with test-based health literacy measures (Hanchate et al., 2008). Thus, Hanchate et al. (2008) developed a tool to impute health literacy from socio-demographic data. This Demographic Assessment for Health Literacy (DAHL) developed by Hanchate et al. (2008) is used to evaluate data from major population surveys.

Skills Based Approach to Measuring Health Literacy

The demands of the health care environment as well as individual characteristics (including the ability to read, write, and to interpret information including quantitative information (numeracy), affect a person's ability to function within the health care system (Baker, 2006). Therefore, individuals are often defined as being health literate if they are able to perform certain skills or apply information to better their health (Rudd et al., 2004; Berkman et al. 2010). Health literacy also requires the ability to understand and navigate complex health systems with the goal of improving health outcomes (Vernon et al., 2007). Thus, the Agency for Healthcare Research and Quality (2011) reported that new measures should be developed to determine health literacy that "assess condition-related skills."

McCormack et al. (2010) developed a 25 item instrument (Health Literacy Skills Instrument) to measure individual health literacy using a skills-based approach. These researchers identified a set of skills and tasks and "real-world related stimuli" to measure the skills (McCormack et al, 2010). The tasks were categorized into domains such as print, and oral and information-seeking, including internet-based information. The final instrument was pilot tested and eventually reduced to a 10-item short form (Bann et al., 2012). McCormack et al. assumed that skills may change depending on advances in health material and technological development (McCormack, 2009).

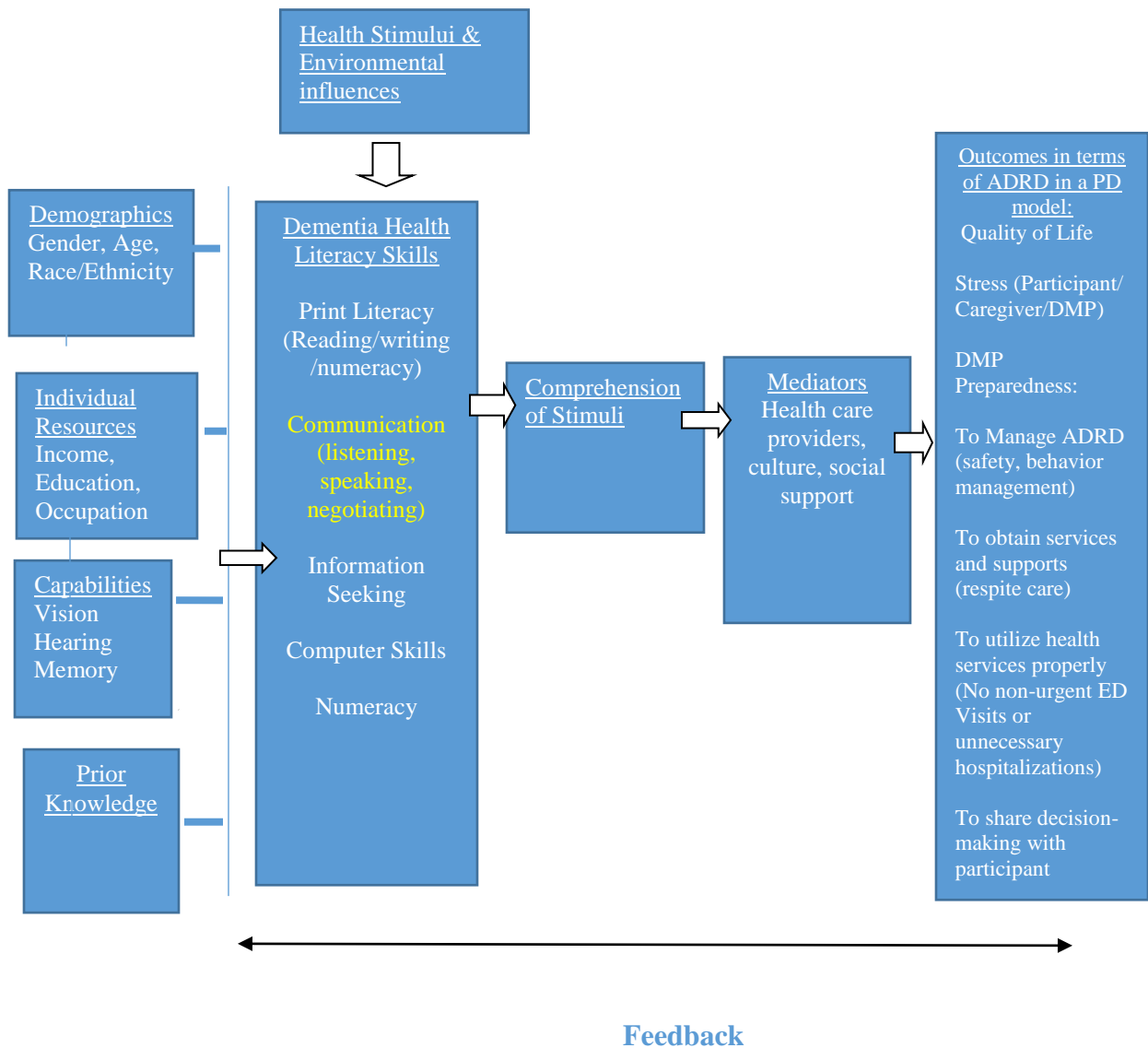
Health Literacy Skills Framework

Building on the concepts used to develop the Health Literacy Skills, several members of McCormack's (2010) research team began conceptualizing a Health Literacy Skills Framework that incorporated key concepts from ten existing health literacy models (Squiers et al., 2012). They evaluated the strengths and weaknesses of existing frameworks and found that few showed the relationship of predictors, moderators, mediators and outcomes of health literacy. These researchers developed a framework that explains how people obtain and apply health literacy skills and how their behaviors are affected by these skills. Within the Health Literacy Skills framework (Squiers et al., 2012), the researchers describe factors such as prior knowledge, capabilities and individual resources that influence the development of health literacy skills including reading and writing print literacy, communication (listening, speaking, negotiating), and information seeking skills. The Health Literacy Skills Framework "hypothesizes the relations between health literacy and health-related outcomes" from an ecological perspective recognizing multiple levels of influence on health literacy skills. Finally, the researchers proposed using their Health Literacy Skills Framework as a "springboard for further explorations" and they encouraged other researchers to test their framework or apply it to a health behavior, such as the management of a specific disease. I expanded on this Health Literacy Skills Framework and applied it to the management of dementia and outcomes in a participant-directed model of care.

Framework for this Study

I developed the following conceptual framework for DMP health-literacy skills (Figure 2) based on Squiers et al. (2012) “Health Literacy Skills Framework”. This framework provided context and helps explain the impact of low dementia health literacy skills on health related outcomes.

Figure 2. Health Literacy Skills Framework for Decision-Making Partners of Individuals with Dementia in a Participant-Directed Care Model



Using the Dementia Health Literacy Skills Framework for DMPs in a Cash and Counseling Model

I selected one health literacy skill within the framework (communication), for further examination in this study. I focused on communication because research indicates that there is often miscommunication or a lack of communication in family caregiving situations between family members, caregivers, and health care professionals (Whitlatch, 2008).

Methods

Data Source

The data that were used for this secondary analysis were obtained from the data collected in the cross-sectional, telephone survey of DMP perceived preparedness (for their role as DMP for individuals with ADRD in the Arkansas IndependentChoices program) (Simon-Rusinowitz et al., in progress; Mahoney et al., in progress). The purpose of that investigation was to address the gap in representative (or DMP) training as it pertains to dementia, and to identify DMP training needs. A full description of the study design, recruitment procedures, instrument development, data collection and analysis, as well as the full survey instrument can be found elsewhere (Mahoney et al., [quantitative component] in progress; Simon-Rusinowitz et al., [qualitative component] in progress).

Quantitative and Qualitative Questions

Selection of Preparedness Questions

For this study, I used three sections of questions that were obtained in the study by Simon-Rusinowitz et al., (in progress); 1) demographic data, 2) responses

from select quantitative survey questions from the 44 question preparedness survey (which was adapted from The Preparedness for Caregiving Scale by Archbold et al., 1990), and 3) transcripts from all participants' responses to 14 open ended qualitative questions. The responses to the survey questions were on a 5 point rating scale from 0 (not at all prepared) to 4 (very well prepared). Therefore the higher the score, the more prepared DMPs felt they were to perform that particular function in their role as a representative for the participant with dementia in the IndependentChoices program.

To identify questions from the preparedness survey to use in this investigation, and to improve the validity of our study, I asked healthcare professionals (who work with individuals with dementia and their families) as well as experts in the field of health literacy and health communication (n=7) to review the survey. I asked these experts to select the questions that pertained directly to communication (verbal and non-verbal) between the DMP and other members of the care team (program participant, paid and unpaid caregivers, IndependentChoices staff, and health care professionals). The panel of experts was asked to consider all aspects of the communication process, such as conveying information, receiving information, and listening, when selecting questions to be used in this study. I included the questions if at least 5 of the 7 experts selected it as a communication question; although most were in agreement about the choice of questions. Fifteen communication questions (**Table 1**), as well as questions about DMP overall preparedness and self-reported preparedness for the stress of their role were used for the quantitative analysis in this study. All of the qualitative questions (**Table 2**) were contained in the transcripts that I evaluated.

Quantitative Questions

Table 1. Core Study Measures of Self-Reported Communication Skills

Communication With:	Survey Question No.	Question
Participant		In your role as a decision-making partner for (name) how well prepared do you think you are:
	1	To know what he/she (name) wants?
Caregivers and Family	2	To involve him/her in making decisions?
	3	To inform a caregiver of his/her (name) physical needs?
	4	To inform a caregiver of his/her emotional needs?
	5	To communicate his/her wishes?
	6	To represent his/her decisions and preferences even if they are different from your own?
	20	To understand and negotiate the views of both (name) and his/her care team?
Paid Caregivers	12	To prepare the paid caregiver to respond to and handle emergencies that involve him/her?
	15	To prepare the paid caregiver for other health conditions in addition to dementia?
Unpaid caregivers	23	To prepare the unpaid caregiver to respond to and handle emergencies that involve him/her?
	26	To prepare the unpaid caregiver for other health conditions in addition to dementia?
Independent Choices Staff	33	To communicate with the counselor?
	34	To communicate with the bookkeeper?
Health Care Professionals	39	To get information you need from health care professionals?

Qualitative Data

Table 2. Qualitative Questions

- In your role as a DMP what are the most important things you do?
- How do you know what the participant wants?
- Do you, he/she and the caregiver always agree, or have there been conflicts?
- What do you know now that you wished you knew before?
- What mistakes have you made?
- What do you worry about?
- In your role as Decision-making Partner, what do you need information about?
- In your role as Decision-making Partner, is there anything you would like to be better prepared for?
- What would help you feel prepared?
- What is the best way to get information that would be helpful to you in your role as Decision-making Partner?
- What did you learn from this experience that you think would be useful for other Decision-Making Partners to know?
- Do you feel prepared to deal with uncertainty?
- What are you most proud of in your role as Decision-making Partner?
- Is there anything else you want to discuss that we did not ask?

Data Analysis

Quantitative Data

Quantitative data analysis was performed using StataIC version 12.0 for Windows (StataCorp, 2011). I calculated frequencies and percentages for demographic variables of all study participants; such as gender, race/ethnicity, and relationship to the program participant, as well as employment status outside of the home, and whether the DMP received training in dementia care or participant-directed care. Means and standard deviation were calculated for DMP age, length of DMP experience, and years of education. I reported percentages of overall preparedness and preparedness for the stress of the DMP role in the study population.

Qualitative Data

Qualitative data which had been processed as a document in Microsoft Office Word were converted into Rich Text Format (RTF) files and loaded into MAXQDA 10 software program (Verbi, Marburg, Germany). A preliminary coding matrix of skills (communication skills) in two broad categories of stress and preparedness was developed using the preparedness survey. Qualitative subcategories or secondary codes were developed for each category by linking hierarchical relationships and identifying related ideas or themes (for example: communication with whom?): [participant, paid caregivers, unpaid caregivers, IndependentChoices staff, or health professionals]. All primary and secondary codes were then be loaded into the software program code system matrix. The qualitative analysis included any reference to communication or the communication skills identified in the framework.

Results

Sample Description

The majority of the DMPs in this study were female (83.3%), and most were daughters of the IndependentChoices Program participants (60%). The DMPs ranged in age from 33 to 86 years old but most were between 40 and 60 years old (mean age: 55.8 years old). Half of the DMP's identified themselves as "Black" or "African American" (50%) and half said they were either "white" (40%) or of "mixed race" (10%). Only 8 DMPs reported they had received training in care that was participant-directed (26.7%) and 5 reported that they had received training in dementia care (16.7%). Although 60% of the study subjects reported "moderate" or "a lot" of stress

when asked “How much stress have you felt in your role as a DMP during the last 4 weeks,” the majority said that it was “very likely” would continue in their DMP role (86.7%). DMP demographic data are shown in **Table 3**.

Table 3. Description of the Decision-Making Partner (DMP) Sample (n=30)

Variable	N (%), Range	Mean (SD)
Gender:		
Female	25 (83.3)	
Male	5 (16.7)	
Race/Ethnicity:		
Black/African American	15 (50.0)	
White	12 (40.0)	
Mixed/Other/Unknown	3 (10.0)	
Hispanic/Latino	0 (0)	
Relationship to Program Participant:		
Spouse	4 (13.3)	
Daughter	18 (60.0)	
Other Relative	1 (3.3)	
Friend/Other	2 (6.7)	
Son	3 (10.0)	
Granddaughter	2 (6.7)	
Age (years)	33-86	55.8 (13.5)
Length of DMP experience (months)	5-216	35.0 (36.0)
Years of Education	9-18	13.3 (2.1)
Live with Participant		
Yes	13 (43.3)	
No	17 (56.7)	
Distance from Participant (minutes)	0-45	6.3 (13.0)
Employed Outside Home		
Yes	16 (53.3)	
No	14 (46.7)	
Received Training (#yes)		
• Participant-Direction	8 (26.7)	
• Dementia Care	5 (16.7)	
Perceived DMP Health		3.8 (1.0)
• Excellent	8 (26.7)	
• Very Good	12 (40.0)	
• Good	5 (16.7)	
• Fair	5 (16.7)	
Perceived Stress (past month)		1.6 (1.1)
• None	7 (23.3)	
• A little	5 (16.7)	
• Moderate	11 (36.7)	
• A lot	7 (23.3)	
Likelihood of Continuing in Role		
• Very likely	26 (86.7)	
• Somewhat likely	2 (6.7)	
• Unlikely	2 (6.7)	
Other Roles (yes)	28 (93.3)	

Quantitative Results

Quantitative Measures

The quantitative measures, including mean DMP preparedness scores, and the percentage of DMPs who feel “very well prepared” for a certain aspect of representing the individual with dementia, are found in **Table 4**. Mean preparedness scores for most tasks (which are the measures of self-reported communication skills) indicated that the DMPs felt “pretty well prepared” (Mean preparedness score ≥ 3.0) in their role to complete the task. The exceptions were the DMP preparedness to involve the participant in making decisions (mean 2.9, SD .211), and preparing unpaid caregivers to handle emergencies (mean 2.97, SD .162) or health conditions other than dementia (mean 2.83, SD .136); for which the DMPs only felt “somewhat well prepared” (mean ≥ 2 and ≤ 3). Few DMPs felt “very well prepared” in performing these communication skills ($\leq 30\%$). Less than half of the DMPs reported they felt “very well prepared” to “represent the participant’s decisions and preferences” (30% reported they were “very well prepared” for this task) or to “understand and negotiate the views of both the participant and their care team” (43% reported “very well prepared”). Overall, 70% of the DMPs reported that they were “very well prepared” to represent the program participant yet only 40% were prepared for the stress of their role.

Table 4. Survey Questions and Preparedness Scores: Mean Preparedness for a Task and Percentage of Decision-Making Partners Reporting “Very Well Prepared”

Survey Section and Question: In your role as a Decision-Making Partner, how well prepared do you think you are to:	Mean Preparedness for Task Score (SD)	% of DMPs Reporting “Very well prepared”
Survey section on <i>Assessing Participant’s Needs/Desires</i>:		
Know what the participant wants?	3.47 (.142)	60%
Involve the participant in making decisions?	2.9 (.211)	30%
Survey section on <i>Communicating Participant’s Needs/Desires</i>		
Inform a caregiver of the participant’s physical needs?	3.73 (.082)	73%
Inform a caregiver of the participant’s emotional needs?	3.13 (.157)	73%
Communicate the participant’s wishes?	3.4 (.132)	50%
Represent the participant’s decisions and preferences?	3.17 (.118)	30%
Survey section on <i>Managing the Paid Caregiver</i>		
Understand and negotiate the views of both the participant and his/her care team?	3.33 (.121)	43%
Prepare the paid caregiver to respond to and handle emergencies?	3.17 (.186)	40%
Prepare the paid caregiver for other health conditions?	3.07 (.172)	40%
Survey section on <i>Managing the Unpaid Caregiver</i>		
Prepare the unpaid caregiver to respond to and handle emergencies?	2.97 (.162)	27%
Prepare the unpaid caregiver for other health conditions?	2.83 (.136)	20%
Survey section on <i>Working with IndependentChoices Program Staff</i>		
Communicate with the counselor?	3.6 (.113)	63%
Communicate with the bookkeeper?	3.6 (.113)	67%
Survey section on <i>Working with Programs Beyond IndependentChoices</i>		
Get information you need from health care professionals?	3.43 (.133)	57%

Overall preparedness to represent program participant.	3.6 (.112)	70%
Overall preparedness for the stress of the DMP role.	3.2 (.139)	40%

Qualitative Results

Preparedness to Represent the Care Recipient

Some DMPs reported that they were unprepared to provide optimum care because of a lack of communication with the participant or others (**Table 5**). DMPs who did communicate with, and received support from family members and health care professionals, reported that they were better able to manage dementia, coordinate care, find the services and supports they need for the care team, and plan for the future. DMPs discussed the best mode of communication for them to understand Alzheimer's disease, other health conditions, treatment options, and the availability of services and supports, which included: booklets or pamphlets, videos, computer websites, and face to face contact through training programs and support groups.

Table 5. Decision-Making Partner Themes Related to Overall Preparedness to Effectively Represent the Care Recipient and Communication Skills

Domains (Theme)	Sub-Theme	Quotes from DMPs with Effective Communication Skills	Quotes from DMPs with Less Effective Communication Skills
Overall Preparedness	DMP's preparedness to provide optimum participant-directed care	<i>"Basically it takes knowin how to talk to Daddy. You can't get aggressive with him-even though he's aggressive. Talk to him calmly and matter of factly and let him know it's his decision" (DMP 103)</i>	<i>"My biggest worry is for her being in the state that she's in to be in pain and not being able to tell the amount of pain that she's in, or tell you what's hurtin her" (DMP 106)</i>
	DMP's preparedness to coordinate care	<i>"my daughter helps me a lot with my husband, and she and I talk things over and I tell her what I expect, and, my grandchildren live with me too, they're 12 and 13, and we have little family conferences to talk about grandpa and his needs" (DMP 117)</i>	<i>"I have a lot of siblings and we don't always agree on what's best (care), and so that becomes a sticky point" (DMP 101)</i>
	DMP's preparedness to manage behavioral symptoms	<i>"Well like uh, Friday she had a crying spell...and she was upset...and we can talk her back out of her crying spells...Try to be calm and just remember to answer her the best way we can" (DMP 134)</i>	<i>... "there was a time when I was getting up about three times in a night to go back to get her back to bed" (DMP 107)</i>
	DMP's preparedness to plan for the future	<i>"...he talked to me a lot-helped me through some things-told me his wishes" (DMP 103)</i>	<i>"Uh, the uncertainty...you know there's just a lot of uncertain things about the future" (DMP 117)</i>

Preparedness for Stress of the DMP Role

In this study, some DMPs reported feeling stress due to the lack of communication (or poor communication) with participants, caregivers, the IndependentChoice's staff, or health care professionals (see **Table 6**). For example, DMP's reported stress due to the participant's declining ability to communicate their care needs verbally and their own inability to understand body language. Many DMP's were stressed by certain participant behaviors associated with Alzheimer's disease; such as screaming and yelling. Some DMPs did not understand the Alzheimer's disease process and felt frustrated or depressed when participants did not understand instructions, or were not oriented to the present. DMPs also reported feeling stress when family members did not understand Alzheimer's disease care, or if there were disagreements about the care that the participant was receiving. Some of the DMP's in this study reported that good communication skills are important for them to: train caregivers who do not know how to manage dementia, explain care issues to family members, find services and supports, and to advocate for the program participant. Some DMPs in this study were not able to communicate well with health care professionals which caused significant stress. They reported that they were confused about the progression of Alzheimer's disease, treatment options, the use of medications and how to properly manage behavioral symptoms of the disease. However, others found health care professionals extremely helpful in explaining Alzheimer's disease and related dementias to them, helping them manage disease symptoms and helping them find services and supports.

Table 6. Decision-Making Partner Themes Related to Stress of the Decision-Making Partner Role and Communication Skills

Domains (Theme) Stress related to:	Sub-Theme Stress due to:	Quotes from DMPs with Effective Communication Skills	Quotes from DMPs with Less Effective Communication Skills
Participant	Participant's declining ability to communicate their care needs verbally.	<i>"I can tell by the look on her face if something's not suiting her. And I try to find out what-a lot of times I can even tell....I've lived with her for over 65 years and we don't have to be verbal to communicate" (DMP 109)</i>	<i>"I find I'm having some problems, she's going through the stage now....screaming and yelling for nothing...And we say mom we're not hurting you...why are you screaming, why are you yelling?" (DMP 125)</i>
Caregivers	Caregivers not understanding how to manage dementia	<i>"I try to teach, I try to say ok, stop....don't get upset. Now let's take the whole thing all over again. Step 1, step 2.....come and ask and we go through it together" (DMP 125)</i>	<i>"I get phone calls from my dad all through the night, you know if my mom sometimes she can't go to sleep, and she gets to thinkin that she's a little kid and she should go home. And so it's really stressful" (DMP 158)</i>
Family members	Family members who are unsupportive or disagree about care	<i>"We went to a lawyer and got everything in writing of her wishes...and she don't want life support...we got that in writing. Where there's no dispute among family members..." (DMP 134)</i>	<i>" the ones that don't do it (family members who don't help with care) are the ones complaining about the people that do" (DMP 101)</i>
IndependentChoices Staff	Information from IndependentChoices staff	<i>"...whenever I talk to everyone (staff) they give me lots of information " "...like they gave me about preparing her meals" (DMP 102)</i>	<i>"We were told that hospice does not work with Independent Choices....I mean what it boils down to is...if hospice comes in, I would lose 30 hours a week personal care (for participant) regardless if they're here an hour a week...and that's not fair to her to lose that amount of care" (DMP 134)</i>

Health Care Professionals	Talking with health care professionals	<i>“Well mostly when I take him to the doctor, I talk to his doctor about stuff that goes on. That’s really the main (way)... I learned about a lot of stuff... through his doctor” (DMP 113)</i>	<i>“I mean he’s got a gallon Ziploc bag full of medications...it’s like you don’t know exactly what one is for...and they (doctors) ...can’t tell you nothing. “And you talk to the doctor this week, but ...next time he’ll say “I don’t know” (DMP 116)</i>
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Discussion

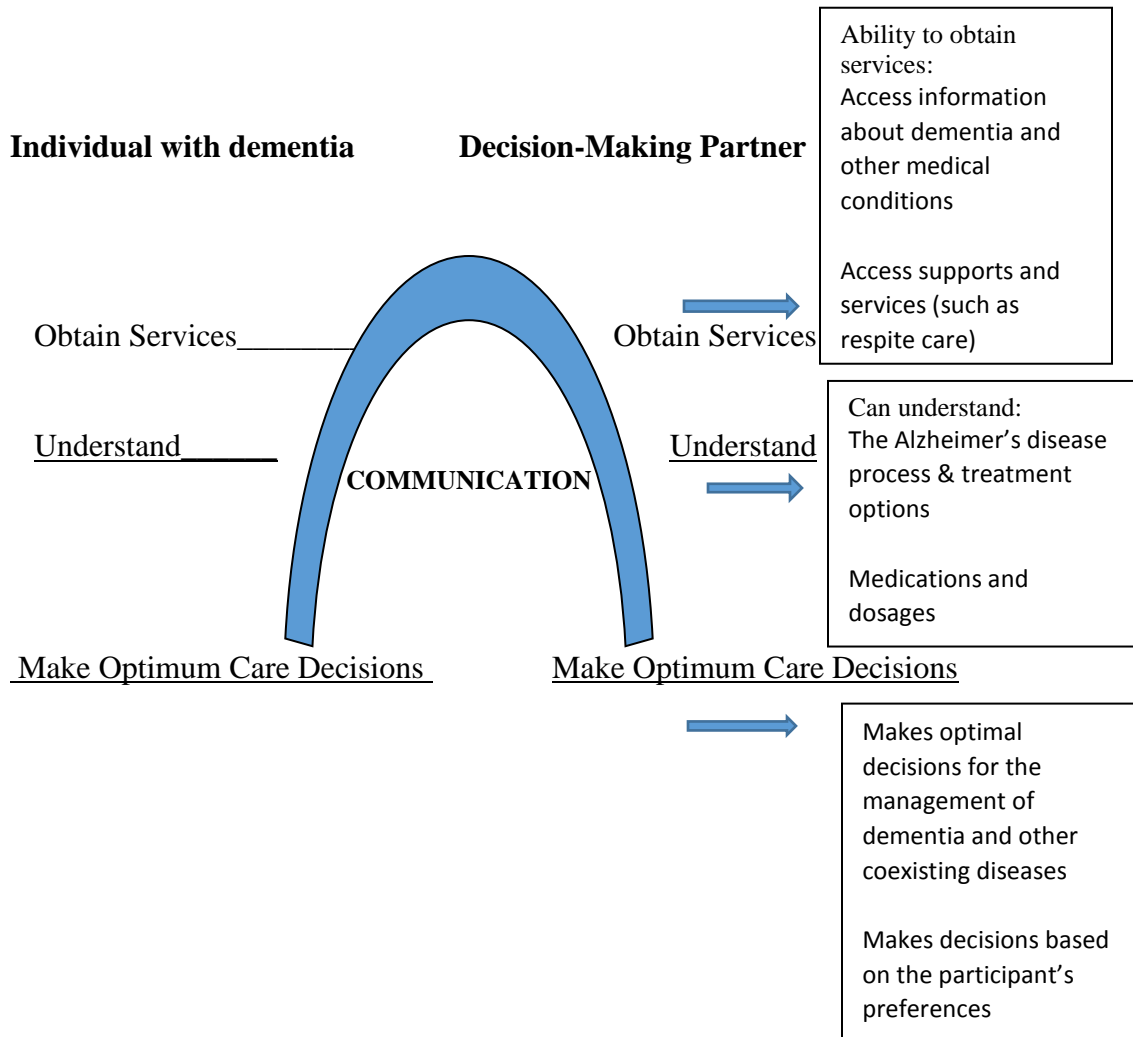
The Role of the DMP in Participant-Directed Services

As depicted in **Figure 3**, DMPs bridge a gap for program participants with dementia who are unable to obtain services and supports, understand information, and make appropriate care decisions. Similar to the findings by Whitlach (2008), in this study we found that the role of “decision-maker” for individuals with dementia is extremely challenging and may cause considerable stress. DMPs stated that they felt stress from their role, and many reported that this was due to poor communication skills. DMPs reported that they felt stress due to the participant’s declining abilities to communicate their needs verbally and due to a lack of communication with caregivers, family members and health care professionals. The lack of adequate communication skills, may interfere with the ability of DMPs to access, understand, and apply information needed to optimally represent elderly care recipients. Some DMPs had a difficult time preparing unpaid caregivers (usually family members) for emergencies and “other health conditions,” or communicating with family members about the care plan for the care recipient. Future studies should examine the impact of communication skills on family communications about care for participants with

dementia in a participant-directed setting (including negotiations and conflict resolution skills).

Figure 3. Decision-Making Partner Role in Participant-Directed Services

(Bridges a gap for the individual with dementia as their cognitive abilities decline)



Despite some DMPs beliefs that they are not “very well prepared” for certain aspects of their role, most (70%) reported that overall they were prepared to represent their loved one. Many reported that they are the best one to represent the individual

with dementia because they are family members or close friends who respect the care values and preferences of the care recipient.

“I know how he feels about certain things and either he’s made his wishes known um and just remembering things that he said, or, um, or when he’s told me things he does or doesn’t like (DMP 138).

“I can tell by the look on her face if she’s something’s not suiting her. And uh- (pause) and I try to find out what – a lot of times I can even tell what’s not what’s not suiting her...” (DMP 109)

Some of the DMPs in this study indicate they cannot evaluate the quality of care information and do not understand the Alzheimer’s disease process (including the behavioral changes that occur with the disease), the problems associated with dementia, treatment options, or the components of care that are truly participant-directed. In fact, only 30% of the DMPs in this study felt “very well prepared” involving the participant in making decisions. Most DMPs were not “very well prepared” to represent the decisions and preferences of participants or to understand and negotiate their views. Thus, DMPs with inadequate communication skills may not be prepared to ensure optimal participant-directed care for participants, to obtain necessary services and supports for the care team, or to plan for future care. DMP training to ensure better communication skills may help DMPs feel “very well prepared” for all aspects of their role improve the quality of care and disease management.

Policy Implications

The impact of low health literacy among DMPs for people with dementia has important implications for national health policy in terms of health disparities and the quality of life for individuals with dementia and their families. Participant-directed models offer participants with dementia and their caregivers more flexibility and control over personal care services (choices) than agency care; and elders with dementia and their caregivers have fared well in this model of care service (Tilly et al., 2011; Feinberg, 2012). However, most of the DMPs in this study report that they have not received training about dementia care, and that poor communication skills may contribute to a lack of confidence in their feeling “very well prepared” for certain aspects of their role. DMPs indicate that communication skills are essential for care coordination and for managing dementia and other medical conditions of the care recipient. Better communication skills may allow DMPs to teach caregivers how to improve safety for the participants, understand non-verbal cues, and to deal with difficult behaviors. This may result in better team work, better health outcomes and less stress for program participants, family members, caregivers, and the DMP. Thus, participant-directed programs should provide DMP training that includes communication skills. Future studies should examine the impact of other health literacy skills on health outcomes for this population.

Study Limitations and Strengths

There are several limitations and strengths to this study that should be noted. One limitation is that this is a secondary analysis of self-reported preparedness by a small number of DMPs. Health literacy was not the original focus of the Arkansas study by Simon-Rusinowitz et al. (in progress). This is a well-defined study population of DMPs for individuals with dementia in a participant-directed setting. The findings from this study are not generalizable and may not apply to other decision-makers for individuals with other chronic conditions or in other settings. Despite these limitations, there are several strengths to this study. I was able to identify DMPs in a participant-directed setting who reported they were not “very well prepared” to optimally perform aspects of their role because of poor communication skills. I used a mixed-methods approach to gather evidence that DMPs need training to improve communication skills. I used findings to promote a change in participant-directed training that I believe will benefit individuals with dementia and improve participant-directed services.

Conclusion

This study was the first study that I know of that examined the health literacy skills of DMPs for individuals with dementia in a participant-directed program. This research offers insight into the impact of low communication skills among DMPs on the well-being of elders with dementia that they represent, and their families. To improve participant-directed services for individuals with dementia and their caregivers, dementia health literacy skills (including communication skills) should be

included as a component of a DMP training program. Increased communication skills may improve: the understanding of medical information and dementia health care, care team planning and preparedness, distribution of care, family dynamics, and informed participant-directed health care decisions. Adding a health literacy component to a DMP training program may improve health outcomes and the quality of life for elders with dementia and their care teams.

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Chapter 4: Effect of Emergency Department Referral Process on Subsequent Utilization of Community Health Centers by Low-Income, Uninsured Adults and Medicaid Beneficiaries

Abstract

Objective: The objective of this study was to identify successful methods of disseminating information on the availability of primary care in community health centers to low-income, uninsured patients and Medicaid beneficiaries seeking care in the emergency department (ED). I explored the effects of factors that led to an initial clinic visit following referral in the ED, and those that influenced subsequent visits, indicating an established relationship with the clinic. **Methods:** I analyzed data on 10,761 ED patients participating in the Emergency Department- Primary Care Connect (ED-PC) program in Montgomery County, Maryland. Data were obtained from all five hospitals in Montgomery County, four participating County clinics, and from Patient Navigators. **Data Analysis:** I used a two-part negative binomial count or “hurdle” model to first estimate the factors associated with the probability of visiting one of the clinics following an ED referral, and then to analyze factors associated with the frequency of clinic visits. **Results:** Patients were more likely to make the initial clinic visit if the referral was made by both the ED Provider and the patient Navigator, relative to referral by the Navigator or ED Provider alone or the ED provider with a voice message or brochure. Age, gender, ethnicity, and the ED in which the patient was seen influenced the decision to make an initial clinic visit following ED referral as well as subsequent visits. Older females (age 40+) who

identified themselves as Hispanic or Latino were most likely to make a clinic visit following ED referral. Referral by the ED Provider was not a significant factor for subsequent clinic visits but Navigator referral was significant. **Conclusion:** In Montgomery County, Maryland, ED providers and Patient Navigators helped patients gain access to primary care services by referring them to community health centers. The use of Navigators was especially successful in helping older, female, Hispanic/Latino ED patients find a “medical home.” Future studies should examine factors that may increase the utilization of community health centers by patients ages 19-39, men, and individuals from other ethnic and minority backgrounds, as well as the influence of chronic diseases on establishing a relationship with community health center. **Implications:** Communities may encourage more appropriate ED utilization and increase primary care visits, by increasing access to primary care services, and by providing culturally and linguistically appropriate referrals to community health centers, thus making it easier for individuals to navigate the healthcare system, and understand how to use it appropriately.

Introduction

The use of costly hospital emergency departments (ED) has risen significantly in the United States over the past fifteen years, resulting in overcrowding in the EDs, longer waiting times for care, and an inefficient use of resources (Choudhry et al, 2007; Cunningham, 2011; Gindi et al, 2012; Centers for Disease Control and Prevention (CDC), 2013). In fact, visits to the ED in the United States increased 34%

between 1995 and 2010 from 97 million to 130 million visits (U.S. Department of Health and Human Services, 2012). At the same time, the number of EDs in the U.S. decreased by 10% increasing the mean volume of patients from 23,000 to 30,000 (Marco et al, 2012). This shift has resulted in overcrowding in most metropolitan hospital EDs that is so significant that ambulances must be diverted away from the hospital, and waiting times for ED patients are twice as long as nationally recommended (Government Accountability Office (GAO), 2009). It is estimated that over \$18 billion dollars per year are wasted on ED visits that are avoidable (Choudhry et al., 2007).

Many ED visits could be prevented if individuals had access to primary care providers or safety-net clinics where they could receive care on a regular basis (Partnership for Medicaid, nd; Choudhry et al, 2007; Cunningham, 2011). People with a regular “medical home” are better able to manage illnesses and chronic conditions and are less likely to seek care in the ED (Choudhry et al, 2007). In addition, it is estimated that the cost of a visit to an outpatient community health center is seven times lower than the cost of an ED visit (Cunningham, 2011). Thus, many communities are seeking ways to link patients to a health care home (Choudhry et al, 2007). In this study I evaluated a three year, county-wide initiative in Montgomery County, Maryland aimed at decreasing ED use by increasing utilization of County community health centers. My goal was to evaluate the most effective strategies for disseminating information in the ED on the availability of accessible primary care clinics and to identify factors that influenced repeated use of community health centers.

Conceptual Framework

Conceptual Framework: The role of Patient Navigators and other health care professionals in redirecting ED patients to community health centers?

Background

Why are People using Hospital Emergency Departments?

A recent study found that 80% of the adults who visit the ED reported that the reason they went there was because of the lack of availability of other health care providers (Gindi et al., 2012). However, many people that visit the ED already have a regular physician (Cunningham, 2011). Estimates from the National Health Interview Survey (January-June 2011) show almost half of the ED patients (48.0%) went to the hospital because “the doctor’s office was not open” (Gindi et al., 2012). Other reasons that individuals gave for using the hospital ED for care include: the patient had no health insurance and could not find a primary care physician (American College of Emergency Physicians, 2013), the problem was too serious for the doctor’s office (Gindi et al., 2012), the ED was convenient or the closest place to go (Cunningham, 2011), and the patient had no choice in going to the ED because they arrived by ambulance (Gindi et al, 2012). Several studies report that people select the ED for care because it presents less communication challenges and less language barriers than their physician’s office (American College of Emergency Physicians, 2013; Marco et al., 2012).

Characteristics of Individuals Using the Hospital Emergency Departments

The sex, age, race/ethnicity, and insurance status of patients are all strongly correlated with the decision to use the ED. Women (55%) are more likely to use the hospital ED than men (45%), although men are treated in the ED for more injuries than women and their triage status is more often considered more emergent (National Hospital Ambulatory Medical Care Survey, 2009). Most adults who visit the ED are between 25 and 44 years old (28% in 2009) (National Hospital Ambulatory Medical Care Survey, 2009). Older individuals (age 65+) account for about one quarter of all emergency department visits, however, ED visits for elders (age 65-74 years old) have increased by 34% between 1993 and 2003 (National Hospital Ambulatory Medical Care Survey, 2009). The ED care received by elders is often considered more urgent than that for younger individuals (National Hospital Ambulatory Medical Care Survey, 2009; Samaras et al, 2010). The National Center for Health Statistics (2010) reports that Blacks (Non-Hispanic) are more likely to have at least one ED visit in a 12 month period than Whites (Non-Hispanic) or Hispanic persons (Garcia, et al., 2010). Racial and ethnic minorities disproportionately use ED services for safety-net care (Hsia, et al., 2012), and recent immigrants rely on EDs for routine healthcare more than native-born Americans (Cunningham, 2011).

Most ED patients have private insurance (39% of ED visits) or they are recipients of Medicaid (29% of ED visits) or Medicare (17% of ED visits) (National Hospital Ambulatory Medical Care Survey, 2009). Although uninsured individuals comprise only about 16% of ED visits, they may utilize the ED because there is “nowhere else to go” (Gindi et al., 2012). The U.S. Senate Subcommittee on Primary

Health and Aging reports that there has been an increase in both insured and uninsured patients in the hospital EDs because of longer waiting times to see a physician (Cunningham, 2011).

Health Literacy of Emergency Department Patients

According to the Agency for Healthcare Research and Quality (AHRQ, 2011), low health literacy (defined as “the degree to which individuals can obtain, process, and understand basic health information and services they need to make appropriate health decisions”) is linked to more ED use. Individual skills such as reading ability, mathematical skills (numeracy), and the ability to use technology, and communicate have been identified as being necessary to be “health literate” (Berkman et al., 2010). Individuals with limited health literacy skills, including poor communication skills, have difficulty accessing and navigating the healthcare system, using preventive services, managing chronic diseases, and understanding medical instructions (Benjamin, 2010). Thus, having low health literacy skills contributes to: poorer health outcomes, making poor health care decisions, and the inefficient use of health care services such as using the ED for non-urgent care (AHRQ, 2011).

Herndon et al. (2011) assessed the health literacy skills of ED patients and reported that 40% of ED patients in their study had limited health literacy and were at or below eighth grade level. Other researchers (Williams et al., 1996; Brice et al., 2008) have reported similar findings. Rates of low health literacy have been reported to be higher in racial and ethnic minority ED patients and those who speak a language other than English than in White patients. Brice et al. (2008) found that approximately 75% of the Spanish-speaking ED patients in their study had low

functional health literacy based on their Test of Functional Health Literacy in Adults (TOFHLA) scores.

Health Care Professionals and Organizations as Mediators in a Health Literacy Framework

Although individual factors may impact an individual's health literacy level, the ability to obtain, process and understand health information may also be affected by systematic factors such as poor communication by health care professionals, or improper management and design of health care facilities (Brach et al., 2012). For example, in a medical care setting, the lack of patient comprehension and recall of discharge instructions may be due to their own stress caused by physical and emotional discomfort (Zeng-Treitler et al., 2008). However, the lack of understanding may be due to poor communication between health care providers and their patients because of challenges the providers are faced with (such as working in a high pressure or overcrowded situation) (Scheeres, 2008). Therefore, health care professionals may be considered mediators to health outcomes within a health literacy skills framework (Squires et al., 2012). Adequate health literacy, and the understanding of the appropriate use of the ED and other health services may depend on both individual, and organizational factors and the demands of the health care system (U.S. Department of Health & Human Services, 2013).

How Can we Direct People to More Appropriate Treatment Settings?

Strategies to direct ED patients to more appropriate treatment settings for care often include educating patients about the appropriate use of EDs, increasing their knowledge about the services of safety-net clinics, and improving access to other

sources of care such as community health centers (Harkin & Sanders, 2011; Cunningham, 2011; Hing & Hooker, 2011). However, in order to educate patients (including patients that do not speak English) about other health care settings, they must be able to understand educational approaches and how to access services. To increase patient comprehension, many hospitals make provisions to increase health literacy by providing culturally and linguistically appropriate services (National CLAS Standards) as called for by the 2010 Patient Protection and Affordability Care Act (PPACA) (Cunningham, 2011). This may entail the use of Patient Navigators and training a culturally competent workforce. In this study, I focused on Montgomery County, Maryland's efforts to redirect ED patients to a more appropriate treatment setting.

Montgomery County, Maryland

Montgomery County, Maryland is considered a wealthy multi-cultural suburb of Washington, D.C, with approximately 970,000 adult residents (during the intervention period) (Primary Care Coalition, 2012). However, over the last few decades, the county has become more diverse with greater numbers of low-income residents, more ethnic minorities and residents who do not speak English, and greater numbers of uninsured individuals. Between 1990 and 2010 the County's non-Hispanic white population decreased from 72% to 49% of the population, and by 2010 one-third of the county residents were immigrants (Metropolitan Policy Program at Brookings, 2013). The Centers for Disease Control and Prevention noted that while most Montgomery County, Maryland residents spoke English as their

primary language (556,680 individuals) more than 96 languages were spoken by county residents, including 93,760 individuals who reported Spanish as their primary language (CDC, 2007). It was also noted that 120,000 of Montgomery County residents were uninsured and 80,000 were Medicaid beneficiaries.

Montgomery County borders on Prince George's County, Maryland, which is considered by state policymakers to be one of the state's most "underserved areas" with higher rates of chronic diseases (such as diabetes, heart disease, hypertension, asthma, and cancer) than Montgomery County (University of Maryland (UMD) School of Public Health, 2012). In a public health impact study by the UMD School of Public Health (2012) it was reported that many Prince George's County residents have health care providers outside of their County and are unable to get an appointment with specialists inside of the County. Thus, many Prince George's County residents seek treatment in hospitals and EDs outside of the County including neighboring Montgomery County, Maryland (UMD School of Public Health, 2012).

ED use in Montgomery County, Maryland

Along with the rest of the U.S., Montgomery County experienced an increase in ED use for both urgent and non-urgent medical conditions over the last decade (Primary Care Coalition, 2012). In fact, ED visits in Montgomery County (in 2009) exceeded Healthy People 2010 goals for all age groups except those over age 65 (Montgomery County Department of Health and Mental Hygiene 2011). The county also noted more health disparities among individuals who visited the ED. For example, in 2009, complications of asthma led to 3,142 visits to hospital EDs in

Montgomery County. The asthma ED visit rate was (approximately) 5.3 times higher among Black residents and 4.8 times higher among patients of “Other” minority and ethnic backgrounds compared to White patients (Montgomery County Department of Health and Mental Hygiene 2011). Thus there have been efforts to reduce ED use and reduce health disparities within the County.

County Project Aimed at Reducing Non-Urgent Use of Emergency Departments

Community Health Centers in Montgomery County, Maryland

The Montgomery Cares Program of Montgomery, County provides community-based health care in more than 25 County locations (Montgomery County Department of Health and Human Services, 2013). Low income and uninsured adults from Montgomery County are offered a variety of services at these community health centers including: mental health and crisis services, disability resources, medical check-ups, medications, oral health care, and screenings. Clinic times vary, with some clinics offering evening and Saturday hours (Montgomery County Department of Health and Human Services, 2013).

According to a study of Montgomery County clinics by the RAND Corporation, entitled *Serving the Underserved* (Gresenz et al., 2009), most clinic patients are female and more than half are ages 40-64 years old. Nearly a third of patients have at least one chronic health condition. The majority of patients are foreign-born with two-thirds identifying themselves as Hispanic. More than half of these foreign-born patients have been in the U.S. for less than five years (Gresenz et al., 2009). Because of the increasing need for health services for underserved

populations, in 2009, Montgomery County government officials developed partnerships with various organizations including faith-based and grassroots organizations, nonprofit groups and other community organizations to develop additional safety-net services within the County (Metropolitan Policy Program at Brookings, 2013).

Use of Patient Navigators

Due to the influx of patients that do not speak English in Montgomery County, Maryland, patient navigators were established to “provide culturally and linguistically competent health services” (MC311 Answering to you: All services, 2013). Navigators, trained by the PCC Eligibility and Enrollment Liaison, help with patient access and interpretation- translation services which are available in 200 languages in Montgomery County. Patient Navigators are based in County hospitals and in community health centers throughout Montgomery County (MC311 Answering to you: All services, 2013; Primary Care Coalition, 2012).

Emergency Department-Primary Care (ED-PC) Project

In an effort to reduce avoidable ED utilization, and link low-income uninsured patients and Medicaid patients in Montgomery County, Maryland to primary care services, the County Department of Health & Human Services partnered with an independent non-profit organization, Primary Care Coalition (PCC), to formulate a new initiative. The goal of the three year project (March 1, 2009-December 31, 2011), known as Emergency Department-Primary Care (ED-PC), was to decrease ED

use by increasing utilization of Montgomery County's community health center services (Primary Care Coalition, 2012).

Individuals who came into one of the five County hospital EDs during the study period (N=12,222) were referred to one of four participating safety-net clinics in the County. Patients were referred to the clinic by ED Providers and/or patient Navigators who were based in the clinic or in the hospital. Referral was made either in person (in the ED) or by telephone. Demographic and contact data were collected by the hospitals, clinics and patient Navigators. The urgency of the ED visit was determined using a classification algorithm developed by New York University Center for Health & Public Service Research (Primary Care Coalition, 2012). The PCC (2012) evaluated the results of ED-PC Connect found the referred population of low-income, uninsured ED patients to be racially and ethnically diverse. The top five reasons that patients visited the ED were: 1) acuity of patient condition, 2) clinic hours, 3) lack of clinic access, 4) perceived clinic capability to treat patient problem and 5) speed of service provided at the ED.

Research Question

I used data from ED-PC to answer the following research question:

What effect does the primary care referral process (method of communication) have on subsequent emergency department visits and utilization of community health center services?

Study Data and Methods

Data Sources

This study uses data from the Emergency Department-Primary Care (ED-PC) project that was collected between July, 2009 and December 2011. Three sets of data were obtained from the PCC including hospital data, clinic data and hospital Navigator sheets. Hospital data were collected from all five Montgomery County hospitals: Holy Cross Hospital, Montgomery General Hospital, Shady Grove Adventist Hospital, Suburban Hospital, and Washington Adventist Hospital. Four clinics in Montgomery County participated in data collection; Holy Cross Hospital Health Center, Mary's Center for Maternal and Child Health, Mobile Medical Care, Inc., and Proyecto Salud. Patient Navigators, based either at the hospital or within the clinics, provided data collection sheets that were also used for this study. The three data sets were combined to form a Master Excel Table which was used for this secondary data analysis.

A total of 12,222 patients were treated in the five hospital EDs within the county and were referred to four participating Montgomery Cares clinics through the ED-PC project. Patient data were dropped if there was no patient record or if the ED date differed between the hospital and the clinic. The final sample used for the analysis included 10,761 patients.

Data Analysis

I used Stata/IC 12.1 (StataCorp, 2011) for statistics and data analysis. I examined demographic variables and the method of communicating the ED referral.

Percentages and means were used to describe the characteristics of our study population. The two-part negative binomial count or “hurdle” model was used to help distinguish the characteristics of patients who selected the clinic for follow-up care to their ED visit and continued to use the clinic for ongoing care from those who did not go to a community health center for follow up care, or those who only went to the center once.

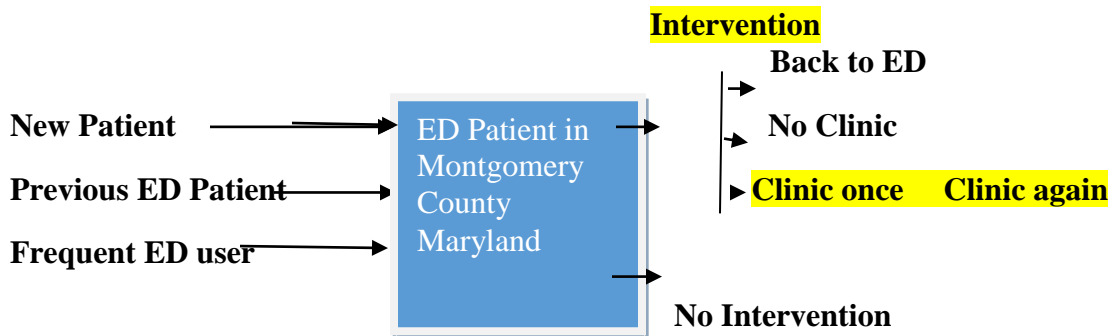
The Model

I selected a “hurdle” model to account for excess zeros in the response variable; “subsequent clinic visits” since most ED patients did not make a clinic visit. This type of two-part model has been used previously to analyze health services data with a high proportion of zeros including studies of the frequency of patient visits and health care utilization (Gurmu, 1997; Lahiri & Xing, 2004; Neelon & O’Malley, 2012) as well as risk assessment research (Albert, Wang & Nelson, 2011; Preisser, Stamm, Long, & Kincade 2012). Neelon et al., (2012) used a hurdle model to explore geographic variation in emergency department visits.

The final model contained variables of both how the patient was contacted (no contact, contact by telephone, sent a brochure, left a telephone left a message) compared to in person contact; and who contacted the patient (ED provider alone, ED provider with a message or brochure, or Patient Navigator alone) compared to contact by both the ED Provider and Navigator. I first evaluated how many low-income uninsured patients from County emergency departments (ED) obtained primary care offered by safety-net clinics in the county following an intervention in the ED (stage

1) represented by the following equation: $\Pr(Y_i=0) = 1-p, 0 \leq p \leq 1$. I then examined how many individuals completed two or more subsequent clinic visits at the same clinic (stage 2; those that were linked to a “medical home”). The highlighted sections of **Figure 1** shows the flow of the study’s target population.

Figure 1: Flow of Target Population



Results

Demographic Information

Table 1 shows the descriptive statistics for demographic variables that were used in the model. The final study population included 10,761 patients ranging in age from 18 to 111 years old. The majority of ED patients (59%) were age 20-39 years old, with a mean patient age of thirty seven years old. There were slightly more men (51%) than women in the study population. There were similar proportions of Black (32%) and White (30%) patients as well as a large number of “Other” races (25%). Approximately 35% of the ED patients in this study identified their ethnicity as Hispanic/Latino.

Table 1. Demographic Information

Category	n =10, 760	%
Age (in years)		
≤ 19	262	2.4%
20-39	6,367	59.2%
40-59	3,524	32.7%
≥ 60	608	5.7%
Gender		
Female	5,291	49.2%
Male	5,469	50.8%
Race		
American Indian/ Alaskan Native	252	2.3%
Asian	359	3.3%
Black	3,430	31.9%
White	3,233	30.0%
Other	2,709	25.2%
Unknown	778	7.2%
Ethnicity		
Hispanic or Latino	3,745	34.8%
Not Hispanic or Latino	5,245	48.7%
Unknown	1,771	16.5%

Estimation Results (Stage 1)

Twenty one percent of ED patients made an initial subsequent clinic visit following a referral in the ED. The decision to initially go to a clinic following ED referral was estimated using the logit equation (**Table 2**) which explains which factors affect the likelihood of clearing the zero hurdle. The choice of going to the clinic was influenced by several demographic characteristics including age, gender, race and ethnicity. Compared to patients age 20 to 39, younger individuals (age 1 to 19) were less likely to go to the clinic and individuals over age 40 were more likely to

go to the clinic with the likelihood increasing with increasing age (age 60+). Males were less likely than females to clear the zero hurdle. Patients who identified their race as Native American/Alaskan Native, were more likely to have an initial clinic visit following ED referral compared to White patients. The initial clinic visits by individuals who identify themselves as Asian, Black or “unknown race” were also greater than that of Whites although the results were not statistically significant. The patients who were classified as “other race” were less likely to go to the clinic than Whites, but that was also not significant. Hispanic/Latino individuals were more likely to visit a health center than non-Hispanic individuals.

The decision to go to a clinic following the hospital ED intervention was also influenced by the method of communicating the referral i.e. who made the referral (ED Provider, Patient Navigator, or the ED Provider and Patient Navigator together), how the referral was made (in person, by telephone by brochure), and where the patient received the referral (Hospitals B, C, D, or E compared to Hospital A). Patients were less likely to visit a clinic if they had no referral or if they were left a message by telephone, than if they were spoken to in person in the ED or by telephone. However, if they were also given a brochure and left a telephone message in addition to being spoken to in the ED, they were more likely to initially visit a clinic than if they were only referred to the clinic in person. Referral by both the ED Provider and the Patient Navigator was the most successful intervention. Although the names of the hospitals were not revealed in these results, patients from hospitals B,C,D, & E were less likely to visit a clinic after ED referral than patients from hospital A.

Estimation Results (Stage 2)

Fourteen percent of ED patients made two or more subsequent visits to a clinic indicating an ongoing relationship with the clinic. In the negative binomial part of the model (**Table 2**), the coefficients indicate whether the variable increases or decreases subsequent clinic visits. Age significantly influenced subsequent clinic visits, with older patients (age 40 and older) more likely to find a “medical home” than younger patients (age 39 or less). Females were significantly more likely to make two or more clinic visits than males. Race was not a significant factor in establishing a relationship with the health center, however, ethnicity was significant. Hispanic/Latino patients were more likely than non-Hispanic patients to make repeated visits to the clinic. Individuals who were seen in the ED of hospital A established an ongoing relationship with a clinic significantly more than people that were seen in the ED of the other four hospitals. In the second stage of the model, contact by the patient Navigator was significant compared to contact by both the Navigator and ED provider, but contact by the ED provider alone was not significant. The coefficients of the remaining variables in the model are negative and not statistically significant.

Table 2.
Results of the Logit Equation (stage 1) of the Negative Binomial-Logit Hurdle
Regression Analysis: Estimation of the decision to visit a clinic following
Emergency Department Referral

Variable	<u>Binary hurdle equation</u> (Logit) (Stage 1)		<u>Hurdle-negative binomial</u> (Stage 2)	
	Coef.	z	Coef.	z
Age \leq 19	-.7880555	-3.27 ^a	-.1696393	-0.55
Age 40 to 59	.7935672	14.67 ^a	.4289639	6.99 ^a
Age 60+	.849411	8.50 ^a	.6584833	6.34 ^a
Male	-.5369846	-10.45 ^a	-.1475028	-2.53 ^a
Native American /Alaskan Native	.3852985	2.51 ^a	-.1165786	-0.80
Asian	.2693429	1.90 ^b	-.1202342	-0.75
Black	.0915621	1.30	-.106094	-1.30
Unknown	.1180521	1.08	-.1478346	-1.21
Other	-.0912043	-1.21	-.1277371	-1.51
Not Hispanic/Latino	-.4543771	-6.22 ^a	-.2900498	-3.45 ^a
Unknown Ethnicity	-.1814026	-1.47	-.1498334	-1.15
No Contact	-1.752199	-4.34 ^a	-1.097195	-1.74 ^b
Telephone Message	-.3113737	-3.78 ^a	-.0653575	-0.65
Brochure	.6559228	2.09 ^a	-.1984341	-0.57
ED Provider Only	-.9649803	-11.89 ^a	-.0161678	-0.17
Navigator Only	-1.042496	-7.59 ^a	.2897597	1.92 ^b
ED Provider with Message/Brochure	-1.950372	-9.22 ^a	-.1559358	-0.76
Hospital B	-.279463	-1.99 ^a	-.2612531	-1.70 ^b
Hospital C	-.4620253	-3.52 ^a	-.3515927	-2.49 ^a
Hospital D	-.41121	-5.80 ^a	-.2944898	-3.67 ^a
Hospital E	-.811577	-7.67 ^a	-.4792957	-3.75 ^a

^a Significant at $\alpha = .05$

^b Significant at $\alpha = .10$

Discussion

Initial ED Visit

The population of low income uninsured or Medicaid enrollee ED patients in Montgomery County, Maryland in this study differs from national statistics of ED patients. Unlike the National Ambulatory Medical Care Survey, in our study, there were more men (51%) than women (national data show 54.8% women), and the patients were younger. I found that only about 6 % of the study population was over age 60 (compared to 12% in the National Hospital Ambulatory Medical Care Survey (2009)). In Montgomery County, there are a large percentage of individuals that were in the 20-39 age group (almost 60% of the total patients) visiting the ED. There are also more ED patients that identify themselves as Hispanic or Latino (almost 35%) compared to 14% nationally; and a large percentage of individuals of “unknown” ethnicity.

The increase in ED use for non-urgent care especially for young, ethnic minorities suggests that the ED provides needed primary care services for this population. It is possible that men are less successful than women in accessing primary care services in the county during regular hours and must resort to using the ED for non-urgent care because it is open 24 hours a day; thus accounting for the greater numbers of men than national data. The demographic composition of ED patients and greater percentage of individuals that identify as Hispanic or Latino probably reflect the changing demographics and diversity within the county. The Primary Care Coalition of Montgomery County reported that the large percentage of

individuals with “unknown” ethnicity may be due to inadequate data collection by ED-PC Connect in this category.

Subsequent Clinic Visits

I found significant age, gender, ethnic differences in the decision to initially go to a clinic following ED referral and in the decision to establish an ongoing relationship with the clinic. Older (age 40 and above), female patients (especially Hispanic/ Latino women) are most likely to make a clinic visit following ED referral. As seen in **Table 3**, people age 40 and older make up only 38% of the ED population in this study. However, more than half (57%) of the individuals who established a relationship with the clinic fell into this age category. Since older individuals are more likely to have chronic conditions they may have a greater need for ongoing care and therefore be more willing to make subsequent visits to the clinics. Females comprise almost 63% of the patients that made two or more visits to the clinic but less than half of the initial ED population. Thus, future studies should examine factors that may increase the number of men that make subsequent visits to community health centers. The large percentage of Hispanic/Latino individuals that established a “medical home” within the community health center (43% of the total patients with 2 or more clinic visits) suggests that there is a need for primary care by this ethnic group. It is possible that individuals who are not Hispanic in the County may already have a primary care physician.

There were also significant differences between those that visited the community health centers and those that did not following ED referral, based on *who* made the referral (ED Provider, Patient Navigator, Both ED Provider and Patient

Navigator), and *how* it was made (In person, conversation by phone, mailed brochure, left a message). The most effective intervention for a clinic visit for this population was a combination of referral by the ED provider and the patient Navigator. However, Navigators were found to have a significant impact on the decision to establish a relationship with the clinic. Patient Navigators (who may also be Hispanic/Latino ethnicity and speak the same language as the ED patient) may reinforce the referral of the ED provider accounting for the larger percentage of Hispanic women who made a second clinic visit. Navigators are able to provide culturally and linguistically appropriate services for ED patients, and may be an important factor in helping patients establish a relationship with community health centers. However, while the presence of the Navigators in the hospital ED may be useful for helping patients navigate the hospital setting, connect with social services, or understand insurance forms, contacting patients by telephone to refer them to a clinic appears to be a successful mode of referral. **Table 3** shows that more than half (51%) of the patients that found a “medical home” were contacted by telephone and only slightly more than a third (35%) were referred in person. It is possible that face to face referral to the clinics in the ED may not be remembered by the patients because they were under stress.

Table 3: Number and Percentage of Patients at three stages in this study (1. Initial emergency department patients 2. Patients who had a follow-up clinic visit- Stage 1 3. Patients with 2 or more visits- Stage 2)

Category	ED patients n=10,761 %		Stage 1 n = 2257 %		Stage 2 n = 1487 %	
Age (in years)						
≤ 19	262	2.4%	20	0.9%	12	1.0%
20-39	6,367	59.2%	1,031	45.7%	621	41.7%
40-59	3,524	32.7%	1,009	44.7%	709	47.6%
≥ 60	608	5.7%	197	8.7%	145	9.7%
Gender						
Female	5,291	49.2%	1,362	60.3%	929	62.5%
Male	5,469	50.8%	895	39.7%	558	37.5%
Race						
American Indian/ Alaskan Native	252	2.3%	102	4.5%	81	5.0%
Asian	359	3.3%	88	3.9%	59	4.0%
Black	3,430	31.9%	693	30.7%	455	31.0%
White	3,233	30.0%	641	28.4%	404	27.2%
Other	2,709	25.2%	542	24.0%	359	24.1%
Unknown	778	7.2%	191	8.5%	129	8.7%
Ethnicity						
Hispanic or Latino	3,745	34.8%	925	41.0%	634	43%
Not Hispanic/ Latino	5,245	48.7%	949	42.0%	605	41%
Unknown	1,771	16.5%	383	17.0%	248	16%
How Referred						
Spoken to By phone	3,282	30.50%	1,135	50%	751	51%
Mailed Brochure	190	1.77%	25	1%	14	1%
Left Message	2,058	19.12%	299	13%	208	14%
In Person	5,231	48.62%	798	35%	514	35%
Who Spoke to Patient						
ED Provider Only	5,154	47.90%	755	33.5%	487	33.0%
Navigator Only	734	6.83%	167	7%	116	8%
ED Provider & Navigator	2,625	24.39%	1,011	45%	662	45%
ED provider with brochure or message	2,248	20.89%	324	14%	222	15%

Policy Implications

Throughout the U.S., hospitals are searching for ways to decrease ED use and increase access to patient-centered “health care homes”. One way to help decrease ED use is to link low-income and uninsured patients to a primary source of care such as safety-net clinics. In this study, I determined that referral to community health centers by ED Providers and Patient Navigators was the most successful strategy for getting ED patients to visit a clinic. However, patient Navigators were significantly important in getting patients to establish a relationship with the clinic. This approach may be more successful if referrals to the clinics are presented in a culturally competent and linguistically appropriate manner. Thus, the use of patient Navigators may be increasingly important to achieve this goal, especially in Montgomery County where the population has become more ethnically diverse. Future research should further examine the Navigator’s role as a mediator in helping an ethnically diverse population access health care. I found older Hispanic/Latino women were more likely than other patient groups to find a “medical home” within the community health center suggesting a need for primary health services for this population in Montgomery County.

National Strategies that may Increase Utilization of Community Health Centers

Several national strategies may help increase access to primary care services and increase the patient’s understanding and ability to navigate the health care system including: increasing health insurance coverage for individuals, and increasing funding for community health centers (to add centers and services) so patients with

low-income can obtain primary care services. Provisions for both of these strategies are included in the 2010 Patient Protection and Affordability Care Act (PPACA) (Adashi et al, 2010; Cunningham, 2011). Strategies to increase patient understanding of the health care system and ensure the appropriate use of ED and other health care services, include the provisions for culturally and linguistically appropriate services (such as the National CLAS Standards), and the use of patient Navigators, which will improve patient health literacy. Provisions for improving health literacy and increasing cultural competency (such as training for diversity) are also included in the PPACA (AHRQ, 2011).

The Patient Protection and Affordability Care Act

Health Insurance Coverage

The goal of the 2010 PPACA is to make health care more accessible and affordable for Americans as well as to improve health outcomes and the delivery of health care (PPACA, 2010). The PPACA includes mandates for all Americans to be covered by a private or public health insurance program, with low-income individuals receiving sliding scale federal subsidies (The Henry J. Kaiser Family Foundation June 29, 2012). While the goal of health insurance coverage provisions is to give individuals greater access to health care providers, a GAO report to the U.S. Senate on hospital ED use (2011) suggests that the use of EDs may actually increase as provisions of the PPACA for individuals to have health insurance are implemented because there will be a greater demand for health care and less physician availability.

Thus, there may be a greater need for primary care services offered by community health centers than expected.

More Community Health Centers

The PPACA also calls for \$11 billion in increased funding for community health centers over five years to increase health center construction and improve operations (Harkin & Sanders, 2011). By increasing the capacity of safety net clinics to provide primary care there may be a decrease in the use of EDs for non-urgent conditions especially among individuals in underserved communities, (Hing & Hooker, 2011). Approximately 92% of the patients that utilize community health centers are low-income (71% are below poverty level) and two-thirds are racial and ethnic minorities (Choudhry et al, 2007). Forty percent of these patients are uninsured. Community health centers have been reported to reduce health disparities and help to effectively manage chronic diseases (Choudhry et al, 2007). Community health centers also provide a less costly alternative to the ED since the average cost for a health center visit (in 2008) was \$108 and the average ED visit was \$792 (Harkin & Sanders, 2011). However, one challenge that community health centers face is educating individuals about their services (Choudhry et al, 2007).

Health Literacy and Cultural Competency of Organizations

Although individual factors may impact an individual's health literacy level (and ability to understand and appropriately utilize ED and community health center services), it may also be affected by systematic factors such as poor communication by health care professionals, or improper management and design of health care

facilities (Brach et al., 2012). Therefore, in addition to addressing individual health literacy issues, we must also address organizational health literacy. The PPACA has provisions for improving health literacy by providing more appropriate patient information (such as providing prescription drug information at a more appropriate reading level) and by increasing the cultural competency of the workforce (Somers & Mahadevan, 2010). In an Institute of Medicine roundtable discussion on health literacy (Brach et al., 2012), experts described attributes of health literate healthcare organizations including having leadership that makes health literacy integral to its mission, structure, and operations and includes health literacy into planning and evaluation measures. Thus, organizations should strive to improve linguistic and cultural competence by preparing the workforce to be health literate and by providing access to health information and services and offering navigational assistance (U.S. Department of Health and Human Services, 2013).

Limitations

There are a number of limitations to this study. The findings in this investigation are not generalizable to other communities or ED patients. Also, I did not differentiate between health conditions that resulted in the initial ED or clinic visits. Thus I was unable to determine if these factors influenced the decision to visit a clinic or led to subsequent clinic visits. Future studies should examine the influence of specific chronic diseases (such as asthma) on establishing a relationship with community health centers. Although, I reported that the ED patients in Montgomery County, Maryland may have low health literacy skills (especially ethnic minorities with limited English language skills) and may not be able to access other primary care

services or understand how to navigate the health care system, I did not measure the health literacy skills of this population. To fully understand the needs of ED patients in Montgomery County, future investigations should measure the health literacy skills of this population, and evaluate the cultural competency of the Montgomery County workforce.

Conclusion

Despite the study's limitations, I was able to identify successful methods of disseminating information on the availability of primary care in community health centers to low-income, uninsured patients and Medicaid beneficiaries seeking care in the emergency department (ED). In Montgomery County, Maryland, ED Providers and Patient Navigators helped patients gain access to primary care services by referring them to community health centers. The use of Navigators was especially successful in helping older, female, Hispanic/Latino ED patients find a "medical home." The findings of this study suggests that ED utilization can be reduced by connecting low- income uninsured patients to community health centers. The use of patient Navigators to eliminate communication barriers, and the development of a culturally competent workforce may increase patient health literacy and help patients establish an ongoing relationship with community health centers. However, to accommodate individuals who cannot visit the clinic during "regular" hours, community health centers may need to improve access to care (such as expanding clinic hours). There should be a County wide commitment, and collaboration across counties to expand the capabilities of safety-net clinics and improve outreach about

clinic services. Individuals with a regular source of care that is convenient and accessible may be better able to manage chronic conditions and other health problems, and less likely to use the ED for care.

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Chapter 5: Research Conclusion: Eliminating the Barrier of Low Health Literacy to Improve Long-Term Care in the United States

Summary

Older adults with chronic diseases, as well as the individuals who provide care and support for them, may have low ‘health literacy’ defined by the Patient Protection and Affordable Care Act of 2010, as “*the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions*” (Center for Health Literacy Promotion, 2013). Therefore, some older adults as well as family caregivers and individuals who help elders make decisions (“Decision-making partners” or DMPs) may not be capable of accessing the services they need to manage chronic conditions or support the care team (Vernon et al., 2007). They may not be able to effectively communicate with health care providers and others about treatment options, or to adequately navigate the healthcare system (Vernon et al., 2007; Berkman et al., 2010). Some individuals may not understand medical instructions or care options well enough to make informed health care decisions, or to plan for future care (Agency for Healthcare Research and Quality (AHRQ), 2011). Disparities often exist in access to care and health outcomes for racial and ethnic minorities, low-income individuals, uninsured adults and Medicaid beneficiaries due to low health literacy (U.S. Department of Health & Human Services, 2013).

The multi-level research in this dissertation contributes to knowledge of health literacy and helps expand both its definition and conceptual framework. Previous

research demonstrated that low health literacy among individuals contributes to their own poor health outcomes (Schillinger et al., 2002; Leichter, 2011; Centers for Disease Control and Prevention (CDC), 2012). Several investigations have also reported that low health literacy among caregivers may have a negative impact on care-recipient health outcomes (Lindquist et al., 2011; Yin et al., 2007; Sanders et al., 2007). The findings from this dissertation provide additional evidence that the health literacy skills of *others*, including family caregivers and DMPs impacts the quality of care for older adults, as well as the ability to properly manage the chronic illnesses of older care recipients. The findings in this research demonstrate that health care professionals, such as Patient Navigators, may have an effect on the access and utilization of care, and may act as mediators to health outcomes in a health literacy skills framework. Therefore, a “health- literate health care organization” can make it easier for individuals to navigate the system and utilize information to improve their health outcomes (Brach et al., 2012).

This final chapter summarizes the major findings of my three-article dissertation research in health literacy. The limitations and strengths of each study are discussed as well as imperatives for future research. Using the multi-dimensional health literacy framework from the first chapter of this dissertation, I have depicted areas for interventions based upon this research (Figure 1). Finally, I discuss the policy implications of this dissertation research, and gaps that remain in our knowledge of the impact of low health literacy on health outcomes.

Findings

Major Findings of Study One

The first investigation in this research series about health literacy involves care teams (program participants, paid & unpaid caregivers, and participant representatives) for individuals with Alzheimer's disease and related dementias in a participant-directed program. In a participant-directed program, individuals with disabilities determine for themselves, with the help of members of their care team, what mix of personal care services and supports works best for them to maintain their independence (The National Resource Center for Participant-Directed Services, 2013). I conducted this ethnographic pilot study of five care teams with another researcher to evaluate how elders in varying stages of Alzheimer's disease and their care teams fared in West Virginia's Personal Options Program (a 'Cash and Counseling' Program), and to gain insight into care team training needs.

Our findings support previous studies, which reported that older individuals with dementia and their care teams fare well in a participant-directed program (Masters, 2006; Feinberg, 2012). In this study, program participants reported that they are more comfortable, and some stated that they have greater autonomy than they would in another care situation. Older individuals with dementia have consistent caregivers and representatives (mostly family members) whom they trust to provide care and help them make decisions. Family caregivers and representatives stated that they are grateful for the program because they are able to honor commitments to the care recipient and other family members, and because the financial help they receive

from the Personal Options program helps them purchase needed supplies and equipment thus relieving some of their financial burden.

However, caregivers and representatives in this study reported feeling a lack of overall preparedness for their roles, and the need for training in dementia care and other skills (such as information-seeking skills and communication skills). Some care team members did not understand the Alzheimer's disease process or know how to address behavioral changes that occur with the disease. Participant representatives stated that they may not always make optimum care decisions or appropriately plan for the future. Care team members also reported that a lack of adequate communication sometimes leads to family conflicts about the appropriateness of care for individuals with dementia.

Since care team members in this study reported that they have difficulty obtaining, communicating about, processing, and understanding basic health information and services needed to make the best PD health decisions, we concluded that these care teams may have low dementia health literacy. We also concluded that for the care teams we interviewed, there is a need for training in dementia care in a participant-directed program, and that there was a gap in our knowledge of participant representatives. Our research indicates that representatives may not be prepared for their role and may need specific training to better represent the care recipient. We therefore planned a second study to examine the preparedness of representatives to represent participants with ADRD in the Arkansas IndependentChoices program. The next article in this dissertation is based on secondary data analysis of the Arkansas preparedness data.

Major Findings of Study Two

The second article in this dissertation examined the health literacy skills (communication skills) of DMPs for elders with dementia in the Arkansas IndependentChoices program. No other research team had examined the health literacy of this population before this study. DMPs play an essential role helping individuals with dementia make decisions and representing their care preferences, yet many DMPs reported that they do not receive training in dementia care. Their role changes over time as the cognitive abilities of the person with dementia declines, therefore optimum training for individuals in this role should be ongoing. Since low health literacy skills (such as poor communication skills) may impact DMP preparedness to adequately represent the care recipient or to handle the stress of their role, I wanted to gain insight into the need for a health literacy component of a training program for DMPs in a participant-directed model of care.

I performed a secondary mixed-methods analysis, using data about DMP preparedness for various aspects of their role that we collected in a telephone survey of DMPs representing 30 individuals with Alzheimer's disease and related dementias (ADRD) in an Arkansas participant-directed program (IndependentChoices) (Simon-Rusinowitz et al., in progress). To examine these data through the lens of health literacy, I first developed a health literacy skills framework for this population based on an existing framework (Squiers et al., 2012). I then selected one health literacy skill (communication) from the framework, and evaluated its impact on health outcomes (overall preparedness to represent the individual with ARDR and preparedness for the stress of their role). I examined mean preparedness scores based

on a likert scale that ranged from 0 = “not prepared” to 4 = “very well prepared.” I also examined qualitative transcripts of interviews with the DMPs where some explained why they were not prepared to communicate with the participant, paid caregivers, unpaid caregivers (usually family members), IndependentChoices staff, and healthcare professionals.

In this study, 8 DMPs (27%) reported that they had received participant-directed training and only 5 DMPs (17%) received dementia care training. Less than half of the DMPs reported that they were “very well” prepared to: involve the participant in making decisions (30%); represent the participant’s decisions and preferences (30%); prepare paid (40%) and unpaid (27%) caregivers to handle emergencies; or prepare paid (40%) and unpaid (20%) caregivers for other health conditions. Poor communication skills or a lack of communication with the care team contributed to 60% of the DMPs reporting that they were not “very well prepared” for the stress of their role. DMPs stated that they had difficulties explaining the management of ADRD to paid and unpaid caregivers and several DMPs had family conflicts about the appropriateness of care or the lack of family support. I reported that future studies of DMPs should evaluate their role in conflict management and negotiations among family members.

I concluded that low health literacy skills may negatively impact health outcomes for individuals with dementia in a participant-directed care model. Better communication skills among DMPs obtained through a DMP training program may improve care for individuals with dementia and may allow DMPs to better represent the care recipient. Improved communication skills may enhance the DMP’s ability to

teach caregivers how to improve safety for participants, understand participants' non-verbal cues, and to deal with difficult behaviors associated with Alzheimer's disease and related dementias. This may result in better representation for the individual with ADRD, better team work, better health outcomes and less stress for family members, caregivers, and DMPs.

Major Findings of Study Three

The objective of the third study of this dissertation was to identify successful methods of disseminating information to 10,761 emergency department (ED) patients from five Montgomery County Maryland hospitals who were low-income, uninsured individuals and Medicaid beneficiaries. Many of these patients identified themselves as racial or ethnic minorities (37.5%) or of "other" (25.2%) or "unknown" race (7.2%). Previous studies found high rates of low health literacy in racial and ethnic minority ED patients and those that speak a language other than English. I wanted to examine the role of Patient Navigators and other health care professionals in redirecting ED patients to community health centers and their repeated use of these clinics. Thus, this study helped us examine communication skills within an organization, and the role of cultural competency in increasing health literacy.

The data analysis method I selected for this study was a two-part negative binomial count or "hurdle" model. This model allowed us to expand on the original data analysis by first estimating factors associated with patients visiting one of four community health centers following ED referral and then analyzing factors associated with subsequent clinic visits. Thus I was able to identify factors that influenced ED

patients in establishing a “medical home.” The model contained variables of both *who* contacted ED patients (ED provider alone, ED provider with a message or brochure, Patient Navigator alone, or ED provider with the Patient Navigator), and *how* the patients were contacted (no contact, contact by telephone, sent a brochure, or contact in person).

I found that age, gender, ethnicity, and the particular ED in which the patient was seen influenced initial and subsequent visits to community health centers. I also found that although the initial visit to the community health center was influenced by referral by both the ED provider and the Patient Navigator, referral by the ED provider was not a significant factor for subsequent visits. Results indicate that Navigators were especially successful in influencing Hispanic women over the age of 40 to make subsequent clinic visits and develop a relationship with a clinic.

I concluded that the use of Patient Navigators may help reduce ED visits, redirect patients to community health centers and influence them to establish a medical home within the clinic by providing culturally and linguistically appropriate education and referrals. Thus Patient Navigators may act as mediators to increase the health literacy of ED patients, allowing them to choose more appropriate settings to receive care and to better utilize healthcare services. Patients with a “medical home” and more continuity of care may receive more preventive health care and be able to manage their chronic conditions more effectively.

Research Limitations and Strengths

The first two studies in this dissertation may have limitations as do all studies, due to data collection, data analysis, and data interpretation. These studies had small sample

sizes of specific study populations of care givers and DMPs for individuals with dementia in participant-directed programs, therefore the findings may not apply to care teams or patient representatives in other settings. It is also possible that there was bias in the information obtained in these studies. There may be selection bias present because the responses of the caregivers and DMPs who were able to participate in these studies may differ from those who were unable to participate. I used self-reported data from caregivers and DMPs about experiences that extended over a period of time. Thus there may be recall bias as well as misclassification of the survey data that was used in the second study. Finally, the interpretation of the qualitative data from both of these studies may have been influenced by the researchers' personal experiences.

There are also limitations to the third study of this dissertation. This study may have limitations because it was a secondary data analysis. The data was not collected for the purpose of examining health literacy or cultural competency, and I did not control the study design or collection procedures. However, since the data came from a dependable source, I believe it to be accurate and reliable. However, I did not determine the urgency of ED care or assess the chronic disease status of ED patients. Therefore, I do not know the influence of these factors in the patients' decision to establish a "medical home" within the community health centers.

Despite the limitations of these studies, there were multiple strengths that should be mentioned. One strength of the first study was that we collected data from all members of the Personal Options care teams (program participants with dementia (if possible), paid and unpaid caregivers, and representatives). Thus we were able to

get information from multiple perspectives about experiences within the Personal Options program and about training needs that will enhance participant-directed services. In the second study, I evaluated the health literacy skills of a population (DMPs) that had not previously been examined in terms of health literacy, significantly adding to this body of knowledge.

Using a qualitative, a mixed methods and a quantitative approach to evaluate health literacy was another strength of this dissertation. The use of qualitative data in the first two studies of this dissertation allowed me to evaluate complex interactions and situations providing greater insight into the health literacy of caregivers and DMPs in a participant-directed care model than if I had used only quantitative data. The qualitative data helped provide an in-depth understanding of why program participants fare well in a Cash & Counseling model of care service, and what the care team training needs are in the words of the study participants. The mixed-methods approach in the second study allowed me to corroborate my qualitative findings with quantitative data. However, the use of quantitative data in my third study allowed me to explore health literacy and cultural competency in a larger study population (10,761 emergency department patients) allowing for greater generalizability of the results to other populations.

Another strength of this dissertation work was being able to expand upon and test the Health Literacy Skills Framework of Squiers et al. (2012). These researchers encouraged other investigators to use their framework as a “springboard” to apply it to the management of a specific disease. I was able to use their framework to identify constructs for a health literacy framework for Decision-Making Partners caring for

individuals with dementia in a participant-directed program. I was able to define factors that influence the development of health literacy for this population, identify mediators within the framework that may influence the relationship between health literacy and health outcomes (such as health care professionals), and identify specific health outcomes. In my third study of the effect of the ED referral process on subsequent utilization of community health centers, I was able to examine the role of Patient Navigators as possible mediators to health literacy outcomes thus expanding the conceptual framework and reinforcing the link between health literacy within an organization and health outcomes, as well as identifying a potential intervention point to improve health literacy skills.

Policy Implications and Future Research

This research has important policy implications for increasing health literacy which may improve the understanding of chronic conditions, access to care services, navigation of the health care system, and communication with health care professionals about treatment options and future care plans. Policies and interventions to increase health literacy can be implemented in various areas (such as the health system or the educational system) and can impact health literacy at multiple levels. The multi-level research presented in this dissertation allowed for the identification of several potential interventions. These interventions can be seen in **Figure 1** added to the framework presented in the first chapter of this dissertation.

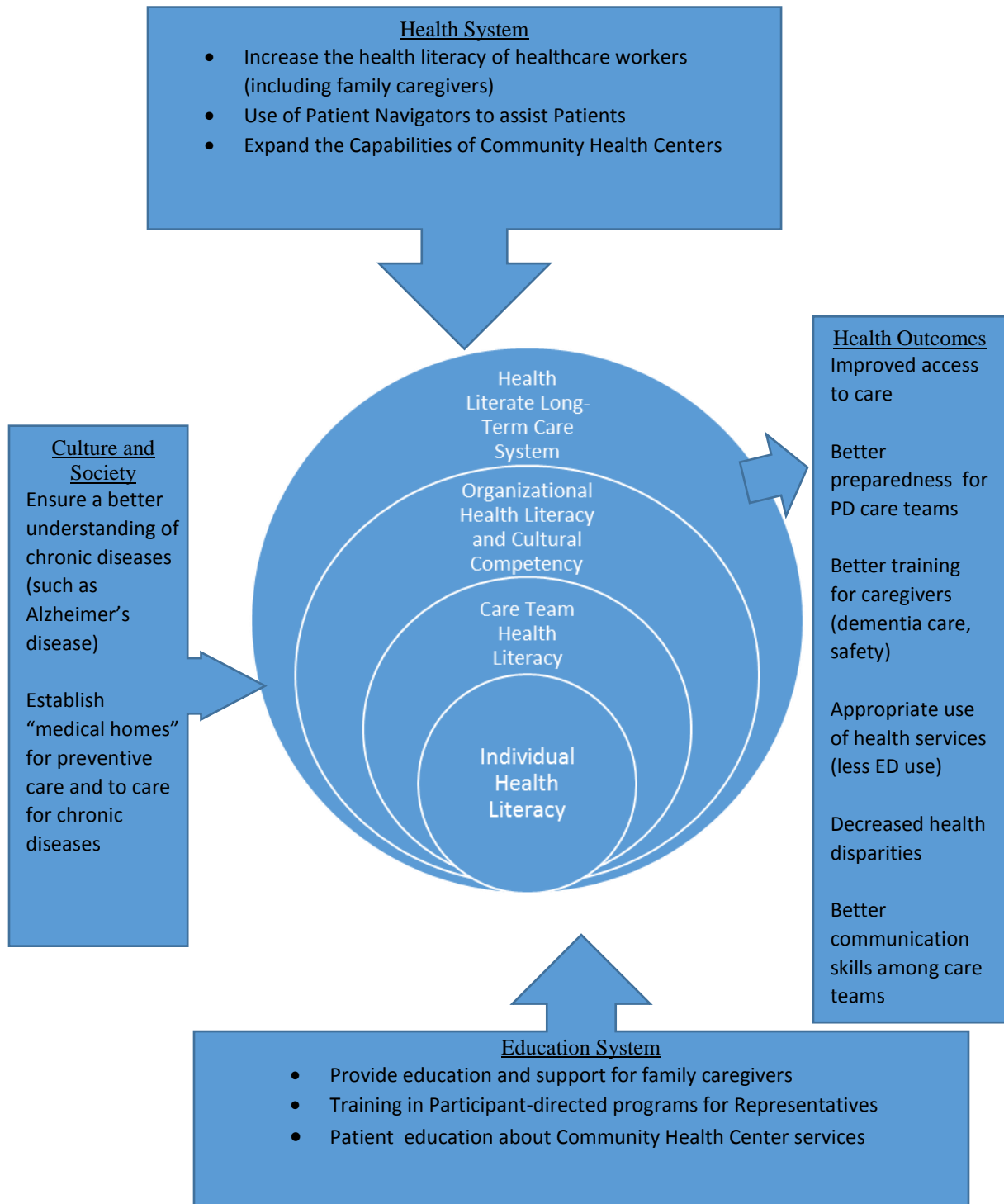
For example, implementation of the PPACA (2010) calls for improving the public health workforce and patient-centered care. In this research, I found that participant-directed programs may be beneficial for elders with dementia and their

caregivers, giving program participants more autonomy and allowing for more flexibility and control over care services. However, low health literacy skills among caregivers and DMPs in a participant-directed model may prevent them from providing optimal care. Inadequate communication skills among DMPs in participant-directed programs makes it difficult for them to feel “very well prepared” for their role. A DMP training program that includes health literacy skills (such as communication skills) is an intervention that may improve the ability of DMPs to coordinate care, train caregivers, understand care options, and plan for future care; thus improving the care provided by the workforce, supporting family caregivers, and improving PD services. Future research should examine additional skills within a health literacy framework that could be included in a DMP training program to enhance participant-directed care.

The PPACA (2010) also has mandates to decrease health disparities and to create “medical homes.” This research demonstrates that improving the cultural competency within organizations may help increase the health literacy of ethnic and minority ED patients and improve their utilization of appropriate treatment settings. Patient Navigators may act as a mediator in the framework of health literacy improving health outcomes by helping patients establish a medical home and decrease utilization of the ED for non-urgent or preventable conditions. These findings suggest that Patient Navigators may help decrease disparities as evidenced by the increase in older Hispanic women who found a “medical home” within a community health center due to referral by a Navigator. Studies should continue to

examine the role of the Patient Navigator and other healthcare providers in the framework of health literacy.

Figure 1. Multi-Dimensional Framework and Intervention Areas to Increase Health Literacy and Cultural Competency



Conclusion

We have an aging and increasingly diverse population in the United States, as well as greater numbers of individuals with chronic conditions who require ongoing care. Many elders with dementia rely on family and friends to assist them with care or decision-making tasks so they are able to remain at home. The results of this research indicate that low health literacy skills (such as poor communication skills) may have a significant impact on the ability of individuals and their care teams to manage chronic diseases (such as Alzheimer's disease), obtain the services and supports they need, and understand their treatment options. Disparities may exist for ethnic and minority individuals who may not properly utilize care services or be able to access primary care services such as community health centers, where they can receive assistance managing chronic conditions. These individuals may not be able to communicate with health care providers well enough to make informed health care decisions due to language barriers. To improve the quality of care and other health outcomes for individuals with chronic illnesses, as well as to decrease health disparities in long-term care, we must we must continue to address health literacy and cultural competency within our health care system.

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