Patient-Centered Health Information Technology:

Engagement With the Plan of Care Among

Older Adults With Multi-Morbidities

by

Karen Jiggins Colorafi

A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved April 2015 by the
Graduate Supervisory Committee:

Gerri Lamb, Chair
Karen Marek
Robert Greenes
Bronwynne Evans

ARIZONA STATE UNIVERSITY

May 2015

ABSTRACT

A core principle in multiple national quality improvement strategies is the engagement of chronically ill patients in the creation and execution of their treatment plans. Numerous initiatives are underway to use health information technology (HIT) to support patient engagement however the use of HIT and other factors such as health literacy may be significant barriers to engagement for older adults. This qualitative descriptive study sought to explore the ways that older adults with multi-morbidities engaged with their plan of care. Forty participants were recruited through multiple case sampling from two ambulatory cardiology practices. Participants were English-speaking, without a dementia-related diagnosis, and between the ages of 65 and 86. The older adults in this study performed many behaviors to engage in the plan of care, including acting in ways to support health, managing health-related information, attending routine visits with their doctors, and participating in treatment planning. A subset of patients engaged in active decision-making because of the point they were at in their chronic disease. At that cross roads, they expressed uncertainly over which road to travel. Two factors influenced the engagement of older adults: a relationship with the provider that met the patient's needs, and the distribution of a Meaningful Use clinical summary at the conclusion of the provider visit. Participants described the ways in which the clinical summary helped and hindered their understanding of the care plan.

Insights gained as a result of this study include an understanding of the discrepancies between what the healthcare system expects of patients and their actual behavior when it comes to the creation of a care plan and the ways in which they take care of their health. Further research should examine the ability of various factors to enhance patient engagement. For example, it may be useful to focus on ways to improve the clinical summary to enhance engagement with the care plan and meet standards for a health literate document. Recommendations for the improvement of the clinical summary are provided. Finally, this study explored potential reasons for the infrequent use of online health information by older adults including the trusting relationship they enjoyed with their cardiologist.

To the patients and the healthcare providers who have shared
their stories, time, and talent with me.
You have a fueled a life-long love affair with the workings of the human heart
by which I am perpetually inspired and for which I am exceedingly grateful.

ACKNOWLEDGEMENTS

The idea that “it takes a whole village” to perform a monumental task is attributed to a proverb common to several African languages. It has been used to express the magnitude of a variety of tasks, for example, “it takes a whole village to raise a child” or “it takes a global village to eradicate poverty”. It seems to me that “it takes a village to earn a doctoral dissertation”. It is in that spirit that I wish to acknowledge:

- those who have mentored, coached, taught, explained, tutored, inspired, or worked to raise a new generation of scientists through your labor, love, expertise, and patience.
- those who have funded this work through grants and scholarships, made my car payment, picked up the tab at lunch, or paid for a vacation whilst being a student.
- those who have listened to me work through emerging ideas, talked to me about theirs, given me an article, book, or suggestion, and those who let me complain, cry, vent, or drone on about all things patient engagement.
- those who have helped with references, built tables in Excel, or reviewed my findings, posters, or papers.
- those who have painted my nails, colored my hair, massaged my aching muscles, cared for my health, made me dinner, given me flowers, gifts, or Starbucks cards to brighten my day, a fun book to read, a craft to try, or a new recipe to try.
- those who offered an encouraging word, card, email or hug.

You have made a difference in my life. This village helped me to achieve a dream, a Ph.D.

TABLE OF CONTENTS

Page

APPENDIX

APPENDIX Page

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

BACKGROUND AND INTRODUCTION

A core principle in national quality improvement strategies is the engagement of chronically ill patients in the creation and execution of their treatment plans. Patient engagement is most commonly defined as the "actions individuals must take to obtain the greatest benefit from the health care services available to them" (Center for Advancing Health, 2010). A growing body of evidence demonstrates that patient engagement for individuals with chronic illness results in better adherence, superior self-management skills, improved quality of life, enhanced functional and symptom status, fewer rehospitalizations, and lower health care costs (Hibbard, Greene, & Tusler, 2009; Hibbard, Mahoney, Stock, & Tusler, 2007). Numerous initiatives are underway to use health information technology (HIT) to support patient engagement, however the use of HIT and other factors such as health literacy may be significant barriers to engagement for older adults.

The Electronic Health Record (EHR) Incentive Program introduced in 2009 with the American Reinvestment and Recovery Act was designed to use HIT to improve the engagement of patients and families and the coordination of healthcare. The Stage 1 Meaningful Use rule mandates the provision of a computer-generated clinical summary to each patient at the conclusion of their healthcare encounter. In Stage 2, beginning as early as January 2014, Eligible Professionals are required to provide a practice-based web portal from which 5% of their patients must retrieve and review the clinical summary electronically in order to earn an incentive (US Department of Health and Human Services, 2010, 2012, 2013b). The clinical summary, whether it is provided on paper or through a patient portal, contains the agreed upon plan of care (POC) and may include medication, diet or exercise regimens, as well as instructions about monitoring or testing. There is an expectation according to national guidelines, that patients have the opportunity to contribute to and modify their POC according to their needs and preferences (Agency for Healthcare Research and Quality, 2012; American Geriatrics Society, 2012; Dykes, 2013). Discourse about patient engagement emphasizes the importance of patients asking questions about proposed recommendations, discussing the opinion and plan of other physicians, nurses, and other healthcare professionals they see, and asking about risks and benefits of proposed tests or medications (Gruman et al., 2010). The POC provides a roadmap for patient engagement by specifying actions taken to maintain health and manage chronic illness. Currently, there is minimal research on engagement of older adults with the plan of care.

As many as 80% of the 38 million adults over the age of 65 in the United States manage at least one chronic disease (Centers for Disease Control, 2009, 2013). For these older adults, the POC they receive provides a foundation for chronic disease self-management and engagement in health-promoting behaviors. However, two decades of research into health literacy confirms that patients in general and older adults in particular often do not understand the material given to them in written or oral formats, nor are they actively involved in the development of the care plan (Agency for Healthcare Quality and Research, 2011a, 2011b; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Glassman, 2014; Hibbard & Cunningham, 2008; Institute of Medicine, 2004). Although patient engagement has been written into national quality improvement strategies, there has been little research to date on the ways in which older adults are capable or willing to engage with a healthcare system that is rapidly modernizing with HIT, and more specifically with a POC that is expected to guide their care across providers and settings. These factors create a “perfect storm” whereby older adults with multi-morbidities may be ill equipped to participate in a new, technologically enhanced healthcare delivery system defined by one's level of engagement. This leaves an already vulnerable population (Agency for Healthcare Quality and Research, 2001, 2011b; Centers for Disease Control, 2013; US Administration on Aging, 2012) exposed to the risks of reduced healthcare access and worsening health outcomes.

This research has focused on a subset of specific engagement behaviors: the creation and use of the Meaningful Use clinical summary, which contains the patient's POC. The purpose of the research was to describe patient engagement with the plan of care contained in the Meaningful Use clinical summary in a sample of older adults with multi-morbidities. This research addresses a fundamental issue: Do older adults and their families have the necessary tools to fully participate in the development, negotiation, and implementation of a POC that is centered upon patient and family needs and preferences and which can be used for care coordination purposes?

Research Question: In what ways do older adults with multi-morbidities engage with their plan of care?

Specific Aims:

1. Describe the contextual factors that influence patient engagement behavior with the POC.
2. Describe the role that process determinates (e.g.: support from technology or the provider office) play in influencing engagement behavior with the POC.
3. Define the engagement behaviors of older adults related to care planning.

Significance

This foundational research is significant because it addresses the way that older adults are engaged in and achieve the goals of health transformation in the United States. Billions of taxpayer dollars are being spent on the engagement of patients through HIT. It is not clear how or if this strategy will be effective for the cohort of Americans who are growing exponentially in number and living with an epidemic of chronic disease. We need to understand how to best engage older adults with multi-morbidities in their health and healthcare and determine the effectiveness of HIT as a method for engagement.

People aged 65 and older comprise a greater proportion of the world's population than ever before and this demographic trend is steadily increasing (RAND, 2001). Today, more than 38 million people in the U.S. are 65 years of age or older (12% of the population). As a cohort, older adults are living longer with more chronic illness. A significant number have limited health literacy that calls the effective use of HIT into question. The engagement of older adults in healthcare redesign is essential: they represent a large and diverse consumer group with the potential for either significantly raising costs or driving substantial cost savings.

While aging may be accompanied by robust health, it is commonly associated with multi-morbidities, defined as the presence of two or more chronic conditions requiring multiple medications, complex treatment plans, and elaborate care coordination efforts (Centers for Disease Control, 2013; Fortin, Dubois, Hudon, Soubhi, & Almirall, 2007; Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007; Mercer, Smith, Wyke, O'Dowd, & Watt, 2009; National Council on Patient Information and Education, 2010). Over two-thirds of Medicare beneficiaries have at least two chronic conditions and 14% of Medicare beneficiaries have six or more (Anderson, 2010; Lochner, Goodman, Posner, & Parekh, 2013). One-third of Medicare beneficiaries have hypertension, high cholesterol, and diabetes or ischemic heart disease. Cardiovascular disease (CVD) is the most common chronic disease among older adults and causes more than 28% of all deaths (34% including stroke) in those 65 years of age or older. The costs associated with chronic illness and chronic illness care for this population are huge and growing. More than 75% of total healthcare spending, now estimated at $3.8 trillion, is attributed to chronic disease care (Centers for Disease Control, 2009), meaning that three out of every four health care dollars is spent on chronic disease management. The average healthcare costs for someone who has one or more chronic conditions is five times greater than for someone without any chronic conditions. CVD alone is estimated to cost the healthcare system $432 billion a year (Mensah & Brown, 2007).

In addition to living with increasing rates of morbidity, older adults manifest dramatically lower levels of health literacy, defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine, 2004). Rates of limited health literacy are high among older adults (Berkman, Sheridan, Donahue, Halpern, Viera, et al., 2011; Institute of Medicine, 2004; Oldfield & Dreher, 2010), with only 3% of older adults scoring in the proficient range (Kutner, Greenberg, Jin, & Paulson, 2006). Health literacy is significantly correlated with the ability to engage in the healthcare system and self-management behaviors (Coulter, 2012; Gazmararian, Williams, Peel, & Baker, 2003; Koh, Brach, Harris, & Parchman, 2013; Parker, 2013).

Older adults with multi-morbidities and limited health literacy may not be able to perform the sophisticated behaviors required of engaged patients. This is potentially of particular concern when they must interact with HIT platforms to succeed. Although 69% of US households reportedly use the Internet, users are disproportionately younger, healthier, wealthier, and more educated than non-users (Choi & DiNotto, 2013a, 2013b ; Wen, Kreps, Zhu, & Miller, 2010). Only about half of all adults over the age of 65 in the US use a computer (Keenan, 2009), and only 34% of those over the age of 76 (Zickhur &

Madden, 2012). These findings along with others have prompted the Consumer Partnership for eHealth to develop guidelines for using HIT to make information meaningful and useful to the elderly, chronically ill, and otherwise underserved (Consumer Partnership for eHealth, 2011; National Partnership for Women and Families, 2012) but there remains little empirical evidence that older adults will make use of re-designed HIT.

This research aims to highlight the unique needs and obstacles for older adults participating in health reform, especially those obstacles to engaging in the pivotal part of reform associated with HIT and the plan of care. Defining the preferences of this population will allow us to design products, processes, and policies that better serve our chronically ill and aging nation and will lay the foundation for defining new ways to engage older adults in the self-management of chronic disease with HIT.

Innovation

This research addresses three areas of innovation related to older adults and healthcare: theory, technology, and policy. Emerging models and prototypes for the electronic longitudinal plan of care, the centerpiece for patient-centered care and care coordination, have not explored the unique role that factors like health literacy, patient preference for HIT, and the role that physical and social environments will play in the successful implementation of HIT for engagement with a growing elderly population. This research addresses patient and family participation and centeredness in healthcare delivery and will provide a foundation for extending theory development and testing in these areas.

This research is among the first to focus on the point of intersection among patient-centered care, health literacy, and HIT to support the engagement of older adults in their health and healthcare with research based design principles. Results will support specific recommendations for development of an electronic plan of care for older adults with multi-morbidities. The Meaningful Use clinical summaries currently in use have been designed by EHR vendors and do not necessarily adhere to design principles that reflect health literacy or patient education standards. This research provides a foundation of content and methodology that will inform research-based redesign of the clinical summary, potentially turning the clinical summary into an engagement tool that will reach vulnerable populations such as older adults with multimorbidities.

Finally, this research will also contribute to the national policy dialogue, addressing the ethics of patient engagement. The healthcare discourse includes discussion of patient “empowerment” and “compliance” which reflects the conscious and unconscious motives of the healthcare industry to shift risk and responsibility for individuals’ care from professionals onto patients, many of whom lack the strength, resource, sophistication and health to take on these tasks (J. Gruman, personal communication, March 7, 2014). Increasing the understanding of what older adults with multi-morbidities can and will do to engage with their health and the healthcare system will allow us to identify approaches to determine optimal guidelines to bring honesty and accountability to various policy conversations about engagement-based incentives, reimbursement, and outcome measures.

CHAPTER 2

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

Theoretical Framework

The selection of a theoretical framework and sensitizing concepts is critical to qualitative research as it provides an initial lens for understanding the phenomena of interest. They guide data collection and analysis, providing a way to organize one’s thinking about the research problem and process. The theoretical framework for this research is Ryan and Sawin's Individual and Family Self-Management Theory (IFSMT) depicted in Figure 1 (Ryan, 1998; Ryan, 2009; Ryan & Sawin, 2013; Ryan & Sawin, 2009). The IFSMT along with the conceptual model adapted from the Ryan and Sawin model, provide the foundational concepts for this research.

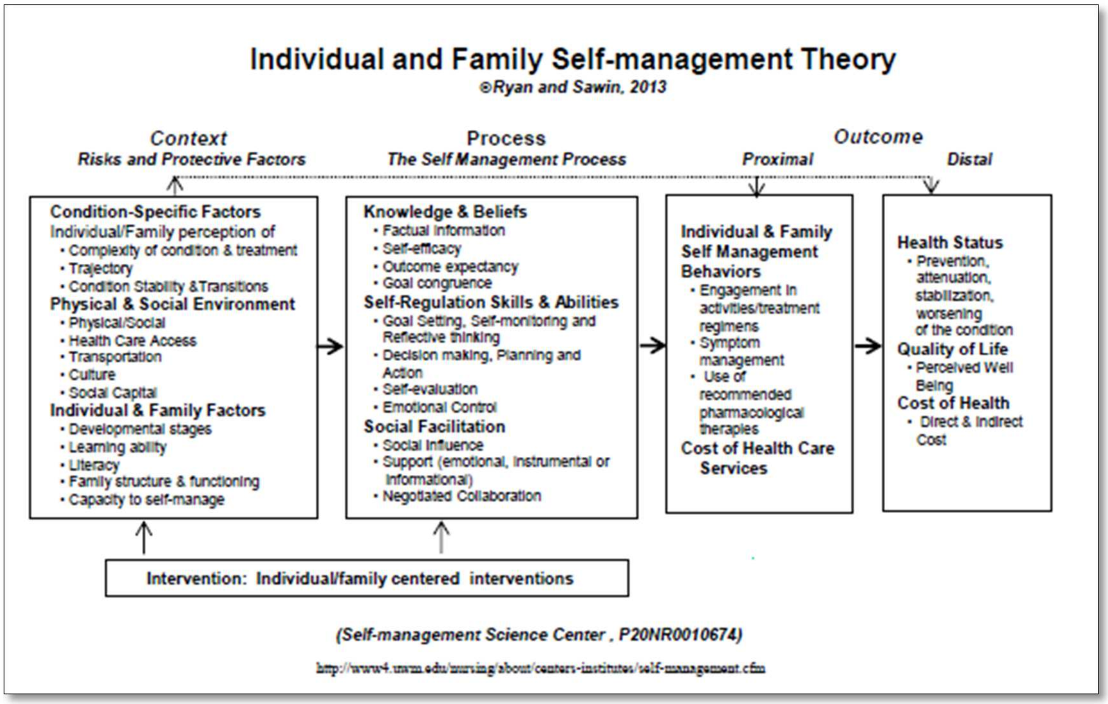


Figure 1. The individual and family self-management theory (Ryan & Sawin, 2013).

The Ryan and Sawin model (2013) focuses on the factors that enable patients and families to successfully manage chronic illness. The model incorporates concepts such as health literacy and information processing which are relevant to understanding how older adults may engage with information technology and their plan of care. Engagement in the treatment regimen is noted as a proximal outcome. Other distal outcomes include the cost of health and care, health status, and quality of life. Ryan and Sawin's model captures many of the engagement behaviors described by CAH (2010) and Gruman et al. (2010).

Ryan and Sawin (2013) posit that both contextual and process factors are antecedent to proximal and distal outcomes such as direct and indirect costs, quality of life, and health status. Contextual factors include condition-specific characteristics of the chronic disease(s) and treatment regimen(s), the physical and social environment in which patients and families seek care, and individual and family factors including literacy and capacity to self-manage. The process of self-management is influenced by the individual's knowledge and beliefs, his/her skills and abilities, and social facilitation factors such as influence, support, and collaboration. The updated 2013 model pictured in Figure 1 includes patient engagement as a proximal and measureable outcome of individual and family self-management behaviors, specifically related to engagement with the plan of care (noted in the model as activities/treatment regimens).

To date, the model has been used to explain the self-management of calcium and vitamin D intake for mid-life women with osteoporosis (Ryan, Maierle, Csuka, Thomson, & Szabo, 2013), and for the self-management of medications with frail older adults receiving home care services (Marek et al., 2013). The model has been used to test the efficacy of computer applications to change behavior (Maierle & Ryan, 2011; Marek et al., 2013). It has not been used to study patient engagement.

Sensitizing Concepts

The foundational or sensitizing concepts guiding this research were developed and identified primarily from the IFSMT. Blumer (1954) is credited with naming and defining sensitizing concepts as tools that give the investigator a “direction in which to look”. Sensitizing concepts provide a “general sense of reference and guidance in which to approach empirical instances” (Bowen, 2006). Qualitative research relies heavily on the use of sensitizing concepts, employing them as starting points and interpretative devices (Charmaz, 2003; Glaser, 1978). They help investigators organize data and understand the observed experience. Charmaz (2003) stresses that sensitizing concepts “provide starting points for building analysis, not ending points for evading it. We may use sensitizing concepts only as points of departure from which to study the data”. The sensitizing concepts utilized in this study (Table 1) have informed the research design (sample and setting), data collection techniques, and data analysis.

Figure 2. Conceptual model for exploring the engagement of chronically ill older adults with the plan of care.

Table 1

Sensitizing Concepts

	Chronic disease	Health literacy	Patient Activation	Social Facilitation	Patient Engagement
Theoretical origin	IFSMT	IFSMT, HL[1]	PAM[2]	IFSMT	Patient Engagement Framework [3]
Research design	Sample inclusion criteria of at least 2 chronic CVD diagnoses, sample exclusion criteria not to exclude patients with cognitive impairment	Sampling strategy (maximum variation) to include older adults with a variety of HL scores	Sampling strategy (maximum variation), to include older adults with a variety of patient activation scores	Selection of setting (through convenience with care to adequately represent the broader population of older adults)	Focus on engagement behaviors as proximal outcome concepts
Data collection	Data collection instrument (demo form), Interview questions	Data collection instrument (SILS)	Data collection instrument (PAM)	Observation, Interview questions	Observation (listed on field notes for easy identification), Interview questions
Data analysis	Explore differences among diagnoses, course	Used to (compare) pivot data in a data matrixes	Used to (compare) pivot data in a data matrixes	Concepts included in initial coding manual	Used behaviors to create initial coding manual

1. Paasche Orlow and Wolfe, 2007. 2. Hibbard et al., 2004, 2005. 3. CAH, 2010; Gruman et al., 2010.

Conceptual model: Engagement of chronically ill older adults with the plan of care. The IFSMT has been modified for this research to focus on concepts relevant to the engagement of older adults with a POC (Figure 2). Sensitizing concepts selected for inclusion in the model are identified here and described in detail in the literature review that follows. Contextual factors, including age, gender, ethnicity, race, income, education, and chronic diagnoses, were selected because of their previously published relationships to the concept of engagement (Hibbard & Cunningham, 2008; Paasche-Orlow & Wolf, 2007). Health literacy was chosen because of the significant impact of limited health literacy on the health status of older adults and the relative absence of research done to link health literacy to patient engagement. Patient activation, which refers to people's ability and willingness to take on the role of managing their health and healthcare (Hibbard & Cunningham, 2008) was selected because it is a valid measure of people's health related behaviors such as seeking health screenings and immunizations, maintaining good diet and exercise regimens, and self-management behaviors such as monitoring chronic conditions and adhering to treatment protocols. Patient activation has not been linked theoretically to health literacy, knowledge and beliefs about HIT, or specific engagement behaviors as outlined by CAH (2010) and Gruman et al. (2010).

The process determinates selected represent the knowledge and beliefs older adults hold about technology in healthcare, of which little is known, and the various ways in which the provider office supports and influences patient self-management through programs and policies that drive provider behavior and the nature of the patient-provider relationship.

Finally, engagement behaviors were selected as the proximal outcome for this study. Although patient engagement is an unspoken expectation of the current system of healthcare delivery, there is virtually no research that has examined engagement behaviors as potential patient-centered outcome measures.

Review of the Literature

Patient preference for engagement and the use of HIT are critical issues for one of the fastest growing demographic groups in the United States, older adults. There is reason to believe that older adults face significant barriers to patient engagement with HIT. This literature review focuses on barriers to engagement and is organized according to the sensitizing concepts presented in the conceptual framework in Figure 2.

Contextual factors. Contextual factors in the IFSMT represent risk or protective factors. They include condition-specific factors such as the complexity of an older adult's chronic condition and the treatment or prevention plan that impacts the amount, type, and nature of behaviors required for self-management. They also include physical and social environment factors that can promote or hinder self-management such as access to healthcare, transitions from one provider or setting to another, transportation, neighborhood, work, school, culture and social capital. Finally, contextual factors can be specific characteristics of a patient or family, such as developmental stage, perspectives, literacy, and information processing capabilities (Ryan, 2009). The contextual factors highlighted in this study include the condition-specific factor of multi-morbidities and two individual factors, health literacy, and patient activation. These three factors may represent significant barriers to patient engagement.

Multi-morbidities. Achieving patient engagement and activating helpful self-management behaviors may be a significant challenge for older adults, particularly those who confront multiple chronic diagnoses (Gazmararian et al., 2003; Hibbard & Cunningham, 2008) for a variety of reasons.

First, the volume of chronic disease is overwhelming the healthcare system. The U.S. is facing an epidemic of chronic disease, defined by the CDC (2009) as non-communicable illnesses that are prolonged in duration, do not resolve spontaneously, and are rarely cured completely. Chronic diseases (i.e. heart disease, cancer, stroke, diabetes, obesity, and arthritis) cause seven in 10 deaths and account for more than 75%

of annual health care costs (Centers for Disease Control, 2013). Almost one in two adults, that is about 133 million Americans, live with at least one chronic disease, yet chronic disease is more commonly found in older adults. Cardiovascular diseases (CVD) are the most common among older adults, causing more than 28% of all deaths (34% including stroke) in those 65 years of age or older. CVD claims the lives of 815,000 Americans (one in three deaths) each year. An astonishing 2,200 people die from CVD each day. CVD (including stroke) can result in serious illness, disability, and decreased quality of life for older adults (Million Hearts, 2011). The projected future annual costs of CVD to the nation is conservatively estimated at $444 billion and does not include the cost of nursing home care or lost productivity for patients and their family caregivers (Heidenreich et al., 2011).

Second, a significant number of older adults with chronic disease experience substantial limitations in what they are able to do every day because of their disease(s), limiting their ability to engage in behaviors that support their health (Gazmararian et al., 2003; Hibbard & Cunningham, 2008). Care planning and coordination activities for older adults with CVD are often complicated by the presence of co-morbidities such as cognitive impairment and mental health diagnoses (e.g. depression) and other chronic conditions such as arthritis or cancer.

Finally, managing multi-morbidities is a highly nuanced and complex task. The plan of care for CVD diagnoses, for example, generally include instruction on the necessity of significant lifestyle change as patients learn to lose weight, reduce or eliminate salt, cholesterol, and fat from their diets, manage stress, begin or accentuate fitness regimes, stop smoking and achieve reasonable control over chronic conditions such as diabetes, hypertension, and dyslipidemia. These plans are complicated by the use of multiple medications. Each chronic diagnosis requires on average two to five prescription medications. They are typically ordered by more than one prescribing provider and are filled at more than one pharmacy. Due in part to the complexity of the medication regimen, non-adherence in this population is estimated to be as high as 55% (Edmondson, Horowitz, Goldfinger, Fei, & Kronish, 2013; Ho, Bryson, & Rumsfeld, 2009; Levine et al., 2013).

Health literacy. Older adults often have a difficult time interpreting and using the health information given to them to support their engagement with the plan of care. Two decades of research indicate that at the most fundamental level, as many as 90 million American adults do not understand the written or oral information given by healthcare providers to help them manage their chronic disease (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Institute of Medicine, 2004). This is frequently referred to as health literacy, defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (IOM, 2004, p. 3). Health literacy is a complex construct that describes more than the ability to read. As many as 44 million people (23% of the US population) are functionally illiterate, or lack the basic skills to read and write beyond a fourth-grade level (Kutner et al., 2006). Literacy is conceptualized as a functional skill: do you have the capacity to manage your daily living and employment tasks (Keenan & Ohene-Frempong, 2014). Health literacy then, describes the sophisticated skills required for successfully navigating the healthcare system and staying healthy, such as the way we evaluate health information for credibility and quality, analyze relative risks and benefits, calculate drug dosages, interpret test results, or locate health information (Glassman, 2014).

Recent studies have shown that older adults with limited health literacy use the Internet less often to locate health information (Mayberry, Kripalani, Rothman, &

Osborn, 2011), have more hospitalizations and emergency care visits, and have a lower probability of receiving preventative services such as immunizations than their more health literate, demographically matched, counterparts (Berkman, Sheridan, Donahue, Hallpern, & Crotty, 2011). Rates of limited health literacy are higher among older adults, the socioeconomically disadvantaged, certain racial and ethnic minorities, immigrants, and residents of rural communities (Berkman, Sheridan, Donahue, Halpern, Viera, et al., 2011; Institute of Medicine, 2004; Oldfield & Dreher, 2010). The 2003 National Assessment of Adult Literacy conducted by the federal government concluded that older adults have lower health literacy scores than all other age groups surveyed; only 3% of the older adults scored "proficient" in health literacy (Kutner et al., 2006).

In keeping with the construct of functional literacy which requires individuals to posses the skills needed to navigate the current healthcare environment and the current state of technology, newer operational definitions of health literacy include measurements of previous experience with, comfort level with, and the perceived value of, using computers and the Internet for seeking health-related information (Choi & DiNotto, 2013; Mayberry, Kripalani, Rothman, & Osborn, 2011; Nahm et al., 2012; Xie, 2011), a construct termed "eHealth Literacy" by Norman and Skinner (2006). The prevalence of eHealth literacy has not yet been assessed at a population level, but we know that minority and vulnerable populations like older adults have lower eHealth literacy rates than younger adults (Werts & Hutton-Rogers, 2013). Older adults with multi-morbidities and limited health literacy may not be able to perform the sophisticated behaviors required of engaged patients. This is particularly concerning when they must interact with HIT platforms to succeed, therefore health literacy is highlighted in this research.

Patient activation. Patient activation, defined as the patient's ability and willingness to engage by taking on the role of managing their health and health care (Hibbard & Greene, 2013), is a global construct related to self-efficacy. It is not about "getting patients to comply", rather, activation focuses on "facilitating the skills, knowledge and confidence" necessary for patients to become more competent self-managers over time (Hibbard & Minniti, 2012). Hibbard, the most prolific writer in the area, has found that highly activated patients enjoy better health outcomes and cost the system less money than their less activated counterparts (Hibbard & Greene, 2013; Hibbard, Greene, & Overton, 2013; Hibbard et al., 2007). Hibbard and her research team have developed a 13-item Patient Activation Measure (PAM) that is used to measure an individual's knowledge, skill, and confidence in managing their health and assigns an activation score that corresponds to one of four progressive states of activation (Hibbard & Greene, 2013; Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard, Stockard, Mahoney, & Tusler, 2004).

Hibbard's research suggests that patients go through phases or levels on their way to becoming effectively engaged self-managers. Activation is a fluctuating state rather than a fixed trait that can change or be bolstered over time (Hibbard & Minniti, 2012). There is little research to suggest how activation can be promoted, but one study demonstrated improvements in activation scores with social support from the healthcare team, friends, family, coworkers, and employers (Becker & Roblin, 2008). Other studies suggest that tailoring support to a patient's activation level is helpful because patients develop a sense of self-efficacy that gives them more confidence to assume greater responsibility (Hibbard et al., 2009; Remmers et al., 2009).

In 2007, investigators collected survey data on patient activation for the first time in a nationally representative sample. Less than half (41%) of all US adults were found to be in the highest stage of activation and 21% were found to be in the lowest level of activation (Hibbard & Cunningham, 2008). The least activated patients were found to be older (65-74) and less educated, had lower incomes and less education, and were more likely to have public insurance (i.e.: Medicaid/Medicare) than their more activated counterparts. Older adults from Hispanic/Latino decent were found to have lower activation levels compared with other ethnic groups, even when controlling for other characteristics. Overall, people with chronic conditions were more likely to have lower levels of activation: 26% in Level 1 or 2 where basic skills are lacking, compared with 18% of people in Level 1 or 2 without chronic conditions (Hibbard & Cunningham, 2008). The fact that activation, which measures propensity to engage, differs across socioeconomic, ethnic, and health status characteristics leads us to believe that if we are to promote engagement strategies within these populations, much more needs to be known about their individual needs and preferences.

Process determinants. In the IFSMT the process dimension, which is based upon health behavior theories, research, and practice, describes the characteristics of successful self-mangers as people who (a) have information that is consistent with their health beliefs and behavior, (b) develop self-regulation abilities to change behavior, and (c) experience social facilitation (influence, support, collaboration) that positively influences their engagement in health promoting behaviors (Ryan & Sawin, 2009). For the purpose of this study, the patient's knowledge and beliefs about health information technology and its ability to promote healthful, engaged, behaviors is addressed under the process dimension. In addition, the influence of federal HIT programs requiring the distribution of a clinical summary and the support patients receive from the healthcare provider are presented as social facilitation factors.

Knowledge and beliefs about health information technology. Research into the use of computers and the Internet challenges our assumptions about who makes use of technology to access health information. Although 69% of US households reportedly use the Internet, users are disproportionately younger, healthier, wealthier, and more educated than non-users (Choi & DiNotto, 2013a, 2013b; Wen et al., 2010). Only about half of all adults over the age of 65 in the US use a computer (Keenan, 2009). In Keenan's national survey of older adults, seven in 10 (71%) computer non-users said they did not want to learn how to use the computer to access the Internet, citing non-interest (46%), lack of time (11%), technical inaptitude (9%), concerns about privacy (4%), and the expense (4%). Pew investigators Zickhur and Madden reported in 2012 that 50% of US adults over the age of 65 are online, although Internet use among those over the age of 76 is still low, at 34% (Zickhur & Madden, 2012). Others have found that less than 15% of current Internet users are over the age of 70 (Choi & DiNotto, 2013a).

Older adults use the Internet primarily for e-mail communication (86%, with 48% checking e-mail daily) and about a third of them use social media websites such as Facebook or LinkedIn. Older adults reportedly use the Internet for a variety of other reasons including researching topics of interest (57%), making purchases (44%) or travel reservations (41%), banking (34%), and reading the news (31%) (Keenan, 2009). Older adults who use the Internet to research topics of interest are likely to do so in order to access health-related information and are more likely to use private (vs. government sponsored) websites, but they do so infrequently, with just 23% of users accessing websites more than once a month (Choi & DiNotto, 2013a, 2013b; Longo et al., 2010; Miller & West, 2007). Older adults do access personal health records and disease management systems online, but use is significantly predicted by education and race/ethnicity (Geller et al., 2008; Glasgow et al., 2011; Kim et al., 2009; Nahm et al., 2012; Sarkar et al., 2011b). Internet use among low-income older adults does not increase when assistance is provided, including free community-based classes, personal mentored assistance, computers, and Internet access (Kim et al., 2009; Xie, 2011a, 2011b). These findings are alarming given that healthcare reform focuses heavily on the patient use of HIT, and older adults are frequent users of the healthcare system.

The influence of Meaningful Use. Meaningful Use is a vehicle designed to promote and enhance patient engagement in hospitals and clinics across the country. The Electronic Health Record (EHR) Incentive Program (known as “Meaningful Use”) administered by the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC), provides financial incentives to physicians and other eligible professionals[1] (EPs) when they attest to the meaningful use of an ONC-certified[2] EHR by meeting a series of measures and objectives during each stage of the program. Meaningful Use was designed to provide a technological infrastructure for healthcare providers as they support patient engagement with the plan of care. In Stage 1 of the program, the provision of a paper-based, EHR-generated, clinical summary is required. Technology vendor developers (e.g. Cerner, Epic, Allscripts) for each certified EHR designed clinical summaries, which contain the plan of care. To meet certification standards, the EHR clinical summary must contain an updated medication list, problem list, a list of procedures, labs and other orders, instructions given to the patient based on clinical discussions that took place during the visit, the times and locations of upcoming tests and appointments, recommended patient decision aids, and any recent test results (ONC, 2014a, 2014b; US Department of Health and Human Services, 2010). Beginning January 2014, Stage 2 requires that patients of EPs access (view), download, and transfer electronic personal health information from a practice-based patient portal to other members of their healthcare team (US Department of Health and Human Services, 2012a, 2014). This is the latest tactic in the CMS/ONC strategy to promote the meaningful adoption and use of EHR among the nation's healthcare providers, thereby enhancing patient engagement and improving the coordination of care (US Department of Health and Human Services, 2010). The provision of the electronic clinical summary through the patient portal is unique to Stage 2, as is the requirement that patients use secure messaging (e-mail) to communicate with providers (US Department of Health and Human Services, 2014). These requirements were designed to further promote patient and family engagement, a national health priority area (Agency for Healthcare Research and Quality, 2013), and a main goal[3] of the EHR Incentive Program (US Department of Health and Human Services, 2010). The EHR incentive program comes at a cost of $33 billion to American taxpayers (US Department of Health and Human Services, 2012b, 2013a, 2014) yet there is little evidence that distributing vendor-designed clinical summaries will in fact facilitate patient engagement or improve care coordination.

During the time frame of this research, physicians attested to either Stage 1 or Stage 2 measures and objectives, depending on which calendar year they began the EHR Incentive Program. The clinical summary that is given to the patient, as a piece of paper or electronically through a patient portal is herein referred to as the plan of care (POC). Emerging national guidelines suggest that the POC should include the documentation of patient preference and engagement in care planning, be co-created by members of an interdisciplinary healthcare team in consultation with the patient and family, and be readily accessed from multiple care settings. This is likely to take the form of an electronic longitudinal plan of care (eLPOC), defined as a single, integrated plan that is patient-centered, reflects the patient's values and preferences, engages all team members (including patient and family caregivers) in its development and reconciliation, supports the achievement of patient goals along the continuum of care, and facilitates cohesive transitions in care (Agency for Healthcare Quality and Research, 2011; American Geriatrics Society, 2012; Dykes, 2013).

The support from a provider. Through various health reform initiatives, older adults are being asked to change they way they interact with the healthcare system by using HIT and to interact with healthcare providers in a way that may be foreign to their previous care-seeking experiences.

Older adults may be accustomed to older, paternalistic models of healthcare delivery in which the provider (vs. an interdisciplinary team) filters information, makes treatment decisions, and communicates in a non-technological way that assures the “doctor knows best”. These relationships stand in stark contrast to modern dyads based on shared decision making and HIT whereby the provider-patient relationship is built upon trust and mutuality and information is readily available and transparent (Fiks, 2011; Tovey, 2006).

Older adults may be accustomed to a relationship with a single physician that lasts over a long period of time, increasing the amount of confidence that the patient and family places in the physician. Today, older adults are likely to seek care in environments where providers change annually based on insurance contracts, specialist availability, emerging Accountable Care Organization membership, and other factors. In addition, older adults may not be familiar with newer types of healthcare providers such as advanced practice nurses (NP) and physician assistants (PA). This research will focus specifically on the relationship older adults have with their physician- cardiologist because (i) NP and PA providers are still relatively new and are limited in number, (ii) older adults likely have more experiencing interacting with physicians vs. NPs or PAs, and (iii) the Medicare EHR Incentive Program focuses on physicians and excludes NP and PA providers.

The complexity and constant change inherent in the healthcare system have the potential to diminish the trust relationship, yet trust is foundational for a successful relationship between patients and providers; it is a key component of the healing process (Stepanikova, Mollborn, Cook, Thom, & Kramer, 2006). When trust is absent, patients are less adherent with agreed upon treatment plans, less satisfied with their care (Hall et al., 2002; Thom & Campbell, 1997), and experience poorer health outcomes (Berrios-Rivera et al., 2006; Mollborn, Stepanikova, & Cook, 2005; Safran, Kosinski, et al., 1998; Stepanikova et al., 2006). Patient involvement with the plan of care has been positively associated with patient's trust in providers. Trusting a physician increases patient willingness to seek care (Trachtenberg, Dugan, & Hall, 2005) and follow provider recommendations (Kowalski et al., 2009).

Furthermore, the nature of the relationship that older adults have with their physicians may be different from the relationship a younger patient experiences today. It was not uncommon for older adults to be socialized from a young age not to question people in authority, such as a physician. According to politeness theory, people who perceive that they are less powerful than another use more indirect and nonverbal actions to communicate, thereby increasing the likelihood that their comments and questions will be given adequate consideration by the listener (Spiers, 1998). Older adults may not be comfortable performing the active behaviors that are required of engaged patients, such as asking questions when explanations or next steps are unclear, expressing concerns about recommendations or the care experience, asking about the evidence for the efficacy of treatment options, and negotiating a treatment plan (Center for Advancing Health, 2010). Older adults may not have the attitudes that facilitate engaged behaviors implicit in healthcare reform.

Proximal outcome. In keeping with the IFSMT, patient engagement is seen as the proximal outcome in this research. Proximal outcomes are defined as actual engagement in self-management behaviors and the costs associated with healthcare use, whereas distal outcomes not measured in this research (health status, quality of life, direct and indirect cost of health), are related to the successful achievement of proximal outcomes (Ryan & Sawin, 2009).

Patient engagement. Patient engagement is receiving an unprecedented amount of attention as various stakeholders seek to promote the national quality agenda of improved population health, an enhanced patient care experience, and control or reduction in the per capita cost of care by engaging patients in their own healthcare (Agency for Healthcare Research and Quality, 2013; Institute for Healthcare Improvement, 2012). Patient engagement is most commonly defined as the "actions individuals must take to obtain the greatest benefit from the health care services available to them" (Center for Advancing Health, 2010). Professional organizations and investigators have contributed to the current literature base on engagement in three areas by defining the principles of engagement, identifying engagement behaviors, and describing the current state of engagement across the country.

Principles. Nurse investigators, administrators, and policy makers have promoted nine principles for patient engagement that advocate for (a) an active partnership among patients, their families, and their providers, (b) acknowledgement that the patient is the best and ultimate source of information about his/her condition and retains the right to make decisions about care, (c) shared responsibilities for patient and provider, (d) the ethics of privacy, competent decision making, and confidentiality through respecting boundaries, (e) patient rights including mutuality as it pertains to the sharing of information, (f) professional assessment of the degree to which patients and families are able and desire to engage, (g) advocacy for patients who are unable to fully participate, (h) an appreciation of culturally, racially, or ethnically diverse backgrounds, and (i) the sharing of information readily understood by patients and families (Sofaer & Schumann, 2013). These principles were developed from a synthesis of the literature and research on patient engagement by a panel of experts and a consensus process driven by the National Alliance for Quality Care and its 22 member organizations. The principles have been widely disseminated through the national nursing community, health care entities, health professions disciplines, consumer groups and stakeholder groups.

Behaviors. Ten specific behaviors are associated with patient engagement. Teams of investigators (Center for Advancing Health, 2010; Gruman et al., 2010) have identified that engaged patients (a) find good care, (b) communicate with health care professionals, (c) organize health care, (d) pay for health care, (e) make good treatment decisions, (f) participate in treatment, (g) promote health, (h) get preventative care, (i) plan for the end of life, and (j) seek health knowledge. Identifying relevant behaviors is the first step in developing strategies that will enhance engagement, such as changing practice design and provider behavior through the patient centered medical home movement, encouraging patient involvement with treatment decisions by providing tools and provider training, increasing public reporting initiatives, or offering chronic disease self-management incentives (Center for Advancing Health, 2010). The proposed research focuses on individual behavior and personal responsibility, primarily as patients and their families make good treatment decisions and participate in treatment as documented in the plan of care.

State of engagement. Engagement has been measured in a variety of ways in multiple studies, most commonly by the achievement of condition specific clinical outcomes (e.g.: blood pressure, cholesterol, blood glucose). The Patient Engagement Measure (PAM) is the only standardized measure used to assess engagement, and it has been used infrequently. The following interventions have been tested for their ability to enhance patient activation, estimating the propensity for engaged behaviors.

The Chronic Disease Self-Management Program (SDSMP) is an evidence-based program that seeks to improve patients' ability to self-manage a variety of chronic diseases through the development of skills over six week group sessions. Multiple randomized controlled trials have demonstrated the effectiveness of CDSMP in improving health related quality of life as well as physical and emotional outcomes such as reductions in fatigue, pain, and social limitations, and increases in exercise, psychological well being, partnerships with providers, disease-specific health outcomes, and self-efficacy (Gordon & Galloway, 2008; Lorig et al., 1999). Twice the CDSMP has been evaluated for its ability to increase PAM scores over time, and both times significant improvements were noted (Druss et al., 2010; Hibbard et al., 2007).

Coaching is another intervention that attempts to increase patient engagement. Nurse coaches meet regularly with patients, educating them about chronic diseases, medications, and treatment plans, helping patients and families to cope with chronic illness. Coaching interventions have led to improvements in mortality, physical and cognitive functioning, medical condition, quality of life, patient, caregiver, and provider satisfaction, while reducing behavioral problems, costs, and expensive inpatient utilization (Chiu & Newcomer, 2007; deBruin, 2012). Only two studies have used the PAM to measure the effectiveness of nurse coaching on patient activation scores. In each study, coaches used pre-intervention PAM scores to tailor health messages appropriately (e.g.: encouraging patients with low activation scores to make small changes to achieve success quickly). This approach was effective at increasing activation scores, LDL medication adherence, and healthy behavior changes, and decreasing hospitalizations and emergency room use (Hibbard et al., 2009; Shively et al., 2013).

Employers responsible for organizational healthcare plans are keenly interested in patient engagement because high activation scores are linked with better health, resulting in less absenteeism and lower costs. Employers are therefore working to create a "culture of health" through workplace wellness program that include health risk assessments, discounted health club memberships, regular health education seminars, the distribution of educational material, information campaigns, the advent of walking meetings, onsite nurse-run clinics, gift cards for meeting health goals, and changes to office cafeterias and vending machines that incorporate heart-healthy diet choices (Anderko et al., 2012). Only one study to date has measured patient activation as an outcome of workplace wellness interventions, finding that PAM scores increased regardless of whether employees were participating in a population-based traditional workplace wellness program or an enhanced program that included personal coaching (Terry, Fowles, Xi, & Harvey, 2011).

Without measuring activation specifically, several HIT intervention have been tested for the ability to enhance engagement measured by various outcomes, particularly in patients with chronic disease (Emont, 2011). Patient websites, including personal health records, increase knowledge (Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009; van der Vaart et al., 2014), the use of patient-centered decision support (Rosenbloom et al., 2012), the perception of high-quality care (Schnipper et al., 2008; Wade-Vuturo, Mayberry, & Osborn, 2013), medication management (Adler, 2006;

Sarkar et al., 2014c), and patient-provider communication (Adler, 2006; Lyles et al., 2013).

Recently Project Open Notes allowed over 13,500 patients of 105 east coast primary care providers to access their provider's notes through a secure patient portal over the course of 18 months. The intervention enhanced patient and provider satisfaction (by an author-created scale) and did not increase utilization as measured by phone calls to the office or longer encounters (Delbanco et al., 2012). A variety of applications on personal computers (e.g.: smart phones, tablets) have been used to monitor a variety of physiological data (e.g.: heart rate, oxygen saturation, ECG rhythms), to access records and to promote healthy behavior (e.g.: weight loss, smoking cessation, taking prescribed medication) (Chung & Tritle, 2013). The use of cell phone apps promotes medication adherence, communication regarding key issues (ie: whether to get a flu shot), improved access to in-network and appropriate care, and the perceived quality of care without increasing health care utilization (Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Logan et al., 2012; Logan et al., 2007; Seto, Istepanian, Cafazzo, Logan, & Sungoor, 2009).

Finally, researchers at Northeastern and Boston Universities have used conversational agents to promote patient engagement. Conversational agents are computer-generated "Avatar" like figures that talk to the patient and respond to patient questions and direction on a tablet computer. Older adults with limited health literacy who were exposed to conversational agents at discharge reported improved satisfaction with the discharge process (Bickmore, Pfeifer, & Paasche-Orlow, 2009). Interestingly, patients in early studies preferred the conversational agent to their doctor or nurse because the agent took its time, was easier to understand, was non-judgmental, and expressed empathy and caring (Bickmore, Pfeifer, & Jack, 2009). Agents used in other studies have been effective at promoting healthy behaviors such as regular exercise and improved medication adherence (Bickmore, Caruso, & Clough-Gorr, 2005; Bickmore et al., 2009; Bickmore & Picard, 2005).

Taken together, these findings suggest that it is possible to increase activation that results in engaged behavior through the tailoring of health-related messages and providing social support that promotes healthy living. To date, little is known about methods for engaging older adults in particular and the use of the PAM is not routine. Exploratory research is integral to advancing interventions tailored to meet the needs and preferences of older adults. Since tailoring is complex and expensive, recent studies that utilize computer technology to support patients without impacting utilization suggest alternative ways to scale a variety of interventions.

Summary

Despite the current emphasis on patient engagement in our healthcare system, current research suggest that older adults may encounter significant barriers to co-creating the plan of care with their physicians and other members of the increasingly multi-disciplinary healthcare team. Older adults are living with multiple chronic conditions and disproportionately bear the burden of limited health literacy and low patient activation. These factors make it more difficult for older adults to engage in the self-management behaviors expected of younger, healthier, and more literate adults. Federal Meaningful Use standards require patients to interact with their healthcare providers electronically, but only 50% of older adults use any kind of computing device with which they can access the Internet for health information. There is little research to suggest that HIT is an effective method for enhancing patient engagement or the types of information that are helpful to older adults managing multi-morbidities and whether HIT can help them to be more successful. Older adults, especially those from lower socio-economic classes and minority ethnicities with limited health literacy, may not posses the characteristics required to successfully self-manage multi-morbidities and improve their health status at a reasonable cost, thwarting national attempts to achieve the Triple Aim.

CHAPTER 3

METHODS

A qualitative descriptive research design was utilized in this study (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000b, 2010). A qualitative methodology was the preferred approach for this research for several reasons. First, little is known about the ways in which older adults with multi-morbidities make use of HIT or the value and importance they place on engaging in their healthcare through negotiating the plan of care with a provider. Second, existing health literacy and self-management theories do not specifically link the concepts of health literacy and the newer concept of patient engagement. Third, knowledge of the process by which older adults with multi-morbidities engage with the POC and with HIT is essential for developing research-based interventions for testing their ability to increase patient engagement.

The qualitative descriptive approach, as described by Sandelowski (Sandelowski, 2000a, 2000b, 2010), entails a basic or fundamental qualitative descriptive style that does “not require a conceptual or otherwise highly abstract rendering of data” (Sandelowski, 2000b, p. 335), which is fundamentally different from high-inference qualitative approaches such as phenomenology or grounded theory. Because qualitative descriptive investigators “stay closer to their data and to the surface of words and events” (Sandelowski, 2000b, p. 336), there is a focus on descriptive validity, whereby diverse investigators agree on the accuracy of an event, described fully in everyday language. In order to further enhance validity, information gathered through interviews was triangulated (Denzin & Lincoln, 1994; Miles & Huberman, 1994) with data gathered from standardized instruments in order to more adequately describe various characteristics of the sample population. Further triangulation occurred as the investigator observed patients interacting with their physician to create the plan of care. The observation was a critical research design element because it represented the only opportunity for the investigator to witness the actual occurrence of care planning.

Other cardinal features of the qualitative descriptive approach include: (a) a broad range of choices for theoretical or philosophical orientations, (b) the use of virtually any purposive sampling technique (e.g.: homogenous, typical case, criterion), (c) the use of observations, document review, or minimally to moderately structured interview or focus group questions, (d) content analysis and descriptive statistical analysis as data analysis techniques, and (e) the provision of a descriptive summary of the informational contents of the data organized in a way that best fits the data (Neergaard et al., 2009; Sandelowski, 2000b, 2001, 2010).

Sample

The inclusion criteria for this study were English-speaking older adults, aged 65 and older, with at least two chronic cardiovascular diagnoses who receive care in an outpatient cardiac clinic participating in the EHR Incentive Program. English language proficiency was not tested formally; rather participants who were readily able to converse with the researcher and respond to questions were included. Older adults with a dementia-related diagnosis on their problem list were excluded from this research. A total of 40 participants was anticipated to be adequate for achieving informational redundancy, defined as the point at which additional data reveals no new properties or insights (Sandelowski, 1995b; Sandelowski, 2000a).

CVD was chosen as a diagnostic category on which to focus because of its prevalence in older adults (Centers for Disease Control, 2011), the necessity of a multi-component plan of care for self-management, and its alignment with national quality priorities (Agency for Healthcare Research and Quality, 2013). The multiple case sampling technique (Miles & Huberman, 1994) used in this research represents the investigator's attempt to examine a range of similar and contrasting cases, allowing for the comparison of respondent perspectives based on the theoretical sensitizing concepts guiding this research: varying health status (number and variety of chronic diagnoses which are common to patients in this age range seen at these settings), degrees of health literacy, patient activation scores, and knowledge/belief of HIT. Purposive, conceptually-driven sampling (Miles & Huberman, 1994) will allow the investigator to highlight the range of experiences of older adults, who are represented in only 5% of the clinical trials published by high-profile journals, despite the fact that older adults account for the majority of healthcare utilization and expenditures (Zulman et al., 2011). Almost half of the published articles reviewed (*n*=109) in Zulman's research excluded participants based on criteria such as physical disabilities or functional limitations, decreased life expectancy, and age related cognitive impairment. Exclusion criteria such as these bias samples toward the involvement of healthier older adults and intentionally exclude participants for the very reason that makes studying them so important. This study did not exclude participants based on the presence of multi-morbidities including cognitive impairment in an attempt to truthfully represent the experience of older adults and their attempts to engage in care planning. Instead, cognitive status was assessed so that variations in cognition can be evaluated for their impact on engagement behaviors.

Physicians recruiting participants for this study have access to a multi-disciplinary problem list maintained within their EHR according to Meaningful Use standards and often have an existing relationship with the patient. Using their professional judgment, chart review, and experience with the patient, they recruited patients they believed would be able to participate in this study. These practices are in line with sampling techniques and inclusion/exclusion criteria used in other research evaluating patient activation and engagement (J. Hibbard, personal communication, June 11, 2014).

Setting

Two cardiology practices were selected for this research, both located in the American southwest: Cardiac Solutions in urban, residential, middle-income, Glendale, AZ, and New Mexico Heart Institute in urban, downtown, low-income, Albuquerque, NM. One recruiting physician has been selected at each site. These particular settings were selected by convenience for the following reasons:

- Both settings use an EHR and comply with federal Meaningful Use regulations, providing access to either a POC or an ePOC for patients at the conclusion of the encounter.
- The investigator has experience working with each clinic to implement and optimize their respective EHRs. Accordingly, the investigator is well-known to the supervising physicians at each site and each site has extensive experience with her presence in the exam room while conducting a clinical encounter, thereby limiting investigator effects on data collection.
- The clinics are located in parts of Arizona and New Mexico with the greatest populations of Hispanic/Latinos and the highest incidence of CVD-related mortality (Humes, Jones, & Ramirez, 2010), reflecting the demographic composition of the southwest states (Table 2), thereby offering the opportunity for maximum comparison across a variety of concepts and variables and increasing the transferability of findings.
- The clinic settings and physicians were selected intentionally to be as similar as possible (Table 2) while allowing for oversampling of certain ethnic groups

(Hispanic/Latinos) who are known to have high rates of CVD, limited health literacy, and computer/Internet proficiency.

Table 2

Research Setting Similarities

Variable	Site	
	Cardiac Solutions, AZ	New Mexico Heart Institute, NM
Practice type	Outpatient cardiology	Outpatient cardiology
Physician type	Cardiologist (non-invasive)	Cardiologist (non-invasive)
Physician gender	Male	Male
Overall mean provider satisfaction score (patient rated)	92% (past month)	94% (past quarter)
Average number of diagnoses/claim	5	4
Top 3 diagnoses (ICD-9)	Atrial Fibrillation (427.31), Essential hypertension, unspecified (401.9), Hyperlipidemia (272.4)	Chest pain (786.50), Atrial Fibrillation (427.31), Long-term current use of anticoagulants (v58.61)
EHR Incentive Program 2014	Attesting to Stage 1	Attesting to Stage 1
Patient Portal	Operational	None
Average age of patients served	73	60
% Male (practice, state*)	48,49.7	48.2, 49.6
Ethnicity (practice, state*):		
% Hispanic/Latino	25.1, 30.3	29.3, 47.3
% Non-Hispanic/Latino	74.9, 69.7	70.7, 52.9
Race (practice, state*):		
% White	60, 84	64, 82.9
% Black/African American	2, 4.6	1.3, 2.5
% Asian/Native Hawaiian/Pacific Islander	0.5, 5.3	1, 1.8
% American Indian/Alaskan Native	0, 3.5	4.2, 10.4

*Gender, Ethnicity, and Race by State: US Census Bureau (2013). 2013 Population Estimates: Annual Estimates of the Resident Population by Sex, Race, and Hispanic Origin for the United States, States, and Counties: July 1, 2013. (Report # PEPSR6H) Available at: https//factfinder2.census.gov

Data Collection

Recruitment strategy. Participants were recruited using purposive, conceptually-driven, multiple-case sampling, in which heterogeneity in literacy, activation, chronic diagnoses, and HIT use could be explored in order to "document diverse variations and identify important common patterns" (Miles & Huberman, 1994, p.29). During their regular clinic appointments, physicians asked patients who met inclusion/exclusion criteria if they were willing to participate in a brief project to discuss patient and physician communication. The investigator obtained informed consent (Appendix A, B) after describing the planned observation of the clinical encounter, an interview lasting no more than twenty minutes, and the completion of a demographic form and standardized instruments at the conclusion of the encounter.

These recruitment procedures were piloted successfully with 14 patients in three different outpatient clinics during preliminary research. Specifically, the presence of an additional healthcare professional in the examination room is considered commonplace in healthcare as experienced practitioners train medical, nursing, and interdisciplinary students by having them observe and participate in clinical encounters. Participants formed a rapid trusting relationship with the investigator during the interview phase because of her introduction by a trusted physician and presence in the exam room. Participants frequently made eye contact, gestures (e.g.: head nods), and facial signals (e.g.: smiling) toward the investigator, who was silent and non-participatory during the encounter, seemingly seeking acknowledgement that they were being heard and attempting to welcome her into the encounter. While the presence of the investigator in the exam room may be seen as a limitation, it appeared to facilitate the trust relationship between participant and investigator during preliminary work. During the interview, participants frequently referred to comments made during the encounter in brief, explained by remarks such as “well, you heard me talk about that” or “you know, when I was asking him about that”. Neither the physicians nor the patients reported feeling awkward or uncomfortable with the investigator’s presence in the exam room. The investigator was never asked to leave an exam room for privacy or other reasons.

Family caregivers were included in the research observation and interview when they accompanied the patient to the provider office and participated in the clinical encounter. Family participation is a central part of the IFSMT guiding this research as it is in national patient and family centered care initiatives (Agency for Healthcare Research and Quality, 2013; Anyfantakis & Symvoulakis, 2011; Institute for Patient and Family Centered Care, 2013; Institute, 2014; Kass-Bartelmes & Hughes, 2003; Patient-Centered Outcomes Research Institute, 2014; Ryan & Sawin, 2009; Siminoff, 2013; Steinhauser et al., 2001). Family caregivers participated in the clinical encounter for multiple reasons: to assist with ambulation and transportation, question-asking, information-gathering, accurate reporting, out of concern for a loved one, and to provide emotional support. In order to elicit family caregiver perspectives without crowding out the voice of the participant, effort was focused on attending to non-verbal cues, looking patients in the eye, directing questions to the patient, and when necessary, directly asking the patient for feedback. Field notes used during the observation as well as interview transcripts were marked in a way that identified patient vs. family caregiver comments and behaviors.

Informed consent. The study protocol was reviewed and approved by the Arizona State Institutional Review Board (STUDY00001433). It was classified as an expedited (low-risk) study requiring informed consent (Appendix A, B).

An overview of the recruitment procedures, including informed consent, are as follows:

1. Physicians at each site identified patients based on the inclusion/exclusion criteria (English-speaking adults aged $\geq$65 with at least two chronic CVD diagnoses and without a dementia-related diagnosis) and introduced the investigator while the patient was being escorted to an exam room.
2. As such patients were willing to learn about the study, the investigator explained the study using IRB-approved information, which was read aloud to participants to circumvent literacy or vision-related issues. Informed consent was obtained and the appropriate document signed.
3. The investigator remained in the exam room so that patients (and their family caregivers, if present) could be observed during the clinical encounter with the physician. Engagement behaviors related to the co-creation of the plan of care were recorded using an observation worksheet.
4. At the conclusion of the clinical encounter, the patient and investigator moved to a private room where patients were interviewed. Semi-structured interview questions derived from the literature and theoretical framework elicited patient (and family caregivers when they were present) preferences for information and the modality in which it was deployed (e.g., hard copies, patient portals or personal health records), to gain insight into patient values and beliefs about their health, knowledge about the plan of care, and the degree to which they desired physician office assistance in care planning.
5. Participants answered questions from a short demographic form including a single item health literacy assessment, the patient activation measure, and completed the Mini-Cog.
6. As a thank-you for participation, the investigator gave each participant a printed copy of the AHRQ tip sheet “Quick Tips for Talking with Your Doctor”

(Agency for Healthcare Research and Quality, 2002), a pen, and a small journal for taking notes at future appointments.

Data Collection Devices

Data were collected with the following devices in this order: an investigator-designed worksheet during the observation (Appendix C), an investigator-designed demographic form (Appendix D), standardized, reliable and valid instruments for measuring health literacy (Appendix D), and patient activation (Appendix E), investigator-designed interview questions (Appendix F), and a standard measure of cognition (Appendix G, H). Table 3 summarizes the psychometric properties of the scales used in this research.

Observation worksheet. An investigator-designed worksheet was used to record observations during the clinical encounter (Appendix C). The worksheet contained a pre-printed list of behaviors derived from the patient engagement framework, proposed to characterize an engaged patient, that could be observed during a clinical encounter, such as "asks about the risks and benefits of recommended treatments" or "brings a summary of medical history and recent test results to discuss" (Center for Advancing Health, 2010), and provides ample space for making field notes. Examples of possible ways that engaged behaviors may be observed in clinical interactions were included in the worksheet. The use and design of the worksheet was assessed during patient observations and twice revised for more efficient data collection (i.e.: categorizing behaviors under general headings). Specifically, behavioral categories were re-ordered to correspond to the way they naturally present during an encounter (i.e.: reporting current symptoms and medications before asking about the risks and benefits of proposed treatments).

The worksheet was primarily used for recording investigator comments and observations (i.e.: making field notes). It was not intended to be used solely as a checklist. The investigator observed for other indications of engagement and other phenomena of interest and was not limited by the list of sample engagement behaviors.

Demographic form. Participants completed an investigator-designed demographic form (Appendix D) that captured data known from the literature to influence health literacy and patient activation including age, ethnicity, race, income, education level, and health status by the listing of current diagnoses (Hibbard & Cunningham, 2008; Paasche-Orlow & Wolf, 2007).

Single item health literacy screener. Participants completed a short health literacy tool, the Single Item Health Literacy Screener (Chew, Bradley, & Boyko, 2004; Morris, McLean, Chew, & Littenberg, 2006), included with the demographic form (Appendix D). The Single Item Health Literacy Screener (SILS) was designed to identify patients with inadequate or marginal health literacy quickly in an office setting. The SILS was created by developing 16 questions based on five domains identified in a qualitative study of patients with limited health literacy (Chew et al., 2004). They were compared against two validated measures, initially with the short version of the Test of Functional Health Literacy in Adults (sTOFHLA), a gold standard in health literacy research (Baker, Williams, Parker, Gazmararian, & Nurss, 1999), and later with the Rapid Estimate of Adult Literacy in Medicine (REALM) (Arozullah et al., 2007; Osborn et al., 2007). Initial testing revealed three questions that detected inadequate health literacy with a 95% CI (Chew et al., 2004): “How often do you have someone help you read hospital materials?”, “How confident are you filling out medical forms by yourself?”, and “How often do you have problems learning about your medical condition because of difficulty understanding written information?” (AUROC = 0.87, 0.80, and 0.76 respectively). In a sample that was 8.5% non-Hispanic white and 52.7% Hispanic-white, (*n*=1796), the "confidence with forms" question best detected inadequate (C-index=0.82, 9.77-0.87, p<.01) and marginal (C index=0.81, 0.76-0.86, p<.01) health literacy and marked the first time the SILS was examined in an ethnically diverse and 48% Spanish speaking sample (Chew et al., 2008). While the use of single-item measures is criticized for reliability issues, the SILS demonstrated higher sensitivity and lower specificity at any cut point in comparison to the sTOFHLA with less time and effort (Sarkar, Schillinger, Lopez, & Sudore, 2011). It consists of one question: "How confident are you filling out medical forms by yourself?" with possible responses ranging from "1" (extremely) to "5" (not at all). Scores greater than 2 indicate possible difficulty with health related material. The instrument has been used exclusively with older adults (>50) in studies validating its use (Chew et al., 2008) and in a sample where greater than one third of participants (*n*=332) were over the age of 65 (Chew et al., 2004).

Three health literacy tools were evaluated during 14 preliminary cases during the fall of 2012 and the spring of 2013 in order to select a health literacy assessment that had strong validity and reliability while being easy to use in the outpatient cardiac office environment. Each of the three tools has demonstrated reliability and validity for measuring health literacy. The decision about the tool used in this study was based on patient responses to each tool, the amount of time required to complete each tool, and insights gained into specific threats to validity and reliability gathered during the pilot. The sTOFHLA, regarded as the "gold standard" in health literacy research, confused five participants. Individuals confused the examples used in the tool with their own clinical situation. In addition, family caregivers persisted in helping complete the tool in spite of instructions to refrain from doing so. A second tool, the Newest Vital Sign (NVS) presented a different challenge. This tool asks the participant to interpret food labels and to complete calculations, for example, "If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?" (Pfizer, 2011; Weiss et al., 2005). All of four participants with whom this tool was piloted stated they disliked it. The tool was commonly handed back to the investigator, with participants telling a story about their food intake instead. Finally, an early version of the SILS, "How often do you have someone help you read hospital materials?" worked well with three of the remaining pilot participants. It was easily understood and could be answered quickly by the patient participant, rather than the accompanying family caregiver. It was subsequently replaced by the stronger "confidence with forms" SILS which was found to better detect inadequate health literacy, as described in detail above, and worked well with the remaining two pilot participants.

Patient activation measure. Participants were asked to complete the 13-item patient activation measure (PAM) that assesses knowledge, skills and confidence for patient engagement through self-management (Appendix E). Using a Guttman format where questions are arranged in such a way that agreement with one question implies agreement with ranked lower-order questions, the Likert-type responses ("disagree strongly", "disagree", "agree", "agree strongly" or "NA") are sorted into one of four progressively higher levels of activation: Level 1 Starting to take a role, Level 2 Building knowledge and confidence, Level 3 Taking action, Level 4 Maintaining behaviors. The PAM has strong construct validity (Hibbard et al., 2005; Hibbard et al., 2004). It has been used almost exclusively in patient engagement studies, providing the opportunity for comparison between low and high scores. The PAM has been used in a nationally representative sample of Americans (*n*=17,800) where most of the difference in activation scores was attributed to education, race/ethnicity, age, and insurance coverage. The PAM has been used in a nationally representative sample of 12,396

Americans, although Hispanics were under-sampled (8%). Patient activation was lower for foreign-born and second generation Hispanics than for non-Hispanic Whites, but no difference was noted among third-generation Americans (Cunningham, Hibbard, & Gibbons, 2011). Older adults were found to be significantly ($p<.05$) less activated than younger adults, and those with multi-morbidities were significantly less activated than those without (Hibbard & Cunningham, 2008). The PAM is a proprietary measure and permission for its use was obtained.

Interview questions. Investigator-designed semi-structured interview questions were used to solicit the patient's preferences and experiences regarding engagement through self-management with the plan of care (Appendix F). The interview questions were created initially in consultation with faculty advisors based on the research question, a review of the literature, the IFSMT, and expert review. They were tested in interviews during the preliminary study for this research, and refined in consultation with faculty advisors through multiple courses and research meetings. Sample questions include, "Think about the time you spent today with your doctor. What was the most important thing you talked about?", "What do you do at home to look after yourself?", "Picture yourself in perfect health. What does that look like?", and "How can your doctor help you to achieve perfect health?" At the conclusion of the interview, patients were encouraged to offer any other thoughts or observations by responding to the final prompt, "Is there anything else you would like to tell me about today's visit?" The interview was digitally audio-recorded.

Mini-Cog. Mayo Clinic investigators recently discovered rates of mild cognitive impairment in non-demented older adults (70-89 years of age) that approached 16% (Petersen et al., 2010) of the general population. Therefore, the level of cognitive impairment in the sample was assessed so that patterns of engagement could be analyzed across different levels of cognition. The tool was not used as a screening tool for participation in the study. As noted earlier, only a diagnosis of dementia was used as an exclusion criteria. Individuals with cognitive impairment without a diagnosis of dementia and able to interact with the researcher were included in the study in order to include the experiences of older adults with multimorbidities in the research.

The Mini-Cog is a simple tool that was used to detect participant cognitive impairment (Borson et al., 2013; Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000). Patients were asked to listen to, remember, and repeat three unrelated words and to draw a clock face, adding numbers to the clock and setting the hands of the clock at 11:10 (Appendix G, H). The Mini-Cog is scored by giving 1 point for each correctly recalled word, 2 points for a normal clock, and no points for an incorrect clock. Scores of 3 to 5 are negative for dementia. The Mini-Cog has sensitivity ranging from 76-99% and specificity ranging from 89 to 93% with a 95% CI. The Mini-Cog may not measure mild changes in cognition over time, but can decisively detect adequate cognition during routine clinical encounters (Borson et al., 2000; Borson, Scanlan, Watanabe, Tu, & Lessig, 2006; Lessig, Scanlan, Nazemi, & Borson, 2008). This tool has been used extensively with older adults, with ethnic minorities (Borson, Scanlan, Chen, & Ganguli, 2003), and with non-native English speakers (Borson et al., 2000) and found to have better sensitivity (99%, $p<0.001$) than the MMSE (Molloy & Standish, 1997), correctly identifying 96% of cognitively impaired subjects with less time and effort.

Table 3

Psychometric Properties of Data Collection Instruments

Construct	**Instrument**	**Psychometric Properties**
Factors that influence health literacy and/or patient activation	Investigator-created demographic form collecting: age, ethnicity, ace, income, education level, health status by the listing of current diagnoses	Content validity, reviewed by experts and compared to the literature.
Health Literacy	Single Item Health Literacy Screener (SILS): *Chew et al., 2004; 2007*	AUROC of 0.74 (95% CI: 0.69–0.79) based on the S-TOFHLA and 0.84 (95% CI: 0.79–0.89) based on the REALM. Construct validity by comparative testing with the sTOFHLA and REALM.
Patient Activation	Patient Activation Measure (PAM): *Hibbard et al., 2004; 2005*	Rasch (real) person scores ranged from 0.69-0.84, Rasch (model) person scores ranged from 0.72-0.8. Construct validity with variables that have been conceptually and empirically linked with the PAM (ie: general prevention behaviors, disease specific behaviors); Comparison of means meet thresholds (F=3.1-74.4, p=.001).
Cognition	Mini-Cog: *Borson, et al., 2000; 2003; 2006*	Alpha coefficient = 0.92 (p<.001). Construct validity (factor analysis and convergent) by comparison with independent physician assessment; Pearson correlation = 0.65 (p<.001).

Data Management

Separate participant folders containing the observation worksheet, demographic form, and standardized instruments were marked with an alpha-numeric identifier according to site and date, and stored in a locked cabinet in a locked research office at ASU. At no time were names attached to data; a master list of patient names for this study was not necessary. Data from the paper forms were entered into Dedoose (Los Angeles, CA) and double-checked for accuracy by the researcher. Contact summary sheets were created for each participant. Interviews were audio-recorded and those audio files, without personal identifiers, were downloaded from the recorder and stored on a dedicated research computer with password protection and encryption using Truecrypt. They were sent to a third-party transcription service by encrypted, secure e-mail and were transcribed verbatim. Interview transcripts were read in their entirety while listening to voice recordings for accuracy as they were returned to the researcher from the transcription service. Only faculty sponsors and the investigator had access to the research data.

Data Analysis Procedures

Data were simultaneously collected and analyzed in keeping with general principles of naturalistic research that endorse: (a) focused attention on the complex social world in which people reside, (b) conducting research in real-world settings where people are comfortable and familiar, and (c) an appreciation that observations provide invaluable evidence to real-life experiences and a person's reaction to those experiences (Creswell, 2013; Denzin & Lincoln, 1994; Glaser & Strauss, 2012; Lincoln & Guba, 1985; Sandelowski, 1995a). Data analysis techniques (Creswell, 2013; Miles & Huberman, 1994; Sandelowski & Leeman, 2012) consisted of descriptive statistical analysis and directed content analysis.

Descriptive statistical analysis. The quantitative data collected were used to deepen the understanding of and integrate with qualitative data, further describing the participants. Relationships between demographic variables and health literacy and patient activation were explored with correlations. Inferential statistical analysis (i.e.: multiple regression tests) were not included in this analysis as significant relationships were not expected with a sample size of 40 (Soper, 2014). Specifically, quantitative data were explored using graphs such as histograms, boxplots, and bar charts, relating to health literacy, patient activation, age, gender, education, and income.

The sample of 40 adults aged 65-86 was described at the beginning of the Findings chapter, representing the analysis of the elements collected on the demographic form as well as scores from the SILS, PAM, and Mini-Cog using descriptive statistics.

Directed content analysis. Content analysis refers to a technique commonly used in qualitative research to analyze words or phrases in text documents. Directed content analysis was used to identify common patterns of patient engagement with the plan of care revealed through observation and interview in this study. This type of content analysis, used extensively by health investigators, allows the investigator to further describe phenomena that are "incomplete or would benefit from further description" (Hsieh & Shannon, 2005), and represented the dominant analysis. The specific procedures used in this study to perform directed content analysis are described next.

Prior to initiating data collection, a coding manual containing a start list of codes (Fonteyn, Vettese, Lancaster, & Bauer-Wu, 2008; Hsieh & Shannon, 2005; Miles & Huberman, 1994) derived from the theoretical framework, the patient engagement literature, and the analysis of preliminary data, was developed by the investigator (Appendix I). Codes are action-oriented words or labels assigned to designated portions of text which reflect themes, or topics which occur with regularity (Miles & Huberman, 1994). The 10 behaviors listed in the patient behavior framework were used extensively in the creation of the coding manual, linking the theoretical framework to data analysis in a critical and meaningful way. The codes "monitoring symptoms" or "setting goals or priorities" for example, come straight from the patient engagement framework. The coding manual was tested against data gathered in a preliminary study, and was revised as codes were found to overlap or be missing entirely. The coding manual was revised iteratively during this study as data collection and analysis proceeded, and then used to re-code previously coded data. Using this procedure, it was used to revisit the data several times.

Wide right margins in each transcribed document, allowed the investigator to apply codes and generate marginal remarks by hand. Codes are tags or labels for assigning units of meaning to information (Miles & Huberman, 1994, p.57). Marginal remarks are hand written comments entered by the investigator. They represent an attempt to stay “alert and non-routine” about analysis, forming ideas and recording reactions to the meaning of what is seen in the data. Marginal remarks often suggest new interpretations, leads, and connections or distinctions with other parts of the data (Miles & Huberman, 1994). Such remarks are pre-analytic and add meaning and clarity to transcripts.

The investigator took sentences or paragraphs in the transcripts and divided them into meaning units, which are segments of text that contain a single idea. Qualitative data gathered during the study included observation notes consisting of specific engagement behaviors related to care planning and participant responses to interview questions. All of the observation field notes and transcription texts were divided into meaning units and were coded by the investigator. One or more codes were applied to each meaning unit during first-level coding which is highly descriptive in nature.

Conceptually similar codes were organized into categories (codes with more abstraction) through theory-based questioning of each code. Miles and Huberman (1994) provide many examples for creating, categorizing and revising codes, including highlighting a technique used by Strauss and Corbin (1990) that includes growing a list of codes and then applying a slightly more abstract label to the code, creating new categories of codes with each revision. This is often referred to as second-level or pattern coding, a way of grouping data into a smaller number of sets, themes or constructs (Miles & Huberman, p.69). During the analysis of this study's data, patterns were generated and the researcher spent significant amounts of time with different categorizations, asking questions, checking relationships, and generally resisting the urge to be "locked too quickly into naming a pattern" (Miles & Huberman, 1994, p.69). For example, descriptive codes/themes such as "developing a strategy", "learning about a device to keep me alive", and "being cleared for surgery" were initially seen as examples of planning (category/cluster) and then re-categorized into clusters of preparing, learning, and decision making. Eventually they were seen to belong to each of three case summary statements: "I schedule routine visits with my doctor", "I act in ways that support my health", and "I participate in treatment planning".

During this phase of analysis, pattern codes were revised and redefined in the coding manual and exemplars were used to clarify understanding of each code. Miles and Huberman (1994) suggest that software can be helpful during this categorization (counting) step, so lists of observed engagement behaviors were also recorded in Dedoose by code so that frequencies could be captured and analyzed. Despite the assistance of Dedoose, the researcher found that hand-sorting codes into themes and categories was best done on paper.

Analytic memos are defined by Miles and Huberman (1994, p.72) using a classic definition by Glaser (1978) to be "the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding". Memos aided in data reduction by tying together different pieces of data into conceptual clusters. Memos were personal, methodological, and substantive in nature (Miles & Huberman, 1994). Examples include memos about mortality, illness and suffering, self-sufficiency, and face theory. The investigator created an analytic memo for each observation and for groups of observations (e.g. acutely ill patients vs. asymptomatic ones, patients who spoke about the need to be closer to family, Hispanic/Latino patients). These analytic memos were further analyzed by summarizing and creating additional analytic memos for groups of observations that contained similarities, effectively reducing the data collected through observation. Memoing was conducted throughout the analysis, beginning with data collection and continuing to the dissertation findings chapter write-up.

Data displays (matrices), or visual representations containing concepts or variables were helpful in analyzing the data. Data displays help the investigator draw conclusions through an iterative process whereby collected data is represented in data displays, thereby reducing data and conducting further analysis (Miles & Huberman, 1994). Data related to health literacy such as age, gender, ethnicity, income, and education levels were juxtaposed with observational and interview data in order to identify patterns and draw preliminary conclusions (Miles & Huberman, 1994). Data displays were used extensively in this study to categorize, organize, and analyze data. For example, in response to the question, "What do you do to look after yourself?" data displays were useful in reducing codes (i.e.: walking the dog, golfing, spending time with family, sewing) and creating more abstract categories (i.e.: physical activity, relationships, hobbies). The health literacy and activation scores of participants were specifically evaluated with data displays as they related to various engagement behaviors related to care planning observed in the clinical encounter. Data displays provided an opportunity to combine quantitative and qualitative findings, triangulating data collected by standardized measures, forms, observations, and interviews both within-case and cross-case. Triangulation refers to the use of more than one approach for investigating the research question in order to enhance confidence in the findings (Creswell & Plano-Clark, 2007; Denzin & Lincoln, 1994; Denzin, Lincoln, & Giardina, 2006; Sandelowski, 2001). An example of a data display is found in Table 4, where health literacy scores are juxtaposed with willingness to access an ePOC. Findings from data displays were used to generate propositions or hypotheses for further analysis and testing by returning to the interview transcripts and coding manual (Miles & Huberman, 1994).

Table 4

Data Display Exemplar: Health Literacy Scores and Portal Use

Participant	HL score	Use ePOC?	Comment
1	Adequate	No	Cannot think why I would do that
2	Adequate	Maybe	I'm nervous about hackers
3	Lo	No	Do not have a computer
4	Adequate	No	My problem isn't significant
5	Lo	Yes	We have a right to the information

Finally, summation sentences written in the voice of the patient, from the patient perspective, were presented in the findings section of the report along with specific recommendations for the creation of a POC that reflects patient preferences (Miles & Huberman, 1994; Munhall & Chenail, 2008; Sandelowski & Leeman, 2012; Stake, 2010; Wolcott, 2009).

In summary, data were gathered by multiple methods, observation, interview, and the use of standardized measures. They were entered into Dedoose, Microsoft Excel, and Microsoft Word documents. Quantitative data were analyzed with descriptive statistical techniques and qualitative data were analyzed by directed content analysis, relying heavily on the techniques described in Miles and Huberman (1994). These included using a coding manual, applying codes and developing themes and categories using data matrices and analytic memos.

Data Quality

Significant effort was directed toward ensuring the verisimilitude or "truth" of the conclusions drawn in this study through specific techniques that may be broadly categorized as data quality. Miles and Huberman (1994) outline 13 tactics for generating meaning from data and another 13 for testing or confirming findings. They also provide five standards for assessing the quality of conclusions. The techniques relied upon most heavily during this study will be discussed next.

Generating meaning. First, the investigator was watchful for patterns and themes that emerged, counting and clustering in order to assess evidence of patterns. Miles and Huberman (1994, p.246) caution that the human mind finds patterns quickly and easily and that the researcher's job is to see evidence of the same pattern and remain open to evidence that disproves the pattern.

Second, the researcher made an effort to test plausibility, or the sense that an explanation "makes sense" or "fits" particularly with the observations and interviews, particularly those from Hispanic/Latino participants. Because the investigator is Non-Hispanic White and approximately a quarter of the sample was Hispanic/Latino, a culturally and linguistically congruent expert was consulted during the analysis phase to assist with pattern recognition. Cultural competence is defined as a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations whereas culture refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups (Cross, Bazron, Dennis, & Isaacs, 1989). The cultural expert enhanced the investigator's understanding of the participant experiences by reviewing the interview transcripts and discussing their meaning. Cultural competency has been identified as one of the crucial elements to closing the disparities gap in health care (Office of Minority Health, 2013). The cultural expert's perspective enhanced data analysis by highlighting Hispanic/Latino health, healing, and wellness belief systems, the cultural perception of chronic illness and their causes, the behaviors of patients and their attitudes toward healthcare providers, and common perceptions of providers towards patients.

Third, as described in the data analysis section, considerable time was spent clustering data into various conceptual bins or boxes. Fourth, the researcher did a lot of counting which helped to "see what you have" (Miles & Huberman, 1994, p. 253). Counting also helped to verify a hypothesis, for example that health literacy was not related to willingness to access an electronic clinical summary. Miles and Huberman suggest that counting helps the researcher to remain "analytically honest" by not overweighing facts or ignoring data in favor of confirming instances.

Fifth, data matrices were especially helpful in doing what Miles and Huberman (1994) call "unbundling" through the partitioning of variables and not being afraid to rework initial clusters and categories, thereby avoiding "premature parsimony" (p.254). Two additional strategies, the subsuming of particulars into the general and noting relationships between variables (e.g.: age, health literacy, cognition, or computer use and engagement behavior) were also made possible through the use of data matrices and frequent memoing. The researcher sought to answer the question, "What is this specific thing an instance of?" which allowed discrete elements to be subsumed into a more general level of abstraction. In a similar way, the researcher sought to consider the more general or underlying concept when examining participant behavior. For example, telling the doctor about weight gain or asking about jaw pain could be seen as communication around cardiac symptoms or the amount of talking versus listening a patient did in the examination room. Network displays, which suggest stages or steps, were useful for examining relationships, and were created both independently and when discussing findings with supervising committee members.

Testing or confirming findings. Miles and Huberman (1994) provide a list of 13 methods for testing or confirming findings that were helpful during data analysis. Methods that were especially helpful during data analysis are described below.

First, the researcher checked for representativeness by checking findings (summary statements) across all 40 cases. This addressed the tendency of qualitative researchers to "rely too much on articular, insightful, attractive, and intellectually responsive participants" (Miles & Huberman, 1994, p.264). Representativeness was also checked by actively defining and looking for outlier cases.

Second, data were generated by various methods (observation, interview, standardized instruments) in an attempt to triangulate. Triangulation helps the researcher support a finding by showing that independent measures are in agreement. For example, the researchers observed patient behavior during the clinical encounter and asked about after the visit, capturing the participant perspective in transcripts. Furthermore, patient understanding was judged not only by asking a direct question but also by measuring health literacy and cognitive status. Similarly, participants were asked to describe their propensity to engage in self-care at home but the PAM measured the same concept. In short, triangulation strategies allowed the researcher to see and hear "multiple *instances* of it from different *sources* by using different *methods* and by squaring the finding with others" (Miles & Huberman, 1994, p.267).

Third, Miles and Huberman (1994, p.270) write that “surprises have more juice than outliers” meaning that surprises help the researcher to examine expectations, implicit theories, and assumptions. Surprises, such as the revelation that some participants felt that going online to view the clinical summary was a challenge to the trust they had in their physician, allowed the researcher to reconsider the conceptual model and theory supporting this work and go back to the data to support emerging conclusions. Two additional strategies, looking for negative evidence and ruling out spurious relations were especially helpful when examining surprises. For example, asking “do all participants with the same (age, health literacy or PAM score, cognitive status, etc.) feel or act in the same way?” and asking about potential sources of other explanations.

Although seeking feedback from participants (known as “member checking”) is a suggested method for determining if the researcher has accurately captured the participant’s story and can bolster interpretative truthfulness (Koelsch, 2013), it relies on the assumption that there is a fixed truth that can be confirmed (Sandelowski, 1993). Instead, participants may struggle with the level of abstract synthesis presented to them, may have a different interpretation than the investigator, and may even tell stories that they regret sharing or see differently when confronted with them a second time (Sandelowski, 1993). The decision was made not to incorporate member checking in this study.

Assessing the quality of conclusions. Several formal strategies were used to enhance the quality and legitimacy of the conclusions drawn from the data, known as “trustworthiness” and “authenticity” in qualitative research and validity and reliability in quantitative research (Lincoln & Guba, 1985; Miles & Huberman, 1994).

Objectivity (confirmability) is conceptualized as relative neutrality and reasonable freedom from researcher bias and was addressed by: (a) describing the study's methods and procedures in explicit detail, (b) sharing the sequence of data collection, analysis and presentation methods to create an audit trail, (c) being aware of personal assumptions and potential bias, (d) retaining study data and making it available to supervising committee members for evaluation. In addition, the choice of the qualitative descriptive method is specifically noted as having objectivity whereby other investigators having the same experience will agree on the description of events (Sandelowski, 2000a).

Dependability (reliability or auditability) was fostered by consistency in procedures across participants over time through the use of semi-structured interview questions and an observation data collection worksheet. The following procedures were put in place to ensure "quality control" (Miles & Huberman, 1994, p.278):

- Study procedures were derived from the research questions and conceptual theory, which was clearly outlined, so that data analysis could be linked back to theoretical constructs.
- The investigator's role and status within the site (student researcher, non-participatory observer) has been clearly described.
- Findings demonstrated parallelism across sources (cases, context of interview vs. observation, etc.).
- The study design allowed for triangulation (Denzin & Lincoln, 1994) through the use of observations, interviews, and standardized measures to more adequately describe various characteristics of the sample population.

- The clinical encounters for all 40 participants were observed by the same investigator who recorded observations on a pre-printed worksheet developed and tested during preliminary work.
- The interviews for all 40 participants were conducted by the same investigator working from a list of interview questions. Each patient was asked the same questions in the same order. These questions were developed based on theory, revised, and tested during preliminary work and in consultation with faculty advisors.
- To guide qualitative data analysis, a coding manual containing a "start list" of codes derived from the theoretical framework and the patient engagement literature (Fonteyn et al., 2008; Hsieh & Shannon, 2005; Miles & Huberman, 1994) was developed. The coding manual was revised as necessary when codes were found to overlap, be missing, or not fit the data, and then used to re-code previously coded data as often as was needed.
- Data analysis was monitored by experienced qualitative faculty investigators who ensured that the investigator did not go "beyond the data" (Sandelowski, 2000b) in interpretation. In keeping with the qualitative tradition, data analysis and collection occurred simultaneously, giving the investigator the opportunity to correct errors or make revisions.

Credibility or verisimilitude (internal validity) is defined as the truth value of data: Do the findings of the study make sense (Miles & Huberman, 1994, p. 278)? Credibility in qualitative work promotes descriptive and evaluative understanding, which was addressed in this study by: (a) providing context-rich "thick descriptions", (b) checking with other healthcare providers during the spring of 2015 that the findings “ring true”, (c) providing a comprehensive account, (d) using triangulation strategies, (e) searching for negative evidence, and (f) linking findings to a theoretical framework.

Transferability (external validity or “fittingness”) speaks to whether the findings of this study have larger import. This includes a discussion of generalizability. Sample to population generalizability is important to quantitative researchers and less helpful to qualitative researchers who seek more of an analytic or case-to-case transfer (Miles & Huberman, 1994). In this study, transferability was assured by: (a) describing the characteristics of the participants fully so that comparisons with other groups may be made, (b) adequately describing potential threats to generalizability through sample and setting sections, (c) using theoretical sampling, (d) presenting findings that are congruent with theory, and (e) suggesting in chapter five ways that the findings from this study could be tested further.

Finally, Miles and Huberman speak to the utilization, application, or action orientation of the data. “Even if we know that a study’s findings are valid and transferable,” they write, “we still need to know what the study does for its participants and its consumers” (Miles & Huberman, 1994, p. 280). To address application, the findings of this study will be make accessible to potential consumers of information through the publication of manuscripts (in the planning stages), poster presentations (scheduled in April 2015), and summary reports written carefully for participant consumers at each clinic (drafted, waiting for review). In addition, the findings have stimulated a list of specific research-based improvements to the clinical summary which can be shared with policy makers and EHR vendors, helping to solve a local problem and providing solid, tangible recommendations for working with older adults.

CHAPTER 4

FINDINGS

This study sought to describe the ways in which older adults with multimorbidities engaged with the plan of care. The specific aims were to explore (a) the contextual factors that influence patient engagement behavior (e.g. health literacy and patient activation), (b) the role that process determinates (e.g.: technology or physician support) played in influencing engagement behavior, and (c) the engagement behaviors of older adults related to care planning. English-speaking adults over the age of 65 with at least two cardiac diagnoses were recruited into the study, which took place at two ambulatory cardiology clinics in Arizona and New Mexico.

This chapter begins with a description of the sample. Findings are outlined in three main section headings according to the specific aims. They are presented in reverse order so that the reader first learns what participants do to engage (aim three), then explores the process determinates that facilitate engagement behavior (aim two), and finally discovers contextual factors that define participant engagement (aim one).

In the following pages, the reader will be immersed in the perspective of the older adults in this study as they sought to engage with the plan of care and their preferences for patterns of interaction with the healthcare professional's office. Findings from the data are presented in broad categories, with themes identified at the beginning of a paragraph with bold italics in the participant's voice, followed by a general description that includes participant words and supporting literature when appropriate.

Description of Sample

A total of 40 patients participated in this study. Informational redundancy, the point at which no new data or themes were collected, was reached by approximately the thirtieth participant, nevertheless, to test for completeness an additional 10 cases were included. The average age of participants was 72.8, ranging from 65 to 86 (Table 6). Sixteen participants (40%) were female. Nine participants, or 23% of the sample, was of Hispanic origin. There were two (5%) black participants and 38 (95%) white.

Table 5

Description of Sample (n=40)

Variable	No.	%	Mean (Range)
Age			72.8 (65-86)
65-74	27	67	
76-86	13	33	
Female Gender	16	40	
Hispanic	9	23	
Black	2	5	
Income			
≥Enough Money	29	73	
Not Enough Money	11	28	
Education			
≥College	23	57	
≤High school	17	43	
Medicare only	7	18	
Medicare + supplement	33	82	
Visits to Cardiologist, last year			2 (1-6)
Visits to PCP, last year			3 (1-10)
Positive Mini-Cog Screen	6	16	
Positive Health Literacy Screen	21	53	
Caregivers present	15	38	
Caregiver present with +MiniCog	4	67	
PAM			
Level 1	13	33	
Level 2	4	10	
Level 3	12	30	
Level 4	11	27	

The majority of participants (22) in this study reported having enough money (55%), another seven reported having more than enough money (18%) and 11 participants (28%) reported not having enough money at the end of the month. Seven participants (18%) reported having only Medicare insurance; the rest had Medicare plus a supplemental. This was a highly educated sample, with over half of the participants

(58%) having at least a college education; 17 (43%) had four-year degrees and 6 (15%) had graduate degrees. Only one participant had not completed high school; 6 others (15%) had completed high school.

Participants reportedly saw their cardiologist an average of two times in the last year (1-6) and their primary care provider (PCP) three times in the last year (0-10). Of note, in Albuquerque, New Mexico there was an extreme shortage of PCPs leading some patients to seek typical primary care services (e.g. the refilling of non-cardiac medication) from their specialty providers.

Charts were reviewed by the recruiting physician to confirm the presence of at least two cardiac diagnoses. Participants were asked for their list of cardiac diagnoses when they were not readily apparent (i.e.: heard during the observation) to confirm their eligibility for the study. Each participant had at minimum two cardiac diagnoses. The most common diagnoses were coronary artery disease, hypertension, dyslipidemia, heart failure, mitral valve disease, and atrial fibrillation.

Participants were asked to complete the Mini-Cog, a simple screening tool used to detect cognitive impairment during routine outpatient encounters. In this study, the participant score on the Mini-Cog was used as a descriptive variable and not as exclusion criteria. Individuals with some degree of cognitive impairment as evidenced by scores lower than three on the Mini-Cog, who did not have a dementia-related diagnosis on the problem list were included as they were able to converse with the researcher and responds to questions (National Institutes of Health., 2009). The intent was to include individuals with a range of cognitive ability while adhering to exclusion criteria and the protection of human rights for severe cognitive impairment. The National Institutes of Health and others have noted that individuals with mild cognitive impairment are commonly excluded from research while they are still able to participate (National

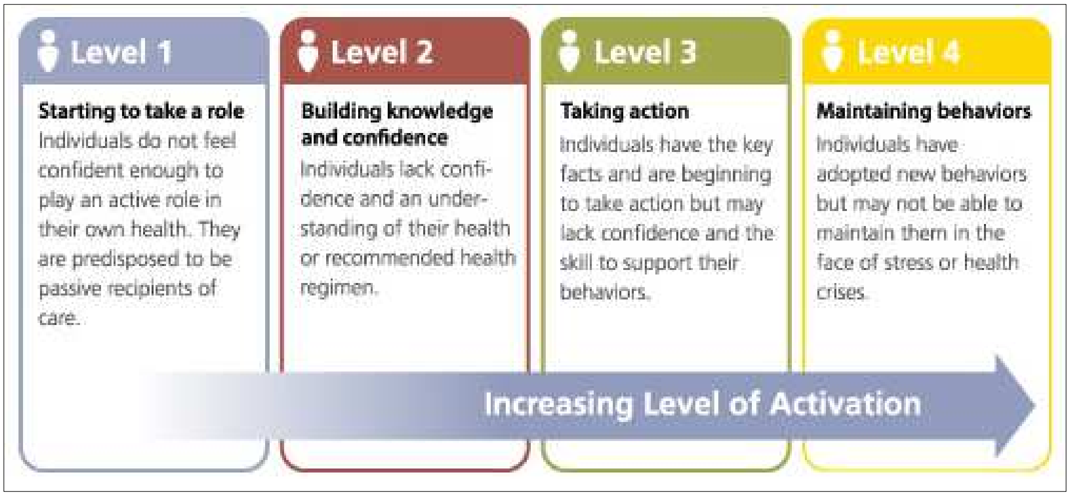
Institutes of Health., 2009; Zulman et al., 2011). In an attempt to represent the population of older adults with multi-morbidities, which commonly includes some cognitive impairment, these participants were intentionally included.

Each of the forty individuals participating in the study did not have a diagnosis of a dementia-related illness and was observed to be able to converse with the researcher and answer questions. Six participants (16%) scored positive for cognitive impairment on the Mini-Cog, approximately representing the national average. According the CDC, 5.1 million people over the age of 65 live with cognitive impairments, representing 12% or 45.1 million, of the older adults in the US (US Bureau of Statistics, 2014; Centers for Disease Control., 2011) and recently, researchers at the Mayo Clinic have suggested that it may be as high as 16% of the population (Zulman et al, 2011).

Fifteen participants (38%) in this study brought a family member with them to the physician's office, identified as the "family caregiver" for the purposes of this study. Four of the six (67%) participants who screened positive for cognitive impairment brought a caregiver and two (33%) did not. Family caregiver responses during the interview and observation were treated as one with the patient's response and were frequently used to elicit clarification from the patient or to support the patient's perception or experience.

Participants were verbally asked to answer the SILS, a measure of health literacy. Approximately half of the sample (21 participants) scored positive (i.e.: scores greater than two), indicating possible difficulty with health related material. These scores are better than the national average. Only 3% of the older adults who were surveyed in the 2003 National Assessment of Adult Literacy were measured as proficient in health literacy skills (Kutner et al., 2006).

Each participant responded to thirteen questions on the PAM, a measure of patient activation (propensity to engage), as they were read out loud to minimize potential barriers due to vision loss or limited health literacy. The PAM is scored according to levels that represent increasing amounts of activation (Figure 3). Individuals in levels one and two have few self-management skills and are either just starting to take a role (level one) in their own health or lack confidence but are in the process of building knowledge and confidence (level two). Individuals in level three are taking action but may lack confidence and/or skills that support behavior change. In level four, individuals have generally adopted new behaviors but may have difficulty maintaining those behaviors during times of stress.



Starting to take a role
Individuals do not feel confident enough to play an active role in their own health. They are predisposed to be passive recipients of care.

Building knowledge and confidence
Individuals lack confidence and an understanding of their health or recommended health regimen.

Taking action
Individuals have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.

Maintaining behaviors
Individuals have adopted new behaviors but may not be able to maintain them in the face of stress or health crises.

Figure 3. Patient activation graphic (www.insigniahealth.com).

PAM scores were as follows: 13 participants (33%) were in Level 1, four (10%) in Level 2, 12 (30%) in Level 3, and 11 (27%) in Level 4. Compared to national data (Figure 4), the older adults in this study had lower PAM scores than the general population of older adults (Hibbard & Cunningham, 2008).

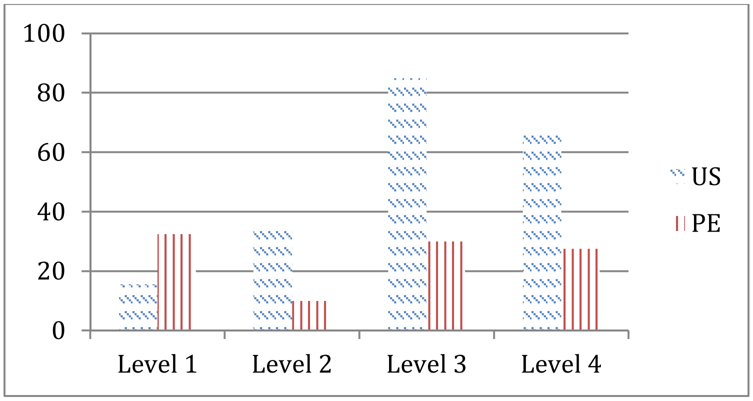


Figure 4. PAM scores for the US population and this study (US = US population score %, PE= current patient engagement study score %).

In the conceptual model, two concepts of interest, health literacy and patient activation were seen to potentially influence the process of self-management that results in patient engagement. Demographic variables were correlated to HL and PAM scores in an attempt to explore relationships between those variables (Table 6). Significant correlations were found between age and the PAM whereby advanced age was correlated with lower PAM scores, as well as education and ethnicity.

Table 6

Pearson Correlations of Variables

	HL	PAM	Age	Eth	>Money	<Money	Edu	Med+
HL	1							
PAM	-.30	1						
Age	.14	**-.40***	1					
Eth	.03	.23	-.13	1				
>Money	.26	-.04	-.02	.05	1			
<Money	-.17	.23	-.06	.05	-.28	1		
Edu	-.17	.02	-.15	**.34***	-.04	-.07	1	
Med+	-.23	-.10	-.06	.25	.15	-.02	.13	1

Significant at the 0.05 level*

In summary, approximately half of the older adults in this sample had at least a high school education, and 75% of them were financially secure. Fewer than 20% of the sample had Medicare without any type of supplemental insurance. These demographic variables may have influenced the 50% health literacy rate noted, much higher than the national average. PAM scores indicate that this sample was less activated than their national counterparts, matched for age and insurance type. Patients with lower levels of activation are more likely to lack the skills and confidence necessary to fully engage with their plan of care.

The Engagement Behaviors of Older Adults: What I Do to Engage With the Plan of Care

The central research question and third specific aim of this study sought to define the engagement behaviors of older adults related to care planning. Engagement is a proximal outcome in the conceptual framework for this study (Ryan & Sawin, 2013). As explained in detail in chapter two, the Engagement Behavior Framework (Gruman et al., 2010) provided sensitizing concepts that allowed the researcher to break down participant responses into discrete behaviors, for example, asking about the side effects of medications, promoting health, or bringing personal health records such as blood pressure logs to the appointment (Appendix C & I provide additional examples of discrete behaviors related to engaging in the POC). The investigator actively searched for behaviors that older adults performed that were related to the plan of care.

The act of care planning is conceptualized as an active negotiation between patient and provider, according to newer models of shared decision making. It for those reasons that the American Geriatrics Society and others (Agency for Healthcare Research and Quality, 2012) have called for the solicitation and documentation of patient goals in the plan of care, in keeping with principles of patient-centered care. These assumptions are consistent with the Ryan and Sawin model, which builds on patient knowledge, beliefs, and skills to facilitate self-management, and with Hibbard's work suggesting that it is necessary to meet a patient where they are at on the continuum of engagement, building on their knowledge and strengths to facilitate behavior change from a patient-centered perspective. It should be noted, however that the MU clinical summary that served to document the POC in this study did not incorporate patient goals or the patient perspective. Instead, it contained a list of actions that the patient agreed to perform, such as taking medications or undergoing additional diagnostic testing. Furthermore, these actions were commonly proposed by the physician, not the patient, who simply agreed to follow the POC as suggested. During the interview portion of the study, participants described at length the type of behaviors they engaged in, but these were not ordinarily elicited during the clinical encounter with the physician. Therefore, the reader will observe the "back and forth" or "asked and answered" nature of shifting perspectives in this section and throughout the chapter as the position of lead actor fluctuates between patient and physician: What we want and expect to see (patient-centered care planning) appears to be different than what was actually observed. Patient expectations about the process of initiation, elicitation, and response to the plan of care are described in the analysis of process determinates.

The older adults in this sample exhibited multiple behaviors in an attempt to maximize their health and the healthcare services available to them, in keeping with the experience of managing chronic disease. The plan of care for cardiovascular disease can include lifestyle changes, medication, medical and surgical procedures, and even formal cardiac rehabilitation programs that aggressively pursue lifestyle and disease management for secondary and tertiary prevention. The goals of treatment include (a) a reduction in or relief of symptoms, (b) the reduction of cardiac risk factors which assists in reversing or decelerating the progression plaque buildup in the coronary and/or carotid arteries, (c) lowering the risk of blood clot formation, (d) and surgically widening narrowed or blocked coronary, carotid arteries among others (National Heart, Lung, and Blood Institute 2014). A wealth of literature has established the relationship between aggressive lifestyle changes (e.g.: frequent exercise, smoking cessation, heart-healthy diets) and risk reduction, therefore clinical practice guidelines for cardiac disease incorporate lifestyle modification counseling. The plan of care for cardiovascular disease then, is necessarily complex and extends to nearly every area of a person's lived experience, including what they eat, how much they sleep, how they move and exercise, and even how they manage their emotional health. The engagement behaviors performed by each of the participants in this study will be presented first. In a subsequent section, the engagement of a subgroup of patients will be discussed.

Engagement behaviors. Older adults with cardiac disease are familiar with common directives to move more, eat less, and take their medication as prescribed, demonstrating engagement with the plan of care. It was not surprising then, that when asked what they did to take care of themselves, their responses included a wide variety of activities. Their engagement behaviors can be organized into four broad categories, discussed below, that include acting in ways that support health, managing health-related information, making visits with the doctor part of their routine, and participating in treatment planning.

I act in ways that support my health. Participants in this study described various actions they took to look after themselves as they sought to maintain optimal function. These fluctuated from basic activities of daily living (ADL) in the frailest patients, such as bathing and dressing, to gardening and golfing among the most active patients. The range of responses is representative of the World Health Organization's broad concept of health as more than simply the absence of illness or injury but more focused toward physical, mental, and social well-being (World Health Organization, 1948).

Some participants commented on performing structured exercise, such as swimming, biking, hiking, weight lifting, or walking; “I exercise every day, five days a week. I walk between a mile and a half and two miles every day”. Others highlighted the importance of avoiding a sedentary lifestyle by generally staying active; “I stay active as far as being outside, doing gardening stuff, and I play with my dogs”, or “I have four dogs so I get up every morning and have to walk them two at a time and then I come home, do little chores around the house. Then we either go out shopping or we play golf.” Many participants, generally women, spoke about remaining active enough to maintain household chores and responsibilities. One saying, “I keep the house up - just keeping life up at 73 is a lot” and another explaining,

> I keep my home clean, you know. I walk. You know, I take care of my cat. I keep my house — I've always got a project around the house, I do. I like to do a lot of things out of the house, you know. I keep my home clean, where it's presentable and it works functionally, so make your bed, clean, do the routine stuff that we all do, that we automatically do and we take it for granted, you know. We just do it and it has to be done. You have to get up, you have to make sure your dishes are clean, your bed is made, you vacuum.

In the same spirit, some men spoke about doing yard work, working around the house or performing home maintenance independently,

> I do farming. I take care of my animals, I clean the yard and the yard's three acres. It's not a little yard. You need a tractor, a lawn mower, a chain saw to cut wood. I do welding, machinery work, just about everything, paint, whatever it needs. My wife keeps the house going and I keep it up around, keep the maintenance.

If being generally active was a marker of vitality for the healthier participants, others, the frailest in the sample, conceptualized physical activity as the ability to perform ADLs, saying,

> *Participant*: I go to the bathroom, I watch TV, I get something to eat for breakfast, and I go to bed by myself. What else? *Wife:* He likes to bathe in the sink. He doesn't like the bathtub but he's meticulous about being clean and so he washes himself constantly. I mean, he can do all those things what an occupational therapist would want. So he does all that for himself.
> I dress. I can go to the bathroom. I can't bathe myself because both of my knees are messed up. But other than drying off and bathing, I think I do pretty well. I can feed myself. I can walk with my walker to the car if we have a doctor's appointment, using that. I cannot walk by myself without some kind of apparatus to help me. I think that's it.

In additional to maintaining a certain level of physical activity, participants spoke about carefully attending to their diets, claiming a conscious intention “not to overeat” and “trying to eat right”, “eating lots of fresh fruits and vegetables”. Some listed the behaviors they had stopped, such as giving up alcohol, snacking, or salt, like the woman who said, “I used to be a Pepsi-holic big time. I’ve cut out all but a max of two cans a day. That’s not every day, but I’ve really tried to cut back on the sugar and the caffeine.”

If following a cardiac treatment plan means exercising regularly and eating a healthy diet, the third pillar can be seen as following medical therapy as prescribed. Yet, when asked what they do to stay healthy, only eight people mentioned the regular use of medication or supplements to support their health, and only two mentioned monitoring blood sugar or taking other therapy as part of their daily routine. In addition to exercise, diet, and medication, participants spoke about the importance of controlling their symptoms and supporting their health practices by “going to bed early” and “sleeping well”.

Participants also spoke about tending to their emotional health, including the importance of “staying positive” and “maintaining a positive outlook on life”. Another man spoke about the psychological aspects of recovering from cardiac surgery and the importance of controlling one’s emotions,

> The only problem I have is the breathing and being weak, but I’m taking the therapy for that. I don’t know. It’s just when I have an attack, it’s more of a sit down and mentally I have to tell myself that I’m going to be all right and to slow my breathing down. That is probably the extent of what I do. It’s a mental thing that I have to do or if I get out of breath, I have to just sit down and let it pass, but it’s more mental than anything else telling myself that I’m going to be fine and then calm my breathing. Then she (referring to his wife) will tell me, “Slow down your breathing. Take it easy. Breathe in through your nose and out through your mouth.” Go through that mental process to get yourself better.

Another man stated that worrying less would “probably help lower my blood pressure for one thing and prevent me from having a stroke, probably”. Men in particular spoke about the importance of maintaining a connection to meaningful work; one man said that he would love to be 35 years old again because “I was on the police department. A lot of that desire is not so much physical, but I was doing what I loved to do. I was a policeman and I miss it. I still miss it.”

Acting in a way that supports health also included spending time with family and friends. For example, “I try to get along with my family. I guess that is important” and “I love my wife”. Participants described important family activities, such as spending time with grandchildren, playing with them, picking them up from school, visiting neighbors, friends, sisters. Participants often included pets in their family structures, discussing the need to care for, feed, play with, and walk the dogs in their lives or “talk to my cat”. Other participants explained,

> I have seven children, a daughter and six sons and I have them all over every week. We call it “Monday Night” and keep it pretty simple, but it’s something that keeps me busy and keeps me going. I have grandchildren, lots of games to attend, lots of birthday parties, that type of thing. A very active social life. I have eight brothers and sisters, and five of us are in the same city, and we meet and have birthday dinners. So far, there is almost, we need to slow down kind of a feeling. My husband and I are still pretty active. We travel. We just got back from New York City. Three of the kids went with us. You know, we have a — just a nice time, a really good time. I feel very fortunate. Yes, we’re very connected, even, oh, six of my seven children are probably within five miles of me. One of them just moved out to Gilbert, and we’re still trying to forgive him!

> I visit with my friends. I have some good friends. And I have some special male friends. But yes, they know me. They knew my husband. My husband passed away and they know how to do what he did and that kind of calms me down. And sometimes I have to fight them off and then sometimes I don't want to!

Participants conceptualized the time they spent in relaxation as supporting their general well-being. Participants described multiple activities that made them unique yet underlined a universal need for rest and relaxation. Participants crocheted, knitted, sewed, quilted, read the bible, spent time on the computer, watched TV, rode motorcycles, camped, gardened, golfed, drove, traveled, painted, and went to the casino for fun.

When participants were not actively following a treatment plan or acting in way to support their health, they acknowledged the gap and expressed a desire to “be more disciplined about that”. One man explains,

> You know, I think that I'm not great at exercise right now because I'm just so busy. I know that's not an excuse but it kind of is. My wife's very active — she's very regimented every morning 6:00 wham, she's out the door. So I hope I can get like that but I think the main thing I try to do is not to overeat because we all

> have a tendency to do that. I've been kind of successful at that but I should do better.

Participants also sought opportunities to improve their health and disease knowledge in an effort to support their health, such as the man who said, “I do a lot of study. You know, I try to find out if there's something else that can be done.” Perhaps in an attempt to situate the chronic illness in the context of a bigger, healthier life, participants frequently engaged in reflective thinking, connecting their current health history to a different time in life, or using the plan of care as a reason to reflect.

> I would never have smoked. I look back at it now and I try to teach my grandsons this. The reason that I end up with bone spurs is because of my over lifting. I would have done things a little differently. Listen — I would have listened to my grandparents, my parents to not do certain things because later on in life you'll suffer for it ... when you're young you're invincible ...You don't see — you may not see anything right then and there until later on in life, like myself, is when I wished that I wouldn't have done these certain things so that I wouldn't have these limitations. That would be perfect health for me.
>
> You know seeing these things here makes me think of my husband. I sure miss him. Now that was a happy time. My husband and I, we had two acres, and we had horses, went horseback riding, went on trail rides, rode in parades. I loved it. And we had a nice house, and we had a lawn work out in the yard, and that was in Illinois. Sometimes I get to thinking about it, you know, and I miss it, but my husband passed away, and I stayed there for four years, and I knew that I was going to have to do something because I just wasn’t moving as fast. The yard was a big yard, but I loved getting out there and working in it, and like I say, I loved going for horseback riding, and like I say, we had the little dog then.

In summary, acting in ways that support health was an important component of engaging and included following treatment plans, tending to physical and emotional health including self-care activities, claiming the intention to change behavior, understanding the chronic diagnoses, and reflecting upon one's health status.

I manage my health-related information. Participants in this study managed their health-related information in four key ways, by maintaining personal health records, learning about test results, seeking the opinion of healthcare professionals, and by asking clarifying questions.

First, they maintained some version of a personal health record. Paper copies of records were commonly stored in binders or files at home and occasionally in a file on the computer. One participant commented, "I want the results (of my ultrasound). Can I have that? Because I need to have everything in my own file." Another explained,

> You know, I am so stuck in old-fashioned ways. I'll have things on my hard drive on the flash drive and in paper. I will keep the paper even though all of it's still recorded on the computer. I trust paper. And with all these hackers and things that are going on, I'm not so sure I would want private information on even though they say it's a secure site, secure has a question mark behind it because of all these geniuses that like to hack into sites. I'd rather have the paper and if I want to go look at it I'll just go open up the album where I keep it all.

Often patients brought elaborate personal health records of weight and blood pressure to share with the physician:

> *Participant*: You can see this is the first time in a long while I've been under 300. See? 344 ...314 ...298. I wanted to ask you though, do you see here that one day I was 291 and that day I spent all day on my feet, then the next day I was 302. That night I was up all night going to the bathroom. How much water can I have in my body?
> *Physician*: Tell me what you ate that day. A diet high in sodium could cause that.

> *Caregiver Wife*: I brought his blood pressure log for you to review.
> *Physician*: These are excellent numbers, I'm very happy with these.

> *Caregiver Wife*: Good to know. I have to write them down, because when you get old, well, you forget things more.

Second, participants made an effort to learn about the results of tests they had undergone:

> *Participant*: How is my EKG?
> *Physician:* It looks good.
> *Participant*: Right. I don't think the problems I'm having relate back to my heart.

This participant explains that by knowing the results of tests, he could take action to improve his health, "I'm always interested in knowing the numbers, whatever they are and then I need to do what I can do on my end to accomplish our goal." Another participant suggested that having record of laboratory results helped with behavior change toward a care plan goal:

> Oh, I've always kept my lab results. I have got every blood test practically I have ever had, and I watch it. I watch my cholesterol. I saw it when it was up to around 200. I have seen it down to — now, it's 109 I think. My triglycerides are down to 97. These are all important to me. My prostate is in better shape. I had cancer. That was all taken care of. Yes, it just keeps me more informed about what my body is doing and what I should do about it because we don't know unless we see these things, and I know how to read them.

Third, participants sought the opinion of their cardiologist as well as other members of their health care team in an effort to become more knowledgeable about their condition. Participants listened intently to the advice of their treating cardiologist, saying "I've gotta come up with solutions to resolve the problem and that's exactly — he's coming up with some valid solutions". Participants valued the time the cardiologist spent explaining their condition, noting,

> Everything was important. All the explanations the doctor, you know, even though subconsciously we know, it's always good to hear it from a doctor and put

> it into practice because if we don't it's senseless to come to a doctor, like as far as the diet and, you know, taking care of ourselves because we're up there in age already and maybe a long time ago we thought it wasn't important but at this point in our lives we need to listen and consider everything.
>
> Well, I, you know, seeing that I do need that angiogram and that my heart is, I guess got damaged some way or however, the doctor was just talking to me about it and I just wonder how — what happened, you know because I've been feeling good and it's just lately stuff that's waking me up at two in the morning that's what scared me, you know, and I thought I better get to a doctor and check. I've heard that women get heart attacks different way than men do so usually when I hear my husband, he'll wake me up and honey, you better take me to the emergency, I'm having chest pains. So, you know, so but I've heard different about women. So it was — I know that he was telling me all the possibilities about the risks, you know, and it's hard to believe but that I have that I have that because I feel good, you know what I'm saying? I'm glad he was talking to me about all that today.

During the clinical encounter, participants frequently relayed information from another treating provider, for example "Dr. V. told me 'you are lucky you did not have a stroke'", and "I'll go to see Dr. A. again and he'll put me on some kind of a course or regimen that will allow me to start breathing normally again. We were just waiting for this appointment with you". Another offered this explanation when a misunderstanding about prescription therapy surfaced, "You know, I didn't mean to speak out of turn. The person that told me this had my best interests at heart to try and calm me because they knew that I was shook up about it and under the circumstances of what's been going on this year I think is why they told me that".

Fourth, participants were quick to ask clarifying questions to further manage their understanding when it was unclear, for example, "Years ago, he had a series of mini-strokes. Could that be happening again?" or "I'm confused a bit about why I'm here today exactly. Someone found a shadow on a chest x-ray but I thought it was COPD. Does that make sense?" Often issues were addressed with simple explanations,

> *Participant*: I just worry about circulation because of arthritis. My hands are always cold.
> *Physician*: The vessels in your skin are very small, it's a micro-circulation system. You have plenty of blood flow to the organs that need it, not to worry.
> *Participant*: That's good to know, because that's been scaring me.
>
> *Participant*: Can I ask you about Metoprolol?
> *Physician*: Of course you can.
> *Participant*: My PCP's been giving it to me but he only gives me a small amount and then I have to fight with the girls in the office to give me more and that makes my blood pressure go up!
> *Physician*: Since that's a medication for your heart and blood pressure, I'm happy to take over that and prescribe it for you. Would you like that? I tend to write routine prescriptions like that for 90 days.
> *Participant*: Oh yes, that would work out great.

I make visits with my doctor part of my routine. Scheduling and attending routine visits with the cardiologist was seen as an engagement behavior that supports one's health. Participants assessed their personal risk factors for disease and illness, and concluded that making and attending routine appointments with their health care provider was a way to stay healthy. One man in for a visit to clear him for upcoming non-cardiac surgery said, "Now that I've seen him, I'm confident that surgery will not be a problem because I am exercising as much as I can, if time allows, and that it's important for my overall health". Another man seen for a post-surgical check-up explained,

> I think over the last few years, I've been functioning, let's say at about a five. I'd like to get back to eight, but I can't seem to do it. So that has had an effect on my expectation of my surgery. I had — when my father had the heart surgery many

> years ago, he was one of these ones that was the best thing, and I was hoping for that. I don't feel a whole lot different having gone through the heart surgery and what you have to go through to do it. So, I've been a little, I do want to say disappointed it, disappointed that I didn't come out of it feeling better. I came today to see if there is a way for me to feel better.

There is a sense of "checking in" with the doctor regularly in order to "know my heart is ok" and feel good about one's condition;

> I think my doctors have done a really good job explaining the situation so I feel very confident and just for a few nagging things that happen with my age group, I feel I'm in pretty good shape, especially when I look around at other people that is my age.
>
> I know I'm not going to live forever, and 80 is getting close to forever. So I don't know how much longer I'll live, but I don't think about it too much because it's, why think about it? If they tell you're going to die, you're doing to die. But today, he said I'm doing ok.

Participants prepared for the office visit by bringing lists of questions and often paper copies of recent test results from other healthcare providers to discuss. When needed, participants brought along a family caregiver to assist with the telling of the story, in the case of a seriously ill older man with obvious cognitive changes, and more often to remember what was said during the encounter; "That's another reason why I asked my husband to come with me today because – and we both do it. We get home and say, 'Okay now what was that?' There's two of us. Maybe we will get it straight." Participants were prepared to report health history and answer questions about their health status, and were quick to express their concerns.

Participants stated that they enjoyed the relationship they had with their doctors, frequently expressing gratitude for the care they had received; "I'm just so grateful for your help, doc. You saved my life that night in the ER!" and often personalized their relationships. Some would talk about shared acquaintances, inquire about the physician's family, even sharing pictures on an iPhone. One man commented,

> On a personal level, I mean, he's a friend of mine, so I mean, we just sit and chat. If I have a problem, I feel free to tell him. I am not afraid to tell him. I only see him once a year, unless he tells me to come in sooner. But we go to – well, we haven't been to too many personal functions lately, but we see each other occasionally.

Furthermore, emotional needs are met by seeing the cardiologist routinely. These participants liked their doctors, saying "I think that he's doing everything possible. I have a lot of trust in him", "I liked him when I first met him 12 years ago and I still do", and "I just like the way he takes his time". Another participant and his wife explain, "*Participant:* He's not a rush in and out doctor. *Wife:* Yeah, he takes his time, and I have always heard great things about him". Another woman explains,

> I appreciate that he's accessible to me. That was very important. That's why I said I appreciated him calling me because that's the first time that had ever happened and that he listened. I think he listened and I was okay with that because when he – when I mentioned about the deaths that I had in my family I saw genuine concern and he said, you need to – and he told me what I know I needed to have done but I just wasn't aware that my primary could do anything about getting me some help, you know. She was the reason I'm on sleep apnea. I'm very satisfied with him. He helps me to keep my health.

In addition to being supportive, physicians could also be "scolding at times" and this too, was seen as supportive. One man explained that he first viewed going to the cardiologist "like punishment", saying,

> I didn't want to go to a cardiologist. Just tell me what to do, and I will be fine — kind of a guy thing, I guess it is. And I was not doing what he said in the beginning, and he told me, "Just do what I said!" I am the kind of person that needs that. Not every doctor will do that. They kind of run around it, but the

> environment I grew up in, the jobs I have had, because I have always worked construction all my life, and it's altogether a different world. But in that world of construction, everybody says it straight– it's different than the run around.

Other participants related to the need to be "pushed" every once in a while away from "being lax" toward the "right behavior", or to "needing a wake-up call" and the routine office visit was exactly the right place for that to happen,

> He said I had to get more exercise and cut out a lot of the carbs. And so, I did. I mean, I pretty much have gotten that kind of help, and it's something I already knew but somebody to push a little bit. You have got to get these numbers down and so forth, so anyway, yeah. When things really get out of line, you're informed of that, and that's enough to make you get motivated to do what you need to do. Dr. K had to kind of get me in line a couple of times. Do you know what I mean? He's not afraid to do that. I identify with that. He has to put me in my place sometimes. You need that when you are—at least I do, my personality needs that.

Seeing the doctor regularly was a way for participants to evaluate their health status. The occasion of the office visit presented an opportunity to assess personal risk and prepare for the visit and it also meet relational and emotional needs.

I participate in treatment planning. Participants played a role in treatment planning, although it was often a more passive than an active role, consistent with Fiks' definition of a paternalistic model of decision making whereby the practitioner makes treatment decisions and communicates them to patients and families (Fiks, 2011). First, participants listened to explanations that were often lengthy, about the nature of their disease offered by the physician. They listened to the risks and benefits of proposed procedures rather than asking direct questions about the pros and cons of a particular course of action. They did not ask multiple questions or re-direct the conversation. When asked about this part of their interaction with the physician, participants summarized it this way,

> I just like his — the way he explains things. You're not left guessing. You don't have to necessarily ask or try to remember to ask certain questions. He pretty much covers everything and makes you feel like you know what's going on, not that it's a mystery.
>
> I can tell you that the doctor, he's very assertive, he's very, you know, he's able to give us information real quick and he's confident in what he's saying. And, you know, even when he was leaving, I felt like I didn't have to ask him a lot of questions. I asked him a couple but he was able to answer them real quick. And then he's just real, how do you put it, knowledgeable, assertive, and he doesn't lack confidence in other words and he's able to just answer questions. And, you know, I feel confident. Even, even the marble thing kind of — I mean, I would have known what he was talking about without the marbles but it puts a better visual on what — I would have understood what he's talking about but it made a better visual for her and including myself too.

Although several participants provided the above noted explanations for not questioning the physician, a set of theories generally known as Face Theory may help explicate the reasons why older adults take a passive vs. active approach to care planning. In 1967, Goffman proposed that everyone has two types of face needs, positive face needs to look good and be liked, and negative face needs to be free from imposition by others (Goffman, 1967). These two, he declared, are always in conflict and are intertwined with a person’s belief system and cultural values (e.g.: honor, virtue, shame, redemption). Years later, Ting-Toomey used face theory to explain the ways that different cultures responded to conflict, advancing our understanding of face theory by suggesting that the need for positive face, or good self-image is a universal phenomenon. When in conflict, face is threatened and the person performs “facework” in order to save or restore face (Ting-Toomey, 1985, 1988). In 1987, linguists Brown and Levinson proposed that politeness, described as a set of prescriptive social norms, was a strategy for facework, because politeness creates and maintains social harmony. Harmony is created by being contextually appropriate, following social norms, being positive and addressing face needs. Being impolite, defined as engaging in aggressive facework to cause social disruption, creates conflict (Brown & Levinson, 1987). The theory has empirical support in a healthcare context from a study of surgeons and operating room anesthesiologists, demonstrating a difference in facework between them (Kirschbaum, 2014). In face theory, we may begin to understand why older adults, who share cultural norms for social behavior through the era in which they were raised, may be hesitant to question their providers, more often than not agreeing with the proposed plan of care. Politeness theory suggests that people who perceive that they are less powerful than another use indirect and nonverbal actions to communicate, thereby increasing the likelihood that their comments and questions will be given adequate consideration by the other. In essence, they are intentionally being polite for the physician who in their mind, holds a position that is exalted (Brown & Levinson, 1987; Spiers, 1998; Ting-Toomey, 1988) by not questioning his decisions or wasting his time to consider options.

Further evidence of passivity or politeness was observed after the older adult was presented with a plan of care. Often, participants indicated agreement with the physician's suggestions rather than proposing the next steps themselves. A common summary statement at the conclusion of each clinical encounter went something along the lines of:

> *Physician*: Does that sound all right to you?
> *Patient*: It sure does.
> *Physician*: Do you have any other questions for me?
> *Patient*: Nope, I'm good.

Of course it is possible that the older adult had no more questions for the physician and understood and agreed with plan of care, but politeness theory suggests that the vulnerable older could be making an assumption that they do not have choice in the matter because they do not understand the intricacies of alternate treatment plans, and so he makes polite decision to agree with what the physician says. Not asking questions of the physician can be seen as an attempt to avoid seeming impolite, not wanting to take the time of a busy professional, or not wanting to appear stupid in front of the knowledgeable, respected other (Spiers, 1998).

Finally, when arriving at a decision point, participants judged the value of the proposed treatment,

> It is important to know that repairs are possible, although in a somewhat limited timeframe because of how old I am and sort of an accumulation of difficulties that are, I'm sure, going to slowly worsen no matter what we do. Which does lead me to a parallel point and that is, for which we don't have the answer, this is a cost benefit analysis kind of thing I'm wondering about. Should I actually do all this stuff or not?

In each instance, participants discussed their concerns about value during the interview with the researcher, not during the clinical encounter with the physician, where only a cursory inquiry into the cost of treatment was made. This may have occurred during the interview when the patient's personal story was encouraged in contrast to the clinical encounter. It may also be explained by Face Theory, as the patient desired to be seen as amenable to the powerful physician, a need that was not present when visiting with a nurse researcher. However, Barnard's work on the Priest Physician also provides insight into this phenomena, explaining that the social, psychological, spiritual, economic, and political problems of older adults that go along with chronic disease are often difficult for a provider trained in the biophysical aspects of disease to manage (Barnard, 1982, 1985).

The physician may be “emotionally overwhelmed” (Barnard, 1985, p.276) by the scope of distress that the patient wishes to express and, as a tactic for managing difficult cases, offers the tools he has at his or her disposal; a stress test, an order for labs, or an invasive procedure to rule out physical disease. Typically the physician seeks to elicit the medical narrative, largely ignoring the social cues that might lead to a discussion about the more existential nature of illness.

In participating in treatment decisions, participants sought the opinion of the cardiologist, listened to the treatment options available, listened to the risks and benefits of recommended treatment options, and consented to the proposed plan of care while sometimes considering the value of the plan. These behaviors and actions are representative of patient choice, self-determination, and decision-making, although they can be seen as passive in nature, possibly owing to the face needs of older adults.

Characteristics of active decision makers. While all 40 participants acted in ways that supported health, managed health-related information, made routine visits with their doctor, and participated in treatment planning, a subset of participants were labelled as Active Decision Makers. This label was applied to differentiate the participants who were called upon to make a particular decision regarding their treatment plan during the clinical encounter. Whereby other participants agreed to go along with the plan suggested by the provider, these participants were called into deep conversation about the pending decision and asked to actively consider it. This group was created by sorting participants according to the nature of their clinical encounter. There were 16 asymptomatic participants (40%) who were seen by the cardiologist for routine follow-up of chronic disease or because the PCP had requested a consultation (i.e.: abnormal EKG or pre-operative clearance). There were 12 symptomatic patients (30%) who were either seen for the original chief complaint, in which testing was ordered or medications were changed, or to discuss the results of recent diagnostic testing, procedures, or therapeutic changes. A subset of 12 patients (30%) were presented with a choice to make because of the nature of their disease and the evidence-based guidelines supporting the physician's practice. The decisions facing the participants in this subgroup are described in Table 7.

Table 7

Decision-Making Themes

Count	Decision
1	To have an automatic implantable cardiac defibrillator (AICD)
1	To pursue lifestyle modifications instead of initiating additional pharmaceutical therapy for hypertension
1	To discontinue Plavix
2	To stop routine cardiac medications
3	To initiate Coumadin therapy for stroke reduction with Atrial Fibrillation
5	To undergo further evaluation of cardiac disease (2 cardiac catheterization, 1 nuclear scan, 1 vascular scan)

After the group of Active Decision Makers was created, an examination of their demographic characteristics was conducted to explore potential relationships between engagement and various demographic parameters. The participants in this subset of 12 Active Decision Makers were not notably different from the other participants in the study based on demographic variables collected (Figure 5), however they appeared to be more highly educated and more frequently responded that they had enough money and had only Medicare insurance. These variables were not seen to influence their membership in the Active Decision Makers group because they were higher than expected in both groups.

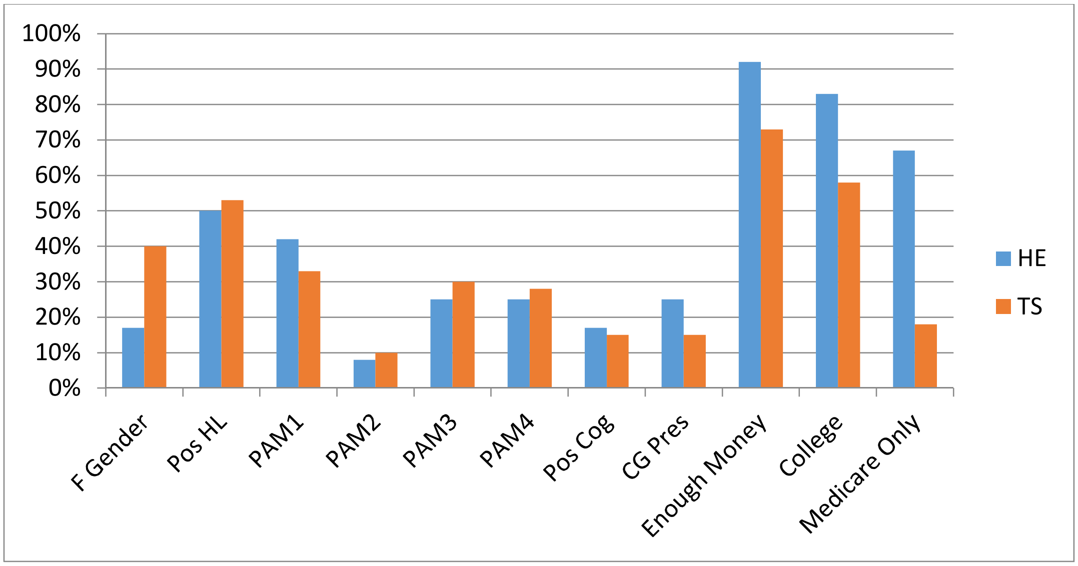


Figure 5. Demographics of the active decision makers compared to the total sample (HE = Active Decision Makers, TS= Total Sample).

I am at a cross-roads. The subset of participants in this study who were deemed to be Active Decision Makers all shared a common characteristic; they had arrived a point in their disease trajectory where they had key decisions to make. CVD is often silent, which makes aggressive disease management challenging for patients who are asymptomatic. For example, the American Heart Association reports from NHANES data (2007-2010) that less than half of the 77.9 million Americans with hypertension are adequately controlled (American Heart Association, 2014) despite a plethora of therapeutic options. Evidence based guidelines help physicians navigate discussions around treatment for CVD, and can be particularly helpful when patients are asymptomatic. Examples from the data suggest that arriving at key decision points in the course of treatment is a time when engagement in care planning is both required and directly observable. This process can be visualized graphically (Figure 6). In the Hartwell model, a person is seen to follow primarily either a healthy trajectory or an illness trajectory. In reality, we know that people often move back and forth between these two realities; they are not strictly linear. The highlighted intervention opportunities (rounded arrows) are critical to this discussion; they represent key decision points and present a situation where health can be regained or illness progresses, broadening the difference in quality of life.

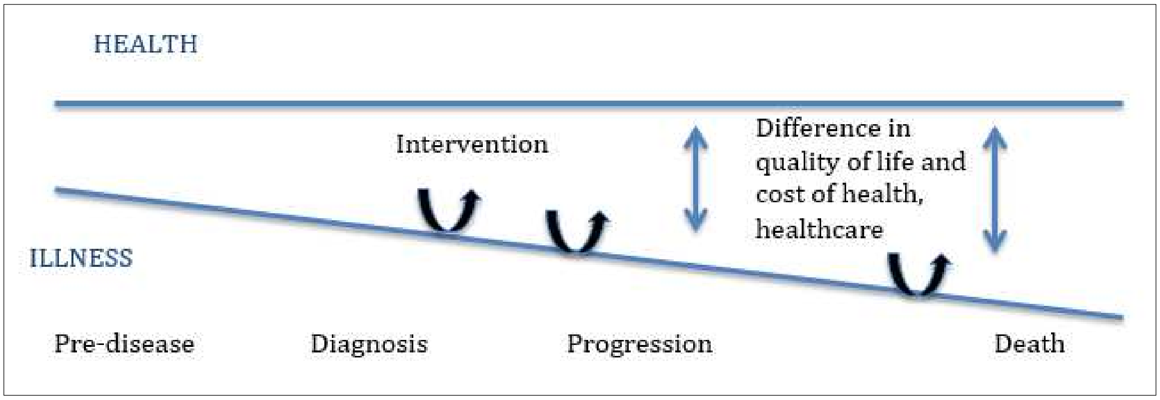


Figure 6. Chronic disease over time. Adapted from L. Hartwell, personal communication, June 7, 2013.

The earlier in the disease trajectory that intervention occurs, the better the patient's opportunity for living out a healthy trajectory; a productive life free from the burdens of chronic disease. The rounded arrows in the figure represent decision points in the illness trajectory and opportunities for the patient and provider to negotiate a plan of care: Are my symptoms cardiac? Am I on the right medication? When should we screen for vascular disease in the aorta and carotids? Are these symptoms alarming enough to perform angiography? How high does my blood pressure have to be before I take medication? When can I safely stop the blood thinner? How often should routine lab work and stress testing be performed? Will an AICD save my life? It is natural then, at these specific forks in the road, that the patient necessarily becomes more involved in treatment planning than at other stages of their disease because they are informed about the options facing them and asked to make a decision. They are at a cross-roads; they must look as far down each path as they can and make a decision accordingly.

Observation notes that exemplify these decision points are provided below.

> *Participant*: (Interrupting physician description of procedure) Why do I have to have this angiogram?
>
> *Physician*: Because if we find that the arteries around your heart are blocked, then we can do something about that to make you feel better and relieve some of the chest pressure you've been having.

> *Participant*: I'm doing everything you said to do! I cut back on salt, I'm exercising, I'm taking these three blood pressure meds. I'm using an Omega-3 because I heard that's good. So why is my blood pressure still so high?
>
> *Physician*: Let's talk about those things a bit. Tell me how you're taking those medicines. Tell me about your diet. What made you choose that supplement?

> *Participant*: I don't want to start Coumadin and all that entails.
>
> *Physician*: Taking Coumadin is the best way to decrease your risk of stroke.
>
> *Participant*: I appreciate that, and I appreciate your advice on this topic, but I'm just not ready to start taking it. Let's wait for the results of this next test before we make that decision.

> *Participant*: It's been five years since my stent and I haven't had a stress test. Don't you think I should?
>
> *Physician*: Well, let's talk about that. It's a matter of what we do with that information when we get it. You are exercising now and you do that without any symptoms, so I'm ok without a stress test, but since it's been five years, your insurance company will pay for you to have another one if you'd like.

> *Physician*: What I'm going to do is send you home with a lab slip so I can re-check your cholesterol before your next visit, which I see is scheduled in March.

Participant: Ok, that's a great plan because I am going to stop taking my cholesterol medicine in January.

Physician: No! Or, I should say, why do you want to do that?

Participant: Well I want to see what my numbers are. I've never had high cholesterol.

Physician: Whether your cholesterol is 100 or 300 it doesn't matter. You're on a statin medication because you've had bypass surgery and we know that statin medications reduce inflammation in the vessels. We're not chasing cholesterol numbers, we're protecting your heart from further damage. There is no value in stopping. But I'm glad you asked.

Participant: I've never had a test where my cholesterol is high.

Physician: Nowadays there is no such thing as "too low".

The Active Decision Makers in this sample (*n*=12) were more likely than others (*n*=28) to ask questions of the physician and listen attentively during the clinical encounter, although participants in each group performed all behaviors to some extent (Table 8). They were less likely to express concern and gratitude. The members of the Active Decision Makers group were the only ones who expressed disagreement with the physician's proposed plan of care.

Table 8

Frequency of Observed Behaviors (%)

Code	Cohort: 12 Active Decision Makers	Cohort: 28 Engaged
Expressing concerns	**33**	**54**
Receiving encouragement	25	29
Reporting health history	58	75
Expressing gratitude	**0**	**11**
Listening attentively	**75**	**61**
Discussing medications	33	25
Maintaining PHR	42	36
Asking questions	**67**	**46**
Communicating opinions	25	21
Meeting emotional needs	17	4
Learning about illness	17	11
Expressing disagreement	**3**	**0**

I am unsure which road to travel. The participants who found themselves at these cross-roads were uncertain about which road to travel. At the cross-roads, a change in therapy was needed and choices were offered by the physician, based on evidenced-based guidelines. This necessitated lengthy and often difficult conversations about complicated topics. The active decision makers in this study struggled with doing the right thing, expressing uncertainty over the best course of action during the interview,

> Deciding to take Coumadin or not take Coumadin or any form of a blood thinner: that’s probably like the most important topic of conversation that came up today. I understood his concern and why he was recommending it, but again, too, I just — again for my risk factor, at this point, I didn’t think it was anything — I’ll research it a little further, but I don’t think for that 2% risk factor, it’s something I really would just jump into without making more of an educated decision with more checking out like the pros and cons because with my mother being on it and stuff. Adding on to it, not that it’s – it’s a hardship just having to go and get on the right medicine and then knowing, again from my mother’s experience to like

> the thing with changing a diet having such an impact on your medicine. I think that’s a big factor in not doing it. Again, too, the other choices would be going on other medications that are quite a bit more costly, which again too, nowadays, it doesn’t seem like as we get older and stuff, we get on a fixed income. All of a sudden more and more medications come to play, and here of late, the prices of medications have gone up, so you are kind of like — and I hate to say, but also, I think probably for most people, that’s a big factor in the choices they make. It’s sad, but I think that impacts a lot of people’s – well, can they afford to do it?

> I am uncertain about that (undergoing angiography) on the merits, not because of the expense but just on the merits. Last winter that pneumonia that I had, for example, was misdiagnosed, and I do not fault my physician for that. He is a one-man show and he was just swamped with patients who were in vastly worse condition than I and some of them were dying right in front of him for a period of several weeks in a row and yes, it was really tough. So all of that notwithstanding, I did not get any help that was germane to my condition for several weeks. I was being given these fairly expensive pills to take every day which didn't do a goddamn thing, in plain English, and finally it was realized that they had missed what was the matter with me and so then they gave me the right medication which cost a mere $30 a pill, this is called Avelox, have you ever heard of it? That's how much Avelox costs for one. I just recently paid off all the bills from all that stuff and that too is behind my remarks to you just now. I simply don't want to go into hock for tens of thousands of dollars or more. I just don't. I won't do it. I have a little money stashed away for my kids when I die, and I don’t want to use it all up paying for medical bills that won’t help me to live a better life.

These decision points are ones that illuminate differences in what Frank and Kleinman refer to as medical and illness narratives. The medical narrative focuses on facts and findings and is regarded as more scientific and objective (Frank, 1993, 1997; Kalitzukus & Matthieseen, 2009; Kleinman, 1988). Medical narratives focus on a history of present illness, focusing on symptoms that contribute to medical decision making; which tests to order, medications to change, diagnosis to make. In recent years, the notion of the medical narrative has changed to include stories about patients and their illnesses and the unfolding and interwoven story between health care professionals and patients, leading to the creation of narrative-based medicine (Charon, 2001, 2006; Kalitzukus & Matthieseen, 2009). Illness narratives, which often but not always accompany the medical narrative, address the patient experience; how she feels about the illness, thinks about it, reacts to it. Illness narratives can be thought of as the stories people tell about their illnesses and its effect on their lives, including their hopes and fears.

Some of the participants in the group of Active Decision Makers verbalized their thought process through the recanting of an illness narrative during the interview with the researcher. Frank says that patients engage in such conversations in order to reveal the meaning of illness, helping the patient to understand themselves and discover what to do (Frank, 1993, 1994, 1997, 1998). The search for the meaning of illness is an ethical act then, as it helps patients “do the best or the right thing” (Frank, 1997, p.133). He argues,

> The fundamental moral problem is that most of the situations that ill people face admit no single “really right thing.” What illness more often demands is to act while accepting that action can never be all that one wants it to be: there is no “really right thing.” (Frank, 1997, p.133)

One questions whether the time allotted to routine visits in an outpatient setting does justice to the patient’s need for storytelling, for working out the “really right thing”. There was evidence of conversation, of question asking, of the listening that is typical when eliciting a medical narrative, but during the interview, the researcher was offered a glimpse at the uncertainty that remained by offering the patient an opportunity to work out decisions through the telling of an illness narrative.

The Active Decision Makers in this study expressed uncertainty over what to do, which road to follow. These participants in particular engaged in meaningful, lengthy, and complex dialogue with the physician about relative risk to determine what was personally best for them. Often, a decision was not reached at the conclusion of the healthcare encounter, instead opting to revisit the issue at the next visit after some time had passed. Presumably this allowed the patient to gather additional information and continue to engage in narrative with others in order to reach a decision.

In summary, this section has described the behaviors of the older adults in this study as they engaged with their plan of care. The findings provide a rich description of the types of behaviors older adults perform when engaging with their plan of care. Section two addresses the factors that were seen to facilitate their engagement.

Influencing Engagement: What Helps and Hinders My Engagement

The second aim of this study was to describe the role that process determinates (e.g.: support from technology or the physician) play in influencing engagement behavior with the plan of care. In Ryan & Sawin's model (2013), these determinants relate to the practice of self-management, described by the individual's knowledge and beliefs, their self-regulation skills and abilities, and social facilitation factors such as influence, support, and collaboration from the healthcare system. Findings from this study emphasize the importance of social facilitation factors, namely the physician-patient relationship and the acceptability of the MU clinical summary to engagement in care planning.

The relationship needs of older adults. Participants in this study relied on a physician they trusted to create the plan of care. In practical terms, this frequently meant listening carefully, considering advice, and agreeing to follow the physician's suggestions. This lies in contrast to often unspoken expectations of the "perfect patient" who reads and understands, is prepared with questions, acts to manage risk factors aggressively, takes prescribed medication properly, reports progress succinctly and complies with orders for testing and procedures. Patients seem to intuitively know that they are expected to follow instructions, evidenced by this man's statement, "I don't know if I'm a good patient or not, but I think I am. I try to do maybe 80% of everything that I'm asked to do."

Fiks described three prototypes for medical decision making. There is a paternalistic model whereby the provider makes decisions and communicates those to patients and families, an informed patient model whereby patients reach their own decisions with information from clinicians and other sources, and a shared decision making model, which depends on the exchange of information between providers and patients and families (Fiks, 2011). In this study, participants fell into more paternalistic types of decision making models, whereby decisions were made by the physician or jointly through conversation, as their emotional needs for reassurance were met through their relationship with the doctor. The following section describes the needs of the older adults in this study and their expectations of the physician with regard to care planning.

I want you to propose a plan of care. Participants in this study were not as assertive in creating the plan of care as the Engagement Behavior Framework (Gruman et al., 2010) suggests they might be. Instead they relied on the physician, with whom they shared a trusting relationship, to create the plan of care, agreeing or disagreeing when necessary. One participant explained,

> Tom is my regular primary physician. He talks with me just like Dr. K did, like he explained, he says, we don't know what you have, these things that could say it was your heart but it doesn't mean it was your heart. It doesn't mean you have blockages because of this. It could be something else. And the way he explains it, and the way Tom is like that also, it helps you to understand it and if you're

> willing to, if you're truly willing to or have the want to better yourself or to stay healthy, you listen to it and you try to do it.

Designing a plan of care was more often directed by the physician than the patient, as the patient listened carefully to explanations and advice and agreed with decisions made by the physician. One participant, when asked what he thought about the emerging plan of care, replied, "Hey, you're the doctor, you tell me what to do". Only one patient came in with a clear list of questions and resolve that he was going to get a stress test as a result of the visit, causing the physician to smile and ask, "Well now, is there anything else I can do for you today?"

Patients were particularly interested in optimizing their medication regimens, frequently expressing a desire to take less medication or none at all, but listening carefully to the rationale for continuing medication regimens. They were often upfront about their intentions (i.e.: wanting to discontinue medications) and accepting of the stated need to continue. During one clinical encounter, the physician commented on how well controlled one woman's blood pressure was, which lead her to ask "Oh good, I hate that beta blocker and really want to stop it. Does that mean I can stop it?" The physician spent quite some time explaining the merits of Metoprolol to her therapeutic regimen, but said that if she was really that bothered by it, they could try a different drug, amlodipine instead. She let it go quickly upon hearing the options, saying "I guess like you said, if it isn't broke, don't fix it". Later in the interview, she expressed feeling listened to, that the physician "really took the time to hear me", but in the end decided to continue with therapy. Another woman was unhappy with the cholesterol-lowering medication Welchol. The physician inquired as to her symptoms and suggested she try a different medication, Tricor. He explained that to manage her cholesterol she would have to be enrolled in the practice's Lipid Clinic, managed by a Registered Nurse who routinely checked labs and provided some dietary advice. The patient consented to that plan of care and described in the interview, how being enrolled in the Lipid Clinic was something the physician was doing to help her achieve her desired health goals,

> Do I think there is anything he can do to help me? Absolutely. I think the first step for today is getting me into this program to have the blood testing and see where we are, and oh, I definitely think this will help me. I am always interested in knowing the numbers, whatever they are and then I need to do what I can do on my end to accomplish our goal.

Patients desired to strike a balance between doing what they wanted and being on optimal medical therapy.

I want you to meet my emotional needs. Participants reported that receiving reassurance, being listened to, seeing a provider who was kind, pleasant, and positive helped them to feel comfortable with the physician's recommendations. Participants reported symptoms, confessing when something "was really bothering me" and that they "needed to be checked out" and expressing gratitude when an explanation was provided or reassurance given. There was a strong need for reassurance that was met by the physician; "The most important part about today was hearing that the valve in my heart was okay. That was the best part!", "Hearing that the results of my echo are normal, that helped a lot. I was concerned about that", "He was good at explaining to me about my EKG and my heart and the way it functions and, "He made me feel properly informed as to what I might need to do … he made me feel comfortable and I like that".

Included in these emotional needs are expectations that the physician will motivate his patient. Patients expressed a need for help in this area, stating that the physician "gets me going in the right direction" or "pushes me a little bit" and sometimes even "puts me in my place".

I want you to meet my knowledge needs. Participants came to the scheduled appointment expecting that the physician would elucidate the unknown, interpret medical jargon not understood, explain why a particular problem came to be, and what could be done about it. As a result, participants spent more time listening than talking during the encounter, as if they were attending an important lecture or watching an interesting documentary and wanted to learn as much as possible about the subject at hand. Participants commented frequently during the interviews that hearing, listening, learning, knowing, and explaining was the most important thing that happened during the encounter,

> *Interviewer:* What was the most important thing about today's visit?
>
> *Participant:* Learning about the condition of my heart.
> *Participant:* Finding out that the results of my EKG are okay.
> *Participant:* Knowing that there is nothing wrong with my heart.
> *Participant:* It was talking about the blackouts.
> *Participant:* I am properly informed as to what I might to do have done.
> *Participant:* When he explained to me about my EKG and about my heart and the way it functions and how it gets stuff. You know, it takes blood and it's kind of, you know, in other words, it gets stiff like your body as you get older, it ages.

I want you to meet my consumer expectations. Patients arrived with expectations of the physician office that were made clear during the interview, including being (a) seen in a timely manner and not kept waiting, (b) considered and remembered as a person, not a case file that is forgotten as soon as they leave the examination room, (c) given high quality and thorough care, and (d) assisted to access other types of healthcare as needed. One woman explained, "I think the service that you get now is good. Maybe it's a little faster than I'd expect", and another noting that she was happy to complete forms on the patient portal because she "thought it might be quicker, just in terms of when we got here, and it was because I didn't have to fill out any paperwork at the desk". Another couple expressed gratitude, saying "I'm so glad you made that call and got us in to see the lung doctor tomorrow. That is a huge relief." Meeting these basic needs helped the patient feel comfortable with the doctor and fall into a trusting relationship. The opposite experience was described in reference to one man's PCP,

> I don't think the average every-day doctor has all of the information about every person he has as a patient. I don't think that they – once he walks out of here, once he puts my folder down, I'm done. He doesn't do any more thinking about me because he has got another patient coming in that he has got to think about. Today is different than it used to be when we were first married 40 years ago where the doctor knew you by your first name. He knew your wife. He knew us as kids. Maybe he delivered the children. It's not the same medical field that it was.

I acknowledge what you cannot heal. Patients were realistic and fair about recognizing the physician's limitations. For example, one participant had survived a traumatic spinal cord injury as a young woman and knew that most of her difficulty was due to the injury and that science had not yet discovered a way to heal her back, and the physicians who cared for her had exhausted the treatments available to them. Other patients acknowledged when health concerns were due to age-related limitations or decline and could not be healed by the physician office. Many participants acknowledged that although they received advice, the responsibility for making changes related to their behavior was "entirely up to me," saying "Oh no, that's all on me." This included struggling with issues like willpower and self-motivation to "do the right thing,"

> I think it's all self-motivation. I don't see where Dr. P or anybody else can—I mean, they can tell me, and they do tell me what I have to do or what I should do, and where I'm at. I have gotten all the information. It's not a lack of information.

The physician-patient relationship was seen as central to engagement with an acceptable plan of care. The relationship was seen as the offering emotional support described in the Ryan and Sawin model (2013). Participants trusted their physicians and therefore agreed with the proposed suggestions. Implied in that trust was the sense that the physician was evaluating their symptoms and the best practice options available to them, making a decision that was in the best interest of an individual patient,

> (My wife and I both) see our doctors every six months. They monitor the heck out of me. I have one in California and one in New Mexico, it's a little clumsy. We've been with our physicians for 17 years and it's quite a nice relationship. There's a certain continuity there that is really ensuring, and the fact that we're confident we're getting the very best information on her condition. Psychologically, it's a wonderful crutch. We feel confident after seeing them. It is important for my peace of mind.

The centrality of trust is supported by the literature which situates trust as foundational for the success of the relationship between patients and their providers, a relationship characterized by risk and uncertainty, and a key component in the healing process (Stepanikova et al., 2006). When trust is absent, patients are less adherent with agreed upon treatment plans (Loghman-Adham, 2003). Patients who have high levels of trust are more satisfied with their care (Hall et al., 2002; Janssen, Ommen, Neugebauer, Lefering, & Pfaff, 2007; Thom & Campbell, 1997; Thom, Hall, & Pawlson, 2004), and have better health outcomes (Berrios-Rivera et al., 2006; Mollborn et al., 2005; Safran, Kosinski, et al., 1998; Safran, Taira, et al., 1998). Trusting a physician increases patient willingness to seek care (Trachtenberg et al., 2005) and to follow provider recommendations (Kowalski et al., 2009).

Clinical summary. In this study, the provision of informational support defined in the Ryan and Sawin (2013) model was conceptualized as the distribution of a paper or electronic (instrumental support) clinical summary. It is one way in which the physician's office can support engagement with the plan of care. Clinical summaries are vendor-created according to standards published by ONC/CMS that must be achieved in order to market a certified EHR that can be used by EPs to attest to Meaningful Use. Depending on the vendor product, some clinical summaries can be altered by the physician office slightly, for example, by choosing to include either Reason for Visit, Current Health Issues, or an Assessed Problem List, depending on preference. CMS (Center for Medicare and Medicaid Services, 2014) defines a clinical summary as,

> An after-visit summary that provides a patient with relevant and actionable information and instructions containing the patient name, provider's office contact information, date and location of visit, an updated medication list, updated vitals, reason(s) for visit, procedures and other instructions based on clinical discussions that took place during the office visit, any updates to a problem list, immunizations or medications administered during visit, summary of topics covered/considered during visit, time and location of next appointment/testing if scheduled, or a recommended appointment time if not scheduled, list of other appointments and tests that the patient needs to schedule with contact information, recommended patient decision aids, laboratory and other diagnostic test orders, test/laboratory results (if received before 24 hours after visit), and symptoms.

During the course of this four-month data collection period, the availability of paper (common to Stage 1 MU) vs. electronic clinical summaries (required in Stage 2 MU) differed in each clinic, representing the Eligible Professionals' stages on the path to Meaningful Use attestation. In Arizona, no paper clinical summaries were printed for patients (except for one afternoon when they were distributed in error). Instead, arriving patients were told at the front desk that they could access their medical records online through a patient portal if they chose to do so, and login instructions were provided to those who were interested. In New Mexico, the clinic went live with a patient portal about half way through data collection. As a result, most participants were asked if they planned to go online and retrieve their records electronically, and some reviewed an actual paper-based clinical summary with the researcher during the interview. Through these queries, we learn about participants' perception of the value of the clinical summary. The clinical summary was designed to summarize the clinical encounter, providing a tool that contains the plan of care so that patients and families can better manage health and healthcare related tasks. Participants in this study were divided as to the value of the clinical summary and were unanimous in their critique of the printed document.

Providing a clinical summary helps me engage with the plan of care. The clinical summary helped participants to communicate with other healthcare professionals; “This will be helpful. I can take it to other doctors,” as well as their own families,

> Just having this, I mean, is this going to be mine? Just having this paper, at least I can pull it up and say look, you don't believe what I'm saying, here it is, you know? You read it; maybe I'm reading it wrong.

Participants reported enhanced perceptions of control over their health when having the information from the clinical summary in hand, stating “the whole thing is helpful”.

> And these down here, my vitals, that's very important because I need to be able to know what they are and they are written down and I can always go back to them if I'm taking my blood pressure like tonight, tonight when I come in tonight from work I'm going to take my blood pressure and I probably will be under the same amount of stress tonight as I am now, maybe a little bit more tonight because right now I'm pretty calm, so I'll be able to compare that.

The clinical summary reportedly helped remind and inform, which was particularly important to those who were “getting forgetful”. This was especially valuable with regard to medications,

> That medication list would be good and very helpful because, you know, I can, you know, I can read it now and like aspirin, I know what aspirin is, but the other one, I can try to memorize it but a half an hour later I'll forget what the name is. I have to — I have to have it marked so I can keep looking at it. My memory is not — it's just – it only wants to be where I'm interested.

The clinical summary may help participants engage with difficult behavior change,

> This is very, very good and I'm trying to remember fully — I'm trying to remember everything that was said because there's so many valid points that what I'll do is I'll put this on my refrigerator and start taking a look at it and seeing if I could start the behavioral modification to reach the attainable objective and this may be, if I keep it on my refrigerator, this may be of benefit.

Some of us will not access the clinical summary electronically. In total, 29 patients were asked directly if they would use a computer to access their medical records online (Figure 7) because for approximately half the patients in one setting during data collection, online access was not available.

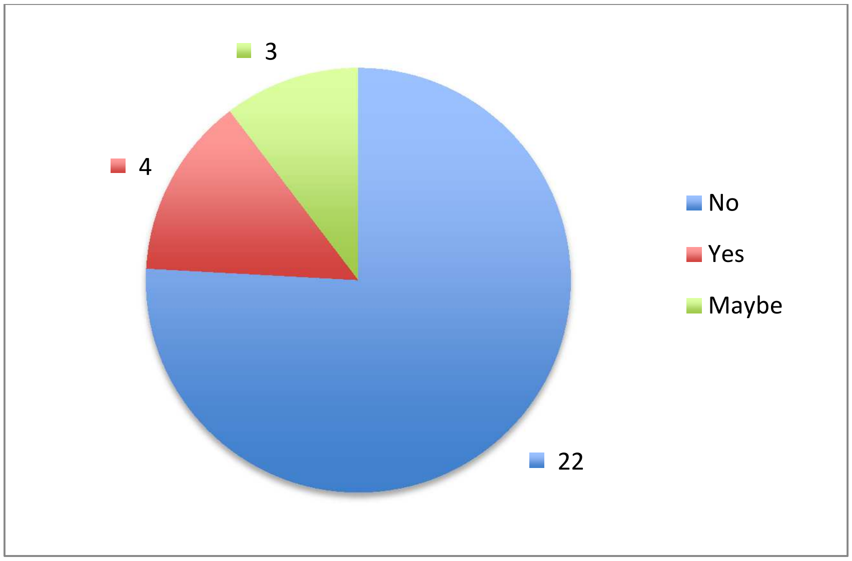


Figure 7. Would you use a computer to access your medical records online?

The overwhelming majority of patients, 76% (22), reported that they would not go online to view their clinical summary or other medical records. Their stated reasons can be explained by the following themes. First, older adults struggled with the technology, claiming they were "not computer savvy" (*n*=3). They were confused by multiple passwords and the extra steps required for a HIPAA-secured login. They were also agitated by navigating from one area to another once inside the patient portal. They were frustrated that the clinical summary was static, unlike other online documents that allowed you to hyperlink to other material for additional information. Second, they expressed concerns over privacy (*n*=5), not wanting to have medical information and social security numbers up on the web, or not wanting to be "nagged" with "one more set of you should do this and you should do that". Third, some did not own a computer (*n*=5) nor possess the interest in learning how to use one (*n*=4), stating "I don't do computer things, I'm a dinosaur". Finally and perhaps most revealing, many of the non-computer users (*n*=13) explained that they could not see any value in going online for their clinical summary, asking what could possibly be of benefit there? One participant commented, “My heart problem isn’t significant enough – I go onto other portals if I’m interested enough in the health problem, like my chronic back pain”. Another said, “There is nothing significant enough to make me interested. Maybe in 10 years down the road when I’ve had more heart stuff, but not now”. Other participants saw the act of going online to look at their medical records as an act of betrayal,

> I know my health status because I come here once a year and he tells me everything I need to know – I have complete trust in the doctor and don’t need to double check him.
>
> That’s not something I would look at on a regular basis because, quite frankly, I think I know more or less what the status of my health is right now based on previous doctor visits. That’s why I came here today – to find out. Why would I do that?

Three patients indicated a willingness to “give it a try”, stating, “I’m nervous about hackers, but I’d give it a try” because,

> It might be helpful, but it depends on what kind of information was there. I already have a copy of my lab results, so I’d want to see some encouragement or a note about making positive changes, that I’m doing the right thing.

In contrast, four patients were very interested in going online to view records for multiple reasons. One participant stated, “we have a right to have our own records”. Another enjoyed having access to results, which avoided an unnecessary call to the clinic. One participant spoke appreciated that using the online portal for entering and retrieving information made the entire visit more efficient, because you didn’t have to re-enter data into a paper questionnaire at the clinic.

Usefulness of the clinical summary. Due to the variety of methods each clinic used to distribute clinical summaries during the time frame of this study, a total of 16 clinical summaries were placed in the hands of patients during the research interview (redacted, annotated sample in Appendix J). Patients were asked to talk through the document, pointing out what was helpful or not helpful. Participants identified multiple issues with the clinical summaries, and their concerns can be expressed by the following categories: (a) information that is inaccurate, (b) information that is unclear (c) information that is not useful, (d) information that is not complete, (e) information that does not respect patient preference.

I want information that is accurate. When reading through the clinical summary, participants were quick to point out information that was inaccurate, saying "Well, information is knowledge. If you know that they know – also, you can correct it if something is in there incorrectly, which I have been through with my mother, I can't tell you how many times". Other examples include, Reason for Visit lists that were identical to the complete Problem list and contained entries that were no longer relevant. For example, one woman pointed out that she used to have edema, but she didn't any more, and that "I didn't come for this". Under the heading "Smoking Status", one patient noted an entry for "current smoker" but the patient hadn't smoked in 40 years. Multiple participants commented on problem lists that were not kept current, and some patients questioned the content of the plan, saying "He never told me this, to follow a low carbohydrate diet. He never told me that. You were there. He didn't talk to me about this". Participants carefully examined the medication lists, and one participant commented that it was not complete because no one had asked her about the supplements she took.

I want information that makes sense. Participants expressed frustration with medical jargon in the clinical summary that was not defined. Both Reason for Visit and Assessed Problem lists contained SNOMED or ICD-9 coded diagnostic language that was hard for participants to understand. Participants asked for "regular people descriptions" and said that "I don't understand this and it's embarrassing to say you don't. You don't want to feel stupid". Participants were confused about the name of tests particularly when acronyms were used in place of a proper description. They were equally frustrated with laboratory results that were presented without context or explanation. One woman commented that she didn't "know what a serum calcium level was or why I need to be concerned about it". Similarly, when values were presented without context, participants were irritated, saying "Right here, heart rate, what does that mean? What is the normal rate?" and "What is BMI? BSA? Why should I worry about that?" One participant called back a few days after being interview to relay his experience at the check-out desk. He was being scheduled for a cardiac catheterization and explained that the paperwork he received was uninterpretable,

> After I saw you, I was handed a bunch of papers from the lady at the front desk, and it took me about three hours to figure out what the hell it all meant! And even now, my understanding of what I am supposed to do is pretty opaque, what the purpose is, what the intent it, what they would mean if I did or didn't do it – most of it remains poorly understood. I need to know what would it mean in layman's language – it's absent! It's just not there at all! As a former (college) instructor, if I had to give these documents as grade, let's just say it wouldn't be a passing one! And you know, that badly diminishes the effectiveness of what is being accomplished. This should be an exercise into inquiry and healing and instead it's "geek speak" I call it. And it doesn't do much to advance the confidence in the medical profession. I consider myself to be a reasonably educated person – I'm not too stupid to fathom what's going on – it's just that what is conveyed is unintelligible.

I want information that is useful. Infrequently, participants noted that the clinical summary contained information that was not useful because they had it already, stating they brought this information with them to the clinic visit, and there had been no changes. Another stated that she kept track of these things herself on a home computer, so the clinical summary did not add to her knowledge of her illness.

I want information that is complete. Several participants expressed a desire for more information, above what was provided in the clinical summary. Regarding the medication list, participants wanted not only the name of the medication, but to know why they were taking it, and what it was doing for them. Regarding the problem list, patients wanted to be able to learn more about a diagnoses and its routine treatment plan. Others were confused by headings that appeared on the clinical summary without content underneath, asking, “Am I supposed to do something about this?” Still others spoke about the clinical summary being “sparse” and not as “animated” as the conversation with the physician, highlighting the voice of the clinical summary; the MU plan of care is clearly a medical narrative, not an illness narrative. Nowhere in the clinical summary could the voice of the patient or the patient’s illness narrative be found.

I want information that respects my preference. Although the vast majority of participants included in this sample appreciated the clinical summary and used it in many ways to enhance their care experience, one participant viewed the clinical summary as proof that she should find a different healthcare provider. She reportedly asked not to be “told her weight” and yet it displayed on the clinical summary. She also replied, when asked at the front desk, that her language preference was Spanish, and shared that she would have preferred a clinical summary printed in Spanish,

> I can understand English very well. The problem is not for me. It's for other people who is afraid to tell you, do you know what I mean? For the Hispanic people, things important like this needs to be in Spanish. That is my opinion.

The Meaningful Use clinical summary was designed to enhance patient and family engagement. Several participants in this study identified ways in which it did help by informing, reminding, and even motivating. However, the participants in this study asked for a better designed clinical summary, one that they could more easily relate to, one that would enhance understanding of their condition and allow them to make better use of the documented the plan of care.

Contextual Factors: What Defines Me

The first aim of this study sought to describe the contextual factors that influence patient engagement behavior with the POC and to examine the relationships between contextual and process factors with the outcome. In the Ryan and Sawin model, contextual factors are antecedents to self-management, and they are well grounded in the literature (Ryan, 2009; Ryan & Sawin, 2009). We know for example that as people age, there is a higher incidence of limited health literacy and chronic disease. We also know that education and income are correlated with health literacy, and that race and ethnicity is correlated with computer use. It was because of the abundance of literature on these parameters that they were collected.

Differences were observed between various demographic variables although the small sample size was not sufficient to test for statistical significance. For example, Figure 8 describes the differences seen in PAM scores from participants with adequate health literacy and those who screened positive for some difficulty. As expected, people with higher amounts of health literacy had higher activation scores. Of the 11 people who scored among the most highly activated (level four), eight had adequate health literacy and three did not. Similarly, of the 13 people who scored among the least activated (level one), four had adequate health literacy and nine did not.

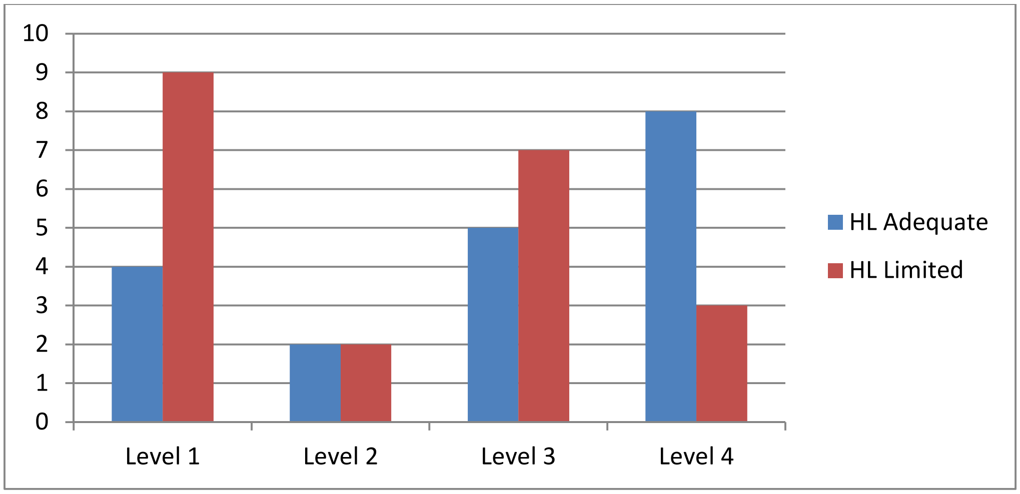
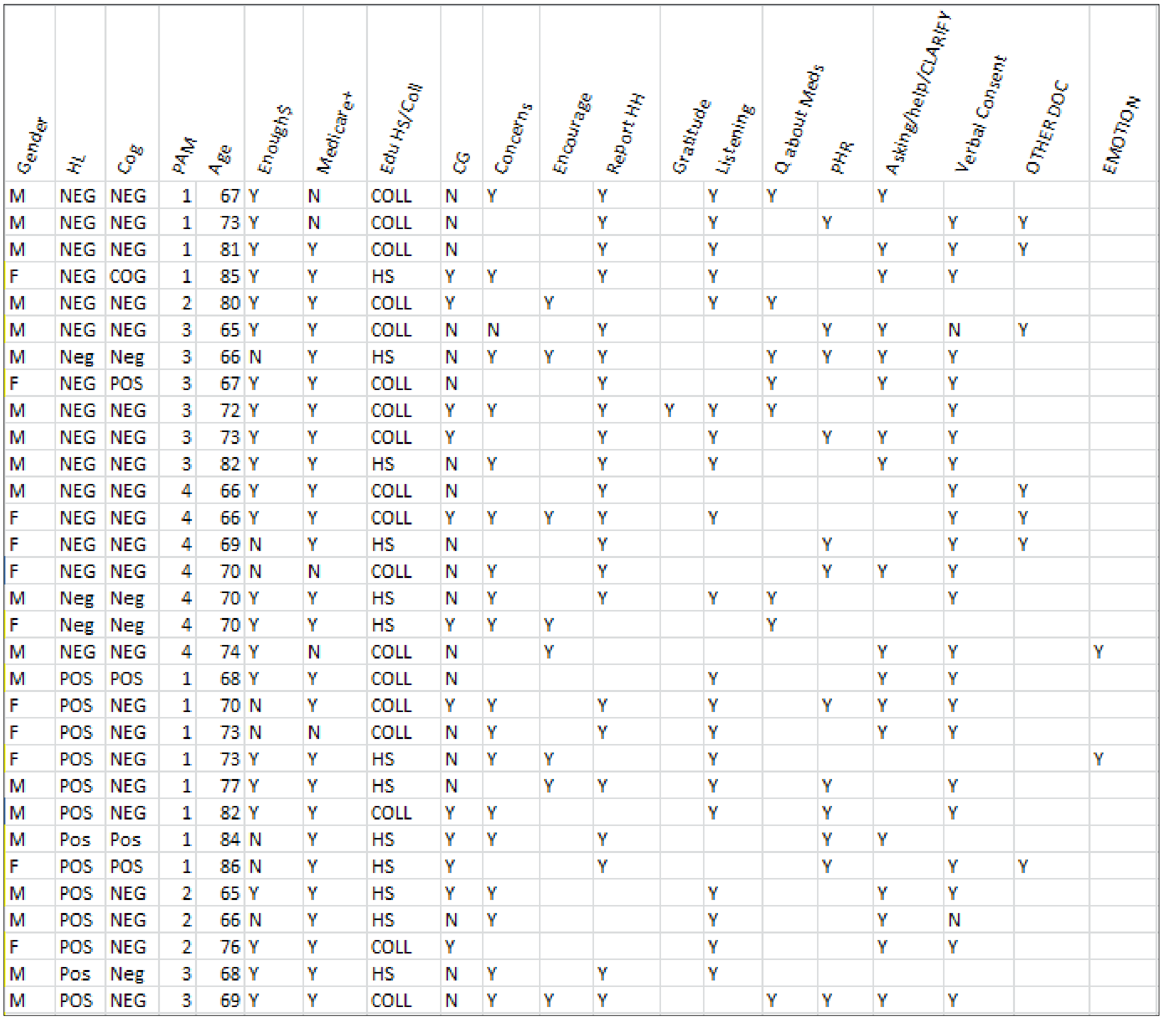


Figure 8. PAM scores by HL status.

These types of relationships were explored and used as a way to pivot the data, asking for example, Do people with low activation scores engage in different behaviors than people with high activation scores? Do people with low health literacy scores ask fewer questions than those with adequate health literacy scores? No discernable differences in engagement were found when evaluating responses by demographic variables through the use of multiple data matrices. Figure 9 provides an example of a data sort of engagement behaviors observed during the clinical encounter by health literacy status as an example.

In particular, a relationship between engagement behavior, health literacy, and patient activation was expected but not observed. For example, participants with positive and negative health literacy scores in Figure 9 (note that only part of the sample is captured in this figure), were observed to express concerns, be encouraged, listen, or produce a personal health record in approximately equal numbers. Regardless of health literacy status, or PAM level, participants described similar goals, to enjoy their health and retirement years and performed similar engagement behaviors to help them do just that.



Gender	HL	Cog	PAM	Age	Enough$	Medicare+	Edu HS/Coll	CG	Concerns	Encourage	Report HH	Gratitude	Listening	Q about Meds	PHR	Asking/help/CLARIFY	Verbal Consent	OTHER DOC	EMOTION
M	NEG	NEG	1	67	Y	N	COLL	N	Y		Y		Y	Y		Y			
M	NEG	NEG	1	73	Y	N	COLL	N			Y		Y		Y		Y	Y	
M	NEG	NEG	1	81	Y	Y	COLL	N			Y		Y			Y	Y	Y	
F	NEG	COG	1	85	Y	Y	HS	Y	Y		Y		Y			Y	Y		
M	NEG	NEG	2	80	Y	Y	COLL	Y		Y			Y	Y					
M	NEG	NEG	3	65	Y	Y	COLL	N	N		Y				Y	Y	N	Y	
M	Neg	Neg	3	66	N	Y	HS	N	Y	Y	Y			Y	Y	Y	Y		
F	NEG	POS	3	67	Y	Y	COLL	N			Y			Y		Y	Y		
M	NEG	NEG	3	72	Y	Y	COLL	Y	Y		Y	Y	Y	Y			Y		
M	NEG	NEG	3	73	Y	Y	COLL	Y			Y		Y		Y	Y	Y		
M	NEG	NEG	3	82	Y	Y	HS	N	Y		Y		Y			Y	Y		
M	NEG	NEG	4	66	Y	Y	COLL	N			Y						Y	Y	
F	NEG	NEG	4	66	Y	Y	COLL	Y	Y	Y	Y		Y				Y	Y	
F	NEG	NEG	4	69	N	Y	HS	N			Y				Y		Y	Y	
F	NEG	NEG	4	70	N	N	COLL	N	Y		Y				Y	Y	Y		
M	Neg	Neg	4	70	Y	Y	HS	N	Y		Y		Y	Y			Y		
F	Neg	Neg	4	70	Y	Y	HS	Y	Y	Y				Y					
M	NEG	NEG	4	74	Y	N	COLL	N		Y						Y	Y		Y
M	POS	POS	1	68	Y	Y	COLL	N					Y			Y	Y		
F	POS	NEG	1	70	N	Y	COLL	Y	Y		Y		Y		Y	Y	Y		
F	POS	NEG	1	73	N	N	COLL	N	Y		Y		Y			Y	Y		
F	POS	NEG	1	73	Y	Y	HS	N	Y	Y			Y						Y
M	POS	NEG	1	77	Y	Y	HS	N		Y	Y		Y		Y		Y		
M	POS	NEG	1	82	Y	Y	COLL	Y	Y				Y		Y		Y		
M	Pos	Pos	1	84	N	Y	HS	Y	Y		Y				Y	Y			
F	POS	POS	1	86	N	Y	HS	Y			Y				Y		Y	Y	
M	POS	NEG	2	65	Y	Y	HS	Y	Y				Y			Y	Y		
M	POS	NEG	2	66	N	Y	HS	N	Y				Y			Y	N		
F	POS	NEG	2	76	Y	Y	COLL	Y					Y			Y	Y		
M	Pos	Neg	3	68	Y	Y	HS	N	Y		Y		Y						
M	POS	NEG	3	69	Y	Y	COLL	N	Y	Y	Y			Y	Y	Y	Y		

Figure 9. Example of a data matrix looking for differences in engagement behavior by health literacy status.

Summary

To meet the specific aims outlined in this study, the behaviors of older adults as they engaged with the plan of care were presented and the circumstances unique to participants who demonstrated a high degree of decision-making surrounding care planning activities were specifically highlighted. In section two, the process factors that facilitated engagement with the plan of care, namely the physician-patient relationship and the Meaningful Use clinical summary were addressed. Finally, in section three, contextual factors were discussed. The findings from this study lead us toward several discoveries that have the potential to further facilitate patient and family engagement.

CHAPTER 5

DISCUSSION

I never want to miss an opportunity to make a difference.

—Anita Ralstin, FNP, New Mexico Heart Institute, 2013

The purpose of this study was to describe the engagement behaviors of older adults with their plan of care, exploring factors that influenced engagement. This purpose was accomplished through the observation and interview of 40 older adults with multi-morbidities attending routine clinical encounters with their outpatient cardiologist. Chapter four presented the wide variety of behaviors that older adults performed in an effort to follow the plan of care, maximize their health, and get the most out of the healthcare services available to them. The utility of the Meaningful Use clinical summary, which records the plan of care, was questioned by the older adults in this study, leaving us with insights into patient preference beyond what is currently considered by designers of consumer-facing HIT. This chapter begins with an interpretive overview of five key points from the results of this study. Section two addresses this study's unique contribution to the nursing and health innovation literature. Section three presents study limitations, and section four presents potential directions for future research. Finally, a summary and concluding remarks are offered in closing.

Interpretation of Results

Five key insights were gained through this study and deserve a thorough discussion in this chapter. They include the gap between patient and provider expectations for following the plan of care, an investigation into what remained unseen during routine clinical encounters, the lack of variation in contextual variables, the inadequacy of the current MU clinical summary as a tool for care planning, and the importance of a trusting patient-physician relationship to care planning.

Raising the bar. The older adults in this study were given multiple opportunities to describe the actions they would take to follow the plan of care and maintain their health. They reported a health history to the physician during the clinical observation, told stories, expressed concerns, reviewed medications and recent test results, and participated in conversations about next steps. During the interview with the researcher, they were asked to describe the efforts they made to stay healthy, and to describe ways in which the physician could help them to achieve their health goals.

When given the opportunity to talk about how they followed the plan of care, patients spoke mostly in generalities; they acted in ways that supported their health by staying active, connecting with family and friends, trying to eat healthy diet, and devoting time to rest and relaxation. They did *not* speak at length about formal exercise programs targeting cardiovascular fitness and weight reduction, or for example, following any of the several recommended dietary plans for cardiac patients (DASH, Mediterranean, Ornish, etc.). Rarely did they conceptualize following a prescribed medication regimen or performing recommended testing and interventions as part of staying healthy and following a plan of care.

Participants managed health-related information by asking clarifying questions during the encounter, asking for copies of test results, relaying information from other members of their healthcare team, and maintaining blood pressure logs. Very few described instances where they made an effort to learn about their heart disease through books, shows, or websites, and fewer still were willing to access healthcare records online. They relied heavily on person-to-person communication to acquire and manage information about their disease, which explains why scheduling and attending regular visits with their cardiologist was seen as an important way to engage with their plan of care. Finally, while the older adults participated in treatment planning, whereby they listened to expert opinion, judged the value of the proposed plan, and provided consent, it would be a stretch to describe this process as belonging to an informed, actively engaged participant in the sense of a shared-decision making model. Far more often than not, the older adults in this study arrived with an expectation that the physician would define the priority health conditions and develop a plan for managing them.

It is important to note that the physicians in the study did not assume this role in a paternalistic "doctor knows best" manner (Fiks, 2011); rather they seemed to sense the needs and preferences of the patient and adapted their approach accordingly. In some instances, advice was offered as a suggestion, "What would you think if we tried this and re-evaluated again in six months?" or "I think you're doing well, and I don't feel the need to run any more tests at this time, but I certainly will if you feel like that's important", and in other instances it was offered in a more assertive manner; "This is where we're at, and this is what I think we should do about it". Patients had the ability to participate in decision-making in an active, passive, or shared manner, consenting or dissenting to the proposal. This behavior is in keeping with previous research, demonstrating that physicians and patients routinely work out their decision-making preferences on a case-by-case basis (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001).

There are two things of note here. First, actual observed participant involvement in the creation of the care plan differed from the healthcare system's imperatives to involve older adults in care planning (American Geriatrics Society, 2012) and the popular notion that all patients want to make their own decisions. Both assumptions violate the principle of patient preference. Although the notion of shared decision-making has been around since the 1970's, we are reminded in a 2012 article by former

IOM chief Harvey Fineberg that shared decision-making should be “shaped by the particular needs and preferences of the patient, which may be to call on a physician to assume full responsibility for decisions or, at the other extreme, to be supported and guided by the physician to make completely autonomous decisions. This suggests that, just as with interventions, which need to match the patient's style and preferences, patient's preferences for degree of involvement also need to be taken into account and respected” (Fineberg, 2012). It also raises the question, “Whose care plan is it, anyway?” The current POC is largely created by providers and used to communicate among health care providers. The MU clinical summary simply grants the patient access to that conversation. A truly patient-centered POC may look different from what we have now and may explain the reason that patients do not always find value in the clinical summary. Perhaps patients would be less likely to ignore the POC if it contained information that really mattered to them or if they had contributed to the development of it, thereby believing they had a stake in it.

The implication is for a willingness to redefine engagement with care planning; the participants in this study who made an informed decision not to follow an evidence-based plan of care were engaged in the decision making process, and older adults who chose to give their physician full responsibility for designing a plan of care did so based on a decision that still represents engagement. This suggests a need to view and measure patient engagement on a continuum, not unlike the way we conceptualize patient activation. Patients are rarely engaged or not engaged; it appears to be a continuous vs. dichotomous variable. Furthermore, the choice to be engaged may change over time, in different situations, and among different providers, perhaps as the patient arrives at a critical junction in their disease course. Therefore, the opportunities for engagement may differ depending on the patient, the chronic disease, the provider seen, and the time point. These discoveries suggest that we assess our methods of measuring engagement, typically defined by provider-defined clinical variables (e.g.: a target blood pressure or in-range cholesterol level). Patient-centered outcomes are likely to focus more on the effort expended to meet a personal goal (e.g.: weight loss, activity level, comfort with various decisions) or personal priority (e.g. interest in chronic back pain that takes priority over chronic dyslipidemia). The line between engagement with creating the plan of care and following the plan of care is blurred, perhaps because the POC is simply another tool that could be used for self-management. Our current definitions and methods of evaluation of patient engagement do not account for these subtleties, nor do they take into consideration the multiple other HIT devices we could be using to facilitate self-management.

Second, following a plan of care for a person with CVD involves aggressive lifestyle management to reduce the risk for worsening and future disease, yet participant's conception of lifestyle management (e.g.: tidying the house and walking the dog) differs greatly from the healthcare provider's concept of lifestyle management (e.g.: performing 30 minutes of moderate to vigorous physical activity most days of the week). In both instances, the patient's perception and abilities appear to fall far below the perceptions and expectations of the healthcare system. People who should take hypertensive medication per protocol do not want to take it. People who could drop hypertensive medication with weight loss totaling no more than 5% of their total body mass cannot lose weight. Evidence based guidelines indicate there is no long term benefit to Plavix one year after a cardiac procedure, but people want to keep taking it. There is a cavernous divide between what we think people ought to do, what they are actually doing, and even what they want to do.

The older adults in this study were engaged with the tests, procedures, and various follow up appointments ordered by the physician, but were less engaged with lifestyle modifications that would support their treatment plan for chronic CVD. The older adults in this study had an expectation that the physician would create a plan of care and typically, they agreed with the recommendations. The care plan created by the physician ought to include lifestyle modification plans, as discussed and agreed upon by the patient. Previous research leads us to believe that physicians routinely over-estimate participation in the plan of care, for example, with medication adherence (Copher et al., 2010) and under-estimate the impact of pain and suffering (Lesho et al., 2009). This suggests that either we either clarify our definition of what behaviors constitute an engaged patient or dramatically raise the bar on patient self-management behavior if we are to ever actualize the benefits of better health outcomes and lower costs demonstrated by current research (Hibbard & Greene, 2013; Hibbard, Greene, & Overton, 2013). We should create care plans that clearly and explicitly outline our expectations for all sorts of chronic disease management behaviors. The job before us appears to be related to defining the types of engagement expected at various points in the chronic disease continuum and testing methods (e.g. oral, video, electronic) for promoting engagement.

Just do it: Institutionalizing engagement. Related to this notion, and to borrow a phrase from the renowned advertising campaign, sometimes "just doing patient engagement" is difficult in our current healthcare environment. The participants observed in this study could be roughly categorized as belonging to one of three groups; asymptomatic patients in for routine follow-up care, symptomatic patients undergoing evaluation, and patients at a critical junction in their disease course. Although there was no discernable difference in the types of behaviors performed by participants in each sub-group, the data suggest that older adults focus on different types of engagement behaviors at different points in the disease continuum. For example, patients at a critical junction in their disease, faced with starting or stopping pharmaceutical therapy or undergoing further evaluation, were seen as active and shared decision makers. In contrast, the two other groups of patients followed a more paternalistic or passive decision making process when it came to engaging with the care plan. Symptomatic patients acted to express their concerns, seek knowledge, and agreed to follow the plan of care provided by the physician. The group of asymptomatic patients, who enjoyed fairly simple and straightforward clinical encounters, enjoyed the fastest visits, as the patient had nothing of concern to report and made no requests beyond medication refills from the physician. A checklist of pertinent negatives was performed, medication lists were reconciled, prescriptions renewed, and follow-up visits arranged. Certainly in the middle of a busy clinic, clinicians must have some simple encounters to keep the schedule running according to plan and get through the day. However these encounters raise the question: Are we missing an opportunity to make a difference in the life of an older adult with a progressive, chronic disease? Perhaps in those encounters, where the patient is free from anxiety about chest pain or shortness of breath, patients can handle more aggressive lifestyle modification counseling; maybe that is precisely the time to tackle the weight, diet, sleep, and stress management issues that may very well change the trajectory of CVD.

Given the widespread commercial availability of mHealth devices, cell phone apps, and wearable sensors (e.g. FitBit), not to mention the billion dollar weight-loss and exercise industry, it is fair to assume that patients have already discovered multiple alternative methods for managing their health over time. These strategies may provide insight into methods that are more patient-centered than the ones we currently employ.

Discussing these issues with the recruiting physicians, one said, “I feel as though my patients follow through with my advice, even if they don’t do it immediately. They come back in follow-up, and they’ve managed to make some changes or we talk about it further and they go home and do a little bit more. These days, I am encouraged by small, incremental changes.” The other commented that this was a tough issue, indicating that he felt inadequately equipped to tackle these complex topics, saying, “I tell people to follow a low-carb diet, but it’s not like I hand out recipes or anything, so how do you really help them change?” Instead he often “prescribed” a video or documentary to be watched in the patient’s home with family members, thinking the more personal experience of watching a story in their own home might be more impactful than his provision of a checklist of healthy behaviors to follow. This type of vulnerability and creativity serves to highlight a need in the everyday clinical practice of caring for older adults with multi-morbidities aimed at the provision of interventions that make sense.

It also underscores the necessity of a team-based healthcare approach and system redesign when caring for older adults (Trehearne, Fishman, & Lin, 2014). People with chronic disease, particularly Medicare-eligible older adults with chronic disease, cost the healthcare system an astounding amount of money and resources, yet we do very little during most healthcare encounters to aggressively prevent the progression of disease, outside of ensuring evidence-based pharmaceutical therapy is in place. Such an approach can be seen in alignment with Ryan and Sawin’s model, which positions social facilitation as essential to self-management. Supporting physicians and other providers of healthcare to conduct aggressive lifestyle counseling and convincing high risk and at risk older adults to engage with risk reduction strategies with members of a multi-disciplinary team may ultimately be necessary to bend the cost curve of chronic illness.

Contextual variation. The variables of health literacy and patient activation were chosen carefully when designing this study because of their presumed influence on patient engagement, however, there were no discernable patterns of behavior that defined participants by these variables nor was there a discernable relationship observed between the variables. For example, patients who screened positive for potential limitations with health literacy were no more likely to point out difficulties understanding the clinical summary than those who did not. This lack of differentiation may be related to any number of reasons.

Health literacy. Health literacy in this study was measured with the SILS, a tool that has established validity and reliability among older adults in outpatient settings. However, there are a plethora of tools that measure health literacy (Agency for Healthcare Research and Quality, 2014) and even experts in the field call for a consolidation and re-testing of instruments. It is possible that the SILS was not specific or sensitive in identifying health literacy limitations in this sample, as other researchers have observed significant differences in the behavior of patients with low and high health literacy scores when accessing their medical records electronically (Levy, Janke, & Langa, 2014). One study among the California Kaiser patients enrolled in a diabetes registry explored the association between health literacy and use of an Internet-based patient portal. In an analysis adjusted for age, gender, race, ethnicity, education, and income, those with limited health literacy had higher odds of never signing on to the patient portal compared with those who did not report any health literacy limitation. Even among those with Internet access, the relationship between health literacy and patient portal use persisted (Sarkar & Bates, 2014). Levy's study (2014) retrospectively examined the relationship between health literacy and use of the Internet at all, as well as the use of the Internet for obtaining health information, and had similar results. Only

9.7% of older adults with low health literacy, compared with 31.9% of those with adequate health literacy, used the Internet to obtain health information, after controlling for sociodemographics, health status, and cognitive ability (Levy et al., 2014). In this study, health literacy did not have a discernable relationship with engagement behavior. As an exemplar, of the four participants who expressed a desire to go online for health information, two had adequate health literacy and two screened positive for potentially difficulty with health related material. Of the 21 participants who stated they would not go online for health related material, 14 were positive for difficulty, and seven were not, indicating some reluctance to go online that could be attributed to health literacy status (Table 9). However, the engagement behaviors of the two groups were not seen as different, perhaps because the non-computer users simply accessed the information they needed to engage in different ways, through person-to-person communication rather than the Internet.

Table 9

Results of the Query: Would You Go Online to Access Your Health Records?

Response	HL-Pos	HL-Neg
No	14	7
Maybe	0	3
Yes	2	2

Health literacy “has been largely overlooked as a determinant of HIT use” (Levy et al., 2014) although exploratory research suggests that the relationship between the two is significant (Colorafi, 2014; Jensen, King, Davis, & Guntzviller, 2010). The IFSMT places literacy as a contextual factor, an antecedent to the self-management process, which is measured by the proximal outcome of engagement behavior. It is possible that health literacy predicts Internet use, but that other, more significant factors moderate its impact on engagement. Bickmore and Paasche-Orlow caution that the growth in HIT is likely to increase health disparities unless focused effort is devoted to development of HIT for disadvantaged groups (Bickmore & Paasche-Orlow, 2012).

Research is beginning to elucidate the relationship between social support from a family member and the older adults' use of the computer (Longo et al, 2010; Nahm et al, 2012). From this work, we can speculate that among the many reasons a patient might choose to bring a family member to a clinical encounter, having support for information orientated tasks may be an important one. Of the fifteen patients who brought a family caregiver, nine of them (60%) were positive for limited health literacy skills and eight of them (53%) had the lowest PAM scores (Levels 1 and 2). In this way, the use of a family caregiver can be seen a strategy for engaging in healthcare; it was an intentional method for addressing a perceived deficit. Future research should explore the impact of social influence on engagement, for example, and whether or not a family caregiver, a trusting patient-physician relationship or a well-designed clinical summary can ameliorate the impact of low health literacy.

Patient activation. The concepts of patient activation and patient engagement, and their relationship to each other, remain murky at best, making the measurement of each difficult for research purposes. Three studies have reviewed the literature and determined that "involvement, engagement, and participation are terms used interchangeably, with little agreement about what they mean" and that they are "interpreted and understood differently by patients, providers, and administrative leaders" (Gallivan 2012), making researchers "unable to recommend best practices" (Domecq et al., 2014) and expounding on the "urgency for a deeper understanding of what patient engagement means in order to develop knowledge useful for innovation both in clinical practice and health policy agendas" (Barello, Graffigna, Vegni, & Bosio, 2014). The PAM was chosen for this study because the author clearly defines activation as a self-efficacy based “willingness and ability to take independent actions to manage … health and healthcare” whereby patient engagement is seen as a “broader concept that includes activation; the interventions designed to increase activation; and patient’s resulting behavior” (Hibbard & Greene, 2013). The activation score, representing the willingness and ability to take independent actions, is in alignment with Ryan and Sawin’s definition of contextual individual and family factors and helps to assess an individual’s capacity to self-manage. However, all patients, regardless of their activation score engaged in certain behaviors that can be described as helpful to self-management.

The purpose of the PAM is to identify patients in different stages of activation and develop interventions tailored to their specific needs, with the goal of increasing their confidence and ability to engage in more sophisticated engagement, or self-management strategies. In this study, activation scores did not demonstrate a discernable pattern with willingness to engage in one behavior over another. Patients in each level of activation were seen to engage with the plan of care. To further the exemplar offered above to access online records, in fact more than half of the unwilling group of participants had the highest levels of activation (PAM scores of three and four), and the group agreeing to go online had the lowest activation scores (Table 10). Multiple data matrices such as these failed to differentiate participant behavior based on PAM score (or health literacy).

Table 10

Results of the Query: Would You Go Online to Access Your Health Records?, With PAM Scores

Response	HL-Pos	HL-Neg	PAM1	PAM2	PAM3	PAM4
No	14	7	10	1	7	5

Maybe	0	3	0	0	1	4
Yes	2	2	2	1	1	0
Totals	16	12	12	2	9	9

We should consider the possibility that that the PAM did not adequately measure the construct in this population. This is exemplified by a depressed participant who claimed to do “nothing to take care of myself” and had a PAM score of 4, and by the personal experience of a researcher on Hibbard’s 2009 study which sought to use measurement to target activation strategies, who attests that patients were categorized into activation levels based on the nurse-assessed activation score, not the PAM, because patient scores were thought to be incongruent with nurse-observed participant behavior (I. Worden, personal communication, January 6, 2015). We should also consider the possibility that the sample size in this study was too small (*n*=40) to adequately explore relationships among quantitative variables, masking a relationship that was truly there. A quantitative methodology or a predominately-quantitative mixed methods design would be better suited to test the relationship between variables (Creswell, 2013; Creswell & Plano-Clark, 2007). Instead, the PAM scores in this qualitative descriptive study served to further describe study participants, in varying stages of activation, trying to engage in behaviors that would help in the management of multiple chronic diagnoses. In large part, the participants in this study acted in similar ways to promote health and get the most out of the healthcare services available to them, regardless of their PAM score.

MU clinical summary re-design. The MU clinical summary represents an important effort in the quest to document a transparent plan of care that can be used and shared by patients, families, and healthcare providers across settings to improve care coordination and promote health. The federal mandate behind it ensures its wide-spread use and emerging research uses it as the foundation of an electronic, longitudinal plan of care that can be shared across healthcare providers and settings to improve care coordination (Dykes, 2013). At last count, more than 94% of hospitals and more than 370,000 eligible ambulatory Medicare and Medicaid eligible professionals were participating in the EHR incentive program (Centers for Medicare and Medicaid Services, 2014), which means that most patients are receiving some type of after-care summary at the conclusion of each healthcare encounter. It is an important step forward. However, the participants in this study expressed frustration with the quality of the MU clinical summary that impeded its use, whether it was provided on paper or electronically through the patient portal. In the field of health literacy and with the help of the IOM, we have moved away from emphasizing an individual patient's lack of ability and toward an organizational responsibility for creating health literate documents for everyone (Brach et al., 2012). In this way, literacy, which is conceived as a contextual factor in Ryan & Sawin's model, may be better described as process determinate (informational support) that either facilitates or hinders self-management.

The current MU clinical summary falls short of meeting current standards for a health literate document (Centers for Disease Control and Prevention, n.d.; Centers for Medicare and Medicaid Services, 2012; National Institutes of Health, 2004) and much can be done to improve it. Recommendations from this study, grounded in the data, include: (a) translating diagnostic language into terms that patients can understand; (b) providing definitions and descriptions for diagnoses, vital signs, tests, and labs; (c) eliminating nonactionable items, for example BSA from vital sign panels or non-smoking status from risk factor lists; (d) editing reason for visit and assessed problem lists so patients receive only current and relevant information; (e) eliminating headings without content beneath; (f) presenting vital signs and lab results in context with normal ranges and descriptions; (g) adding personalized instructions or encouragement to the plan; (h) adding templated access instructions to the plan (i.e.: imaging lab company addresses and telephone numbers); (i) adding cost comparison information to the plan (i.e.: a stress test at this facility will cost this much in comparison to having it done at another location); (j) avoiding acronyms and short forms such as FU, SOB, HL, MCOT; (k) adding meaningful risk reduction items and education to the plan of care and using it to supplement what there was not time for in the exam room; (l) linking to resources that an engaged patient could pursue as interested; (m) including generic and trade names for prescriptions, defining the instructions for taking the medication and a note as to why the medication is being taken; (n) including in the plan issues under consideration, for example, “Consider starting Coumadin. We’ll talk about this at your next scheduled visit,” or “Think about whether you want to spend $200 to have a vascular scan at our office sometime next year. Your insurance will not cover it”; and (o) documenting patient goals and including meaningful pieces of the patient’s illness narrative in the clinical summary.

Improving the quality of the clinical summary is important, because the summary provides informational support to the process of self-management. The older adults in this study relied heavily on person-to-person communication strategies; the interaction with the physician was seen as preferential to the written clinical summary. The existing clinical summary is a document that represents the medical decision making that took place during the encounter. It is not a patient-centered document that focuses on patient and family concerns, and it does not represent the depth of conversation that took place. Frank’s work begins to help us understand why a medical narrative, as opposed to an illness narrative, may not be as helpful to patients as they work through the meaning of chronic illness in their lives and what to do about it. We must turn our attention to asking what a patient-centered clinical summary might look like and how a truly patient-centered plan of care might facilitate engagement.

Only a small percentage of older adults in this study saw instrumental value in the online clinical summary. Despite the evidence that computer-based personal health records create a digital divide, there is ample evidence that well designed and even simple HIT interventions have an incredible opportunity to level the playing field and reduce disparities in healthcare (National Partnership for Women and Families, 2012). Technology simplifies the tailoring of health information to meet the needs and preferences of different age, racial, ethnic, income, and educated populations. One of the most successful federally funded HIT initiatives was “text4baby”, an intervention delivered via text message to participants’ cell phones, aimed at improving pre and postnatal outcomes in low income, ethnically-diverse moms (Evans, Wallace, & Snider, 2012). Furthermore, the technology itself does not have to be sophisticated; video-taped discussions about the end of life reduced the variability in do-not-resuscitate orders between high and low health literacy populations of terminally ill patients in intensive care settings (McCannon et al., 2012). A better-designed clinical summary has the potential to facilitate understanding of and engagement with the plan of care, whether or not it is offered through HIT.

Trust and care planning. Perhaps the most fascinating insight of the study was the notion that older adults did not feel the need to access online records or to use an electronic plan of care; they could not find value in such tools. Previous studies have linked willingness to use electronic health records to higher health literacy status but regardless of health literacy status in this study, older adults delivered a clear message: I came the doctor. He told me what I needed to know. Why would I bother to go online and read the same thing?

The position of the participants in this study contrasts with recent research into patient perceptions of the value of online access to health records. Notably, during Project Open Notes, up to 87% of the 5391 patients who accessed at least one encounter note from their primary care office reported feeling more in control of their care, up to 78% reported increased medication adherence, and less than 10% reported feeling confused or worried by what they read (Delbanco et al., 2012). In December 2014, a national survey study found that more than four in five patients with online access to their health records (86%) used their online records at least once and more than half (55%) used them three or more times a year (National Partnership for Women and Families, 2014). However, the average age of participants in the Open Notes study was 51, and fewer than 25% of respondents in the National Partnership study were over the age of 65, highlighting the "digital divide" whereby certain age cohorts are less likely to use online health records and the purpose behind selecting a sample of older adults for this study (Yamin et al., 2011). The preferences of older adults remains poorly documented in the HIT literature.

There are two things of note in older adults' reluctance to access online records that warrant further discussion. If reluctance to access health records is simply a question of value, then it ought to be relatively straightforward to craft messages aimed at changing perception and demonstrating the value proposition in the online plan of care. Various theoretical frameworks endorse this perspective, including the Health Belief Model (Sharma & Romas, 2012) and the Diffusion of Innovation (Rogers, 1995). The Ryan and Sawin model identifies knowledge and beliefs as a process determinate to self-management. However, this may not simply be a perception problem. As discussed above, there may very well *not* be enough value in the clinical summary or POC to make it worth someone's time to go online and retrieve it. The MU clinical summary is, in the words of one participant, “a little sparse” in its current state. Perhaps if clinical summaries were better designed to meet the needs of older adults, and reflected the illness narrative as well as the medical narrative, there may be more value in going online to use it. There is an indisputable need to improve the care plan in the clinical summary before it will be perceived as valuable to patients.

In addition, the other roadblock to electronic access of the care plan appears to be emotional. Time and time again, participants expressed pride, trust, gratitude and professional friendship toward their physicians; they respected them, they liked them, they wanted to visit with them. Going online to retrieve additional information was seen as unnecessary or worse, as an act of betrayal. The physician-patient trust literature linking trust to a variety of outcomes is almost two decades old, although Thom’s team of researchers have positioned the concept of trust as essential to emerging healthcare payment structures and ought to be further revisited in this era of electronic healthcare. Most recently they have argued for the routine measurement of physician-patient trust because of its impact on quality care and cost outcomes (Thom et al., 2004). Perhaps future research will determine that the more trust an older adult places in her physician, the less likely she is to access records electronically. These notions introduce new and interesting variables in the quest to understand the adoption practices of consumer HIT that should be tested.

Contribution to Nursing and Health Innovation

This study highlights the contribution to and implications for knowledge development in the areas of theory, practice, education, and policy.

Implications for theory and knowledge development. The findings from this study help to advance our understanding of the theoretical intersections between process determinates and outcomes in the Ryan and Sawin model, an area of the model that is supported by literature but has not been rigorously empirically tested (Ryan, 2009). Specifically, this study highlighted the importance of social facilitation factors; emotional support in the form of a trusting patient-physician relationship, informational support from a Meaningful Use clinical summary, and instrumental support from access to online records to engagement behaviors. These findings may support theory-based interventions that facilitate patient engagement through social facilitation, whereby most self-management interventions have focused on bolstering self-efficacy or teaching self-regulation skills. Finally, the lack of discernable patterns of behavior according to the contextual factors in the IFSMT suggest the possibility that process determinates are important moderators of contextual factors and that research is needed in this area if we are to understand fully what makes an older adult engage in care planning.

Practice. The widespread use of HIT has permeated modern healthcare in an attempt to enhance patient and family engagement, but in practice, the adoption of HIT by older adults remains low. This study provides insight into why HIT such as patient portals and electronic personal health records containing the plan of care are seldom utilized in the population of older adults with multi-morbidities, arguably the people with the greatest need for practical, tangible engagement and self-management tools. The older adults in this study did not see value in accessing electronic health records beyond what they are told in the examination room during the clinical encounter with their physicians. This has several implications for practice. First, when speaking to older adults, we discover that describing the value in HIT tools is important. Simply "going online" may not hold value in and of itself, rather, the value proposition must be clearly communicated. Older adults should be told explicitly that the records they access online can be useful when talking to other healthcare providers, or that they can read over them to ensure the information is correct. Second, the technology we offer must be improved so that that it is genuinely helpful to older adults with multi-morbidities looking for an action plan that can be shared with family and members of their professional care teams. HIT must be created for a diverse group of users and be accessible to older adults with limited health literacy. Finally, we must be prepared to offer non-electronic engagement tools for older adults who will not use the computer or Internet to access them.

Education. If these represent implications for practice, we must take care to educate nurses and other healthcare professionals about the issues surrounding HIT use among older adults. There is ample evidence that people with low health literacy have difficulty accessing all different types of HIT. Because of the prevalence of limited health literacy in the population of older adults, routine assessment is no longer recommended. Instead, practitioners ought to assume that limitations in health literacy exist and assess HIT for its ease of use before recommending tools to older adults. In addition, professionals must be taught about the principles of health literate organizations and be willing to identify and redesign information that is not packaged appropriately for older adult audiences (Brach et al., 2012). The barriers an older adults faces in utilizing HIT, including cost, Internet access, and variability in access, also should be assessed (Bickmore & Paasche-Orlow, 2012). Emerging research shows potential in having a trusted friend or family member help to access HIT (Kim et al., 2009; Nahm et al., 2012).

Interdisciplinary education could be useful in training a team of professionals who could ultimately support the older adult with multi-morbidities in ambulatory environments to achieve better health and the get the most out of the healthcare services available to them. The older adults in this study reportedly looked for assistance with their diets, exercise regimes, symptom and medication management in their home settings. These are things that Registered Nurses, Dieticians, Physical Therapists, etc., could help with outside of the regular clinical encounter with a physician or other healthcare provider.

Policy. This study contributes to our knowledge of the concept of patient engagement from the patient's perspective. The older adults in this study communicated an abundance of ways that they behaved in order to engage, yet inside of and among all of that activity, we see a lack of progress in halting the downward spiral of chronic disease. Patient engagement is a concept in desperate need of a patient-centered definition and outcome measure. The results of this study demand an exploration of the ethics of patient engagement, asking, who defines engagement? This type of evaluation should precede federal policy aimed at incentivizing providers for patient behavior, such as viewing, downloading, and transmitting personal health information from an online personal record, or using secure messaging to email their healthcare providers. Eligible Professionals who adopt EHR technology and use it to meet federal Meaningful Use standards can earn at least $44,000 over five years in the Medicare program or $63,750 over six years in the Medicaid program (US Department of Health and Human Services, 2013c). Financially incentivizing this behavior compels providers, burdened by declining reimbursements and climbing costs of practice, to maximize their total reimbursement by caring for patients who can meet the current definition of engagement. This study clearly demonstrates the reluctance of older adults to engage in the use of HIT, leaving an important policy question to be investigated: Who will be incentivized to look after a growing, aging, and multi-morbid population who are unable or unwilling to use HIT?

Study Limitations

Great attention was paid to, and structure built into, the process of conducting data collection and performing qualitative descriptive analysis so as not to bias the results with holistic fallacy or elite bias (Miles & Huberman, 1994), as discussed at length in chapter three. Nonetheless, several limitations may have influenced the findings of this study and will be discussed in this section.

First, patient engagement is a relatively new concept with multiple definitions and a variety of yet-to-be properly evaluated outcome measures (Barello et al., 2014; Domecq et al., 2014; Gallivan, Kovacs-Burns, Belows, & Eigenseher, 2012). It is easy to imagine that many factors are likely to influence engagement with plan of care. Ryan and Sawin's model was helpful in framing this study as individual contextual factors (e.g.: age, ethnicity, race, income, education, health literacy, patient activation, cognition) and process determinates (e.g.: support from the physician and the MU clinical summary) could be included for measurement in the conceptual model. However, it is possible that those factors were not the most important antecedents to patient engagement and that focusing on others may have shifted the results.

Along the same lines, little is known about the influence that providers have upon engagement behaviors. In an attempt to minimize variability, two male cardiologists were chosen for this study, but it is possible that female providers, or different types of providers (Nurse Practitioners, Surgeons, or Physician Assistants, for example) may approach patients in a manner that is significantly distinct and therefore influence engagement behaviors in an entirely different fashion. The impact of the provider on the engagement behavior of the patient was not fully explored.

Third, family caregivers were included in this study when they accompanied the patient to clinical encounter. Sometimes the family member helped to tell the story, remember details, and make decisions, as if the patient brought the family caregiver in an attempt to enhance engagement with care planning. Family caregivers were viewed as supporting patient engagement rather than as a distinct variable (e.g.: the family unit). The focus remained on the patient, asking how the family caregiver interacted with the

POC. Nonetheless, it is possible that the family caregiver should have been considered a unique variable, similar to the influence of a provider, on the process of engagement.

Furthermore, it is theoretically possible that a patient's degree of engagement changes over time and across settings, as activation is known to do (Hibbard & Minniti, 2012), meaning that the examination of engagement behaviors of the same participant in a family practice or an ophthalmology practice later that day or weeks later may have prompted different results. This study captured data and patient experience at one point in time and did not examine the impact of time on engagement.

Fifth, in qualitative research that includes observation in the field, the very presence of the researcher is acknowledged to affect the results, known as observer bias, whereby the observer may lose objectivity as she begins to identify with the participants under study or unduly influence the individuals whose behavior they are recording, in this case, physicians and patients. Miles and Huberman (1994) call this "going native". Indeed the researcher's career in cardiac nursing increased the likelihood of observer bias, and steps to reduce the impact of this bias were taken, including (a) being highly structured and routine in the collection of data, (b) triangulating data with observations, interviews, and standardized measures, (c) seeking clarification of observed behaviors during the subsequent interview, (d) testing case-based assumptions with multiple data matrices against all cases, (e) discussing the observation experience with research mentors and (f) writing analytic memos throughout the research process.

Sixth, engagement with the plan of care was defined largely by participant description of the activities they performed to take care of themselves, maintain health, and maximize the healthcare services available to them. Follow-up visits or chart reviews, for example, did not occur in this study to assess the accuracy of participant reports. It is possible that participants over or under estimated the effort extended to support their plan of care.

Finally, Miles and Huberman (1994) outline five specific strategies for assessing quality, addressed in detail in chapter three. It is possible that the quality of findings were influenced by researcher behavior, although the following tactics were put in place to ensure quality. First, there is a standard for objectivity or confirmability that provides readers reasonable freedom from researcher bias. The researcher's perspective and beliefs, body language, tone, facial expression, and even manner of dress can influence data collection. This was met by approaching each interview and observation with an open and inquisitive mind, recording any and all things of interest. The researcher intentionally wore plain clothes without extra make-up or jewelry in an attempt not to call undue attention to herself, and used warm and welcoming, empathic listening skills to make participants comfortable. Second, there is a standard for reliability or dependability of data which was met by having tight quality control procedures in place. For example, the same researcher asked the same questions during interview and used the same field notes for recording interview observations. The researcher practiced interviewing skills during a pilot study prior to this study where interview questions and procedures were tested. Third, there is a standard for internal validity or credibility which asks, do the findings of this study make sense? This standard was met by comparing findings to existing theoretical constructs and by discussing findings with others in the field. Fourth, there is a standard for external validity or transferability or "fittingness" of the data. This standard seeks to understand if the findings of the study have greater importance and fit with other contexts. It was met by talking about the general needs of older adults and the things providers can do to encourage engagement behaviors. Finally, there is a standard for utilization or application that speaks to what the study can do for its participants. To meet this standard, solid, tangible recommendations for the improvement of the MU clinical summary were provided (Appendix K).

Direction of Future Research

Several ideas for the design of future research studies have emerged from these findings. First, the design and development of a clinical summary that is better suited to patient health literacy needs and to the task of engagement or the self-management of chronic cardiac disease, is sorely needed. A research team at Northwestern led by Dr. Michael Wolf provides an exemplar for this type of research. A 2006 study discovered that patients did not understand the medication instructions on prescription bottles (Davis, Wolf, Bass, Thompson, et al., 2006a, 2006b) and subsequent studies published the outcomes of a re-designed set of instructions on comprehension with significantly improved results (Sahm et al., 2012; Wolf et al., 2012a, 2012b; Yin et al., 2012). Recently, the state of California passed a law requiring all prescription bottles to conform to these patient-centered labeling standards (view samples at www.pharmacy.ca.gov/licensing/labels.shtml).

Second, several interesting theoretical concepts arose, such as the implications of trust between patients and providers and the willingness of older adults to access online records or to make use of a clinical summary for the purposes to enhancing engagement. These are best explored through quantitative model testing (Jacaard & Jacoby, 2010; Shadish, Cook, & Campbell, 2002). It would be interesting to test the impact of a trusting provider-patient relationship, including a commitment to understanding the patient's illness narrative and meeting emotional needs, as a moderator on the engagement behaviors of older adults with multi-morbidities.

Third, attention ought to be focused at the way engagement is measured. Most patient engagement and self-management studies use clinical outcomes to measure the concept, for example, defining engagement as the lowering of blood pressure levels in patients with hypertension, or cholesterol levels in patients with dyslipidemia. The change in the raw score is theorized to incorporate a large number of engagement behaviors, including medication adherence, exercise, dietary changes, obtaining routine preventative care, and the maintenance of personal health records for tracking purposes, but patients are labeled dichotomously as either engaged or not engaged. Measuring engagement behavior by clinical outcome might not represent a patient-centric approach to measurement, called for by PCORI and others (www.pcori.org), because of its emphasis on adherence to prescribed therapy. The Engagement Behavior Framework attempted to rectify this ethical dilemma by outlining a broad range of discrete behaviors that patients perform in an effort to maximize health and get the most out of the healthcare services available to them. These emphasize behaviors such as preparing a list of questions in advance, making appointments and arriving on time, maintaining insurance coverage, learning about newly prescribed medications and minimize behaviors such as changing behavior with diet or exercise (Gruman et al., 2010). Patient engagement definitions ought to include patient perspectives, priorities, and preferences, as should patient engagement outcome measures that are continuous.

Finally, the findings from this study suggest that providers have the ability to impact patient engagement behavior and as such, we should examine the qualities of provider behavior as well as care delivery models that that facilitate and hinder engagement behavior, in the same way, for example, that researchers have identified factors that promote trust or satisfaction among patients and their health care providers, in order to develop guidelines for best practices.

Summary and Conclusion

This study described the engagement behavior of older adults with multimorbidities and explored the factors influencing their engagement, one of the few empirical research studies to emphasize the voice and experience of the older adult with HIT through qualitative inquiry. The participants in this study acted in ways to promote health, manage health-related information, make visits with their doctor a part of their routine, and participate in treatment planning. A subset of the sample, when at a cross-roads in their disease course, expressed a high degree of uncertainty over which decisions to make. The physician-patient relationship provided emotional support for engagement behavior, and the MU clinical summary provided informational support for engagement, although participants were quick to identify issues with the clinical summary that hindered its usefulness and their reluctance to access it online.

Patient engagement as a concept provides a fundamental backdrop for research in self-management and the use of HIT for managing health and healthcare, because it serves to remind us of the end-game: better health for patients, by patients, as defined by patients and their families. The results from this study allow us to move forward with patient-centered recommendations for the design and future use of the MU clinical summary as it relates to engagement with the plan of care, an essential component of aging well with chronic disease. The voices of the participants in this study also provide insight into the factors that facilitate and hinder engagement, inviting us to explore the ways that we can better serve this vulnerable population in the future.

NOTES

1. Eligible Professionals (EPs) under the Medicare EHR Incentive Program include: doctors of medicine or osteopathy, doctors of dental surgery or dental medicine, doctors of podiatry, doctors of optometry, and chiropractors. A hospital-based EP furnishes substantially all of his or her Medicare-covered professional services in a hospital inpatient or emergency room setting. Hospital-based EPs are not eligible for incentive payments (USDHHS, 2014).

2. Prior to Meaningful Use, the Certification Commission for Health Information Technology (CCHIT) certified EHR products based on robust and extensive testing criteria, for which vendors had to apply. Successful completion of the coveted CCHIT certification was considered a “gold standard” in the industry and was used for marketing and sales promotions. With the arrival of Meaningful Use, ONC had to take ownership of the certification process so that they could require products to achieve technology standards (e.g.: HL-7 interfacing with laboratory and radiology companies, secure messaging, medication reconciliation, allergy and drug-drug interaction alerts) that were written into the Meaningful Use rules. ONC selects particular non-governmental organization to do the testing based on criteria they provide (USDHHS, 2010; 2012).

3. The five goals of the Meaningful Use program are: (a) improving quality, safety, efficiency, and reducing health disparities, (b) engaging patients and families in their health, (c) improving care coordination, (d) improving population and public health, and (e) ensuring adequate privacy and security protection for personal health information (USDHHS, 2010).

REFERENCES

Adler, K. G. (2006). Web portals in primary care: An evaluation of patient readiness and willingness to pay for online services. *Journal of Medical Internet Research, 8*(4), e26. doi:10.2196/jmir.8.4.e26

Agency for Healthcare Research and Quality (AHRQ). (2013). *2013 annual progress report to Congress: National strategy for quality improvement in health care*. Retrieved from http://www.ahrq.gov/workingforquality/nqs/nqs2013annlrpt.htm

Agency for Healthcare Research and Quality (AHRQ). (2001). *Improving the health and health care of older Americans: A report of the AHRQ task force on aging*. Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from http://www.ahrq.gov/research/findings/final-reports/olderam/oldam2.html

Agency for Healthcare Research and Quality (AHRQ). (2002). *Quick tips for talking with your doctor*. Retrieved from www.sheriffleefl.org/main/index.php?r=site/showResource&id=8637

Agency for Healthcare Research and Quality (AHRQ). (2011a). *Care coordination measurement framework: Care coordination Measures Atlas*. Rockville, MD: AHRQ.

Agency for Healthcare Research and Quality (AHRQ). (2011b). *Principles for the national quality strategy*. Retrieved from http://www.ahrq.gov/workingforquality/nqs/principles.htm.

Agency for Healthcare Research and Quality. (2013). *2013 annual progress report to Congress: National strategy for quality improvement in health care*. Retrieved from arhq.gov/workingforquality/nqs/nqs2013annlrpt.htm.

Agency for Healthcare Research and Quality (AHRQ). (2014). Health literacy measurement tools (revised): Fact sheet. Retrieved from www.ahrq.gov/professionals/quality-patient-safety/qualityresources/tools/literacy/index.html

American Geriatrics Society. (2012). Patient-Centered care for older adults with multiple chronic conditions: A stepwise approach from the American Geriatrics Society. *Journal of the American Geriatrics Society, 60*, 1957-1968. doi:10.1111/j.1532-5415.2012.04187.x

American Heart Association. (2014). Statistical fact sheet 2014 update: High blood pressure. Retrieved from http://www.heart.org/idc/groups/heart-public/@wcm/@sop/@smd/documents/downloadable/ucm_462020.pdf

Anderko, L., Roffenbender, J. S., Goetzel, R. Z., Howard, J., Millard, F., Wildenhaus, K., . . . Novelli, W. (2012). Promoting prevention through the Affordable Care Act: Workplace wellness. *Preventing Chronic Disease, 9*, E175. doi:10.5888/pcd9.120092

Anderson, G. (2010). *Chronic care: Making the case for ongoing care.* Retrieved from http://www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf54583

Anyfantakis, D., & Symvoulakis, E. K. (2011). Medical decision and patient's preference: 'Much ethics' and more trust always needed. *International Journal of Medical Sciences, 8*(4), 351-352.

Arozullah, A. M., Yarnold, P. R., Bennett, C. L., Soltysik, R. C., Wolf, M. S., Ferreira, R. M., . . . Davis, T. (2007). Development and validation of a short-form, rapid estimate of adult literacy in medicine. *Medical Care, 45*(11), 1026-1033. doi:10.1097/MLR.0b013e3180616c1b

Baker, D., Williams, M., Parker, R., Gazmararian, J., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling, 38*(1), 33-42. doi:10.1016/S0738-3991(98)00116-5

Barello, S., Graffigna, G., Vegni, E., & Bosio, A. (2014). The challenges of conceptualizing patient engagement in health care: A lexicographic literature Review. *Journal of Participatory Medicine, 6,* e9.

Barnard, N. (1982). The gifts of trust: Psychodynamic and religious meanings in the physician's office. *Soundings: An Interdisciplinary Journal, 65*(2), 213-232.

Barnard, N. (1985). The physician as priest, revisited. *Journal of Religion and Health, 24*(4), 272-286. doi:10.1007/BF01533009

Becker, E. & Roblin, D. (2008). Translating primary care practice climate into patient activation: The role of patient trust in physician. *Medical Care, 46*(8), 795-805. doi:10.1097/MLR.0b013e31817919c0

Bennett, I., Chen, J., Soroul, J., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventative health behavior in older adults. *Annals of Family Medicine, 7*(3), 204-211. doi:10.1370/afm.940

Berkman, N., Sheridan, S., Donahue, K., Halpern, D., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine, 155*(2), 97-107. doi:10.7326/0003-4819-155-2-201107190-00005

Berrios-Rivera, J. P., Street, R. L., Jr., Garcia Popa-Lisseanu, M. G., Kallen, M. A., Richardson, M. N., Janssen, N. M., . . . Suarez-Almazor, M. E. (2006). Trust in physicians and elements of the medical interaction in patients with rheumatoid arthritis and systemic lupus erythematosus. *Arthritis & Rheumatology, 55*(3), 385-393. doi:10.1002/art.21988

Bickmore, T., Caruso, L., & Clough-Gorr, K. (2005, April). *Acceptance and usability of a relational agent interface by urban older adults.* Paper presented at the Computer-Human Interaction (CHI), Portland, Oregon, April 2-7.

Bickmore, T., & Paasche-Orlow, M. (2012). The role of information technology in health literacy research. *Journal of Health Communication: International Perspectives, 17*(Sup 3), 23-29. doi:10.1080/10810730.2012.712626

Bickmore, T., Pfeifer, L., & Jack, B. (2009). Taking the time to care: Empowering low health literacy hospital patients with virtual nurse agents. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1265-1274). New York, NY: ACM. doi:10.1145/1518701.1518891

Bickmore, T. W., Pfeifer, L. M., & Paasche-Orlow, M. K. (2009). Using computer agents to explain medical documents to patients with low health literacy. *Patient Education & Counseling, 75*(3), 315-320. doi:10.1016/j.pec.2009.02.007

Bickmore, T., & Picard, R. (2005). Future of caring machines. *Studies in Health Technology and Informatics, 118*, 132-145.

Blumer, H. (1954). What is wrong with social theory. *American Sociological Review, 18*, 3-10.

Borson, S., Frank, L., Bayley, P., Boustani, M., Dean, M., Lin, P.-J., . . . Ashford, W. (2013). Improving dementia care: The role of screening and detection of cognitive impairment. *Alzheimer's and Dementia, 9*, 151-159. doi:10.1016/j.jalz.2012.08.008

Borson, S., Scanlan, J. M., Chen, P., & Ganguli, M. (2003). The Mini-Cog as a screen for dementia: Validation in a population-based sample. *Journal of the American Geriatrics Society, 51*(10), 1451-1454.

Borson, S., Scanlan, J., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry, 15*(11), 1021-1027. doi:10.1002/1099-1166(200011)15:11<1021::AID-GPS234>3.0.CO;2-6

Borson, S., Scanlan, J., Watanabe, J., Tu, S., & Lessig, M. (2006). Improving identification of cognitive impairment in primary care. *International Journal of Geriatric Psychiatry, 21*(4), 349-355. doi:10.1002/gps.1470

Bowen, G. A. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods, 5*(3)(Article 2), 1-9. Retrieved from http://www.ualberta.ca/~iiqm/backissues/5_3/PDF/bowen.pdf

Brach, C., Keller, D., Hernandez, L., Baur, C., Parker, R., Dreyer, B., . . . Schillinger, D. (2012). *Ten attributes of health literate health care organizations*. Washington, DC: Institute of Medicine.

Brown, P., & Levinson, S. (1987). *Politeness: Some universals in language usage*. Cambridge, England: Cambridge University Press.

Bruera, E., Sweeney, C., Calder, K., Palmer, L., & Benisch-Tolley, S. (2001). Patient preferences versus physician perceptions of treatment decisions in cancer care. *Journal of Clinical Oncology, 19*(11), 2883-2885.

Cafazzo, J. A., Casselman, M., Hamming, N., Katzman, D. K., & Palmert, M. R. (2012). Design of an mHealth app for the self-management of adolescent type 1 diabetes: A pilot study. *Journal of Medical Internet Research, 14*(3), e70. doi:10.2196/jmir.2058

Center for Advancing Health (CAH). (2010). *A new definition of patient engagement: What is engagement and why is it important?* Washington, DC: Center for Advancing Health.

Centers for Disease Control and Prevention. (n.d.). *Clear communication index user guide*. Retrieved from http://www.cdc.gov/ccindex/

Centers for Disease Control and Prevention. (2009). *The power to prevent, the call to control*. Retrieved from www.cdc.gov/chronicdisease/resources/publications/AAG/chronic.htm

Centers for Disease Control and Prevention. (2011). *Healthy aging: Helping people to live long and productive lives and enjoy a good quality of life*. Retrieved from http://www.cdc.gov/chronicdisease/resources/publications/AAG/aging.htm

Centers for Disease Control and Prevention. (2013). *The state of aging and health in America 2013*. Atlanta, GA: Centers for Disease Control. Retrieved from http://www.cdc.gov/features/agingandhealth/state_of_aging_and_health_in_america_2013.pdf.

Centers for Medicare and Medicaid Services. (2012). *Toolkit for making written material clear and effective*. Retrieved from http://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index.html?redirect=/WrittenMaterialsToolkit/

Centers for Medicare and Medicaid Services. (2014). Data and program reports. Retrieved from http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/DataAndReports.html

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist models. In N. Denzin & Y. Lincoln (Eds.), *Strategies for qualitative inquiry* (2nd ed., pp. 249-291). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles, CA: Sage.

Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession, and trust. *Journal of the American Medical Association, 286*(15), 1897-1902. doi:10.1001/jama.286.15.1897

Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. New York, NY: Oxford University Press.

Chew, L., Bradley, K., & Boyko, E. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine, 36*(8), 588-594. doi:10.1111/j.1525-1497.2006.00532.x

Chew, L., Griffin, J., & Partin, M., Noorbaloochi, S., Grill, J., Synder, A., . . . VanRyan, M. (2008). Validation of screening questions for limited health literacy in a large VA outpatient population. *Journal of General Internal Medicine, 23*(5), 561-566. doi:10.1007/s11606-008-0520-5

Chiu, W. K., & Newcomer, R. (2007). A systematic review of nurse-assisted case management to improve hospital discharge transition outcomes for the elderly. *Professional Case Management, 12*(6), 330-336. doi:10.1097/01.PCAMA .0000300406.15572.e2

Choi, N., & DiNitto, D. (2013a). Internet use among older adults: Association with health needs, psychological capital, and social capital. *Journal of Medical Internet Research, 15*(5), online. doi:10.2196/jmir.2333

Choi, N., & DiNitto, D. (2013b). The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/internet use. *Journal of Medical Internet Research, 15*(5), e93. doi:10.2196/jmir.2645

Chung, B., & Tritle, B. (2013). The power of mobile devices and patient engagement. In J. Oldenburg (Ed.), *Engage! Transforming healthcare through digital patient engagement* (pp. 87-98). Chicago, IL: Health Information Management System Society (HIMSS).

Colorafi, K. (2014). Computer use by older adults: A review of the literature. *Journal of Gerontology and Geriatric Research, 3*(4), 164-177. doi:10.4172/2167-7182.1000164

Colorafi, K. (2015). *A content analysis of the Meaningful Use clinical summary: Does the clinical summary promote patient engagement?* Manuscript submitted for publication.

Consumer Partnership for eHealth. (2011, May). *The consumer platform for Health IT: Advancing patient and family engagement through technology*. Retrieved from http://go.nationalpartnership.org/site/DocServer/CPeH_Platform_for_Health_IT_Final_5.6.2011.pdf

Copher, R., Buzinec, P., Zarotsky, V., Kazis, L., Iqbal, S., & Macarios, D. (2010). Physician perception of patient adherence compared to patient adherence of osteoporosis medications from pharmacy claims. *Current Medical Research and Opinion, 26*(4), 777-785. doi:10.1185/03007990903579171

Coulter, A. (2012). Patient engagement: What works? *Journal of Ambulatory Care Management, 35*(2), 80-89. doi:10.1097/JAC.0b013e318249e0fd.

Creswell, J. & Plano-Clark, V. (2007). *Designing and conducting mixed method research*. Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Los Angeles, CA: Sage.

Cross, T., Bazron, B., Dennis, K., & Isaacs, M. (1989). *Towards a culturally competent system of care*. Washington, DC: Georgetown University Child Development Center.

Cunningham, P., Hibbard, J., & Gibbons, C. (2011). Raising low 'patient activation' rates among Hispanic immigrants may equal expanded coverage in reducing access disparities. *Health Affairs, 30*(10), 1888-1894. doi:10.1377/hlthaff.2009.0805

Davis, T. C., Wolf, M. S., Bass, P. F., 3rd, Middlebrooks, M., Kennen, E., Baker, D. W., . . . Parker, R. M. (2006a). Low literacy impairs comprehension of prescription drug warning labels. *Journal of General Internal Medicine, 21*(8), 847-851. doi:10.1111/j.1525-1497.2006.00529.x

Davis, T. C., Wolf, M. S., Bass, P. F., 3rd, Thompson, J. A., Tilson, H. H., Neuberger, M., & Parker, R. M. (2006b). Literacy and misunderstanding prescription drug labels. *Annals of Internal Medicine, 145*(12), 887-894.

deBruin, N. V., Lidwien Lemmens, Claudia Molema, Fracois Schellevis, Giel Nijpels, Caroline Baan. (2012). Comprehensive care programs for patients with multiple chronic conditions: A systematic literature review. *Health Policy, 107*, 108-145. doi:10.1016/j.healthpol.2012.06.006

Delbanco, T., Walker, J., Bell, S. K., Darer, J. D., Elmore, J. G., Farag, N., . . . Leveille, S. G. (2012). Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Annals of Internal Medicine, 157*(7), 461-470. doi:10.7326/0003-4819-157-7-201210020-00002

Denzin, N. (2006). *Sociological methods: A sourcebook* (5th ed.). New Brunswick, NJ: Aldine Transaction.

Denzin, N., & Lincoln, Y. (1994). *The handbook of qualitative research*. New York, NY: Sage.

Denzin, N., Lincoln, Y., & Giardina, M. (2006). Disciplining qualitative research. *International Journal of Qualitative Studies in Education, 19*(6), 769-782. doi:10.1080/09518390600975990

Domecq, J., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., . . . Hassan Murad, M. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research, 14*(89). doi:10.1186/1472-6963-14-89

Druss, B. G., Zhao, L., von Esenwein, S. A., Bona, J. R., Fricks, L., Jenkins-Tucker, S., . . . Lorig, K. (2010). The Health and Recovery Peer (HARP) program: A peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophrenia Research, 118*(1-3), 264-270. doi:10.1016 /j.schres.2010.01.026

Dykes, P. (2013). *A patient-centered longitudinal plan of care: Vision versus reality.* Paper session presented at the meeting of the American Medical Informatics Association, November 17-20, Washington, DC, USA.

Edmondson, D., Horowitz, C. R., Goldfinger, J. Z., Fei, K., & Kronish, I. M. (2013). Concerns about medications mediate the association of posttraumatic stress disorder with adherence to medication in stroke survivors. *British Journal of Health Psychology, 18*(4), 799-813. doi:10.1111/bjhp.12022

Emont, S. (2011). *Measuring the impact of patient portals: What the literature tells us.* Los Angeles, CA: California Healthcare Foundation.

Evans, W. D., Wallace, J. L., & Snider, J. (2012). Pilot evaluation of the text4baby mobile health program. *BMC Public Health, 12*, 1031. doi:10.1186/1471-2458-12-1031

Fiks, A. (2011). Designing computerized decision support that works for clinicians and families. *Current Problems in Pediatric and Adolescent Health Care, 41*(3), 60-88. doi:10.1016/j.cppeds.2010.10.006

Fineberg, H. (2012). From shared-decision making to patient-centered decision making. *Israeli Journal of Health Policy Research, 1*(6). doi:10.1186/2045-4015-1-6

Firestone, W. (1993). Alternative arguments for generalizing from data as applied to qualitative research. *Educational Researcher, 22*(4), 16-23.

Fonteyn, M. E., Vettese, M., Lancaster, D. R., & Bauer-Wu, S. (2008). Developing a codebook to guide content analysis of expressive writing transcripts. *Applied Nursing Research, 21*(3), 165-168. doi:10.1016/j.apnr.2006.08.005

Fortin, M., Dubois, M. F., Hudon, C., Soubhi, H., & Almirall, J. (2007). Multimorbidity and quality of life: a closer look. *Health and Quality of Life Outcomes, 5*, 52. doi:10.1186/1477-7525-5-52

Fortin, M., Hudon, C., Bayliss, E. A., Soubhi, H., & Lapointe, L. (2007). Caring for body and soul: the importance of recognizing and managing psychological distress in persons with multimorbidity. *International Journal of Psychiatry and Medicine, 37*(1), 1-9.

Fortin, M., Soubhi, H., Hudon, C., Bayliss, E. A., & van den Akker, M. (2007). Multimorbidity's many challenges. *British Medical Journal, 334,* 1016-1017. 10.1136/bmj.39201.463819.2C

Frank, A. (1993). The rhetoric of self-change: Illness experience as narrative. *Sociological Quarterly, 34*(1), 39-52. doi:10.1111/j.1533-8525.1993.tb00129.x

Frank, A. (1994). Reclaiming an orphan genre: The first-person narrative of illness. *Literature and Medicine, 13*(1), 1-21.

Frank, A. (1997). Illness as moral occasion: Restoring agency to ill people. *Health, 1*(131).

Frank, A. (1998). Just listening: Narrative and deep illness. *Families, Systems & Health, 16*(3), 197-212. doi:10.1037/h0089849

Fuller, D. (Ed.). (2004). *The SAGE Encyclopedia of social science research methods*. Thousand Oaks, CA: SAGE.

Gallivan, J., Kovacs-Burns, K., Belows, M., & Eigenseher, C. (2012). The many faces of patient engagement. *The Journal of Participatory Medicine, 4.* Retrieved from http://www.jopm.org/evidence/research/2012/12/26/the-many-faces-of-patient-engagement/

Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling, 51*(3), 267-275. doi:10.1016/S0738-3991(02)00239-2

Geller, B. M., Shelly, J. M., Dorwaldt, A. L., Howe, K. D., Dana, G. S., & Flynn, B. S. (2008). Increasing patient/physician communications about colorectal cancer screening in rural primary care practices. *Medical Care, 46*(9), S36-S43. doi:10.1097/MLR.0b013e31817c60ea

Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociology Press.

Glaser, B., & Strauss, A. (2012). *The discovery of grounded theory: Strategies for qualitative research.* New Brunswick, USA: Aldine Transaction.

Glasgow, R. E., Christiansen, S. M., Kurz, D., King, D. K., Woolley, T., Faber, A. J., & Dickman, J. (2011). Engagement in a diabetes self-management website: Usage patterns and generalizability of program use. *Journal of Medical Internet Research, 13*(1), 73-87. doi:10.2196/jmir.1391

Glassman, P. (2014). *Health literacy.* Retrieved from http://nnlm.gov/outreach /consumer/hlthlit.html

Goffman, E. (1967). *Interaction ritual: Essays on face-to-face interaction.* New York, NY: Anchor Books.

Gordon, C., & Galloway, T. (2008). *Review of findings on chronic disease self-management program (CDSMP) outcomes: Physical, emotional & health related quality of life, healthcare utilization and costs.* Palo Alto, CA: Evidence-Based Healthy Aging Program.

Gruman, J., Holmes-Rovner, M., French, M., Jeffress, D., Sofaer, S., Shaller, D., & Prager, D. (2010). From patient education to patient engagement: Implications for the field of patient education. *Patient Education and Counseling, 78*(3), 350-356. doi:10.1016/j.pec.2010.02.002

Guba, E. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology, 29*(2), 75-91.

Hall, M. A., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., & Balkrishnan, R. (2002). Measuring patients' trust in their primary care providers. *Medical Care Research Review, 59*(3), 293-318.

Heidenreich, P. A., Trogdon, J. G., Khavjou, O. A., Butler, J., Dracup, K., Ezekowitz, M. D., . . . Woo, Y. J. (2011). Forecasting the future of cardiovascular disease in the United States: A policy statement from the American Heart Association. *Circulation, 123*(8), 933-944. doi:10.1161/CIR.0b013e31820a55f5

Hibbard, J., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs, 32*(2), 207-214. doi:10.1377/hlthaff.2012.1061

Hibbard, J. H., Greene, J., & Overton, V. (2013). Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. *Health Affairs, 32*(2), 216-222. doi:10.1377/hlthaff.2012.1064

Hibbard, J. H., Mahoney, E. R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research, 42*(4), 1443-1463. doi:10.1111/j.1475-6773.2006.00669.x

Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. *Health Services Research, 40*(6 Pt 1), 1918-1930. doi:10.1111/j.1475-6773.2005.00438.x

Hibbard, J., & Cunningham, P. (2008). *How Engaged are Consumers in Their Health and Health Care, and Why Does It Matter?* (Research Brief No. 8). Washington, DC: Center for Studying Health System Change.

Hibbard, J., & Greene, J. (2013). What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs (Millwood), 32*(2), 207-214. doi:10.1377/hlthaff.2012.1061

Hibbard, J., Greene, J., & Tusler, M. (2009). Improving the outcome of disease management by tailoring care to the patient's level of activation. American Journal of Managed Care, 15(6), 353-360.

Hibbard, J., & Minniti, M. (2012). An evidence-based approach to engaging patients. In D. B. Nash, J. Clarke, A. Skoufalos, & M. Horowitz (Eds.), *Health Care Quality: The Clinician's Primer*. Tampa, FL: American College of Physician Executives.

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Services Research, 39(4 Pt 1), 1005-1026. doi:10.1111/j.1475-6773.2004.00269.x

Ho, P. M., Bryson, C. L., & Rumsfeld, J. S. (2009). Medication adherence: Its importance in cardiovascular outcomes. *Circulation, 119*(23), 3028-3035. doi:10.1161 /circulationaha.108.768986

Hornbrook, M., Stevens, V., Wingfield, D., et al. (1994). Preventing falls among community-dwelling older persons: Results from a randomized trial. *Gerontologist, 34*(1), 16-23.

Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277-1288.

Humes, K., Jones, N., & Ramirez, R. (2011, March). *Overview of race and Hispanic origin: 2010*. Retrieved from http://www.census.gov/prod/cen2010 /briefs/c2010br-02.pdf

Institute for Healthcare Improvement (IHI). (2012). Framework for public and family engagement. Retrieved from http://www.ihi.org/Engage/Initiatives /PatientFamilyCenteredCare/Pages/default.aspx

Institute of Medicine (IOM). (2004). *Health literacy: A prescription to end confusion*. Washington, DC: Author.

Institute for Patient and Family Centered Care. (2013). Advancing the practice of patient- and family-centered care in primary care and other ambulatory settings. Retrieved from http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf

Institute for Patient Centered Outcomes Research. (2014). Why PCORI Was Created. Retrieved from www.pcori.org/about-us

Jacaard, J., & Jacoby, J. (2010). *Theory construction and model-building skills: A practical guide for social scientists*. New York, NY: The Guilford Press.

Janssen, C., Ommen, O., Neugebauer, E., Lefering, R., & Pfaff, H. (2007). How to improve satisfaction with hospital stay of severely injured patients. *Langenbecks Archives of Surgery, 392*(6), 747-760. doi:10.1007/s00423-007-0186-1

Jensen, J. D., King, A. J., Davis, L. A., & Guntzviller, L. M. (2010). Utilization of Internet technology by low-income adults: The role of health literacy, health numeracy, and computer assistance. *Journal of Aging and Health, 22*(6), 804-826. doi:http://dx.doi.org/10.1177/0898264310366161

Kalitzukus, V., & Matthieseen, P. (2009). Narrative-based medicine: Potentials, pitfalls, and practice. *The Permanente Journal, 13*(1), 80-86.

Kass-Bartelmes, B., & Hughes, R. (2003). *Advance care planning: Preferences for care at end of life*. Rockville, MD: Agency for Healthcare Research and Quality.

Keenan, J., & Ohene-Frempong, J. (2014). *Writing and designing effective communication: A comprehensive course*. Paper presented at the Institute for Healthcare Advancement, May 6-8, Irvine, CA.

Keenan, T. (2009). Internet use among midlife and older adults: An AARP bulletin poll. Washington, DC: AARP.

Kim, E., Stolyar, A., Lober, W., Herbarugh, A., Shinstrom, S., Zierler, B., Soh, C., & Kim, Y. (2009). Challenges to using an electronic health record by low-income elderly population. *Journal of Medical Internet Research, 11*(4), e44. doi:10.2196 /jmir.1256

Kirschbaum, K. (2014). Face and politeness. In T. Thompson (Ed.), *Encyclopedia of Health Communication*. New York, NY: Sage.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books.

Koelsch, L. (2013). Reconceptualizing the member check interview. *International Journal of Qualitative Methods, 12*, 168-179.

Koh, H., Brach, C., Harris, L., & Parchman, M. (2013). A Proposed 'Health Literate Care Model' Would Constitute A Systems Approach To Improving Patients' Engagement In Care. *Health Affairs, 32*(2), 357-367. doi:10.1377 /hlthaff.2012.1205

Kowalski, C., Nitzsche, A., Scheibler, F., Steffen, P., Albert, U. S., & Pfaff, H. (2009). Breast cancer patients' trust in physicians: The impact of patients' perception of physicians' communication behaviors and hospital organizational climate. *Patient Education and Counseling, 77*(3), 344-348. doi:10.1016 /j.pec.2009.09.003

Krefting, JL. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 45*(3), 214-222.

Kutner, M., Greenberg, E., Jin, Y., & Paulson, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Health Literacy*. Washington, DC: Institute of Educational Sciences.

Lesho, E., Foster, L., Wang, Z., Sarmiento, D., Dennison, S., Vahey, M., . . . Smalls, C. (2009). The accuracy of physicians' perceptions of patient's suffering: findings from two teaching hospitals. *Academic Medicine, 84*(5), 636-642. doi:10.1097 /ACM.0b013e31819facf1

Lessig, M. C., Scanlan, J. M., Nazemi, H., & Borson, S. (2008). Time that tells: Critical clock-drawing errors for dementia screening. *International Psychogeriatrics, 20*(3), 459-470. doi:10.1017/s1041610207006035

Levine, D. A., Morgenstern, L. B., Langa, K. M., Piette, J. D., Rogers, M. A., & Karve, S. J. (2013). Recent trends in cost-related medication nonadherence among stroke survivors in the United States. *Annals of Neurology, 73*(2), 180-188. doi:10.1002/ana.23823

Levy, H., Janke, A., & Langa, K. (2014). Health literacy and the digital divide among older Americans. *Journal of General Internal Medicine*. Epub. doi:10.1007/s11606-014-3069-5

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. New York, NY: Sage.

Lochner, K., Goodman, R., Posner, S., & Parekh, A. (2013). Multiple chronic conditions among Medicare beneficiaries: State-level variations in prevalence, utilization, and cost, 2011. *Medicare and Medicaid Research Review, 3*(3), E2-E19. doi:10.5600/mmrr.003.03.b02

Logan, A. G., Irvine, M. J., McIsaac, W. J., Tisler, A., Rossos, P. G., Easty, A., . . . Cafazzo, J. A. (2012). Effect of home blood pressure telemonitoring with self-care support on uncontrolled systolic hypertension in diabetics. *Hypertension, 60*(1), 51-57. doi:10.1161/HYPERTENSIONAHA.111.188409

Logan, A. G., McIsaac, W. J., Tisler, A., Irvine, M. J., Saunders, A., Dunai, A., . . . Cafazzo, J. A. (2007). Mobile phone-based remote patient monitoring system for management of hypertension in diabetic patients. *American Journal of Hypertension, 20*(9), 942-948. doi:10.1016/j.amjhyper.2007.03.020

Loghman-Adham, M. (2003). Medication noncompliance in patients with chronic disease: Issues in dialysis and renal transplantation. *American Journal of Managed Care, 9*(2), 155-171.

Longo, D., Schubert, S., Wright, B., LeMaster, J., Williams, C., & Clore, J. (2010). Health information seeking, receipt, and use in diabetes self-management. *Annals of Family Medicine, 8*(4), 334-340. doi:10.1370/afm.1115

Lorig, K., Sobel, D., Stewart, A., Brown, B., Bandura, A., Ritter, P., Gonzalez, V., Laurent, D., & Holman, H. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical Care, 37*(1), 5-14.

Lyles, C. R., Sarkar, U., Ralston, J. D., Adler, N., Schillinger, D., Moffet, H. H., . . . Karter, A. J. (2013). Patient-provider communication and trust in relation to use of an online patient portal among diabetes patients: The Diabetes and Aging Study. *Journal of the American Medical Informatics Association, 20*(6), 1128-1131. doi:10.1136/amiajnl-2012-001567

Maierle, D., & Ryan, P. (2011). Evaluation of satisfaction and use of electronic intervention for behavior change. *CIN: Computers, Informatics, and Nursing, 29*(11), 622-629.

Marek, K., Stetzer, F., Ryan, P., Bub, L., Adams, S., Schidt, A., . . . O'Brien, A.-M. (2013). Nurse care coordination and technology effects on health status of frail older adults via enhanced self-management of medication: randomized clinical trial to test efficacy. *Nursing Research, 62*(4), 269-278.

Mather, M., Pollard, K., & Jacobsen, L. (2011). *First results from the 2010 Census*. Washington, DC: The Population Reference Bureau.

Mayberry, L. S., Kripalani, S., Rothman, R. L., & Osborn, C. Y. (2011). Bridging the digital divide in diabetes: Family support and implications for health literacy. *Diabetes Technology & Therapeutics, 13*(10), 1005-1012. doi:10.1089/dia.2011.0055

McCannon, J. B., O'Donnell, W. J., Thompson, B. T., El-Jawahri, A., Chang, Y., Ananian, L., . . . Volandes, A. (2012). Augmenting communication and decision making in the intensive care unit with a cardiopulmonary resuscitation video decision support tool: A temporal intervention study. *Journal of Palliative Medicine, 15*(12), 1-6. doi:10.1089/jpm.2012.0215

Mensah, G., & Brown, D. (2007). An overview of cardiovascular disease burden in the United States. *Health Affairs, 26*(1), 38-48.

Mercer, S. W., Smith, S. M., Wyke, S., O'Dowd, T., & Watt, G. C. (2009). Multimorbidity in primary care: developing the research agenda. *Family Practice*, *26,*. 79-80.

Miles, M., & Huberman, M. (1994). *Qualitative data analysis*. Thousand Oaks: Sage.

Miller, E., & West, D. (2007). Characteristics associated with use of public and private web sites as sources of health care information: Results from a national survey. *Medical Care, 45*(3), 245-251.

Million Hearts. (2011). About heart disease and stroke: Consequences and cost. Retrieved from millionhearts.hhs.gov/abouthds/cost-consequences.html

Mollborn, S., Stepanikova, I., & Cook, K. S. (2005). Delayed care and unmet needs among health care system users: When does fiduciary trust in a physician matter? *Health Services Research, 40*(6 Pt 1), 1898-1917. doi:10.1111/j.1475-6773.2005.00457.x

Molloy, D. W., & Standish, T. I. (1997). A guide to the standardized Mini-Mental State Examination. *International Psychogeriatric Association, 9*(Suppl 1), 87-94.

Morris, N., McLean, C., Chew, L., & Littenberg, B. (2006). The single item health literacy screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice, 7*(21), 1-7. doi:10.1186/1471-2296-7-21

Munhall, P., & Chenail, R. (2008). *Qualitative research proposals and reports: A guide* (3rd ed.). Boston, MA: Jones and Bartlett.

Myers, M., & Newman, M. (2007). The qualitative interview in IS research: Examining the craft. *Information and Organization, 17*, 2-26.

Nahm, E. S., Resnick, B., Orwig, D., Magaziner, J., Bellantoni, M., Sterling, R., & Brennan, P. F. (2012). A theory-based online hip fracture resource center for caregivers effects on dyads. *Nursing Research, 61*(6), 413-422. doi:10.1097 /NNR.0b013e318270712a

National Council on Patient Information and Education. (NCPIE). (2010). *MUST for seniors: Fact sheet on medicine use and older adults*. Retrieved from http://www.mustforseniors.org/documents/must_factsheet.pdf

National eHealth Collaborative (NeHC). (2012). *Patient engagement framework*. Retrieved from National eHealth Collaborative website: http: //www.nationalehealth.org/patient-engagement-framework

National Heart, Lung, and Blood Institute. (2014). *How is coronary artery disease treated?* Retrieved from http://www.nhlbi.nih.gov/health/health-topics/topics/cad/treatment

National Institutes of Health. (2004). *Making health communication programs work*. Retrieved from http://www.cancer.gov/cancertopics/cancerlibrary/pinkbook /pink-book.pdf

National Institutes of Health. (2009). *Research involving individuals with questionable capacity to consent: Points to consider*. Retrieved from grants.nih.gov/grants /policy/questionablecapacity.htm

National Partnership for Women and Families. (2012). *Using health IT to reduce health disparities: A review of the literature*. Washington, DC: National Partnership for Women and Families.

National Partnership for Women and Families. (2014). *Engaging patients and families: How consumers value and use health IT*. Retrieved from http: //www.nationalpartnership.org/research-library/health-care/HIT/presentation-patients-speak.pdf

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitativedescription—The poor cousin of health research? *BMC Medical Research Methodology, 9*, 52-56. doi:10.1186/1471-2288-9-52

Norman, C. D., & Skinner, H. A. (2006). eHealth literacy: Essential skills for consumer health in a networked world. *Journal of Medical Internet Research, 8*(2), 1-7.

Norman, C., Skinner, H. (2006). eHeals: The eHealth Literacy Scale. *Journal of Medical Internet Research, 8*(4), e27. doi: 10.2196/jmir.8.4.e27

Office of Minority Health. (2013). Standards for culturally competent care. Retrieved from http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&lvlid=6

Office of the National Coordinator for Health Information Technology (ONC). (2014a). *Getting started with certification: Certification for eligible professionals and hospitals*. Retrieved from http://www.healthit.gov/policy-investigators-implementers/certification-eligible-professionals-and-hospitals

Office of the National Coordinator for Health Information Technology (ONC). (2014b). *Health information technology: Standards, implementation specifications, and certification criteria for electronic health report technology, 2014 edition; revisions to the permanent certification program for health information technology*. Retrieved from http://www.gpo.gov/fdsys/pkg/FR-2012-09-04/pdf/2012-20982.pdf

Oldfield, S. R., & Dreher, H. M. (2010). The concept of health literacy within the older adult population. *Holistic Nursing Practice, 24*(4), 204-2012. doi:10.1097 /HNP.0b013e3181e90253

Osborn, C. Y., Weiss, B. D., Davis, T. C., Skripkauskas, S., Rodrigue, C., Bass, P. F., & Wolf, M. S. (2007). Measuring adult literacy in health care: performance of the newest vital sign. *American Journal of Health Behavior, 31*(Suppl 1), S36-46. doi:10.5555/ajhb.2007.31.supp.S36

Paasche-Orlow, M. K., & Wolf, M. S. (2007). The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior, 31*(Suppl 1), S19-S26.

Parker, R. (2013). *Advancing health literacy*. Paper presented at the Health Literacy: A Prescription for Patient Engagement Conference, February 12, 2013, Kansas City, MO.

Patient-Centered Outcomes Research Institute. (2014). Why PCORI was created. Retrieved from www.pcori.org/about-us

Petersen, R. C., Roberts, R. O., Knopman, D. S., Geda, Y. E., Cha, R. H., Pankratz, V. S., . . . Rocca, W. A. (2010). Prevalence of mild cognitive impairment is higher in men. The Mayo Clinic Study of Aging. *Neurology, 75*(10), 889-897. doi:10.1212 /WNL.0b013e3181f11d85

Pfizer. (2011). *The newest vital sign*. Retrieved from http://www.pfizer.com/files/health/nvs_flipbook_english_final.pdf

RAND. (2001). *Preparing for an aging world: The case for cross-national research*. Washington, DC: National Academies Press. Retrieved from www.rand.org /pubs/research_briefs/RB5058/index1.html.

Remmers, C., Hibbard, J., Mosen, D. M., Wagenfield, M., Hoye, R. E., & Jones, C. (2009). Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *Journal of Ambulatory Care Management, 32*(4), 320-327. doi:10.1097/JAC.0b013e3181ba6e77

Rogers, E. (1995). *Diffusion of innovations* (5th ed.). New York, NY: Free Press.

Rosenbloom, S. T., Daniels, T. L., Talbot, T. R., McClain, T., Hennes, R., Stenner, S., . . . Purcell Jackson, G. (2012). Triaging patients at risk of influenza using a patient portal. *Journal of the American Medical InformaticsAssociation, 19*(4), 549-554. doi:10.1136/amiajnl-2011-000382

Ryan, P. (1998). *Interventions to facilitate behavior change*. Marquette, WI: Marquette University College of Nursing.

Ryan, P. (2009). Integrated theory of health behavior change: Background and intervention development. *Clinical Nurse Specalist, 23*(3), 161-170. doi:110.1097 /NUR.1090b1013e3181a42373.

Ryan, P., Maierle, D., Csuka, M. E., Thomson, A., & Szabo, A. (2013). Computer-based intervention to enhance self-management of calcium and vitamin D intake in women. *Western Journal of Nursing Research*, *35*(8), 986-1010.

Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook, 57*(4), 217-225. doi:210.1016/j.outlook.2008.1010.1004.

Ryan, P., & Sawin, K. (2013). *The individual and family self-management theory*. Retrieved from http://www4.uwm.edu/nursing/research/self-management.cfm

Safran, D. G., Kosinski, M., Tarlov, A. R., Rogers, W. H., Taira, D. H., Lieberman, N., & Ware, J. E. (1998). The Primary Care Assessment Survey: Tests of data quality and measurement performance. *Medical Care, 36*(5), 728-739.

Safran, D. G., Taira, D. A., Rogers, W. H., Kosinski, M., Ware, J. E., & Tarlov, A. R. (1998). Linking primary care performance to outcomes of care. *Journal of Family Practice Management, 47*(3), 213-220.

Sahm, L. J., Wolf, M. S., Curtis, L. M., Behan, R., Brennan, M., Gallwey, H., & Mc Carthy, S. (2012). What's in a label? An exploratory study of patient-centered drug instructions. *European Journal of Clinical Pharmacology, 68*(5), 777-782. doi:10.1007/s00228-011-1169-2

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8,* 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16*(2), 1-8.

Sandelowski, M. (1995a). Qualitative analysis: What it is and how to begin. *Research in Nursing and Health, 18,* 371-375. doi:10.1002/nur.4770180411

Sandelowski, M. (1995b). Sample size in qualitative research. *Research in Nursing and Health, 18*, 179-183. doi:10.1002/nur.4770180211

Sandelowski, M. (1996a). Focus on qualitative methods: Using qualitative methods in intervention studies. *Research in Nursing and Health, 19*(4), 359-364. doi:10.1002/(sici)1098-240x(199608)19:4<359::aid-nur9>3.0.co;2-h

Sandelowski, M. (1996b). One is the liveliest number: the case orientation of qualitative research. *Research in Nursing and Health, 19*(6), 525-529. doi:10.1002 /(sici)1098-240x(199612)19:6<525::aid-nur8>3.0.co;2-q

Sandelowski, M. (2000a). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing and Health, 23*(3), 246-255.

Sandelowski, M. (2000b). Whatever happened to qualitative description? *Research in Nursing and Health, 23*, 334-340.

Sandelowski, M. (2001). Focus on research methods. Real qualitative researchers do not count: the use of numbers in qualitative research. *Research in Nursing & Health, 24*(3), 230-240.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health, 33*(1), 77-84. doi:10.1002/nur.20362

Sandelowski, M. (2011). When a cigar is not just a cigar: Alternative takes on data and data analysis. *Research in Nursing and Health, 34*, 342-352. doi:10.1002 /nur.20437

Sandelowski, M., Barroso, J., & Voils, C. I. (2007). Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. *Res Nurs Health, 30*(1), 99-111. doi:10.1002/nur.20176

Sandelowski, M., & Leeman, J. (2012). Writing usable qualitative health research findings. *Qualitative Health Research, 22*(10), 1404-1413. doi:10.1177 /1049732312450368

Sarkar, U., & Bates, D. (2014). Care partners and online patient portals. *Journal of the American Medical Association*. doi:10.1001/jama.2013.285825

Sarkar, U., Karter, A., Liu, J., Adler, N., Nguyen, R., Lopez, A. & Schillinger, D. (2011). Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *Journal of the American Medical Association, 18*(312), 318-321.

Sarkar, U., Lyles, C. R., Parker, M. M., Allen, J., Nguyen, R., Moffet, H. H., . . . Karter, A. J. (2014). Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. *Medical Care, 52*(3), 194-201. doi:10.1097/mlr.0000000000000069

Sarkar, U., Schillinger, D., & Lopez, A. (2011). Validation of self-reported health literacy questions among diverse English and Spanish-speaking populations. *Journal of General Internal Medicine, 26*(3), 265-271. doi:10.1007/s11606-010-1552-1

Schnipper, J. L., Gandhi, T. K., Wald, J. S., Grant, R. W., Poon, E. G., Volk, L. A., . . . Middleton, B. (2008). Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. *Informatics in Primary Care, 16*(2), 147-155.

Seto, E., Istepanian, R. S., Cafazzo, J. A., Logan, A., & Sungoor, A. (2009). UK and Canadian perspectives of the effectiveness of mobile diabetes management systems. *Conference Proceedings of IEEE Engineering and Medical Biology Society, 2009*, 6584-6587. doi:10.1109/IEMBS.2009.5333998

Shadish, W., Cook. T., & Campbell, D. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Belmont, CA: Wadsworth Cengage Learning.

Sharma, M., & Romas, J. (2012). The health belief model. In M. Sharma & J. Romas (Eds.), *Theoretical foundations of health education and health promotion* (2nd ed., pp. 74-95). Sudbury, MA: Jones & Bartlett.

Shively, M. J., Gardetto, N. J., Kodiath, M. F., Kelly, A., Smith, T. L., Stepnowsky, C., . . . Larson, C. B. (2013). Effect of patient activation on self-management in patients with heart failure. *Journal of Cardiovascular Nursing, 28*(1), 20-34. doi:10.1097/JCN.0b013e318239f9f9

Siminoff, L. A. (2013). Incorporating patient and family preferences into evidence-based medicine. *BMC Medical Informatics andDecision Making, 13*(Suppl 3), S6. doi:10.1186/1472-6947-13-s3-s6

Sofaer, S., & Schumann, M. J. (2013). *Fostering successful patient and family engagement: Nursing's critical role*. Washington, DC: Nursing Alliance for Quality Care.

Sommerhalder, K., Abraham, A., Zufferey, M. C., Barth, J., & Abel, T. (2009). Internet information and medical consultations: 1experiences from patients' and physicians' perspectives. *Patient Education and Counseling, 77*(2), 266-271. doi:10.1016/j.pec.2009.03.028

Soper, D. (2014). Sample size calculator. Retrieved from www.danielsoper.com/statcalc3/calc.aspx?id=1

Spiers, J. A. (1998). The use of face work and politeness theory. *Qualitative Health Research, 8*(1), 25-47. doi:10.1177/1049732398008

Stake, R. (2010). *Qualitative research: Studying how things work*. New York, NY: The Guilford Press.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., & Tulsky, J. A. (2001). Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of Pain Symptom Management, 22*(3), 727-737.

Stepanikova, I., Mollborn, S., Cook, K. S., Thom, D. H., & Kramer, R. M. (2006). Patients' race, ethnicity, language, and trust in a physician. *Journal of Health and Social Behavior, 47*(4), 390-405.

Stewart, M. (2001). Towards a global definition of patient centered care: The patient should be the judge of patient centered care. *British Medical Journal, 24*(322), 444-445.

Terry, P. E., Fowles, J. B., Xi, M., & Harvey, L. (2011). The ACTIVATE study: Results from a group-randomized controlled trial comparing a traditional worksite health promotion program with an activated consumer program. *American Journal of Health Promotion, 26*(2), e64-73. doi:10.4278/ajhp.091029-QUAN-348

Thom, D. H., & Campbell, B. (1997). Patient-physician trust: An exploratory study. *The Journal of Family Practice, 44*(2), 169-176.

Thom, D. H., Hall, M. A., & Pawlson, L. G. (2004). Measuring patients' trust in physicians when assessing quality of care. *Health Affairs (Millwood), 23*(4), 124-132.

Ting-Toomey, S. (1985). Toward a theory of conflict and culture. In W. Gudyknust, L. Stewart, & S. Ting-Toomey (Eds.), *Communication, culture, and organizational processes* (pp. 71-86). Newbury Park, CA: Sage.

Ting-Toomey, S. (1988). Intercultural conflicts: A face-negotiation theory. In Y. Y. Kim & W. Gudykunst (Eds.), *Theories in intercultural communication* (pp. 213-235). Newbury Park, CA: Sage.

Tovey, D. (2006). The informed patient. *Singapore Medical Journal, 47*(9), 741-745.

Trachtenberg, F., Dugan, E., & Hall, M. A. (2005). How patients' trust relates to their involvement in medical care. *The Journal of Family Practice, 54*(4), 344-352.

Trehearne, B., Fishman, P., & Lin, E. (2014). Role of the nurse in chronic illness management: Making the medical home more effective. *Nursing Economics, 32*(4), 178-184.

US Administration on Aging. (2012). *A profile of older Americans: 2012*. Retrieved from www.aoa.gov/AoARoot/Aging_Statistics/Profile/index.aspx.

US Census Bureau. (2013a). *State and county quick facts: Arizona*. Retrieved from http://quickfacts.census.gov/qfd/states/04000.html

US Census Bureau. (2013b). *State and county quick facts: New Mexico*. Retrieved from http://quickfacts.census.gov/qfd/states/35000.html

US Census Bureau. (2014). State and county quick facts. Retrieved from http: //quickfacts.census.gov/qfd/index.html

US Department of Health and Human Services (USDHHS), Centers for Medicare and Medicaid Services. (2010). Medicare and Medicaid programs: Electronic health record incentive program; final rule. *Federal Register, 75*(144). Retrieved from http://www.gpo.gov/fdsys/pkg/FR-2010-07-28/pdf/2010-17207.pdf

US Department of Health and Human Services (USDHHS), Centers for Medicare and Medicaid Services. (2012a). Medicare and Medicaid programs: Electronic health record incentive program—stage 2; health information technology: standards, implementation specifications, and certification criteria for electronic health record technology, 2014 edition; revisions to the permanent certification program for health information technology; final rules. *Federal Register, 77*(171). Retrieved from http://www.gpo.gov/fdsys/pkg/FR-2012-09-04/pdf/2012-21050.pdf

US Department of Health and Human Services (USDHHS), Centers for Medicare and Medicaid Services. (2012b). More than 100,000 health care providers paid for using electronic health records [Press release]. Retrieved from http://www.hhs.gov/news/press/2012pres/06/20120619a.html

US Department of Health and Human Services (USDHHS), Center for Medicare and Medicaid Services (CMS). (2013a). *Data and program reports*. Retrieved from http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/DataAndReports.html

US Department of Health and Human Services (USDHHS), Center for Medicare and Medicaid Services. (2013b). *Eligible professional meaningful use core measures measure 13 of 14*. Retrieved from http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/13_Clinical_Summaries.pdf

US Department of Health and Human Services (USDHHS), Center for Medicare and Medicaid Services. (2013c). *Medicaid EHR incentive payment schedule for eligible professionals*. Retrieved from http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Basics.html#BOOKMARK2

US Department of Health and Human Services. (2014). Electronic health record incentive program - Stage 2; Health information technology: Standards, implementation specifications, and certification criteria for electronic health record technology, 2014 edition; Revisions to the permanent certification program for health information technology; final rules. Washington, DC. *Federal Register*. Retrieved from http://aspe.hhs.gov/poverty/12fedreg.pdf.

van der Vaart, R., Drossaert, C. H., Taal, E., Drossaers-Bakker, K. W., Vonkeman, H. E., & van de Laar, M. A. (2014). Impact of patient-accessible electronic medical records in rheumatology: use, satisfaction and effects on empowerment among patients. *BMC Musculoskeletal Disorders, 15*, 102. doi:10.1186/1471-2474-15-102

Wade-Vuturo, A. E., Mayberry, L. S., & Osborn, C. Y. (2013). Secure messaging and diabetes management: experiences and perspectives of patient portal users.

Journal of the American Medical Informatics Association, 20(3), 519-525. doi:10.1136/amiajnl-2012-001253

Weiss, B., Mays, M., Martz, W., Merriam Castro, K., DeWalt, D., Pignone, M., Mockbee, J., & Hale, F. (2005). Quick assessment of literacy in primary care: The newest vital sign. Annals of Family Medicine, 3(6), 514-522. doi: 10.1370/afm.405

Wen, K.-Y., Kreps, G., Zhu, F., & Miller, S. (2010). Consumers' perceptions about and use of the Internet for personal health records and health information exchange: Analysis of the 2007 Health Information National Trends Survey. *Journal of Medical Internet Research, 12*(4), 122-137. doi:http://dx.doi.org/10.2196/jmir.1668

Werts, N., & Hutton-Rogers, L. (2013). Barriers to achieving eHealth literacy. *American Journal of Health Sciences,* (4), 3.

Wolcott, H. (2009). *Writing up qualitative research* (3rd ed.). Los Angeles, CA: Sage.

Wolf, M. S., King, J., Jacobson, K., Di Francesco, L., Bailey, S. C., Mullen, R., . . . Parker, R. M. (2012). Risk of unintentional overdose with non-prescription acetaminophen products. *Journal of General Internal Medicine, 27*(12), 1587-1593. doi:1510.1007/s11606-11012-12096-11603

Wolf, M. S., King, J., Wilson, E. A. H., Curtis, L. M., Cooper Bailey, S., Duhig, J., . . . Lambert, B. (2012). Usability of FDA-approved medication guides. *Journal of General Internal Medicine, 27*(12), 1714-1720. doi:10.1007/s11606-012-2068-7

World Health Organization. (1948). WHO definition of health. Retrieved from http://www.who.int/about/definition/en/print.html

Xie, B. (2011a). Effects of an eHealth literacy intervention for older adults. *Journal of Medical Internet Research, 13*(4), e90. doi:10.2196/jmir.1880.

Xie, B. (2011b). Experimenting on the impact of learning methods and information presentation channels on older adults' e-health literacy. *Journal of the American Society for Information Science and Technology, 62*(9), 1797-1807. doi:10.1002 /asi.21575

Yamin, C., Emani, S., Williams, D., Lipsitz, S., Karson, A., Wald, J., & Bates, D. (2011). The digital divide in adaption and use of a personal health record. *Archives of Internal Medicine, 171*(6), 568-574.

Yin, H. S., Parker, R. M., Wolf, M. S., Mendelsohn, A. L., Sanders, L. M., Vivar, K. L., . . . Dreyer, B. P. (2012). Health literacy assessment of labeling of pediatric nonprescription medications: examination of characteristics that may impair parent understanding. *Academic Pediatrics, 12*(4), 288-296. doi:10.1016 /j.acap.2012.02.010

Zickhur, K., & Madden, M. (2012, June 6). Older adults and Iuse. *Pew Research Internet Reports*. Washington, DC: Pew Research Center. Retrieved from http: //www.pewinternet.org/2012/06/06/older-adults-and-internet-use/

Zulman, D., Sussman, J., Chen, X., Cigolle, C., Blaum, C., & Hayward, R. (2011). Examining the evidence: A systematic review of the inclusion and analysis of older adults in randomized controlled trials. *Journal of General Internal Medicine, 26*(7), 783-790. doi:10.1007/s11606-010-1629-x

APPENDIX A

INFORMED CONSENT, PATIENT

Title of research study: Preparing for Patient Centered Health Information Technology: An exploratory study of factors influencing engagement of older adults with their plan of care

Investigator: I am a doctoral candidate in the College of Nursing and Health Innovation at Arizona State University. We (Dr. Lamb, Karen Colorafi) are conducting a research study.

Why am I being invited to participate in a research study? We invite you to take part in a research study to understand what information adults over 65 years old need to take care of their health and how they talk with their doctors.

Why is this research being done? Right now, policy makers and health insurance companies are very interested in a concept called "patient engagement". They talk about how involved a patient should be in their own health care. We would like to make sure that the voices of older adults are included in the conversation.

How long will the research last? Your participation will include the time you spend with the doctor plus about 20 minutes with Karen after your visit with the doctor, before leaving the clinic. You will have no long term contact with the investigator.

How many people will be studied? We expect about 40 people to participate in this study.

What happens if I say yes, I want to be in this research? Your participation will involve:

1. An observation of you and your doctor in the exam room.
2. Filling out a brief questionnaire after your visit.
3. Answering a small number of interview questions after your visit.

Karen may take some notes during the time you talk with your doctor, but they are general comments and do not have anything to do with your specific medical problem or specific concerns. The questionnaire will ask you about your demographics (for example, your age and education). In the interview, Karen will ask you about the written summary you receive from your doctor and about information you find helpful in taking care of yourself. We would like to audiotape this interview but we will <u>not</u> audiotape the visit with your doctor.

What happens if I say yes, but I change my mind later? You can change your mind at any time. Just let Karen know and she will leave the exam room, or stop recording the interview. You have the right not to answer any question, and to stop at any time. Participation in this study is completely voluntary. It is ok for you to say no. Even if you say yes now, you are free to say no later, and withdraw from the study at any time. Whether or not you participate will not affect your health care or visit with your doctor in any way.

Is there any way that being in this study could be bad for me? There are minimal risks for participation in this study. If you feel confused or upset while we review the information on your clinical summary, please let Karen know. Arrangements will be made for you to visit again with the health care provider in the clinic before you leave to clarify anything you wish.

Will being in this study help me in any way? Although there may be no direct benefits to you, the possible benefit of your participation is an opportunity to improve the clinical summary document that this clinic hands out to patients and the ways that this clinic provides patient information.

What happens to the information collected for the research? All information obtained in this study is strictly confidential. Your information will only be reported as a group. The results of this research study may be used in reports, presentations, and publications, but the researchers will not identify you. Your survey and your interview sheets will never be identified by your name. Instead, Karen will assign a generic code so that your identify will not be associated with it. Anything on an interview transcript that identifies you will be deleted. All data collected today will be kept in a secure location. Only Karen and her supervisors at the university will ever have access to them. After the research is complete, the survey, tape, and interview sheets will be destroyed.

Who can I talk to? If you have questions regarding this study, you may contact Karen Colorafi at Karen.colorafi@asu.edu or Dr. Gerri Lamb at gerri.lamb@asu.edu or by calling (602) 496-2644. This research has been reviewed and approved by the Social Behavioral IRB at Arizona State University. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Your signature documents your permission to take part in this research.

Signature of participant:
____

Printed name of participant: ___________________Date: _________________

Signature of person obtaining consent: ________________________________

Printed name of person obtaining consent: Karen Colorafi Date: ___________

APPENDIX B

INFORMED CONSENT, PATIENT AND FAMILY

Title of research study: Preparing for Patient Centered Health Information Technology: An exploratory study of factors influencing engagement of older adults with their plan of care

Investigator: I am a doctoral candidate in the College of Nursing and Health Innovation at Arizona State University. We (Dr. Lamb, Karen Colorafi) are conducting a research study.

Why am I being invited to participate in a research study? We are inviting patients and their family caregivers to take part in a research study. We seek to understand what information adults over 65 years old and their family members need to take care of their health and how they talk with their doctors.

Why is this research being done? Right now, policy makers and health insurance companies are very interested in a concept called "patient engagement". They talk about how involved patients and families should be in their own health care. We would like to make sure that the voices of older adults and their family members are included in the conversation.

How long will the research last? Your participation will include the time you spend with the doctor plus about 20 minutes with Karen after your visit with the doctor, before leaving the clinic. You will have no long term contact with the investigator.

How many people will be studied? We expect about 40 people to participate in this study. We are inviting the family caregivers of our participants to join the interview if they come to the doctor's office with their loved one.

What happens if I say yes, I want to be in this research? Your participation will involve:

1. An observation of you, your family member, and the doctor in the exam room.
2. Filling out a brief questionnaire after your visit.
3. Answering a small number of interview questions after your visit, along with your family member.

Karen may take some notes during the time you talk with the doctor, but they are general comments and do not have anything to do with your specific medical problem or specific concerns. The questionnaire will ask you about demographics (for example, age and education). In the interview, Karen will ask you and your family member about the written summary you receive from the doctor and about information you both find helpful in taking care of your medical problems. We would like to audiotape this interview but we will <u>not</u> audiotape the visit with your doctor.

What happens if I say yes, but I change my mind later? You can change your mind at any time. Just let Karen know and she will leave the exam room or stop recording the interview. You have the right not to answer any question, and to stop at any time. Participation in this study is completely voluntary. It is ok for you to say no. Even if you say yes now, you are free to say no later, and withdraw from the study at any time. Whether or not you participate will not affect your health care or visit with the doctor in any way.

Is there any way that being in this study could be bad for me? There are minimal risks for participation in this study. If you feel confused or upset while we review the information on the clinical summary, please let Karen know. Arrangements will be made for you and/or your family member to visit again with the doctor in the clinic before you leave to clarify anything you wish.

Will being in this study help me in any way? Although there may be no direct benefits to you, the possible benefit of your participation is an opportunity to improve the clinical summary document that this clinic hands out to patients and their families and the way that this clinic provides information to patients and families.

What happens to the information collected for the research? All information obtained in this study is strictly confidential. Your information will only be reported as a group. The results of this research study may be used in reports, presentations, and publications, but the researchers will not identify you. Your survey and your interview sheets will never be identified by your name. Instead, Karen will assign a generic code so that your identify will not be associated with it. Anything on an interview transcript that identifies you will be deleted. All data collected today will be kept in a secure location. Only Karen and her supervisors at the university will ever have access to them. After the research is complete, the survey, recording, and interview sheets will be destroyed.

Who can I talk to? If you have questions regarding this study, you may contact Karen Colorafi at Karen.colorafi@asu.edu or Dr. Gerri Lamb at gerri.lamb@asu.edu or by calling (602) 496-2644. This research has been reviewed and approved by the Social Behavioral IRB at Arizona State University. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Your signatures document your permission to take part in this research.

Signature of participant: ____

Printed name of participant: ________________________ Date: ____________

Signature of family caregiver: ____

Printed name of family caregiver: __________________ Date: _____________

Signature of person obtaining consent: _______________________________

Printed name of person obtaining consent: Karen Colorafi Date: ____________

APPENDIX C

OBSERVATION WORKSHEET

Observation Worksheet

Participant Code: ________________________

Family Caregiver Present? ____ Yes ____ No

	Observed Behaviors (Corresponding CAH Engagement Behavior)	Notes
HISTORY	*Communicates with healthcare professional*	
	☐ **Brings list of questions for discussion** (Prepare in advance a list of questions/issues for discussion) ☐ **Reports health history and status of physical and mental symptoms** (Report accurately on the history and current status of physical and mental symptoms)	
	Organizes healthcare	
	☐ **Brings a summary recent test results to visit such as labs** (Bring a summary of medical history, current health status and recent test results to visits as appropriate)	

MEDICATION	*Communicates with healthcare professional*	
	☐ **Brings list of all current medications** (Bring list of all current medications and be prepared to discuss their benefits and side effects) ☐ **Asks question or offers information about benefit or side effect** (Brings list of all current medications and be prepared to discuss their benefits and side effects)	
	Participates in treatment planning	
	☐ **Initiates a discussion about which medications need to be refilled at this time** (Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician before discontinuing use) ☐ **Responds to doctor's question about which medications need to be refilled at this time** (Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician before discontinuing use)	
	Seeks health knowledge	
	☐ **Describes a time when he/she made an effort to learn about medication, e.g. – Internet, TV, lecture, etc.** (If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge)	

	Makes good treatment decisions	
PLAN	☐ **Ask questions about doctor's recommendations** (Ask questions when explanations are not clear, express concerns about recommendations or care experiences) ☐ **Brings to doctor's attention the opinion, concern, or plan of other doctor such as PCP or other specialist** (Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment) ☐ **Asks about risks and benefits of proposed tests or medications** (Ask about the evidence for the efficacy of recommended treatment options - risks and benefits) ☐ **Initiates discussion about the pros/cons of treatments doctor suggests** (Evaluate treatment option) ☐ **Provides verbal consent to doctor's suggestions** (Negotiate a treatment plan with the provider) ☐ **Indicates that he/she does not want to do what doctor suggests** (Negotiate a treatment plan with the provider) ☐ **Seeks clarification to what doctor suggests** (Negotiate a treatment plan with the provider)	

PLAN	*Participates in treatment planning*	
	☐ **If he/she has one, initiates discussion about life of device** (Maintain devices) ☐ **If he/she has one, responds to doctor's discussion about life of device** (Maintain devices)	
	Seeks health knowledge	
	☐ **Describes plans for making/attending FU appointment with doctor** (If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge)	
	Gets preventative care	
	☐ **Describes plans for making/attending appointment for testing** (Evaluate and receive recommended diagnostic/follow-up tests in discussion with health care providers)	

EDUCATION	*Participates in treatment planning*	
	☐ **Describes situations in which he/she would go to ER or call office, ie - chest pain** (Monitor symptoms/condition including danger signs that require urgent attention) ☐ **Verbally acknowledges doctor's description of situations in which he/she would go to ER or call office, e.g. - chest pain** (Monitor symptoms/condition including danger signs that require urgent attention)	
	Seeks health knowledge	
	☐ **Describes a time when he/she made an effort to learn about condition/med, e.g. – Internet, TV, lecture, etc.** (If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge)	
	Promotes health	
	☐ **Initiates discussion about target values, i.e. – reports or inquires** (Know personal health targets (e.g., target blood pressure) and what to do to meet them ☐ **Verbally acknowledges doctor's description of target values** (Know personal health targets (e.g., target blood pressure) and what to do to meet them	

APPENDIX D

DEMOGRAPHIC FORM WITH THE SINGLE ITEM HEALTH LITERACY SCREENER

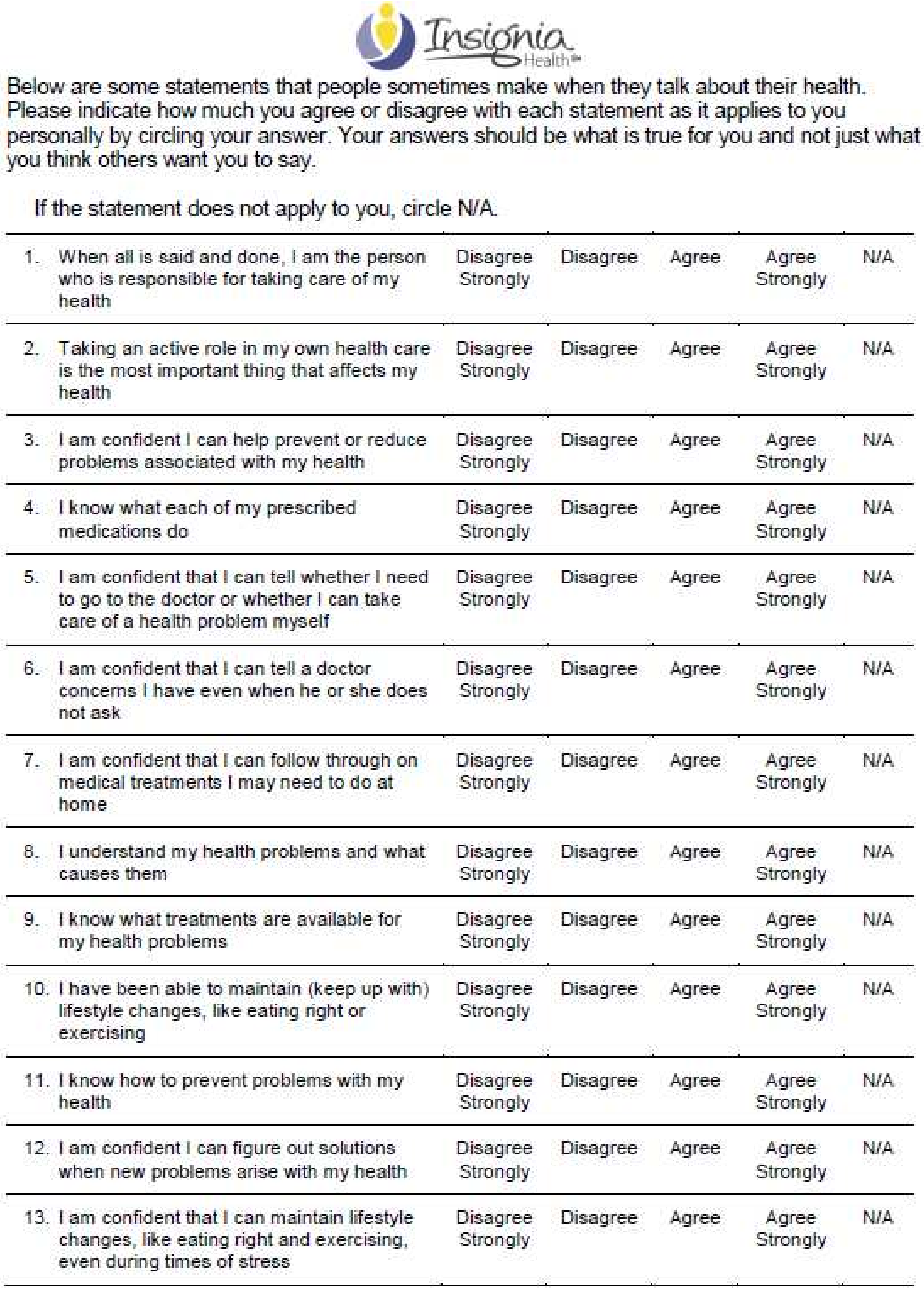
Demographic Form with the Single Item Health Literacy Screener

DEMOGRAPHIC FORM	**PARTICIPANT CODE:** ______________
What is your age?	_________ years
What is your gender?	☐ Male ☐ Female
What is your ethnicity?	☐ Hispanic/Latino ☐ Non-Hispanic/Latino
What is your race?	☐ White ☐ Black/African American ☐ Asian ☐ Native Hawaiian/Pacific Islander ☐ American Indian/Alaskan Native
At the end of the month, do you have:	☐ Enough money? ☐ Not enough money? ☐ More than enough money?
Do you have health insurance *in addition to* medicare/medicaid:	☐ Yes ☐ No
What is the highest level of education you have completed?	☐ Some high school ☐ High school ☐ College ☐ Bachelor's degree ☐ Master's degree ☐ PhD or terminal professional degree
How many times in the last year have you seen the cardiologist?	____________ times
How many times in the last year have you seen your primary care provider?	____________ times
What are your chronic diagnoses?	1. ____________________ 2. ____________________ 3. ____________________ 4. ____________________ 5. ____________________
How confident are you filling out medical forms by yourself?	☐ Extremely ☐ Quite a bit ☐ Somewhat ☐ A little bit ☐ Not at all

APPENDIX E

PATIENT ACTIVATION MEASURE

Patient Activation Measure



Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

APPENDIX F

INTERVIEW QUESTIONS

Interview Questions:

1. Think about the time you spent today with your doctor. What was the most important thing you talked about?
   Prompts, if needed:
   a. What else?
   b. Which health issue was most concerning?
   c. What part of the conversation helped you the most?

2. What do you do at home to look after yourself?
   Prompts, if needed:
   a. What are you able to do now?
   b. What do you want to be able to do?

3. Picture yourself in perfect health. What does that look like?
   Prompts, if needed:
   a. What would motivate you to achieve that perfect picture?
   b. How might you do that?

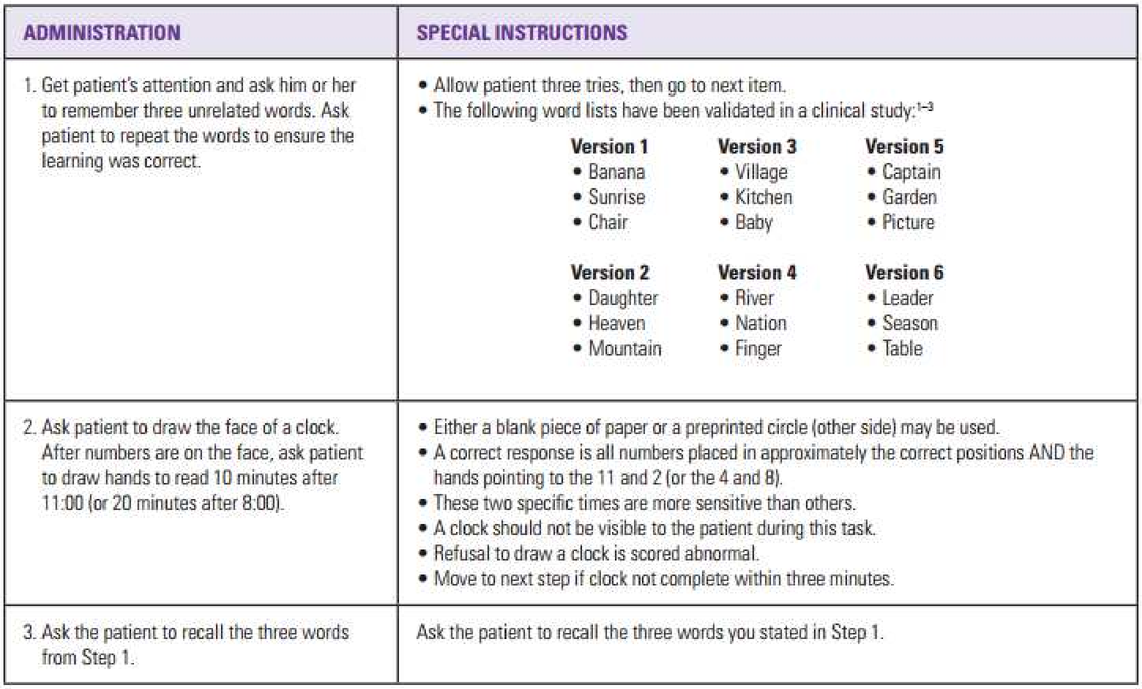
4. How can your doctor help you to do that?
   Prompts, if needed:
   a. Would it be helpful if your doctor made information available to you online?
   b. Would it be helpful if your doctor shared information about your health with other people that you wanted to support you?

5. Let's review your clinical summary (*Having picked up the clinical summary while the patient completed the Demo form and PAM, the interviewer will hand it to the patient and say "Take a moment to look over this. Talk to me about what is helpful")*.
   Prompts, if needed:
   a. How could we change this to make it more helpful?
   b. Would it be helpful if you were able to view this clinical summary online?

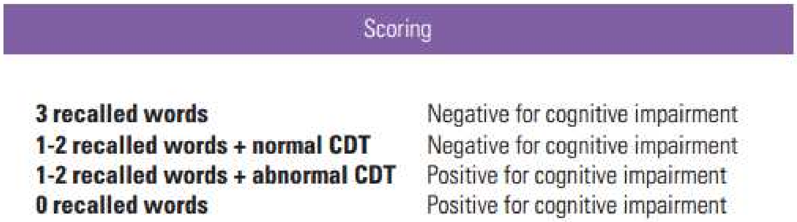
APPENDIX G

MINI-COG™ INSTRUCTIONS FOR THE INVESTIGATOR

Mini-Cog^{tm} Instructions for the Investigator



ADMINISTRATION	SPECIAL INSTRUCTIONS
1. Get patient's attention and ask him or her to remember three unrelated words. Ask patient to repeat the words to ensure the learning was correct.	• Allow patient three tries, then go to next item. • The following word lists have been validated in a clinical study:[1–3] **Version 1**: • Banana • Sunrise • Chair **Version 3**: • Village • Kitchen • Baby **Version 5**: • Captain • Garden • Picture **Version 2**: • Daughter • Heaven • Mountain **Version 4**: • River • Nation • Finger **Version 6**: • Leader • Season • Table
2. Ask patient to draw the face of a clock. After numbers are on the face, ask patient to draw hands to read 10 minutes after 11:00 (or 20 minutes after 8:00).	• Either a blank piece of paper or a preprinted circle (other side) may be used. • A correct response is all numbers placed in approximately the correct positions AND the hands pointing to the 11 and 2 (or the 4 and 8). • These two specific times are more sensitive than others. • A clock should not be visible to the patient during this task. • Refusal to draw a clock is scored abnormal. • Move to next step if clock not complete within three minutes.
3. Ask the patient to recall the three words from Step 1.	Ask the patient to recall the three words you stated in Step 1.



Scoring

3 recalled words	Negative for cognitive impairment
1-2 recalled words + normal CDT	Negative for cognitive impairment
1-2 recalled words + abnormal CDT	Positive for cognitive impairment
0 recalled words	Positive for cognitive impairment

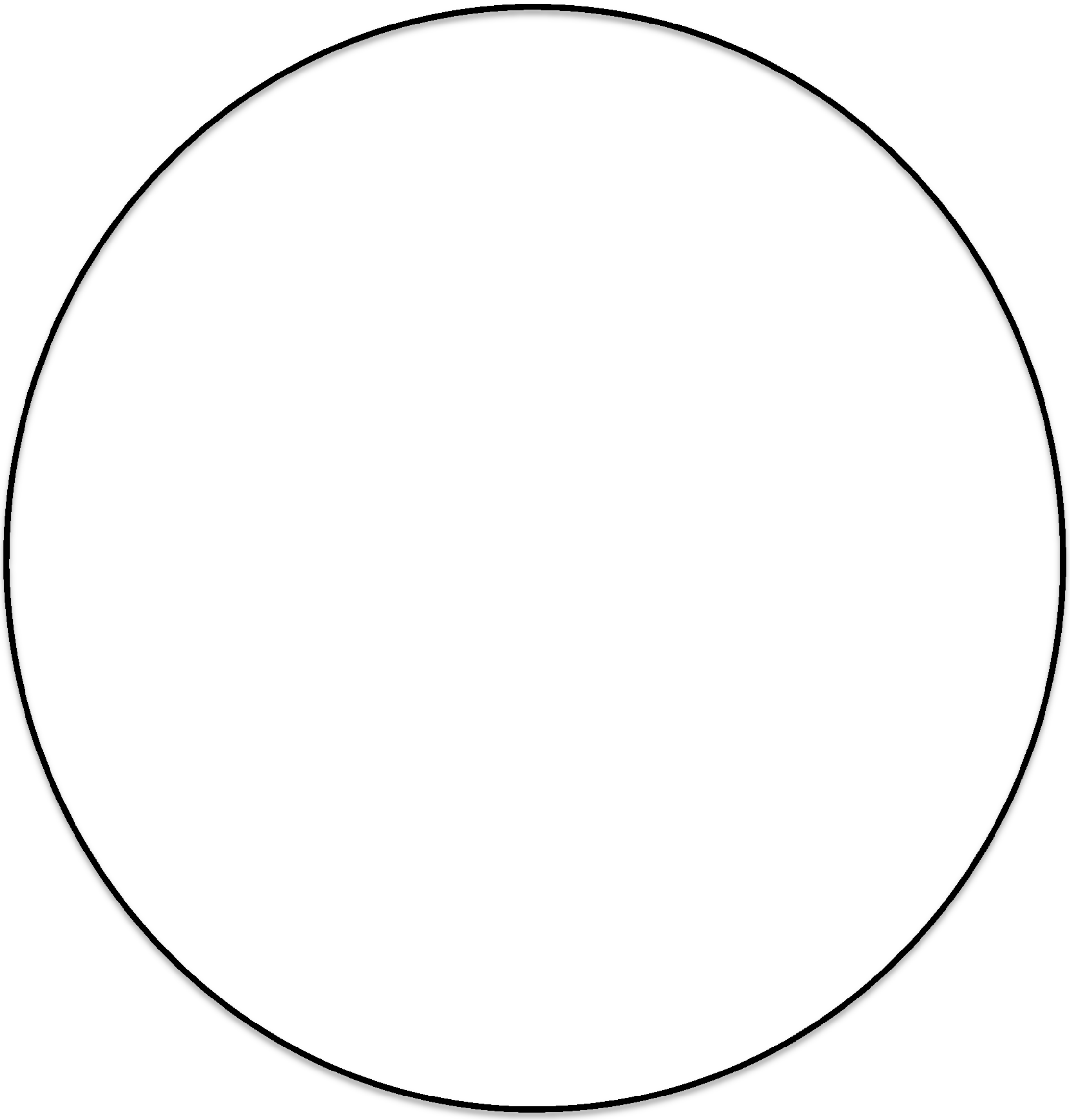
APPENDIX H

MINI-COG™ DRAWING SHEET FOR PARTICIPANTS

Mini-Cog™ Drawing Sheet for Participants

Mini-Cog™ Clock Drawing Test Participant Code:
____

Please draw hands on the clock so that the time displayed is 11:10.



APPENDIX I

INITIAL CODING MANUAL

Initial Coding Manual

1	**Make Good Treatment Decisions** *(Understanding proposed treatment plans + Negotiating a plan of care)* ↑Is a component of ↑	
1A	**Gathering expert opinions** Seeking information from other health care professionals on any serious diagnosis prior to beginning any course of treatment	5, "I was very happy that they have a line where you can call and talk to anyone all the time. The nurse can answer your question and the doctor is always accessible. So you can talk to someone all the time."
1B	**Asking about evidence** Ask about the risks and benefits of recommended treatment options	0, Proposition: *Older adults do not question the substance of the provider's plan of care.* (There are zero instances of this behavior in the 10 interview transcripts reviewed.)
1C	**Evaluating options** Ask about the treatment options available and weigh the information with individual preferences	
1D	**Negotiating treatment plans** Design a treatment plan with the provider(s)	
2	**Participate in Treatment** *(Actively following the plan of care)* ↑Is a component of ↑	
2A	**Learning about new treatments** Study any newly prescribed medications, devices, or treatments, including possible side effects or interactions with existing medications and devices	2, "She doesn't do much of the reading, I do. I take care of her. I read pamphlets or you know, when they have things out in the waiting room. I'll pick up things and read them."
2B	**Taking medicine as prescribed** Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician when discontinuing use	3, "The list of medications that they put you on, that is nice. I have it on my computer anyway. I print it out before I come and give it to them."

2C	**Maintaining therapeutic regimen** Do what it takes to look after health/devices, etc. and keep them in good working condition	2, "The other thing that has helped me the most, like when I got this machine for my diabetes ((points to an insulin pump)) is that the person who gave it to me and taught me about it actually had diabetes for a very long time. So I have a problem with this pump, we're supposed to call our family doctor, but sometimes he just doesn't know about it because he doesn't have it. He's not diabetic. So we have found that if we just call her, she looks back at her records and just tells me exactly what to do. And if we really don't get it, she has us come in and she shows us. You know, you can call the company, but they just don't know either. If you aren't talking to someone who actually has these problem they don't know what you are talking about and I don't know what t3, hey are talking about."
2D	**Evaluating the results of tests** Assess the results of recommended diagnostic and follow-up tests in discussion with health care providers	*Note: this was seen in observation but no one specifically talked about it during interviews so I will keep the code for future use.*
2E	**Monitoring symptoms** Carefully monitor symptoms and conditions (e.g., for diabetes — monitor glucose regularly, check feet; for depression — medication and/or counseling and monitor symptoms; for hypertension — measure blood pressure regularly, maintain blood pressure diary), including danger signs that require urgent attention and personal limitations	4, "[I like knowing] the different medical conditions that people have – you can't know everything, so it's nice to know what to look out for. A description of the problem, what symptoms to look out for, when should you seek medical attention right away." AND "I am all for the practical things. For example, I take all these things to dry me out because I have too much water. And then I'm also taking Vesicare. I know these two things are fighting against each other, but that's what I have to do and now they are in pretty good balance. Before I had to wear pads all the time and water was just flowing out of me."

3	**Promote Health** *(Identifying opportunities for better health + Actively making behavior changes to meet personal goals)* ↑Is a component of ↑	
3A	**Setting goals and priorities** Set and act on priorities to optimize health and prevent disease	1, “I also keep a running history so I can look back and see when I had the last chest xray or colonoscopy or whatever it is they are asking about. Those kinds of things are the things I can’t remember. I mean when you only have a colonoscopy every five years, who is going to remember the date of that? Then they know when it’s time to have another one.”
3B	**Changing behavior** Identify and secure services that support changing behavior to maximize health and functioning and maintain those changes over time	1, “[The clinical summary helps me to know] the fats and the carbs. What I need to, I guess, more when I need to exercise, you know my diet and exercise, I need to know that. What would be the most beneficial for me, other than sit there on the couch! ((laughs)) Any kind of movement is better than none.”
3C	**Managing symptoms** Act in a way to minimize symptoms by following treatment plans, including diet, exercise and medication use agreed upon by them and the provider	1, “I like this here. ((Patient points to problem list)). Where it tells you about the different problems. Makes me want to watch what I’m eating and see if there is something I can do about it.”
4	**Seek Health Knowledge** *(Understanding the nature of one’s health and illness)* ↑Is a component of ↑	
4A	**Assessing personal risk** Judge personal risks for poor health, disease and injury, and seek opportunities to increase knowledge about health and disease prevention	1, “If you’re going to assess something, then you should tell the patient as compared to what … give me a way to compare how I’m doing with what is normal.”

4B	**Understanding chronic diagnoses** If diagnosed with a chronic disease, recognize the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge	3, "Yes they have got to use words instead of numbers and these short forms. His EF is 45% well I have no idea what EF is. What is AICD? These numbers are hard to read (referring to ICD code behind diagnosis). When we get our blood test it says what yours is and what is normal. Just like what Dr. Kates said, that normal for his blood pressure is between 112 and 130. I didn't know that! We have never known that. I thought blood pressure had to be 120/80. I didn't know it could go under or over. I need to have a measure. Then I can tell if there is a problem. Is it high? It doesn't say anything. There is no information here that a layman can understand. Under the problems, it says Atrial, Fibrillation, Permanent. What does that mean? If it's permanent, why are we doing all these things to make it go away if it will never go away? Why are they putting in a pacemaker then? It says History of chest pain and a number, 786, what is that?" *(Proposition: Older adults seek information about their chronic conditions from their providers)*
4C	**Knowing personal target** Identify personal health targets (e.g., ideal blood pressure) and taking action to do to meet them	
4D	**Managing information** Keeping careful records of health and health care and sharing information with health care team as needed; making corrections as needed	8, "This is helpful. This is what he gets every time. It helps because at a glance it has everything – problems, medications, allergies, everything. If we have this with us and we see different doctors, then we can tell different doctors what he has".
4E	**Using information to orient** Connecting current health history to a larger life context (ie: family history); using the poc to orient oneself or put current health status into a larger life context	4, "[When was] the last time I had my cholesterol checked? My sisters both have major cholesterol problems, but I have never had. But my sisters are 50-100 pounds heavier than I am!"

5	**Knowledge & Beliefs** *(Recognizing the influence of individual values and preferences)* ↑Is a component of ↑	
5A	**Ability to succeed** Knowing that one's health goals can be met; confident in one's ability to meet them (self-efficacy)	3, "Most helpful … to you, would be just to know if everything is ok, is everything normal or are things a little over or a little under. I want to know that everything is ok."
5B	**Expecting change because of actions** Evidence of motivation for behaving in a way that will lead to desired outcomes; outcome expectancy	2, "Well I do a lot of exercising, which I hadn't done in many years. I have lost 10 or 15 pounds since the heart attack. My stomach is harder with all the exercise but the doctors want me to lose more weight. I realize there is fat, but the stomach muscles are harder."
5C	**Knowing oneself** Alignment of personal goals, values and beliefs to achieve the desired, overriding health outcome; acting to achieve goal congruence	5, "I try to avoid putting personal information, especially financial, on the web. But I could do it if that is what was required" AND "They have to give me positive information. Why do they call it heart failure? That just says I'm a failure. If that's what it is called and they can't do anything about it, then just don't say the word to me. I understand when they say "congestive", that there is fluid back up and all that water and that's the congested part, but what is the failure? Being positive helps."
5D	**Kernel of doubt** Identifying situations in which one's ability to meet health goals is called into question, or that the provider has the patient's best interests at heart	2, "He left a doubt with me now – I don't have a good feeling about that now at all. He said it was too complicated because of the situation. This leaves a feeling a doubt with me now. It makes you wonder. Did he not put it in because he ran out of time? He didn't explain to me about that. That is worse than any paperwork or anything else you want to talk about. That is very concerning to me right now. He always changes his mind. That makes us lose confidence in him. He is always in a hurry. He has far too much to do."

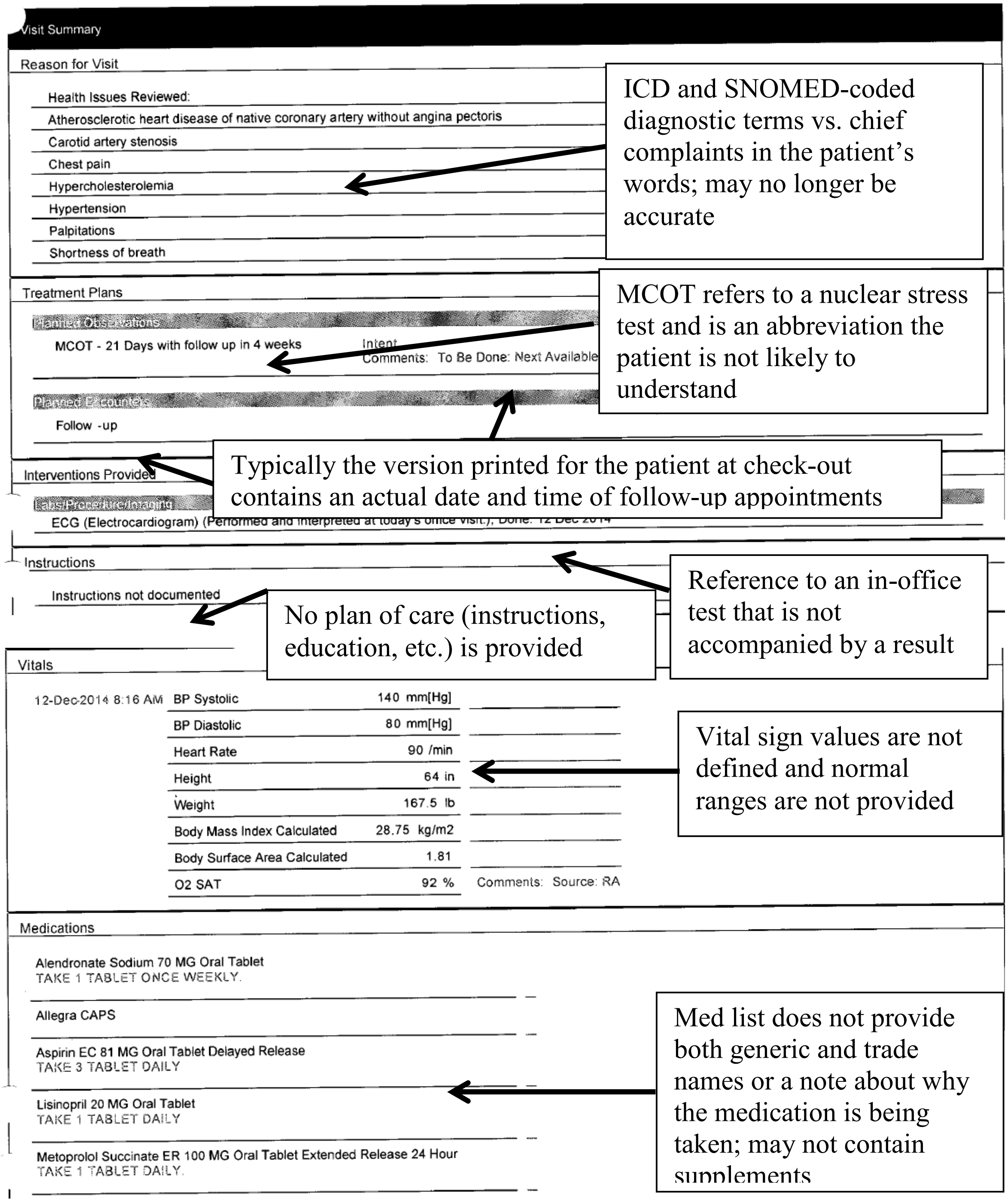
6	**Face Needs** *(Communication strategies used to interact effectively with health care professionals while maintaining a sense of competency, liking, appreciation, or esteem)* ↑Is a component of ↑	
6A	**Preserving face** Interaction patterns that protect the sense of self-esteem or autonomy/control and enhance image, including the feeling of competence in one's intelligence and ability to cope	3, "Well I'm just not sure about this blood pressure but I keep at it and I'm still around so I guess I'm doing ok."
6B	**Being polite** Making requests in an indirect way to protect against inconvenience or embarrassment	1, "The doctor has been pretty thorough. I did ask him one time when I take my blood pressure. I take at first and it will be high, and then I rest and it will go down 10 or 20 points. I asked him about it and he said "I'm not worried about that". (laughs) So I guess I don't have to either."
6C	**Feeling like you don't understand** Not knowing what the provider is saying or what you are reading	7, "I don't know what that first one is. ((Points to a problem with an ICD-9 code on the problem list)) I don't know what that first one is. That I know. ((Points to another)) I don't know what that one is. ((Points to another))" AND "This is not my industry so I don't know what these codes are or what they mean."

APPENDIX J

CLINICAL SUMMARY EXEMPLAR

Clinical Summary Exemplar

This is an example of a clinical summary (i.e. a plan of care that could be printed or pushed to a patient portal) annotated with the issues that participants identified:



Visit Summary

Reason for Visit

Health Issues Reviewed:
Atherosclerotic heart disease of native coronary artery without angina pectoris
Carotid artery stenosis
Chest pain
Hypercholesterolemia
Hypertension
Palpitations
Shortness of breath

ICD and SNOMED-coded diagnostic terms vs. chief complaints in the patient's words; may no longer be accurate

Treatment Plans

Planned Observations

MCOT - 21 Days with follow up in 4 weeks
Intent
Comments: To Be Done: Next Available

MCOT refers to a nuclear stress test and is an abbreviation the patient is not likely to understand

Planned Encounters

Follow -up

Typically the version printed for the patient at check-out contains an actual date and time of follow-up appointments

Interventions Provided

Labs/Procedure/Imaging

ECG (Electrocardiogram) (Performed and interpreted at today's office visit.), Done: 12 Dec 2014

Reference to an in-office test that is not accompanied by a result

Instructions

Instructions not documented

No plan of care (instructions, education, etc.) is provided

Vitals

12-Dec-2014 8:16 AM	BP Systolic	140 mm[Hg]	
	BP Diastolic	80 mm[Hg]	
	Heart Rate	90 /min	
	Height	64 in	
	Weight	167.5 lb	
	Body Mass Index Calculated	28.75 kg/m2	
	Body Surface Area Calculated	1.81	
	O2 SAT	92 %	Comments: Source: RA

Vital sign values are not defined and normal ranges are not provided

Medications

Alendronate Sodium 70 MG Oral Tablet
TAKE 1 TABLET ONCE WEEKLY.

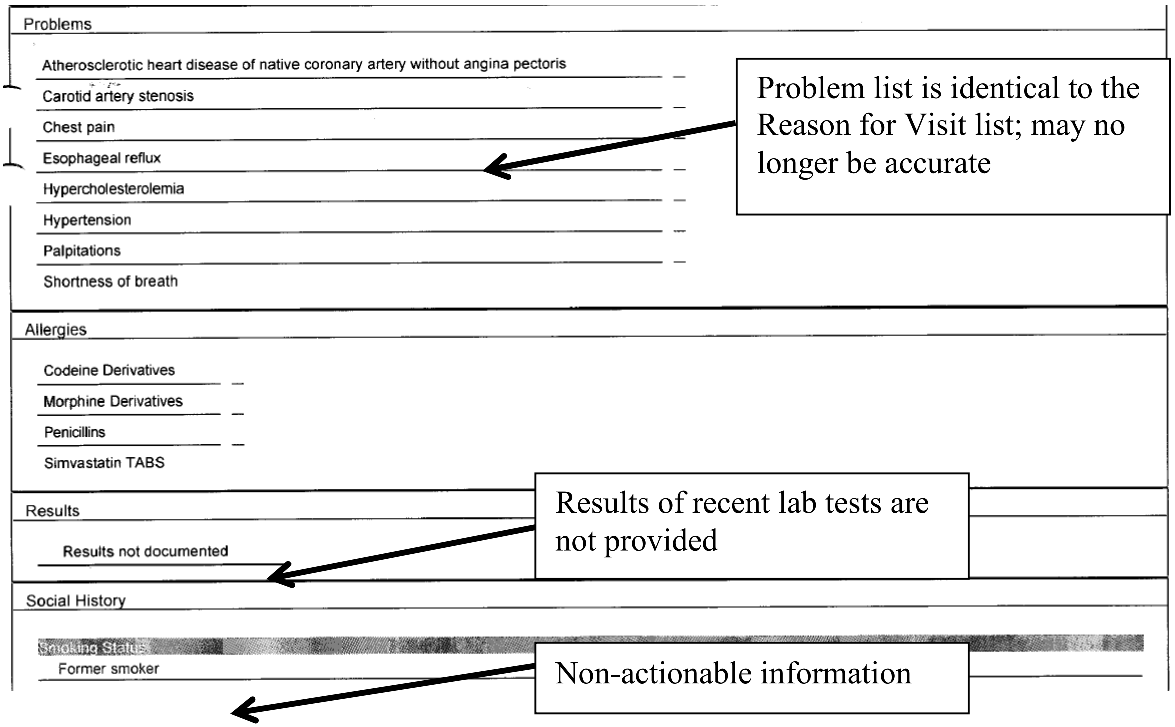
Allegra CAPS

Aspirin EC 81 MG Oral Tablet Delayed Release
TAKE 3 TABLET DAILY

Lisinopril 20 MG Oral Tablet
TAKE 1 TABLET DAILY

Metoprolol Succinate ER 100 MG Oral Tablet Extended Release 24 Hour
TAKE 1 TABLET DAILY.

Med list does not provide both generic and trade names or a note about why the medication is being taken; may not contain supplements



Problems

Atherosclerotic heart disease of native coronary artery without angina pectoris
Carotid artery stenosis
Chest pain
Esophageal reflux
Hypercholesterolemia
Hypertension
Palpitations
Shortness of breath

Allergies

Codeine Derivatives
Morphine Derivatives
Penicillins
Simvastatin TABS

Results

Results not documented

Social History

Smoking Status

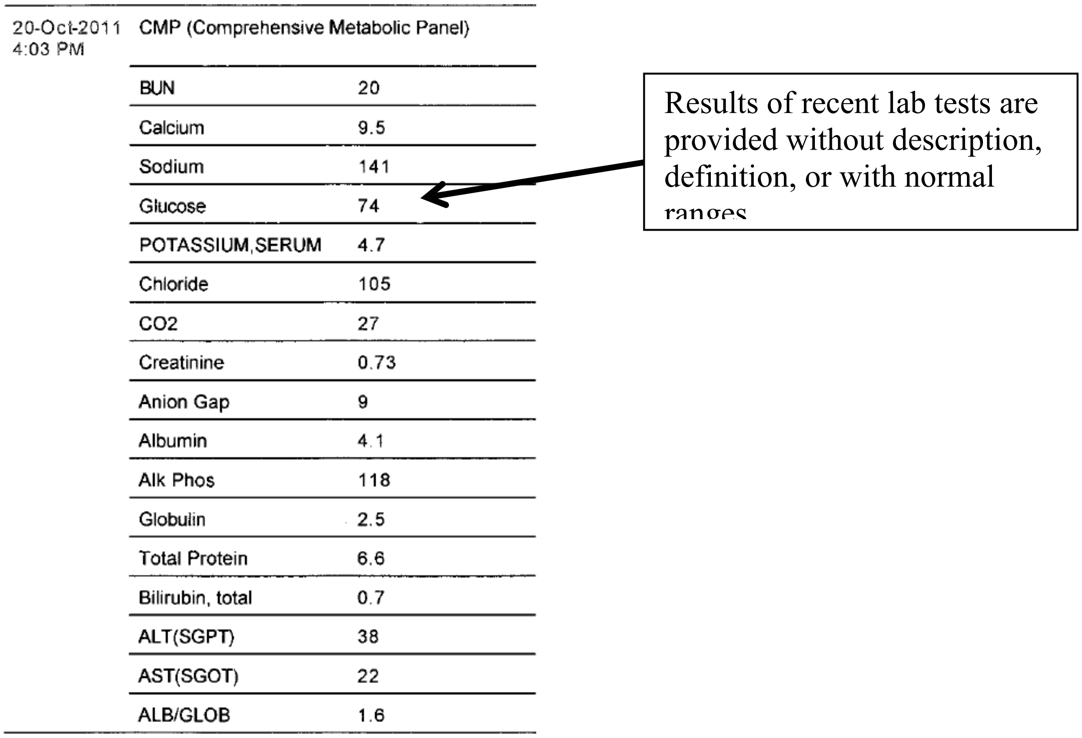
Former smoker

Problem list is identical to the Reason for Visit list; may no longer be accurate

Results of recent lab tests are not provided

Non-actionable information

This is the way that laboratory results displayed in the clinical summary, when available:

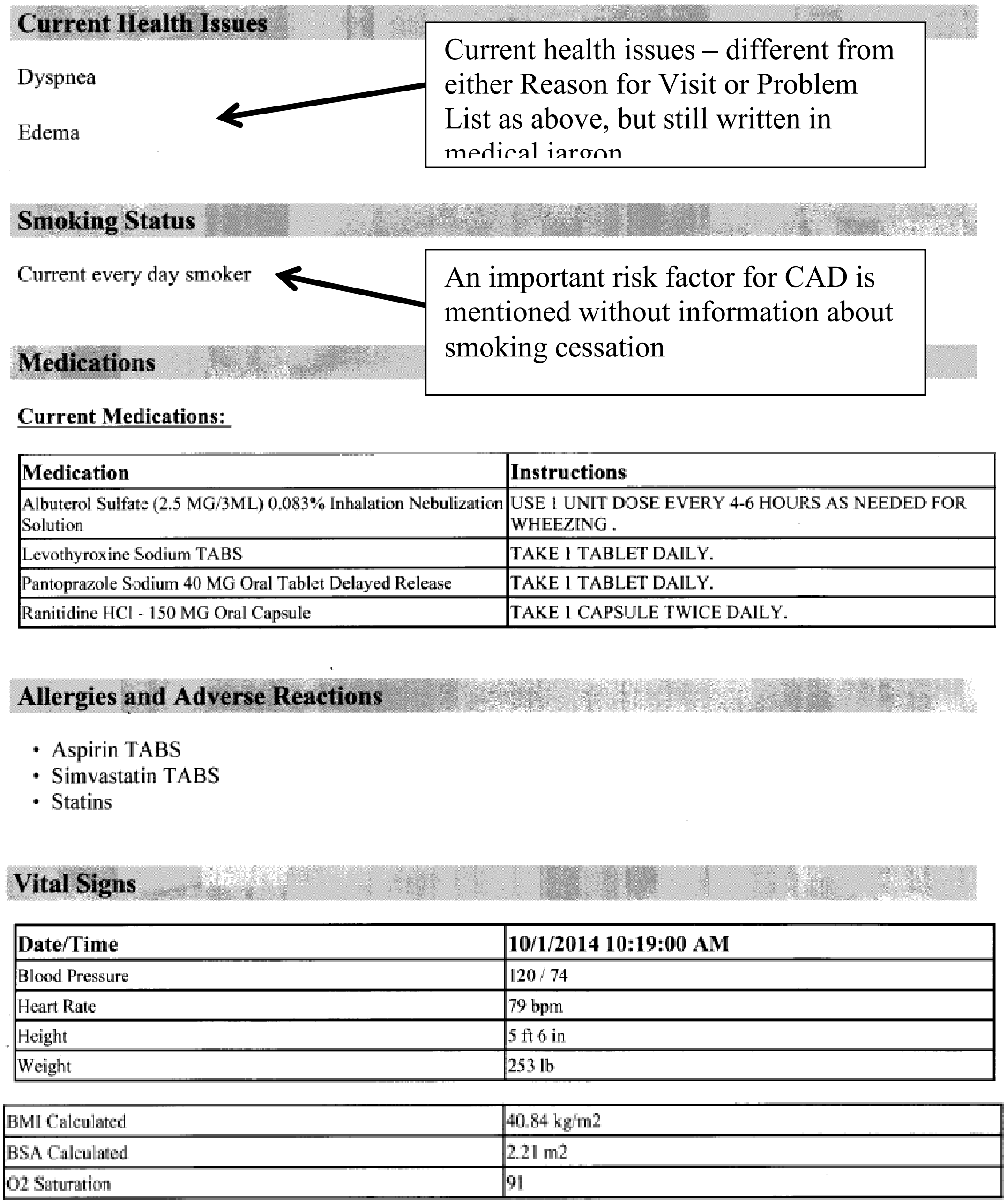


20-Oct-2011 4:03 PM CMP (Comprehensive Metabolic Panel)

BUN	20
Calcium	9.5
Sodium	141
Glucose	74
POTASSIUM,SERUM	4.7
Chloride	105
CO2	27
Creatinine	0.73
Anion Gap	9
Albumin	4.1
Alk Phos	118
Globulin	2.5
Total Protein	6.6
Bilirubin, total	0.7
ALT(SGPT)	38
AST(SGOT)	22
ALB/GLOB	1.6

Results of recent lab tests are provided without description, definition, or with normal ranges

This is another example of a clinical summary, a version that would be printed for a patient:



Current Health Issues

Dyspnea

Edema

Current health issues – different from either Reason for Visit or Problem List as above, but still written in medical jargon

Smoking Status

Current every day smoker

An important risk factor for CAD is mentioned without information about smoking cessation

Medications

Current Medications:

Medication	Instructions
Albuterol Sulfate (2.5 MG/3ML) 0.083% Inhalation Nebulization Solution	USE 1 UNIT DOSE EVERY 4-6 HOURS AS NEEDED FOR WHEEZING .
Levothyroxine Sodium TABS	TAKE 1 TABLET DAILY.
Pantoprazole Sodium 40 MG Oral Tablet Delayed Release	TAKE 1 TABLET DAILY.
Ranitidine HCl - 150 MG Oral Capsule	TAKE 1 CAPSULE TWICE DAILY.

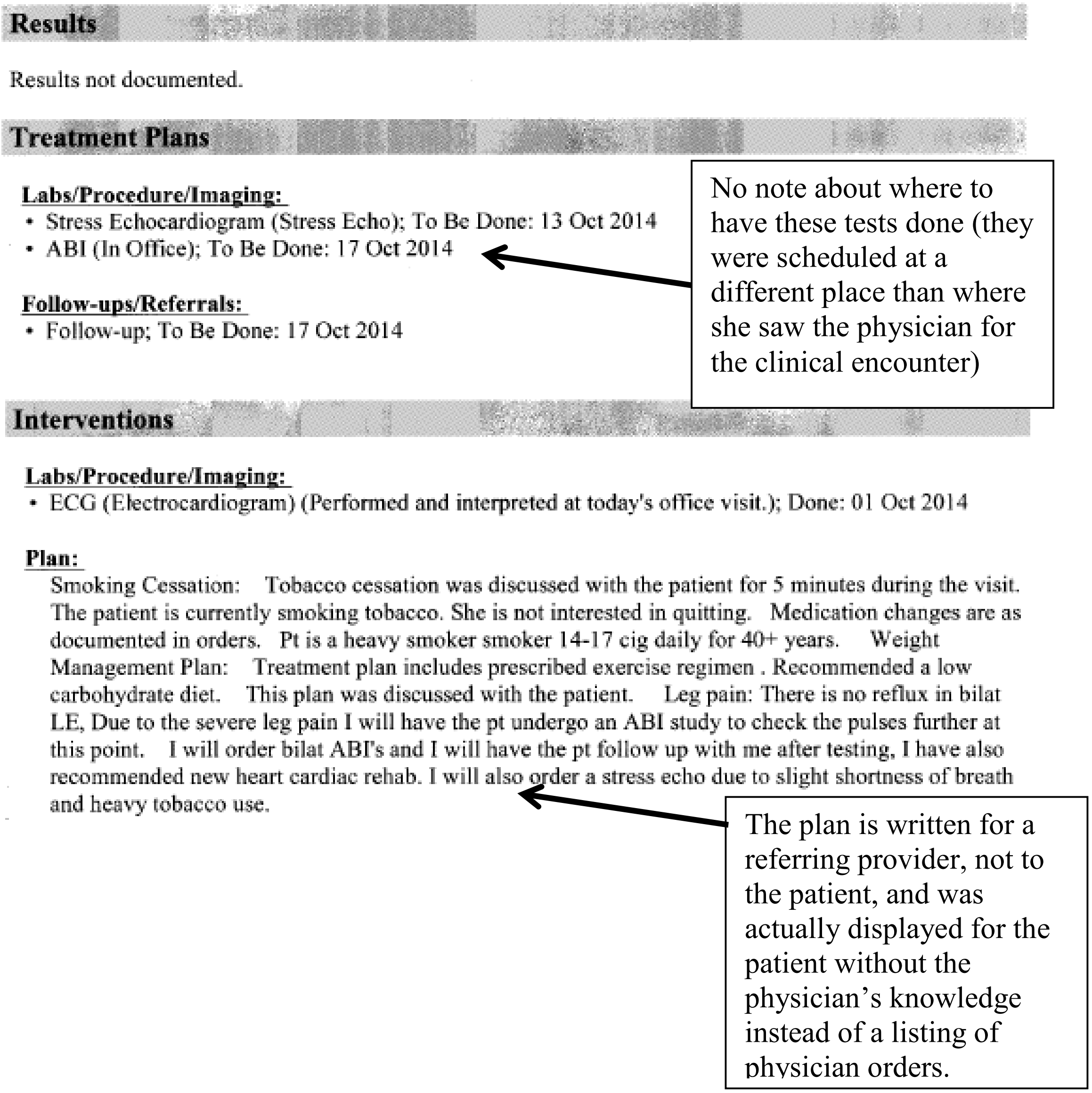
Allergies and Adverse Reactions

- Aspirin TABS
- Simvastatin TABS
- Statins

Vital Signs

Date/Time	10/1/2014 10:19:00 AM
Blood Pressure	120 / 74
Heart Rate	79 bpm
Height	5 ft 6 in
Weight	253 lb

BMI Calculated	40.84 kg/m2
BSA Calculated	2.21 m2
O2 Saturation	91



Results

Results not documented.

Treatment Plans

Labs/Procedure/Imaging:
- Stress Echocardiogram (Stress Echo); To Be Done: 13 Oct 2014
- ABI (In Office); To Be Done: 17 Oct 2014

Follow-ups/Referrals:
- Follow-up; To Be Done: 17 Oct 2014

Interventions

Labs/Procedure/Imaging:
- ECG (Electrocardiogram) (Performed and interpreted at today's office visit.); Done: 01 Oct 2014

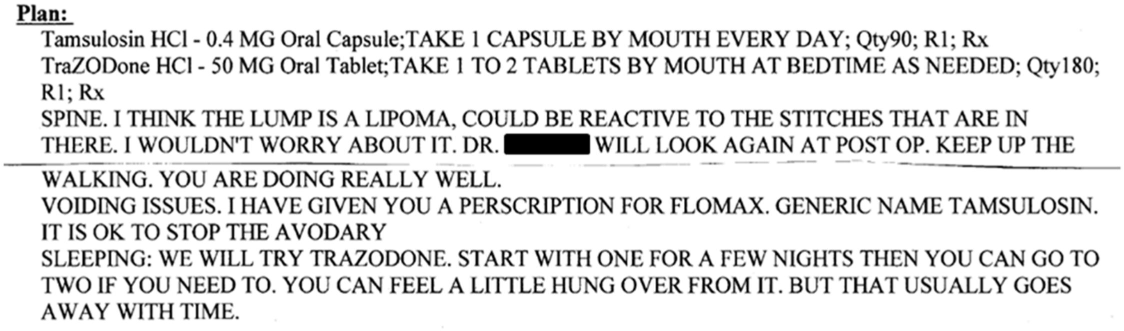
Plan:

Smoking Cessation: Tobacco cessation was discussed with the patient for 5 minutes during the visit. The patient is currently smoking tobacco. She is not interested in quitting. Medication changes are as documented in orders. Pt is a heavy smoker smoker 14-17 cig daily for 40+ years. Weight Management Plan: Treatment plan includes prescribed exercise regimen . Recommended a low carbohydrate diet. This plan was discussed with the patient. Leg pain: There is no reflux in bilat LE, Due to the severe leg pain I will have the pt undergo an ABI study to check the pulses further at this point. I will order bilat ABI's and I will have the pt follow up with me after testing, I have also recommended new heart cardiac rehab. I will also order a stress echo due to slight shortness of breath and heavy tobacco use.

No note about where to have these tests done (they were scheduled at a different place than where she saw the physician for the clinical encounter)

The plan is written for a referring provider, not to the patient, and was actually displayed for the patient without the physician's knowledge instead of a listing of physician orders.

This is an example of a more comprehensive plan of care, printed from the same electronic health record from a different practice, written for the patient, to demonstrate a more helpful plan of care (Colorafi, 2015):



Plan:

Tamsulosin HCl - 0.4 MG Oral Capsule;TAKE 1 CAPSULE BY MOUTH EVERY DAY; Qty90; R1; Rx
TraZODone HCl - 50 MG Oral Tablet;TAKE 1 TO 2 TABLETS BY MOUTH AT BEDTIME AS NEEDED; Qty180; R1; Rx
SPINE. I THINK THE LUMP IS A LIPOMA, COULD BE REACTIVE TO THE STITCHES THAT ARE IN THERE. I WOULDN'T WORRY ABOUT IT. DR. [redacted] WILL LOOK AGAIN AT POST OP. KEEP UP THE WALKING. YOU ARE DOING REALLY WELL.
VOIDING ISSUES. I HAVE GIVEN YOU A PERSCRIPTION FOR FLOMAX. GENERIC NAME TAMSULOSIN. IT IS OK TO STOP THE AVODARY
SLEEPING: WE WILL TRY TRAZODONE. START WITH ONE FOR A FEW NIGHTS THEN YOU CAN GO TO TWO IF YOU NEED TO. YOU CAN FEEL A LITTLE HUNG OVER FROM IT. BUT THAT USUALLY GOES AWAY WITH TIME.

APPENDIX K

RECOMMENDATIONS FOR THE MU CLINICAL SUMMARY

Recommendations for the MU Clinical Summary

Providing a clinical summary helps older adults engage with the plan of care. Because older adults want information that is accurate, makes sense, is useful, complete, and respects personal preference, the following recommendations are offered for the enhancement of the MU clinical summary.

1. Translate diagnostic language into terms that patients can understand.
2. Provide definitions and descriptions for diagnoses, vital signs, tests, and labs.
3. Eliminate non-actionable information, for example BSA from vital sign panels or non-smoking status from risk factor lists.
4. Edit reason for visit and assessed problem lists so patients receive only current and relevant information.
5. Eliminate headings when there is no content beneath (ie: Lab Results when there are none to share).
6. Present vital signs and lab results in context with normal ranges and descriptions.
7. Add personalized instructions or encouragement to the plan for motivation.
8. Add templates with access instructions to the plan (ie: Imaging lab company addresses and telephone numbers).
9. Add cost comparison information to the plan (ie: a stress test at this facility will cost this much in comparison to having it done at another location).
10. Avoid acronyms and short forms such as FU, SOB, HL, MCOT.
11. Add meaningful risk reduction items and education to the plan of care; use it to supplement what there was not time for in the exam room.
12. Link to resources that an engaged patient could pursue as interested (ie: information about Atrial Fibrillation and stroke risk).
13. Include generic and trade names for prescriptions, defining the instructions for taking the medication and a note as to why the medication is being taken.
14. Include in the plan issues under consideration, for example, “Consider starting Coumadin. We’ll talk about this at your next scheduled visit”, or “Think about whether you want to spend $200 to have a vascular scan at our office sometime next year. Your insurance will not cover it.”
15. Document patient goals and include meaningful pieces of the patient’s illness narrative.