Meeting the Geriatric Care Needs of an Aging Population: Older Adult, Family Caregiver, and Provider Perspectives

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Health Services Organization and Policy)
in the University of Michigan
2020

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Dedication

To my grandparents, who taught me compassion, curiosity, endurance, and creativity, and, to my parents, for your humor, patience, advice, and for all of your love.

Acknowledgements

As I write my acknowledgements, I am struck by how many people form the fabric supporting this dissertation, and my growth professionally and personally. In fact, it would comprise another entire dissertation.

I would like to thank my dissertation chair, Shoou-Yih Daniel Lee, for introducing me to the field of organizational studies in health care, and for teaching me to embrace challenge and to allow both theory and heart to drive my research.

Jody Platt, I'm at a surprising loss for words given my typical verbosity. I'm indebted to you and so deeply appreciative of all of your guidance, your constant support, for reminding me that art and the other things in life don't take away from work, they add meaning to it. For always encouraging me to ask my questions because there is always more to learn.

Denise Anthony, I am inspired by your mentorship. I have learned from you to always remember the story I am telling through my work, and the importance of clarity in order to make change.

Tom Fitzgerald, for supporting the vision of my research in the field of aging, for your optimism, and for your humor.

I have been lucky to have mentors outside of my committee. Jane Banaszak-Holl, thank you for your advice through my training and especially as I pursued my interests in global health and gerontology. Juliet Rogers, thank you for encouraging me to dive in and test my ideas, and also, for reminding me to take a step back and take in every moment of life.

To my colleagues and friends in “Thursday lab meetings”, I’m grateful for your role in helping me to appreciate research as an art and for your friendship. To my colleagues and friends in HSOP, you are extraordinary and have been inspiring and so supportive.

Thank you to the Department of Learning Health Sciences, the Rackham Graduate School, and the Blue Cross Blue Shield Foundation of Michigan for supporting my training and my research. Thank you also, to the staff in HMP for helping me to navigate this journey.

My love for stories and narrative is a significant part of my love for research. I am immensely thankful to my research participants who have shared their stories with me and have entrusted me with their thoughts, concerns, fears, and joys. I am lucky to have had assistance from Cyndi O’Connor and Molly Pomeroy, whose excellent questions and ideas helped me grow as a researcher and as a teacher.

Patrick, thank you for being patient and for reminding me to be patient with myself, for your kindness, for encouraging me to appreciate the good that comes from challenge.

To Prithvi, Nitya, and three lovely little ladies (Leela, Suri, and Mira), for always being supportive and for being my loudest cheerleaders.

And, thank you to my mom and dad, for everything. And especially, for reminding me that I will find meaning in the journey, not just in the destination.

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Abstract

There is a critical need to ensure the provision of high-quality health care for a growing population of adults age 65 and older (older adults). Recent policy initiatives emphasize the need for a health care workforce that is well equipped to support older adults who may require health care from multiple providers while navigating other social and economic transitions. Older adults are also increasingly supported by family caregivers who may be involved in daily activities and medical decision-making. Simultaneously, primary care physicians are overwhelmed with increasing patient panels and policy pressures, resulting in insufficient attention to the unique needs of older patients. Geriatric care was developed as a health service specifically for the care of older adults; yet, there is a significant geriatrics workforce shortage. Further, utilization of geriatric care is low although demand is expected to increase in the future. Geriatrics practitioners have suggested that clarifying the value of geriatrics may be required to move the subspecialty forward and ultimately meet the needs of an aging population.

In this dissertation, I examine geriatric care from the perspectives of older adults, family caregivers, and medical trainees. First, I conduct focus groups with older adults and family caregivers to learn about their experiences with the health care system and characteristics of health care that they value as they think about their aging experience. Thematic analysis reveals that older adults' and family caregivers' experiences with the health care system are related to perceived needs related to characteristics of providers, care delivery, and the health system.

In my second study, I use analyses from focus groups to develop and field a survey to a sample of over 300 older adults and family caregivers. This study seeks to understand how experiences with providers, care delivery, and the health system—along with clinical and social circumstances—are related to perceived value of geriatric care. I find that among older adults and family caregivers, clinical complexity and perceiving higher technical quality of current provider are each associated with higher perceived value of geriatric care while awareness of geriatrics is associated with lower perceived value. Older adults with a caregiver perceive greater value in geriatric care while caregivers living in the same household as their older relative perceive lower value.

In my third study, I conduct qualitative interviews with internal medicine residents and geriatrics fellows across three prestigious medical institutions to understand how personal background, social and peer support, and institutional characteristics may be related to professional identity and interest in geriatrics. I find that institutional characteristics such as the proximity to geriatricians and geriatrics clinics and conceptualizations of prestige in medicine are important to trainees as they think about their professional identity and consider geriatric medicine as a subspecialty. Building institutional capacity to train geriatricians and promote geriatrics may be as important as financial incentives.

Geriatric medicine has the potential to ensure the provision of high-quality care to older adults, and my findings suggest that older adults and family caregivers perceive value in the field. Incorporating the needs and preferences of family caregivers may make for more robust decision-making. There is a need for raising awareness of geriatrics, and for medical training institutions to broaden the meaning of medicine and to involve geriatricians further in leadership and mentorship positions.

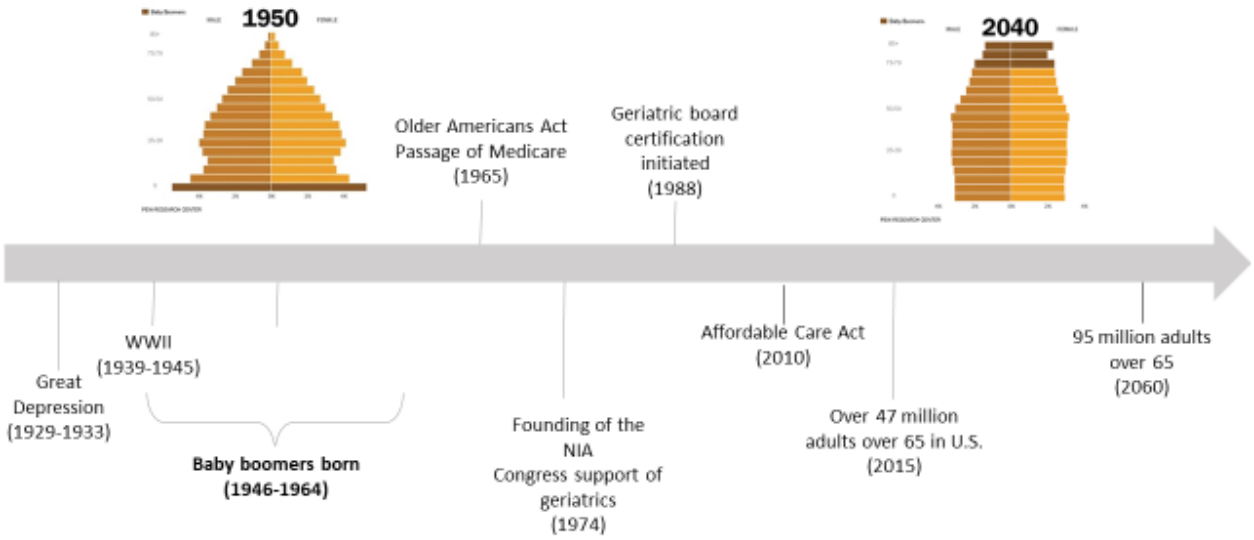
Chapter 1: Introduction

By 2050 the population of adults over 65 (older adults) is expected to reach 83.7 million (25% of the population), nearly doubling since 2012.(Ortman, Velkoff, & Hogan, 2014a; The American Geriatrics Society, 2017) There is a critical need to ensure that the U.S. health system is equipped to provide high quality care to older adults. This includes developing and sustaining an adequate – and well supported – formal (e.g. physicians and nurses) and informal (e.g. family caregivers) workforce. It also requires engaging with health care providers, family caregivers, and older adults themselves in order to begin building a system that understands and responds to the unique, specific needs of older adults in a patient or person-centered and effective way. Indeed, in 2001, Dr. Avedis Donabedian, founder of the study of quality in health care noted upon a personal encounter as a hospital patient: *"The idea that patients should be involved in their care is not really practiced in a responsible way."*(Mullan, 2001) Central to this dissertation is the notion that in order to improve the quality of care, we must garner insights from multiple key stakeholders—in this case, older adults, family caregivers, and healthcare providers. Then, we can gain insight into how to develop a system capable of ensuring provision of high quality care for older adults.

Health services are part of an intricate sociocultural context. Health care institutions and organizations, and the ways in which they organize to deliver care, are highly dependent on social, cultural, and economic circumstances.(Anderson, 1973) According to the National Institute on Aging (NIA), aging is a biological, physiological, environmental, psychological, behavioral, and social process. Over the course of the 20th century to present day, a number of

social, political, economic, and cultural shifts have shaped the environment within which individuals are aging later in life.(Martinez-Maldonado, Vivaldo-Martinez, & Mendoza-Nunez, 2016; National Institute on Aging, 2020) Developing appropriate policies and programs to ensure the quality of care for older adults requires consideration of the major policies and programs that have been implemented throughout an older adult's life course.(Cain Jr., 1964; Elder, Johnson, & Crosnoe, 2003; Yu, 2006) To begin, I will contextualize the population in the U.S. who I will refer to as "aging" or "older adults"; i.e. adults age 65 or older.(Lundebjerg, Trucil, Hammond, & Applegate, 2017) In Figure 1.1, I illustrate a subset of social and health policies through the life course of an older adult today that are relevant to the following chapters of this dissertation. I include population pyramids from 1950 and 2040 to reflect population aging in the U.S. and the population of interest in this dissertation.

Figure 1.1 Life course timeline of major health and social policies in the 20th and 21st centuries



Sociocultural considerations and aging in the U.S.

Discussions around aging in the U.S. are typically focused on adults who were born prior to, and during the "baby boom" between 1946 and 1964. The youngest of the "baby boomers" are not yet 65, but the policies and programs we develop are expected to proactively support them later in life.

Myriad social and economic changes occurred in the 20th century, many of which informed the development and implementation of policies. It is important to note that many of these policies were developed reactively—that is, a social or economic crisis that occurred early in the 20th century that affected adults who were older at that time. Though they function preventively or proactively as policies that have persisted over time thereby benefiting today's older adults, there is a trend of reactivity in our history's health and social policies especially when it comes to supporting older adults.

The 1930s, prior to the birth of the baby boomers, was a significant decade due to the Great Depression. The Great Depression made salient the risks and challenges associated with aging— namely resulting from unemployment, loss of savings, and displaced families that particularly affected older Americans; simultaneously the demand for hospital care grew.(Achenbaum & Carr, 2020; Department of Veterans Affairs, n.d.) In 1930, one-third of older adults were considered poor, and soon after, the Social Security Act was enacted under President Roosevelt to assist retired older adults.(Morley, 2004) The Great Depression is a critical turning point not only because of its influence on the field of gerontology and rising interest in the issues faced by older adults, but also because children of that decade, who are today considered the "oldest old" in their late 80s and older, were particularly affected by

economic hardships of the 1930s.(Elder Jr., 1974; Gruman, 1957; McLoyd, 1989) Almost 25% of women of childbearing age during the Great Depression did not have children due to unfavorable economic conditions, but just a decade later—soon after World War II—the baby boom occurred with a once again rising birth rate.(Elder Jr. & Liker, 1982; Redfoot, Feinberg, & Houser, 2013) The implications of this extended beyond the circumstances of older adults, but also for the care they would receive in the home from family caregivers.

Caregiving has become important for many reasons. Due to death or separation from a spouse/partner, and the low birth rate, as adolescents and young adults of childbearing age during the Great Depression were less likely to have family caregivers (i.e. adult children) as they approached older adulthood. These individuals would have been over 100 years of age today.(Elder Jr. & Liker, 1982) However, studies observed that those who were children (who are now in their 80s and 90s) and experienced economic and familial loss and hardships were strikingly dedicated to strengthening family bonds in their own adulthood and old age. They represent the parents of today's "baby boomers" and are today the "oldest old". They also are likely to receive care from their adult children who may be "baby boomers" and are themselves older adults. Yet, in the next few decades, older adults in the baby boomer generation are expected to have fewer family caregivers upon whom they can rely because of another decline in the birth rate—simultaneously, we see that those who are family caregivers, are providing a greater range and intensity of supports.(Redfoot et al., 2013; J. L. Wolff, Spillman, Freedman, & Kasper, 2016)

Organization of the health service system and aging

Policies and organizations have an increasingly salient role in designing health service systems to meet the needs of older adults, particularly upon consideration of the sociocultural context and life course of older adults today.(Anderson, 1973) An organizational approach considers the structure of the health system and how this informs health and utilization of health services.(Gibson, 1972) Passage of the Older Americans Act and Medicare and Medicaid are critical moments in the life course perspective of older adults today. Though they were implemented in response to the needs of older adults at the time and today's older Americans would have been children and young adults at the time of its passage, these policies were also timely interventions. From the perspective of organizing and delivering care, Medicare and Medicaid ensured the access of some level of health care for older adults and for low income adults—including those who are older.(Berkowitz, 2005) From a sociocultural perspective, Medicare, in particular, supported health insurance for older adults. However, the quality of care has remained questionable. Emerging questions include: Who will support the health care needs of older adults? How do we design a health care system that not only responds to the current needs of older adults but also proactively supports the needs of individuals who will become 65 or older in the coming decades? How do we ensure provision of quality health care for older adults?

Health care quality

Health care quality is challenging to evaluate, measure, and address. Myriad descriptions of health care quality exist—from the World Health Organization's six dimensions (efficiency, effectiveness, timeliness, patient-centeredness, equity, and safety) to Donabedian's framework for evaluating quality (structure, process, and outcomes).(Donabedian, 1966, 2005; World Health

Organization, 2006) Multiple social and health entities and professionals within and outside of the health care system are responsible for ensuring the provision of care to a growing population while containing costs and improving population health through upstream approaches.(Berwick, Nolan, & Whittington, 2008) The Affordable Care Act (ACA) has made efforts to improve the quality of care, focusing on notable issues such as care coordination, communication, and patient safety by using health information technologies (HIT) such as the electronic health record (EHR). (E. S. Anthony, 2017; Blumenthal, Abrams, & Nuzum, 2015; Sommers, Gunja, Finegold, & Musco, 2015; Thune, Alexander, & Roberts, 2015) Increasing pressures on organizations to implement these policies effectively have led to further attention to the needs and concerns of physicians who are supporting growing patient panels with complex health care needs.(Bodenheimer & Sinsky, 2014)

Even with multiple conceptualizations of quality in health care, it is important to recognize that "quality" in health care may not look the same across the population. For example, for older adults nearing the end of life, positive health outcomes may not be as realistic a reflection of the quality of care as, perhaps, whether they report enjoyment in their life. For children, we would hope that if care is delivered with high quality, they will grow or recover from illness, and look forward to decades of life, work, and play. Conceptualizing quality in terms of its dimensions represents an efficient approach for organizations and systems to evaluate and improve. Yet, a common phrase in health care quality says that we need to ensure that *the right care* is delivered *at the right time,* and *at the right place*. Therefore, we need to ensure that care provided to older adults is appropriate and optimal for their clinical needs as well as for their circumstances. We also need to ensure that health care services consider and respond to their needs, values and goals—i.e., what is important to them. To do this, we need to

understand what is important to older adults, and we need to identify experiences and needs that may influence how older adults engage with their health care system including the types of services they use or may consider using. Ultimately, we want patients to use the right type of care, at the right time, and at the right place.

One indicator we can use to examine whether patients are using the right type of care for their circumstances is health care utilization.(R. Andersen, Aday, & Chen, 1986) Utilization broadly may indicate that people are seeking services for illnesses and that we have created system that is meeting patient needs or offers needed services. It can also indicate concerns related to health status, for example, if patients are using or over-utilizing hospital services or emergency department services. It is important to note that utilization as a measure on its own tells us just that– whether and the extent to which patients are using a service. This is critical at a systems level to understand whether or not a service is being used. If a service is being used considerably, is it the best for that particular population? If it is not being used, why not? For example, even though older adults are high users of the health care system in general, less than 10% of older adults use geriatric care services.(Elliott, Stolee, Boscart, Giangregorio, & Heckman, 2018; *Medical Expenditure Panel Survey (MEPS)*, 2015) To understand why patients utilize particular health services, we need to draw on patients' individual and contextual characteristics.(Carrasquillo, 2013)

Health services use

Andersen and colleagues have proposed several iterations of their Behavioral Model of Health Services Use (ABM), a framework that captures the individual and contextual characteristics that guide one's decisions about health services use and engagement in health behaviors (Appendix A

Figure A.1).(Aday & Andersen, 1974; R. M. Andersen, 1995, 2008) The model, which has evolved over the past several decades, has been used in a variety of contexts including long term care, the homeless, childhood abuse, and healthcare use among immigrants, establishing its applicability to a broad scope of populations(Bonomi et al., 2008; Bradley et al., 2002; Leclere, Jensen, & Biddlecom, 1994; Stein, Andersen, & Gelberg, 2007). In its most recent version, the ABM suggests a relationship between predisposing (i.e., demographic, social, and beliefs), enabling (i.e., policy, financing, and organization), and needs (i.e., evaluated and perceived) characteristics that inform health behaviors (i.e., personal health practices, the process of medical care, and use of personal health services) and subsequent outcomes including perceived health, evaluated health, and patient satisfaction. The framework is dynamic and recursive, and collectively, urges us to recognize and consider the personal and contextual factors, characteristics, and circumstances that surround the use of different health services..(R. M. Andersen, 2008)

Using this framework, we can begin to understand whether, when, and why certain types of health services are used. We can also begin to understand the how quality of care may be related to use of health services; and, in turn, how use of a particular type of health service might be related to higher quality of care for subsets of the population. Ultimately, this can help us to achieve three system level goals. First, we can improve patient experience by designing models of care that are aligned with patient needs and values. Second, we can decrease costs by ensuring that patients are receiving effective care that may also be more efficient in the longer term. Third, we can improve population health, in this case among older adults, by delivering care that is optimal for their circumstances.(Berwick et al., 2008)

Much of the prior literature employing the ABM as a theoretical framework has investigated the use of health services (a) to understand the role of a common subset of variables—typically predisposing and enabling factors; and (b) in either primary/general and mental health care contexts investigating the general adult population, or, in very specific cases such as long-term care.(Babitsch, Gohl, & von Lengerke, 2012) In fact, Babitsch and colleagues (2012) in their literature review specifically call for primary studies that not only apply the ABM but also seek to operationalize its complexity. Therefore, while the ABM represents a guiding framework for the collective of the following chapters, in this dissertation I seek to unravel some complexity of the ABM specifically by (a) drawing upon multiple stakeholder perspectives who each, in their individual stakeholder-level decision-making contribute to a broader collective understanding of health services use, (b) using a mixed-methods, primary research approach to capture in-depth stakeholder perspectives in a Michigan sample with the potential for future extension to a national sample, and (c) focusing on the context of older adults, whose needs and decision-making may be different from the general adult population. In order to understand health service utilization and care-seeking behaviors, and ultimately to improve quality of care and population health, there is a need for research that examines the nature of different types of decisions patients and other stakeholders make and the behavioral, situational, and organizational factors that affect decision-making.(Anderson, 1973)

Older adults' health and care needs

The inclusion of older adults in clinical and behavioral research has been limited resulting in a lack of understanding of their decision-making processes, their needs, values, concerns and preferences, as well as optimal treatments and recommendations specific to their unique

physiology and sociocultural needs.(Cruz-Jentoft, Carpena-Ruiz, Montero-Errasquín, Sánchez-Castellano, & Sánchez-García, 2013; Lewis et al., 2003; McGarvey, Coughlan, & O'Neill, 2017) Societal ageism and an assumption that inferences based on research with younger and middle-aged adults can easily extend to older adults contribute in part to this dearth of research.(Cruz-Jentoft et al., 2013; Hess, 2006; Marshall, 2014; T. D. Nelson, 2005; Wyman, Shiovitz-Ezra, & Bengel, 2018) Therefore, it is critical to continue primary and secondary research engaging specifically with older adults to understand how to create health and health care systems that meet their needs. As illustrated earlier, through the life span of an older adult today, there are myriad socioeconomic, cultural, and environmental conditions and transitions—such as in the work environment, living and working conditions, availability and access to health care services, and housing— along with social, community, and individual lifestyle factors, that are likely to have differentially influenced the health status of older Americans when compared with younger and middle adults. Simultaneously, society is shifting towards an elderly-dependent population indicating that support for older adults—particularly in terms of financing social and health services for older adults (e.g. through Medicare)—is increasingly dependent on a disproportionately smaller population of working adults who contribute to funds and resources for these social services.(Ortman et al., 2014a)

As life expectancy has increased, there has been a simultaneous rise in multimorbidity among older adults and associated challenges that are often unique or amplified among older adults when compared to middle and younger adults.(Barnett et al., 2012; Fortin, Stewart, Poitras, Almirall, & Maddocks, 2012) Over three-quarters of older adults have at least one chronic condition and 68% have two or more. Hypertension, high cholesterol, and arthritis are the most common conditions and at least 11% of older adults have Alzheimer's Disease or other

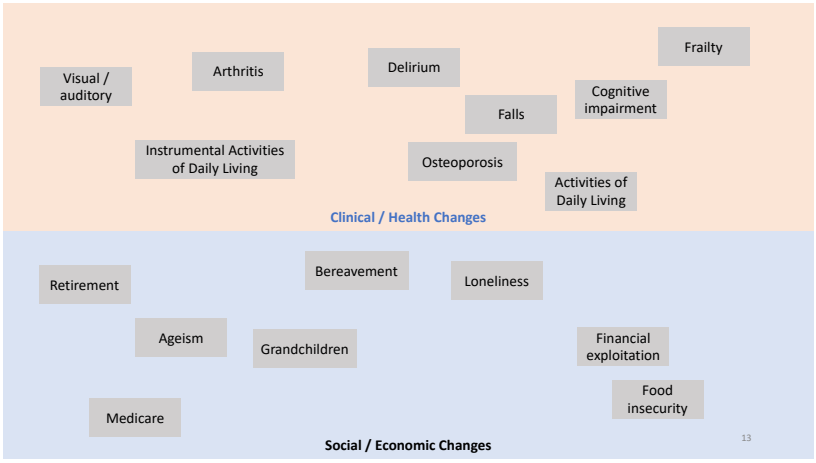
forms of dementia.(National Council on Aging, 2017) Studies suggest that older adults with multiple chronic conditions (MCC) are more susceptible to deterioration in activities of daily living (ADL; eating, bathing, dressing, toileting, moving around within the house) and instrumental activities of daily living (IADL; transportation, shopping, finances).(Jackson et al., 2015) More than 20% of adults age 85 and older require assistance with at least one ADL.(National Health Interview Survey, 2017) Conditions such as delirium, falls, incontinence, and frailty (geriatric syndromes) also affect older adults and may or may not be related to MCC.(Inouye, Studenski, Tinetti, & Kuchel, 2007) These conditions may require extensive support within and outside of the health care setting.

In fact, over 40 million informal caregivers—including family members, neighbors, and friends—provide unpaid support to older relatives ranging from ADL and IADL support to medical decision making.(Committee on Family Caregiving for Older Adults, Board on Health Care Services, & National Academies of Sciences, Engineering, 2016; Eby, Molnar, Kostyniuk, St. Louis, & Zanier, 2017; J. L. Wolff, Spillman, et al., 2016) Family caregivers are critical to the health system's capacity to meet the health and health care needs of older adults. First, they increasingly supplement care provided by formally trained health care professionals in the home (e.g. via assistance with managing medications). Second, they can support clinical activities by providing important contextual details or observations about their older care recipients, thereby potentially contributing to improved quality of care (e.g. coordinating care between multiple providers). It is important to also note that over one-third of caregivers are themselves 65 or older.("Caregiving in the U.S. 2015," 2015) This suggests an imperative for ensuring the development of policies and design of practices within organizations and models of care that are also sensitive to the needs of older caregivers. Further, improving the quality of care for older

adults has the potential for spillover effects to caregivers who are also aging or will be aging in the future.(Wittenberg, James, & Prosser, 2019)

The implications of having MCC and geriatric syndromes—in addition to the other social (e.g. caregiving, grandparenthood, bereavement), financial (e.g. retirement), and sociocultural (e.g. ageism)— are myriad and require considerate and responsive care. Many of these other circumstances and changes that older adults experience are illustrated in Figure 1.2. Despite receiving support in managing their needs from family caregivers or formal caregivers, older adults' quality of life may suffer as a result of functional decline as well as due to perceiving themselves to be burdensome.(Parekh & Goodman, 2011; Riffin, Van Ness, Iannone, & Fried, 2018; Shen, Feld, Dunkle, Schroepfer, & Lehning, 2015)

Figure 1.2 Clinical, health, social, and economic changes to which older adults may be more susceptible



Health care for older adults

Unsurprisingly, older adults with MCC and geriatric syndromes are susceptible to negative health outcomes and higher healthcare costs. According to the Kaiser Family Foundation, although older adults constituted 16% of the population in 2016, their health care costs

comprised 36% of total health care spending (Appendix A Figure A.2).(Coleman, 2003; Ferris et al., 2017; Hyttinen, Jyrkka, & Valtonen, 2016; Kaiser Family Foundation, 2016; *Medical Expenditure Panel Survey (MEPS)*, 2015) Broader efforts to improve coordination and quality of care such as through the EHR have become an expectation for primary care physicians (PCPs), but there is robust evidence that PCPs—who are in short supply—are overwhelmed with increasing patient panels with more clinically complex patients.(Altschuler, Margolius, Bodenheimer, & Grumbach, 2012; Bennett, Phillips, & Barr, 2010; Boult, Counsell, Leipzig, & Berenson, 2010) Moreover, PCPs are inadequately trained to provide care to clinically complex older adults within a fragmented health system that requires more than just clinical care coordination.(Salsberg & Grover, 2006; The Institute of Medicine, 2001; Wenger et al., 2003) These complexities along with limited understanding of the aging experience have resulted in a medical environment wherein health care professionals themselves feel insufficiently equipped and also reluctant to work with older adults.(Boswell, 2012) For example, older patients are less likely to receive needed care such as preventive screenings and immunizations (Asch et al., 2006; Farrow, 2010; McGlynn et al., 2003). Recognizing the need for health care specifically for conditions associated with aging later in life, board certification for geriatric medicine was initiated in the 1980s.

Geriatric care: An approach to improving quality of care for older adults

Robert Butler, a physician appointed by President Ford to direct the newly created National Institute on Aging in 1976, found himself disgruntled with ageism he observed during his medical training. Subsequently, he dedicated himself to championing the reframing of aging from a negative, demeaning experience to one that can also be productive and filled with joy:

> *The tragedy of old age is not the fact that each of us must grow old and die but that the process of doing so has been made unnecessarily and at times excruciatingly painful, humiliating, debilitating, and isolating through insensitivity, ignorance, and poverty."* (Butler, 1975)

In 1983, Butler spearheaded the establishment and development of initial standards for a geriatric medicine curriculum.(Achenbaum, 2014)

Geriatric medicine is an individualized, holistic approach to medicine that draws upon the unique physiological and psychosocial needs of older adults to guide clinical care. Geriatrics uses an interdisciplinary team-based approach to caring for older adults, and teams are typically led by a geriatrician and includes providers such as nurse practitioners, social workers, psychiatrists, nutritionists, speech and hearing specialists, and may extend to include other specialists such as orthopedists and neurologists within a physical facility (e.g. inpatient or ambulatory) or referral network.(Wieland, Kramer, Waite, & Rubenstein, 1996) Physicians trained in internal medicine or family medicine residency may pursue a one year fellowship in geriatrics (with an optional additional two years in research) that provides them with knowledge and understanding of the physical, financial, emotional, and social circumstances of older adults; circumstances that may often require coordination with multiple specialists (Heinemann, 1991; Wieland et al., 1996). Trainees gain specific experience in caring for older adults in contexts such as the VA Geriatric Evaluation and Management (GEM), palliative care, hospice, or geropsychiatry. Geriatricians may practice in community settings, in the hospital as part of geriatrics consultation services, or in long term care facilities.(Day & Rasmussen, 2004; Inouye et al., 2007; Rubenstein, Stuck, Siu, & Wieland, 1991; Ward, Reuben, Schmader, & Sullivan, 2016)

Robust evidence consistently demonstrates that geriatric care is superior to usual care (i.e., non-geriatric care) for older adults—in particular for those with geriatric syndromes and MCC. It has the benefits of improved diagnostic accuracy, improved functional status, improved affect and cognition, effective medication management, decreased nursing home and hospital service use, lower costs per admission and lower costs due to shorter length of stay, smaller increases in instrumental activities of daily living impairments (IADL), and prolonged survival.[1] Studies continue to build evidence in support of geriatric care by developing appropriate outcome measures to evaluate and improve quality of care specifically for older adults.(Akpan, Roberts, Bandeen-Roche, Batty, & Bausewein, 2018; Hogan & Fox, 1990; Popplewell & Henschke, 1983; Schuman, Beattie, & Steed, 1978). Moreover, with its attention to quality of life and functioning, geriatric care supports "aging in place" – that is, the ability to live in one's own home and community of their choice safely and independently or with caregivers.(Wiles, Leibing, Guberman, Reeve, & Allen, 2012)

The transition to geriatric care is less defined than other transitions such as from pediatrics to primary care, which is determined almost exclusively by age and medical need. While one 80-year-old patient may exhibit symptoms of geriatric syndrome with MCC, another may be healthy, active, and independent.(Di Anni, Eng, & Islam, 2016; Moreno, 2013) Older adults may undergo a comprehensive geriatric assessment by a geriatrician who identifies potential clinical need for enrollment in geriatric care.(Extermann et al., 2005; Ward et al., 2016) Still, healthy older adults may also benefit from geriatric care that provides guidance on preventive care according to behaviors, functional status, multi-morbidities, and life-expectancy

[1] (Applegate, Akins, & Van der Zwaag, 1983; Applegate, Miller, & Graney, 1990; Baztan et al., 2009; Brocklehurst & Carty, 1978; Burns, Nichols, Martindale-Adams, & Graney, 2000; Cheah & Beard, 1980; Collard et al., 1985; Counsell et al., 2007; Eloniemi-Sulkava et al., 2009; Gilchrist, Newman, & Hamblen, 1988; Grigoryan et al., 2014; Hogan et al., 1987; Liem, Chernoff, & Carter, 1986; Polinquin & Straker, 1977; Popplewell & Henschke, 1983; Prestmo et al., 2015; Reifler & Eisdorfer, 1980; Rubenstein, Josephson, & Wieland, 1984; Rubenstein et al., 1991; Schmader, Hanlon, & Pieper, 2004; Sorbero et al., 2012).

suggesting that geriatric medicine is a valuable health service from a clinical perspective and may be critical for ensuring the provision of high quality care in an aging population.(J. H. Flaherty, Morley, Murphy, & Wasserman, 2002; Mokdad, Marks, Stroup, & Gerberding, 2005; M. C. Spalding & Sebesta, 2008)

Yet, in what can be described as a "chicken and egg" situation, the geriatrics workforce faces a significant shortage and older adults are underutilizing geriatric care according to rough estimates.(*Medical Expenditure Panel Survey (MEPS)*, 2015; The American Geriatrics Society, 2013, 2017) Geriatrics is a child among medical subspecialties despite growing demand and need for its services to support an aging population. The American Geriatrics Society estimates a need for training 30,000 geriatricians to meet estimated demand from 30% of older adults based on clinical need; yet, actual utilization of geriatric care is lower, especially among those who could benefit, despite extensive benefits.(Evers, Meier, & Morrison, 2002; Kedia, Chavan, & Boop, 2017; *Medical Expenditure Panel Survey (MEPS)*, 2015). Indeed, the shortage of geriatricians in community settings imposes a challenge in patients' ability to make an appointment in underserved areas or with physicians who are already serving clinically complex older patients. However, this may only be part of the story. There is a need for insights from (a) older adults who may consider geriatric care; (b) family caregivers who may encourage or facilitate their older relatives' use of geriatric care; and (c) health care providers who comprise the workforce. For the field to endure, there is a need for greater understanding of the value of geriatric medicine from these three key stakeholder groups who represent both supply of, and demand for, geriatric care.(Deephouse & Suchman, 2007; DiMaggio & Powell, 1983; Powell, 2007) Consistently, the American Geriatrics Society posits that geriatrics as a field needs to be

redefined with greater clarity in what constitutes "high quality" care for older adults and how the field aligns with those goals.(Tinetti, 2016)

In this dissertation, I seek to understand how we can ensure the provision of high quality care for older adults in the U.S. Geriatric medicine presents this opportunity, yet, there is a need to clarify its value and the factors and experiences that may be related to its use. I draw upon perspectives of older adults, family caregivers, and providers and ask:

I. How do older adults and family caregivers think about patient-centered care?
II. How do older adults and family caregivers draw upon specific experiences in their health care to identify characteristics of health care that are important to them?
III. How do older adults and family caregivers perceive the value of geriatric care?
IV. How are key experiences and characteristics of importance to older adults and family caregivers related to their perceived value of geriatric care?
V. How do medical trainees think about geriatric medicine, including its value within the field of medicine and its value to society?
VI. How do institutional characteristics influence the ways in which medical trainees think about their professional identity, their meaning from work, and their interest in geriatrics?

In Chapter 2, I present the results of focus groups conducted with older adults and family caregivers to understand what patient-centeredness means to older adults and family caregivers. Motivated by Dr. Donabedian's observation that we need to responsibly facilitate patients' involvement in their care, I facilitate eight separate sessions with participants and ask them to discuss their experiences with the health care system and characteristics of health care that are

important to them as they think about their needs or their older relative's needs. With a better understanding of what patient centered care might mean to older adults, I identify areas for study in Chapter 3 that seek to understand the relationship between these experiences and needs and perceived value of a health service.

In Chapter 3, I present findings from a survey I developed and fielded informed by findings from Chapter 2. This survey was administered to older adults and family caregivers across the state of Michigan. This study reflects one of the first to ask both older adults and family caregivers how they think about geriatric care. It also contributes to theoretical perspectives on perceived value of a health service. Perceived value is typically studied retrospectively—i.e., following a service encounter after which a patient may reflect on the value of the service based on what was gained from the service versus invested. Here, I consider perceived value as value that is anticipated without having necessarily used the service. In order to help older adults prepare for health service utilization decisions, we need to understand the value they perceive in services they may anticipate using in the future.(Creutzfeldt & Holloway, 2020) Further, we need to understand how family caregivers, who are increasingly involved in medical decision making, perceive the value of services like geriatric care, on behalf of their older relative.

In Chapter 4, I seek to understand how personal, peer and social support, and institutional characteristics may be related to trainee professional identity, meaning from work, and interest in geriatrics. I use qualitative in-depth interviews with internal medicine residents and geriatrics fellows at three institutions that are top ranked in geriatrics and are geographically representative. From this study, I contribute to sociological and organizational frameworks of

career decisions and professionalization, and identify recommendations for medical training institutions in their efforts to generate a sustainable geriatric medicine workforce.

In the final chapter, I reflect on the findings of all three studies, consider implications for practice and policy, and propose areas for future study.

Conclusion

Over the course of the past century our health care system has responded to the needs of older adults reactively, rather than proactively. Indeed, these efforts—development of the field of gerontology, passage of Medicare and Social Security, founding of the National Institute on Aging—have shown promise for supporting older adults. Yet, there are areas for improvement and we must address them now. Efforts spearheaded by Robert Butler particularly to develop and strengthen the geriatrics workforce have been critical for beginning to close this gap in support for older adults, but geriatrics is a young field and justification of its contribution and legitimacy as a field requires concerted efforts to explicate its value.(Deephouse & Suchman, 2007; Tinetti, 2016) The perspectives of individuals using, supporting, or providing the service—older adults, family caregivers, and providers, are critical to incorporating patients' health priorities into the design of care and into care decisions; and understanding these perspectives is the goal of my dissertation.(Ferris et al., 2017) Insights can inform development of medical training for geriatric medicine, improved referral and shared decision-making practices for providers, and educational tools for older adults and family caregivers. They can also inform the development of policies to support a geriatrics workforce and the design of models of care that support the needs of older adults. Finally, findings from this dissertation can contribute to an understanding of the relationship between perceived value of a field and its subsequent endurance.

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Chapter 2

Understanding Patient-Centeredness: Qualitative Perspectives from Older Adults and Family Caregivers

INTRODUCTION

Ensuring that health care for older adults is of high quality involves providing patient or person-centered care. Patient-centered care requires identifying, considering, and responding to what patients need, prefer, and value.(Berwick et al., 2008; R. M. Epstein & Street, 2011; Osterman, 2017; The Institute of Medicine, 2001; Wiles et al., 2012) A number of organizational and policy initiatives have attempted to increase patient-centeredness. One example is implementation and use of the electronic health record and patient portal to facilitate communication between providers and patients and to enable patients to become more involved in their care via access to their health information.(Chase et al., 2014; Thune et al., 2015; Ventres, Kooienga, & Marlin, 2006) Another is the training of physicians to make shared decisions with patients about their concerns and treatment options.(Barry & Edgman-Levitan, 2012; Ronald M. Epstein & Street, 2007; Migdal, Namavar, Mosley, & Afsar-manes, 2014; Schottenfeld et al., 2016; Shachak & Reis, 2009; Street et al., 2014; Zhang et al., 2015)

It is important to note that patient-centeredness must be approached with caution in some circumstances. For example, perhaps an older adult showing early signs of cognitive impairment should not drive in order to protect themselves and others from harm. However, we need to

better understand what older adults need, prefer, and value from the health care system and from health care providers, and then, we can identify safe and effective practices that are still patient-centered.(Aronson, 2015) By better understanding what is important to older adults—just as we must also consider what is important to providers as they deliver care—we may take steps towards achieving care that considers older adults and their family caregivers as partners in health care.(Pomey, Ghadiri, Karazivan, Fernandez, & Clavel, 2015) As Dr. Charles Bardes offers:

> *Patient and physician must therefore meet as equals, bringing different knowledge, needs, concerns, and gravitational pull but neither claiming a position of centrality. A better metaphor might be a pair of binary stars orbiting a common center of gravity, or perhaps the double helix, whose two strands encircle each other, or — to return to medicine's roots — the caduceus, whose two serpents intertwine forever.*(Bardes, 2012)

To do this well requires that we first understand the perspectives of older adults and the family caregivers who support them.

This study represents the first phase of an exploratory sequential design. In this chapter, I will describe the design and findings of exploratory focus groups that I conducted with the objective of understanding, broadly, what patient-centeredness means to older adults and their family caregivers. Rather than using a deductive approach to my analysis informed by an extant theoretical framework, I use an inductive approach to understand what patient-centeredness means—i.e., what are older adults' and family caregivers' experiences within the health care system, and how do these experiences inform what is important to them in their health care. Since the goal of the focus groups was informed by the conceptualization of patient-

centeredness—i.e., needs, preferences, and values, next, I will define these concepts based on prior literature. I use these concepts to guide the focus group discussions, but my analysis uses an inductive approach to understand older adults' and family caregivers' experiences and valued characteristics within health care.

Theoretical background on patient-centeredness: Needs, preferences, and values

The literature describes different types of needs.(Bradshaw, 1977; L. Lawton, 1999) One type of *need* is assessed or normative, such as a clinical diagnosis or an objective screening measure that indicates a gap between a person's status or function and an accepted or expected norm. This type of need has been studied more extensively in the empirical literature on older adults as evaluated needs have clear implications for treatments and therapies in the clinical setting.(R. M. Andersen, 2008; Beach et al., 2018; Gaugler, Kane, Kane, & Newcomer, 2005; Zuverink & Xiang, 2019) Another type of *need* is perceived, which may overlap slightly with assessed need but is distinct in that it is expressed by patients themselves.(Cohen-Mansfield & Frank, 2008) For example, an older adult may have an assessed need for a geriatrician based on their age, diagnosis of multiple chronic conditions (MCC), and risk of cognitive impairment. However, the older adult himself/herself, while struggling with management of MCC and having concerns about cognitive impairment, may not perceive a need for a geriatrician and may instead express a need for fewer medications. Perceived needs may be specific to a particular service or aspect of care.(Calsyn & Winter, 2001; Coulton & Frost, 1982) Related but distinct concepts that contribute to patient-centeredness—albeit used interchangeably in the literature, are preferences and values.(R. M. Epstein & Street, 2011) For example, a perceived need for a particular type of

service could lead to a perceived value of that service, subsequently informing preference for a professional who provides that service.

Value—a challenging concept to measure and assess in health care—has been described at the system level as the health outcomes achieved per dollar spent.(Porter, 2010) From the patient's perspective, however, perceived values—i.e. those that are not formally evaluated but are expressed by patients themselves—underlie preferences.(Bastemeijer, Voogt, van Ewijk, & Hazelzet, 2017; R. M. Epstein & Peters, 2009) That is, a patient may *value* a particular service, physician or a characteristic of a service or provider, and may subsequently *prefer* one service or physician over another. For example, a patient may prefer a particular treatment or physician based on valuing care that caters to improving quality of life rather than extending life. They may then express their preference for a physician whose approach aligns with this value over another physician.

The purpose of the current study was to examine what patient-centeredness means to older adults and family caregivers by asking them to describe their experiences and expectations with regard to their health care. Since the overarching objective of the dissertation was to learn more about how stakeholders think about geriatric care, an additional objective was to gain exploratory insights into how older adults think about geriatric care and express their preference for a geriatrician, given a set of specific needs and values of hypothetical older adults presented via vignettes. With a better understanding of the experiences and expectations that may be common among older adults—and that may be commonly observed among family caregivers—this study represents the first phase of an exploratory sequential study design informing Chapter 3, where I will explore how these experiences and perceived needs may be related to older adults' and family caregivers' perceived value of geriatric care.

METHODS

I conducted four focus groups with community-dwelling older adults and four focus groups with family caregivers of older adults in Southeastern Michigan. Focus groups are a qualitative technique for collecting data via a group discussion actively facilitated by a researcher.(Morgan, 1996) Focus groups are commonly used in disciplines such as public health to understand contexts such as aging.(Duncan & Morgan, 1994; Knodel, 1995) They are advantageous for exploratory research that seeks to generate new ideas and gain insight into complex behaviors and motivations that may emerge via the interactions between members in the group.(Carey, 1994; Carey & Smith, 1994; Fern, 1982) These interactions can provide rich detail because of the ways in which participants not only respond to the facilitator's prompts, but also, to each other via questions and comments. Such insights are less likely to emerge in individual interviews or in surveys.(Kitzinger, 1995; Morgan, 1996)

Moreover, recent literature has indicated that over one-quarter of older Americans live alone and many of them experience loneliness and social isolation.(Hawkley & Kocherginsky, 2017) Although a number of senior centers have emerged nationally to improve connectedness and foster physical, cognitive, and spiritual activity for older adults, aging is still a stigmatized experience.(Richeson & Shelton, 2006) I found in preliminary conversations that many older adults seemed to desire connectedness and wanted to talk about their experiences related to their health and health care with others who would understand—especially since often, even their doctors were younger than them. Despite a potential limitation that focus groups would primarily appeal to older adults who desired or were at least comfortable interacting with others, this approach presented an opportunity to act as an intervention fostering social connectedness.

Participants

I conducted separate focus groups with older adults and family caregivers (e.g., adult children, spouse/partners) of older adults. While focus groups that included dyads may have provided different insights, in preliminary discussions to inform the study design, older adults described that they may be reluctant to discuss their concerns if they are with their family caregivers. Similarly, family caregivers explained that they would be less likely to candidly describe their experiences (i.e., the good as well as the overwhelming) if in the presence of their own relative. As such, rather than conducting focus groups with dyads, I conducted two types of focus groups: one, with older adults and the other, with family caregivers. This was expected to minimize discomfort and foster candor.

Participants were recruited using flyers and an online health research platform managed by a large academic medical center in the mid-western U.S. The study was described as involving participation in a focus group to understand the health care experiences and needs of adults over 65 from the perspective of older adults and family caregivers. The online health research platform allowed me to specify inclusion criteria for recruitment. Inclusion criteria for older adult focus groups included: a minimum age of 65; comfort with speaking English in a group setting; and having received health care in the U.S. for at least one year. I included these eligibility criteria as part of the platform advertisement. I also specified that individuals with a diagnosis of cognitive impairment (e.g., dementia) should not see the study information so that those who wanted to participate would not be offended or experience discomfort if they participated. Caregiver inclusion criteria included: a minimum age of 25; actively providing care as an adult child, niece/nephew, spouse/ partner, or grandchild for an adult over age 65; and

comfort with speaking English in a group setting. Participants in both groups had to live in a zip code within 50 miles of Ann Arbor, Michigan. This may have influenced the discussion as it is possible that the majority of participants receive care from one institution and are also highly involved in research reflecting some selection bias. However, including this criterion was intended to minimize potential burden for older participants who may have otherwise had to travel far distances to participate.

Interested participants who met these criteria were then presented with a screening questionnaire in which they were asked to self-identify either as an "adult over age 65", "family caregiver of an adult over 65", or "both". Participants over 65 who identified only as a caregiver were placed in caregiver focus groups. Those who identified as "both" were asked whether they had a preference for the focus group in which they wished to participate. For example, some participants who identified as both felt that they would be able to contribute more fruitfully in a discussion about caregiving than in a discussion about aging. Participants who were in this category of being both a caregiver and over 65 were primarily older caregivers for their spouse/partner. In addition, I asked participants in the screening questionnaire to indicate whether they had ever seen a geriatrician in order to develop a sense of the level of use of geriatric care in the area.

The recruitment was conducted from September 2018 to November 2018 and identified 140 individuals expressing interest in the study who met inclusion criteria. I selected participants intentionally to ensure diversity in race/ethnicity, age, and health status. Health status was based on the number of medical conditions listed on profiles on the research platform. I selected participants and conducted focus groups with preliminary analyses following each session until achieving saturation—i.e. when no new themes were emerging, and further, when themes

emerging across focus group for each participant type were consistent.(Fusch & Ness, 2015; Morgan, 1992; Saunders et al., 2017) I purposively recruited participants to one female-only caregiver focus group and one male-only caregiver focus group to assess consistency in candor. Most groups included one participant who had seen a geriatrician.

I conducted a total of four focus groups with older adults and four focus groups with family caregivers for a total of eight focus groups. Each session included 4-6 participants. I deliberately conducted small to medium-sized focus groups to facilitate richness of discussion by allowing for participants to share more in-depth experiences.(Morgan, 1992) Table 2.1 summarizes the number of participants in each focus group.

Table 2.1. Number of participants in each focus group

	Group 1 (n)	**Group 2 (n)**	**Group 3 (n)**	**Group 4 (n)**	**Total**
Older adults	5	7	3	3	18
Family Caregivers	5	3	4	6	18

Setting

Participants were provided study details, the location, and the time of the focus group they would be participating in. Participants were sent a "save the date" card and a reminder two days prior to the session. All focus group sessions were conducted in Ann Arbor, MI. Five sessions were conducted at a senior center and three at a local library. Focus groups were approximately 1.5 hours in duration. Six sessions were conducted during lunch, one was conducted on a weekend afternoon, and the other one was conducted on a weekday evening to accommodate family caregivers who work during the day.

Procedures

I facilitated the focus groups and was accompanied by an undergraduate note-taker who observed group dynamics and wrote notes and comments about focus groups that may not have been recordable.(Krueger, 1998) At each session, participants were reminded that they were not required or expected to disclose any medical conditions and that stories shared during the session should not be repeated outside of the session. Participants were provided refreshments at the beginning of the session and a $25 gift card at the end of the session and completed a demographics questionnaire at the end of the session. Sessions were recorded and transcribed by a professional transcription service with identifying information deleted upon permission from participants. The study was granted permission with exemption by the University of Michigan Institutional Review Board.

The focus group discussion focused on (A) experiences with, and (B) expectations from, the health care system and providers, within the context of health care for older adults. Specific framing of the discussion around experiences and expectation indicated gaps that have been suggested as reflecting perceived needs.(Parasuraman, Berry, & Zeithaml, 1991) A third area explored the idea of (C) preferences for providers. This activity asked participants to read vignettes detailing a variety of needs and circumstances of adults over 65 and to decide what type of provider the individual in the scenario should see. This activity enabled me to understand how a variety of different patient characteristics, social support characteristics, and needs—both evaluated and perceived—might be related to preferences about different types of providers. I will describe each of these three phases of the focus groups in greater detail next.

A. *Experiences*

In the first phase of the focus groups with older adults, participants were asked to discuss their experiences with the health care system with a focus on interactions with health care providers. Family caregivers were also asked to discuss experiences based on either direct observations during the care recipient's interactions with the system and providers, or, based on what they had heard from their older relative. I used a poster board for visual brainstorming and wrote down words or phrases used by participants to describe their "experiences." Participants could clarify terms and phrases as they felt necessary and verify that the descriptive words or phrases used were representative and reflective of their comments. Participants seemed to appreciate having a poster board to remind them of topics that were discussed earlier and acknowledged that it prompted them to think of experiences to add to the discussion while others were speaking. This, in turn, led to more interaction between participants as they could comment on each other's experiences.

B. Expectations

Next, I asked participants to discuss their expectations of the health care system and providers and their ideal characteristics of each. I positioned a new poster entitled "expectations" next to the poster on "experiences". Participants related and described experiences they had discussed earlier to expectations, and also discussed other expectations that were not necessarily related to their actual experiences but signaled aspects of care that were important to them.

C. Evaluating preferences using vignettes

Use of vignettes in focus groups can be helpful for allowing participants to express their ideas or preferences without feeling vulnerable to others in the group.(McQuarrie, 1996; Schoenberg &

Ravdal, 2000) These vignettes typically feature a scenario about a hypothetical situation so that participants can distance themselves from the situation; yet, their own ideas will still come across.(Emlet & Poindexter, 2004; Hughes & Huby, 2002; N. J. Spalding & Phillips, 2007) Studies have shown that this approach can be particularly helpful in focus groups that involve older adults as participants when discussing sensitive topics.(Brondani, MacEntee, Bryant, & O'Neill, 2008) In several informant interviews with older adults, I found that discussion of geriatrics—even as a term—was a sensitive issue. As such, rather than asking participants to discuss geriatric care in a group, I used the vignette method to elicit their preferences related to geriatric care in a way that distanced them from the situation.

I developed two sets of four vignettes describing the health, medical, and social circumstances of a hypothetical, female patient. There were two sets because one set featured a 67-year old patient, and the other set featured a 91-year old patient. To capture the influence of age on its own, a "healthy" vignette described either a 67- or 91- year old individual who is active and reports no health concerns other than prescription glasses. To capture the influence of clinical complexity, a second vignette described either the 67- or 91- year old individual as having multiple chronic conditions, issues with medication management resulting in hospitalization, and activity of daily living impairments requiring assistance. To capture the influence of clinical complexity as well as values of quality of life and characteristics of providers, the third vignette featured a 67- or 91- year old with multiple chronic conditions who is experiencing side effects of her medications and is concerned about the amount of time her doctor spends with her. Finally, the fourth vignette sought to understand the role of health risks along with concerns about social support and social engagement, in relation to provider

preferences. This vignette featured a 67 or 91- year old female experiencing bereavement, with a family history of Alzheimer's disease and concerns about social engagement.(Andersson, Sundberg, Falkenberg, & He, 2012; Chou et al., 2018; Cooper, Smith, & Hancock, 2008; Demiris, Hensel, Skubic, & Rantz, 2008; Farin, Gramm, & Schmidt, 2013; Holt, Pincus, & Vogel, 2015; Kawi, 2014; Prins et al., 2010; Rowell & Polipnick, 2008; Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2013) Vignettes are shown in Table 2.2.

Table 2.2 Vignettes shown to participants

Vignette	Description	Characteristics
1A	Laura is 67 years old and healthy other than prescription glasses that she has worn for several years. She is active, exercises 4 times a week, and enjoys gardening since she has retired.	Healthy and Active
1B	Anne is 91 years old and healthy other than prescription glasses that she has worn for several years. She is active, exercises 4 times a week, and enjoys gardening since she has retired.	Healthy and Active
2A	Laura is 67 years old, and was recently diagnosed with breast cancer. She was diagnosed with diabetes in her 40s, and has had severe balance problems since her 50s. Due to her issues with balance, Laura requires assistance with daily activities like bathing and dressing from an assistant who visits daily, and she usually calls her son to help her out when she needs to be driven to doctor appointments or to the grocery store. She has been admitted to the hospital once in the past month due to mixing up her medications.	Multiple chronic conditions Requires extensive assistance Hospitalizations
2B	Anne is 91 years old, and was recently diagnosed with breast cancer. She was diagnosed with diabetes in her 40s, and has had severe balance problems since her 50s. Due to her issues with balance, Anne requires assistance with daily activities like bathing and dressing from an assistant who visits daily, and she usually calls her son to help her out when she needs to be driven to doctor appointments or to the grocery store. She has been admitted to the hospital once in the past month due to mixing up her medications.	Multiple chronic conditions Requires extensive assistance Hospitalizations

3A	Laura is 67 years old, and has visited several specialists to help her manage her multiple chronic conditions along with her primary care physician, who she sees twice a year. Recently, Laura has been experiencing terrible side effects from some of the medications she has been prescribed. Even though Laura has been seeing her primary care doctor for several years, nowadays, her doctor visits are getting shorter even though her list of concerns is getting longer.	Multiple chronic conditions Quality of life Quality of care
3B	Anne is 91 years old, and has visited several specialists to help her manage her multiple chronic conditions along with her primary care physician, who she sees twice a year. Recently, Anne has been experiencing terrible side effects from some of the medications she has been prescribed. Even though Anne has been seeing her primary care doctor for several years, nowadays, her doctor visits are getting shorter even though her list of concerns is getting longer.	Multiple chronic conditions Quality of life Quality of care
4A	Laura is 67 years old and has a family history of Alzheimer's disease on her father's side. Laura's primary care physician knows about her family history of Alzheimer's disease, and has suggested some activities she can do to keep her mind active. Laura's husband recently passed away and her children live about four hours away. She has a number of friends that she often goes went to lunch with, but recently she has been staying at home fearing that something will happen to her if she goes out.	Alzheimer's disease Social support Social engagement
4B	Anne is 91 years old and has a family history of Alzheimer's disease on her father's side. Anne's primary care physician knows about her family history of Alzheimer's disease, and has suggested some activities she can do to keep her mind active. Anne's husband recently passed away and her children live about four hours away. She has a number of friends she often goes to lunch with, but recently she has been staying at home fearing that something will happen to her if she goes out.	Alzheimer's disease Social support Social engagement

Participants were randomly given 1-3 different vignettes shown on separate sheets of paper. Each sheet provided definitions for *primary care physician* ("A primary care physician is a doctor who might be the first person to diagnose a person with a health concern, and also

continues to care for a variety of medical conditions not limited by cause, organ system, or diagnosis") and *geriatrician* ("A geriatrician is a doctor who might be the first person to diagnose a person with a health concern, and also continues to care for a variety of medical conditions not limited by cause, organ system, or diagnosis. A geriatrician focuses on health care of elderly people, including organizing and coordinating health care for older people.") For every vignette they received, participants were asked: "Which type of doctor do you think [patient name] should see?" and were then prompted to indicate if they thought the hypothetical patient should (a) switch to a geriatrician, (b) continue care with their primary care physician, or (c) enroll in care under a geriatrician and also continue seeing their primary care physician.

Since participants were distant from the scenario, they did not necessarily express their preferences based on personal experience; however, considering literature suggesting that values underlie preferences, I could gain a preliminary sense of how different types of health concerns or needs and circumstances, and different characteristics of providers, may shape preferences.(R. M. Epstein & Street, 2011)

In one early focus group session with caregivers, I modified the approach to the vignettes in order to verify the circumstances presented in vignettes to other participants. Here, rather than presenting vignettes, I asked participants to think about their older relative's health, social, and medical circumstances, consider their relative's providers, and then choose between the three provider options (switching to a geriatrician, continuing care with their primary care physician, or enrolling in care with both providers). Then, they presented a summary of their older relative's circumstances to others in the group. Next, each participant made a provider selection and discussed what led them to make that selection. This approach validated the circumstances that were presented in the vignettes, which were subsequently used for all other focus groups.

Analysis

I conducted qualitative analyses in two phases. First, I used key terms and themes from the brainstorming poster used during sessions to create a codebook. I used this codebook for thematic analysis, which is a qualitative approach to identifying patterns and themes that emerge from data.(Boyatzis, 1998; Vaismoradi, Turunen, & Bondas, 2013) These themes reflected experiences older adults and family caregivers described, and that they then related to needs or health care characteristics that are important to them.

Although the concepts underlying patient-centeredness (need, values, and preferences) provided a useful framework for guiding the focus group discussion, the purpose of the analysis was not to measure the relationship or evaluate the distinction between each of the concepts. Rather, the thematic analysis gave me insight into how older adults and family caregivers relate their experiences to characteristics of care that are important to them.

I descriptively analyzed responses to vignettes, which reflected participant preferences for primary care physicians vis a vis geriatricians based on various hypothetical clinical, social, and provider circumstances. The purpose of analyzing vignettes was to understand how participants thought about making decisions about providers after having discussed what is important to them in their own health care. The vignettes, having been developed prior to the focus groups, were expected to help me to understand the role of other patient characteristics—e.g. age, and health status—which participants may not have discussed during the first phase of the focus group sessions, in making decisions about physicians.

RESULTS

Eighteen older adults and eighteen family caregivers participated in the focus groups. Demographic information is provided in Table 2.3. Both groups had 11 females and 7 males. All participants had at least some college-level education. Older adult participants ranged from age 66-92 (mean = 74); family caregiver participants ranged from age 26-77 (mean = 52). The majority of family caregivers provided support to at least one parent or parent-in-law (n = 11); others provided support to a spouse/partner (n = 3), aunt/uncle (n = 2), or grandparent (n = 2).

Table 2.3. Demographic characteristics of focus group participants

	Older Adults	**Family Caregivers**
Total N	18	18
Sex		
Female	11	11
Male	7	7
Race		
White	13	9
Black	2	3
Other	3	6
Age		
Mean (Range)	74 (66-92)	52 (26-77)
Education		
High school or less	0	0
Some college	4	0
B.A. or higher	14	18

Since some family caregivers were also older adults themselves, these participants discussed their observations of their older relatives as well as their own experiences as older adults, which also resulted in interesting dialogues between younger and older caregivers with different life experiences.

Thematic analysis of older adults' and family caregivers' health care experiences and expectations

In response to the first prompt asking for a description of experiences with health care, the majority of participants in the older adult focus groups began by describing positive experiences with providers. Initially, they had few comments other than, for example, *"I like my doctor."* However, in each group session, after one participant shared an example of a negative experience and their associated concerns, there seemed to emerge an atmosphere of trust and rapport that facilitated more candor. In contrast, family caregivers were more open about expressing their experiences, expectations, and their care recipient's needs regarding the health care system and providers. They explained that their older relatives tended to be too forgiving of their providers, in denial about their health issues, or silent about their needs and concerns because they didn't feel qualified to question their provider or because they felt they were better off than their friends. This was consistent with the ways that older adult participants discussed their experiences.

Older adults and family caregivers discussed experiences and expectations in terms of characteristics of (a) health care providers, (b) health care delivery and approach to medicine, and (c) the health care system. Using the framework of patient-centeredness was helpful for facilitating participants in relating their experiences to expectations and important characteristics of health care. That is, participants described their experiences and subsequently discussed their expectations. While some experiences directly mapped onto expectations—reflecting a perceived need—in other instances, participants described distinct expectations that reflected what they value, or what is important to them when they think about health care. Preferences were explicitly explored through vignettes, but in the initial phase of the focus group discussion,

participants explained how their experiences, which either met or did not meet their expectations, led them to stay with their current physician or see a new physician—which in some circumstances, was a geriatrician. A summary with examples of needs, values, and preferences as discussed by participants at the three levels of characteristics (providers, care delivery, and health system), is provided in Table 2.4.

Table 2.4 Summary of needs, values, and preferences as related to characteristics of providers, care delivery, and the health system as described by participants

	Needs (Perceived)		**Values**	**Preferences**
	Experience	Expectation		
Characteristics of providers	Doctor misdiagnoses condition	Doctor has an understanding of how older adults are distinct from younger/middle-aged adults (e.g. symptoms)	Interpersonal quality - E.g. doctor shows respect, listens Technical quality - E.g. doctor has appropriate skills and training	Choose a new doctor who addresses concerns and whose practices align with values
Characteristics of care delivery	Doctor asks patient about their mental health following retirement.	Doctor considers health care for older adults holistically by considering mental and physical health	Holistic care - E.g. consider and address both mental and physical health Integrate family caregivers - E.g. Facilitate caregiver involvement via technology or teamwork	Stay with current doctor who provides holistically and seeks insights from family caregivers during the clinical encounter
Characteristics of health system	Doctor refers patient to several specialists in disparate locations to manage multiple conditions.	Older adult expects that they would be able to receive all care in the same facility given transportation difficulties.	Address social and environmental factors - E.g. consideration of transportation needs of older adults Trust and persistence - E.g. Limit dismissal of needs and concerns of older adults; attend to distinct and equally	Choose a new doctor whose practice either resembles a patient-centered medical home, or who refers to a social worker to help

			important needs of older adults	older patient navigate their various appointments and providers.

Characteristics of health care providers

Older adults and family caregivers both discussed specific characteristics of health care providers that are important to them. Specific experiences and general concerns about their future needs led to discussion of the importance of providers who are skilled and understanding of the specific clinical and social needs and circumstances of older adults. Further, participants expressed that providers should demonstrate respect and empathy, preserving the dignity of older adults who may otherwise feel especially vulnerable and even dismissed by providers.

When describing experiences, older adults were strikingly forgiving of incidents such as diagnostic errors. They attributed these experiences to the tremendous demands on doctors and to their own medical complexities. Still, they described strain and risks associated with some of these issues. For example, one participant explained that acquiring strep throat could be extremely dangerous for him. He knew from prior experience that his symptoms varied each time he had strep, but when he went to his doctor, she was not convinced that it was strep. Despite having a history of strep throat with complications, the participant was not given a diagnosis or subsequent treatment because he did not present "classic symptoms" and later ended up in the emergency department. He was forgiving—and other participants affirmed with nods—of doctors, explaining that *they too, are human*. However, in the discussion that followed, participants expressed the need for specialized skills and training for providers to understand that

the medical needs, symptoms, and concerns of older adults may be unlike those of younger or middle-aged adults, thereby ideally improving diagnostic accuracy.

Family caregivers described experiences related to care coordination and follow-up. They were frustrated that too often, their older relative's doctor was reading old health information or repeating or even neglecting critical information from other providers involved in their relative's care. For example, some family caregivers had relocated their older relatives to be closer for caregiving purposes and were struggling to coordinate care between various EHR systems (i.e. their older relative's previous physician's EHR and current physician's EHR) because of lack of coordination between the physicians themselves. Others explained that they coordinate between various specialists and their older relative's general practitioner, particularly on behalf of older adults who cannot use or refuse to use technology. They described coordination as a characteristic of care that a provider should recognize as being critical and fundamental to the care of older adults who may (and are more likely to) receive care from multiple doctors. They suggested that doctors should receive training in how to coordinate care effectively—both with and without the EHR—and that there should be clear leaders when multiple providers or even teams co-manage a patient's care in order for greater coordination and accountability.

One of the issues resulting from lack of coordination and limited training among providers that was described by both groups of participants, was conflicted prioritization of concerns during doctor visits. This resulted in the need for additional follow-up appointments—often without guarantee of addressing other concerns—or, in the sacrifice of attention to other health issues that were sometimes more inconvenient or concerning. Family caregivers attributed much of this inefficient or conflicted prioritization to doctors' over-reliance on the medical record instead of personal conversations. For example, one family caregiver explained that their

relative's doctor saw a flagged test result from a previous appointment and took the entire appointment to address that issue even though it was already resolved. Consequently, their relative's insomnia and mental health concerns were left unaddressed.

While family caregivers attributed issues with prioritization to overuse or ineffective use of the EHR, older adults explained that these conflicting priorities were due to health care providers often dismissing their concerns or not taking them seriously. For example, one participant described that after explaining his symptoms, his physician simply said that the issue was because of his age—and moreover, did not attempt to minimize the burden on quality of life caused by these symptoms. He suggested:

> *Aging shouldn't just ... Just because you're aging, he shouldn't write ... He or she shouldn't write you off, and just say, "Well, that's part of aging. -Older adult*

This was related to a third theme that emerged related to characteristics of providers that was mentioned more commonly by family caregivers. They discussed a need for patient, respectful, empathetic providers who treat older adults with dignity. In particular, participants caring for older adults with cognitive impairment recounted instances where providers or clinic staff seemed apathetic towards the experiences and behaviors of older adults. One family caregiver of an older adult with Alzheimer's disease recalled an incident at a clinic.

> *So we went to [the clinic] and I was very, very embarrassed because my father-in-law is naturally loud, not to mention that he lost his hearing aids twice already. So he's loud. Everyone is looking at you, like 'how impolite'. It's not who he is… I didn't feel that they understand what's going on with people with dementia who have to ask the same*

question ten times… And the nurse was sitting really irritated and said "If I give him an amplifier would he be happier"? -Caregiver

Participants emphasized the need for empathy—especially because they (or their older relatives) were amidst various medical, social, economic, and psychological transitions within a complex health system. They urged that the way in which care is delivered should recognize these complexities.

Characteristics of health care delivery

Participants described experiences with ways in which health care is delivered leading to discussion of the importance of a holistic approach to health care that considers the clinical as well as social and environmental circumstances of patients.

Older adult participants felt that care they received was often siloed by symptom; one participant thought she was experiencing depression but was told that her symptoms were more likely a side effect of her recent stroke. Since the symptoms were attributed to stroke rather than to a primary diagnosis of depression, she felt that her mental health concerns were left unaddressed by her doctor; and was further troubled that she was not pointed to resources (i.e., a psychologist). Similarly, family caregivers discussed a need for holistic care, especially for mental health, cognitive health, and options for non-allopathic pain management such as acupuncture or massage. They explained that their older relatives tended to suppress these types of complaints, not wanting to be a burden or due to the feel stigma of having mental health issues; thus, making it even more imperative for the system to detect early signs for appropriate treatment. One participant described a positive experience:

When my mom came over to visit us and we took [her] to see the geriatric doctor and it was a pretty interesting experience… at that time, my dad had just passed away about a year and a half earlier. He actually asked my mom "Do you ever have suicidal thoughts in your life?" And my mom says, "Yes." I was shocked… he noticed my mom actually had depression which is something that we didn't know. Yeah, my dad passed away so she's kind of sad, in grief or something, but in reality, she's in depression. So he prescribed medicine but having depression is a big taboo in our culture. So apparently, she had depression before any of us knew. -Older adult, speaking about her caregiving experience

Participants in general perceived a need for more explicit attention to mental health, for example, for depression resulting from the "chronic bereavement" occurring in older adults who are losing their friends. In addition, they described a need for greater assistance and attention to functional impairments, issues with mobility, and medication management, supporting their independence and quality of life. Along with risk of cognitive impairment, one of the primary concerns of older adult participants was the risk of losing mobility and depending on another for assistance. Older adult participants were typically satisfied with the support they were receiving for functioning and managing conditions, but they felt that the approach to care should be proactive, rather than exclusively reactive.

In relation to experiences with issues related to care coordination and conflicting prioritization, along with describing the need for skilled and empathetic providers, family caregivers discussed a need for procedures for integrating caregivers as part of care delivery which would enable them to have a more active role in their relative's care. Even though they

were sometimes troubled that they had to arbitrarily "step up" to perform tasks they felt unqualified to carry out, they saw themselves as advocates for their older relatives. Yet, their experiences during the delivery of care made them feel that they are not always regarded as advocates as their insights were ignored despite their tremendous supportive role. For example, they explained that sometimes their relative's providers would ignore their comments and redirect questions to their relative. In other cases, because of short appointment times, in combination with their older relatives' lengthy lists of concerns, caregivers did not have an opportunity to explain their observations and concerns with providers.

When asked whether if they want to be formally integrated into care teams, family caregivers were generally receptive and likened potential eldercare integrated models to pediatric models where a parent/guardian is included in information sharing and decision-making. In one focus group, participants discussed their conceptualization of having a role within the health care team for their relative:

> *Participant 1: Well that's not a bad idea. But I think it would be difficult if I was the person at the center giving the information to my husband, I don't know that I would want four different people you know calling me and saying you know we discovered this and then you know 20 minutes later I get another call from somebody else about, I mean if we are talking about the medical profession you know I don't know anything about the medical profession. I mean I don't, I relay information to my husband all the time now, but it'd be nice if you were a part of that team I guess, I don't know.*

Participant 2: As far as having the caregiver being the point of contact for the patient, that's going to be interdependent on their dynamics in the home. Because if the person has dementia, you're running the show.

Participant 3: I think it would be hard for the caregiver to be the main person to pass on information to the patient. Because the expectation of your role is different even though you are actively participating in all of the coordination and being an advocate. I think it still has to come from a health professional. But rather than I talk to individual providers or specialists individually, probably there could be a team meeting where you can participate…Sometimes that could be hard to do with the patient on site because … the patient does not have that kind of patience to sit alone to listen to everything. But if you can meet with them and then be able to know all in one nutshell rather than having to contact them individually without the connection. -Caregivers

Family caregivers unanimously described themselves as advocates and coordinators of care, and further, as liaisons with the health care system in general. For example, they described spending hours on the telephone to navigate Medicare and providing transportation to their relatives. Older adult participants described experiences with the system and structures around them that shaped their assessment of needed characteristics of the health care system.

Characteristics of the health care system

Older adult participants discussed that there is a need for the health care system to improve ease of access to different types of health services as well as access to care itself—i.e., addressing the

social determinants of health to support older adults' access to high quality care. They also shared a profound desire for a system that trusts them, and one that is persistent in its efforts to improve quality of care and quality of life.

Many older adult participants discussed transportation challenges with getting to doctor appointments, for example, if they could no longer drive due to poor eyesight. Others discussed concerns with scheduling procedures requiring a companion to take them home following anesthesia. Finding transportation was particularly distressing to older adults living independently; several described it as a pivotal moment in their realization that they were isolated. For example, one participant explained that he had planned to take a bus to his scheduled surgery, thinking that he simply needed to find someone to take him to the procedure and bring him home. Upon arriving at the outpatient clinic he was told he needed to reschedule the procedure and find a companion who could observe his post-operative recovery:

One thing that I'm... I live alone, and one thing that I'm running into quite regularly now is that particularly if I have a procedure, they won't perform it, unless I have a companion or someone accompany me. And over the last few years, it has become more and more difficult to find someone because the people that I associated with during my life and work, they've either died, or they're in retirement homes, or they have moved down south, or like me they can't drive anymore… - Older adult

In another group, a participant who is experiencing mobility issues following a stroke explained that her doctor recommends going to a stroke support group, however, she has not been cleared to drive and local shuttles are typically late or do not travel far enough. Participants explained that their providers need to be aware of their social circumstances and further, the health care system and social policies need to address barriers to accessing care. Noting the high

demand on doctors, they suggested that the system could utilize the skills of social workers and other types of health professionals to identify and try to address some of these other circumstances.

Older adults were also aware of the opioid epidemic, which had become more prominent of a topic in the news during these focus groups. They explained that the health care system treats them like a statistic rather than as individuals. For example, they were frustrated that misusing behaviors of other patients and inappropriate prescriptive behaviors of providers have challenged their access to necessary pain medications due to chronic pain, arthritis, or in the case of one veteran participant, an ear infection:

> *Now I'm at the VA in ... My medical records are there. The reason they gave me for not being able to prescribe me narcotics is because of the opioid crisis. Well, I don't have a history of opioid abuse. I'm in pain. You know that I'm in pain. I have a punctured eardrum. I have infection in my ear. It's a dead monkey on the line somewhere. I don't want to hear about the opioid crisis when I'm in pain. I don't need, like the nurse told me, "Well, the only thing we can, or the only think I can tell you is to suck it up." Well, I talked to their supervisor afterward. But anyway, long story short, whatever you've done, whatever somebody else has done, that causes the system to get to be this way, I shouldn't have to suffer for it. Especially when I haven't abused anything. -Older adult*

They related this to two characteristics of the health system they felt are important to consider when caring for older adults. First, the health system needs to be persistent in its efforts to help older adults, and in turn, it needs to trust them. This was a characteristic expressed by family caregivers as well—i.e., that it is easy for providers and the system as a whole to be

dismissive and give up on older adults. Instead, it should persist in its efforts to promote their health maintenance (even if not improvement) and thereby preserve their dignity. As one group of older adult participants explained:

> *Participant 1: Yeah, that's all. We hear it all the time. "Well, what do you expect? You're 60." Not really, but maybe 70 or 80. For sure 90. Oh my god. I understand that there are certain things that you can't fix. I don't know what they are … You know you have the problem, and they don't know what to do for you. And what do you do?*
>
> *Participant 2: I haven't had that experience, but I would want them to keep trying.*
>
> *Participant 1: I agree. Especially when you're a little over what they thought is [old] enough. We haven't figured it [what to do] out yet, but maybe someday, we'll have it.*

Second, the system needs to reframe its goals such that the focus is on improving quality of life rather than quantity of life. Participants attributed some of this to physician training, suggesting that older adults should be more involved (and allowed) as standardized patients. They described this at the level of the system rather than in terms of providers themselves or the approach to care because they related this negligence of quality of life to societal ageism.

Older adults' and family caregivers' physician preferences

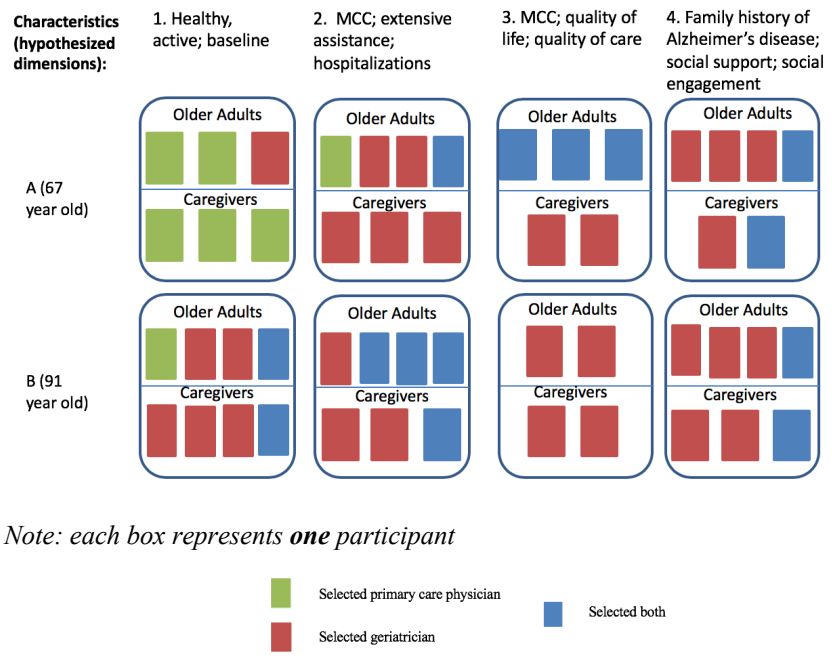
Vignettes were analyzed to assess how participants made decisions about providers based on different types of information about a distanced, hypothetical older adult. Notably, participants did not discuss the selections they made regarding providers based on the various vignettes.

However, since vignettes were conducted at the end of the focus group session, it is possible that the focus group discussion also influenced the preferences participants indicated. The "real life" scenarios that were used in the focus group with caregivers to verify vignettes suggested that the circumstances presented in the vignettes were reflective of considerations when making a decision about providers. As one caregiver from this group described:

> *"If you're an old person who has one disease, then you go to that "one thing" doctor. But if a geriatrician is anything like a pediatrician they are supposed to be able to be more cognizant not only of the disease that they're presenting but also the stage of life. Both psychological and physical challenges that go along with a specific period in a person's life."*

In their responses to the vignettes, caregivers selected *geriatrician* or *both* in all scenarios except for Laura, the 67-year-old healthy, retired, and active patient. Older adults selected *geriatrician* or *both* for the most part as well, other than for the 67-year-old health patient. Some participants who recommended *both* additionally wrote *"in one person"* meaning that the geriatrician should also be the primary care physician. Some suggested *both* so the patient could recover quicker or give the patient extra time with another doctor to manage care as needed, which they explained in writing. Caregivers favored switching to geriatric care when compared to older adults, who seemed to prefer enrolling in care with both—possibly to maintain continuity of care with their primary care physician and also benefiting from geriatric care. A summary of participants' preferences is illustrated in Figure 2.1.

Figure 2.1 Illustration of participants' preferences for providers based on vignettes



*Note: each box represents **one** participant*

DISCUSSION

Older adults are expected to navigate a fragmented health care system within which they must make decisions about the best care that meets their clinical needs and also considers their values, needs, and preferences. Family caregivers often support older relatives in this process.(J. L. Wolff, Boyd, Gitlin, Bruce, & Roter, 2012; Jennifer L Wolff & Spillman, 2014) These aspects of patient-centeredness are related to the ultimate use of health services (such as geriatric care) as well as patients' satisfaction with the services they have used, and ideally, their outcomes including quality of life.(R. M. Andersen, 2008) In this study, I begin to explore the health care characteristics and the clinical and social circumstances that may be important to older adults when they think about their health care. I explore how older adults and family caregivers express their experiences, and then, how they relate these experiences to characteristics that are important to them in their health care. Finally, I examined how older adults and family

caregivers express their preferences for geriatric care drawing on characteristics of a hypothetical older patient.

In this study, based on their experiences, older adults and family caregivers expressed characteristics of health care providers, the approach to care delivery and medicine, and the health system that are important to them or that they need. At the provider level, the technical and interpersonal quality of providers were important to participants and they discussed these characteristics after drawing from experiences of misdiagnoses or dismissive comments from their doctors. These characteristics of providers—their technical and interpersonal quality, which have been described in other literature, are perhaps linked to characteristics of care delivery and the approach to medical care described by participants.(Fung et al., 2005) Older adults and family caregivers both described a need for holistic care that considers the various circumstances within which older adults function and addresses their physical and mental health. While older adults spoke to their personal experiences, family caregivers discussed the challenge of observing their older relatives struggle in the home with mental health and trying to reason with them to talk to their doctor and overcome cultural norms or stigma. Yet, participants expressed that incorporating mental health into care delivery should be a standard of care rather than a priority for which older adults have to initiate or caregivers have to advocate.

Family caregivers often described themselves as being the sole advocate for their older relative and felt that providers were more likely to act as an authority, but not as an advocate. For this reason, family caregivers saw a critical need for their involvement in health care settings as has been suggested by others.(Dalton, 2003; Rabow, Hauser, & Adams, 2004; Reinhard, Given, Petlick, & Bemis, 2008) Jokingly, they highlighted that they wouldn't mind compensation, and these discussions illuminated the tremendous effort of caregiving that often went unrecognized

and unappreciated in health care settings. Caregiver participants did not want a reward for their support, but they wanted their voice to be heard and respected in the health care setting, especially because they are responsible for carrying out therapies or managing medications. This was especially true among caregivers of older adults with cognitive impairment. Still, even family caregivers of older adults experiencing typical aging (i.e., not having multiple health conditions) wanted to have a role in their relative's health care so they could be proactive. These findings are consistent with prior literature suggesting the need for integrating family caregivers in order to inform provision of high-quality care that is patient- and family- centered. Older adults and family caregivers both indicated that trust from the system and its providers is essential for ensuring that they receive appropriate care, but also, for fostering shared decision-making. This perspective has been asserted in recent literature as well with an emphasis on physician trust in patients in order to strengthen partnerships and improve quality of care defined in multiple ways.(Grob, Darien, & Meyers, 2019)

The use of vignettes provided some exploratory insight into, first, whether older adults and family caregivers will select geriatric care at all, and second, some of the circumstances under which they may do so. A limitation of this approach is that it is unclear whether the discussion guided provider preferences or whether participants selected the provider type based exclusively on the circumstances presented in the scenarios. However, given that vignettes were presented at the end of the session it is possible that participants' preferences reflect some of the experiences and characteristics they discussed during the earlier phase of the session. Findings suggest that older adults and family caregivers may see value in geriatric care even with a basic definition of the services they provide, and may express a preference for a geriatrician given increasing clinical complexity as well as social circumstances.

Following focus group sessions, at least two older adults and three caregivers mentioned that they were planning to look into the possibility of enrolling in (or enrolling their older adult care recipient) in geriatric care. Only one had not heard of a geriatrics; the others were aware of a geriatrician's role, but had simply had not thought about it as a possibility until it was explicitly brought to their attention. In a way, the focus group session may have raised awareness of geriatrics. Though it was not an objective of this study, future research could use longitudinal study designs to identify the role of such methods in actually raising awareness or acting as an intervention for participants. With regard to my secondary motivation for conducting focus groups—to function as an opportunity for connectedness—older adults as well as family caregivers reported on debrief forms that they were appreciative that the session gave them a chance to interact with others, and that they were comforted by similarities in experiences and concerns.

The future of geriatric care as a subspecialty requires a deeper understanding of its value to older adults and family caregivers.(Tinetti, 2016) The development of models of care for aging adults and transitional care services requires insight into how older adults' and family caregivers' experiences shape care characteristics that are important to them, and subsequently, how they make decisions about different types of services. In the case of geriatric care a workforce shortage presents a barrier to the current availability of geriatricians to provide care for older adults. As a result, utilization remains low. However, findings from this study can be used to inform the development of surveys to understand how factors—including individual and clinical characteristics as well as experiences and perceived needs—may be related to the perceived value of geriatric care. This objective will be explored in Chapter 3.

In addition, this study contributes to a better understanding of what patient-centeredness means to older adults and family caregivers, and prompts consideration of how we might measure patient-centeredness and respond to needs. Although conceptually, patient-centeredness encompasses needs, values, and preferences, participants related their actual experiences to needs and important provider, care delivery, and system characteristics. Current applications of frameworks for understanding and evaluating quality struggle with identifying how to respond to patient experience information even though patient experience and processing of information is part of the process by which patients ultimately make decisions about providers.(Berwick, James, & Coye, 2003; Schlesinger, Kanouse, Rybowski, Martino, & Shaller, 2012) Here, I find that older adults and family caregivers use these experiences to identify aspects of health care that are important to them and even offer suggestions. Organizations and policies pursuing health system quality in general, and patient-centeredness specifically, will benefit from application of frameworks that consider insights from patients—such as older adults—and their family caregivers and identify how to drive change using multi-stakeholder perspectives.

Implications for research and practice

Future research should examine how experiences and needs that underlie patient-centeredness relate to the perceived value and use of geriatric care. Further, research should compare the perspectives of older adults and family caregivers. For example, in this study older adults were strikingly forgiving and trusting of their providers and of the health system—and this could in part be due to their longer relationship with their providers.(Musa, Schulz, Harris, Silverman, & Thomas, 2009) However, for the same reason it is critical to understand how

family caregivers think about their older relatives' experiences, and how they consider and facilitate decisions about services like geriatric care.

Notably, many participants clarified that they had not switched doctors because of the challenges of building rapport with a new provider, issues with accessing a new provider, habit, or even loyalty. Other participants described that they had been forced to switch doctors following their physician's retirement, moving away, or passing away. Future research should examine the role of mediating factors, such as loyalty, trust, and attitudes toward aging, to better understand the conditions that older adults select geriatric care or even generally, change physicians.

There is a need for development of robust measures to evaluate quality of care for older adults in order to guide practices and policies that consider the unique needs and circumstances of older adults. In this study, I find that older adults do, indeed, express their expectations from providers and the system. However, an additional contribution is the perspective of family caregivers who may observe aspects of quality that their older relatives may not recognize or may forgive. Further, family caregivers may contribute to insights and shared decision making with providers that ultimately facilitate provision of higher quality care. This study represents a first step towards understanding how older adults and family caregivers think about high quality care for older adults. If family caregivers do become more integrated into health systems, there will be a need for evaluating the quality of this type of integration, and further, for modifying our approach to measuring and evaluating quality of care for older adults—because this care is not, and will not be exclusively provided by the formal health care system.

There are some limitations of this study that may be ameliorated in future studies. First, participants in our sample were primarily recruited through a research platform, which suggests

that they are engaged in research and may be more exposed to health and medical research. This involvement may have influenced their conceptualization of needs to a greater extent than others who may not have similar interactions with research and health care. However, the discussions generated in these focus groups generated themes and ideas that can inform the development of future focus group or interview protocols that may be also be appropriate for older adults and family caregivers who are less active as research participants. There may also have been some selection bias – for example, interested participants may have had recent negative experiences with the health care system that informed their decision to participate in the study, which would have also influenced their comments during discussion. During the icebreaker sessions, when asked why participants decided to enroll in this study, most participants responded either that they wanted to contribute in order to help others, or, that they were interested in learning more about the health care system.

Further, all participants were able to attend the focus groups; this in itself signals a certain level of health status. However, that these participants also mentioned the need for greater support and information about functioning and mobility from providers suggests that it is a salient concern even among relatively healthy older adults. In fact, it is possible that perceived needs for assistance with functional impairments or managing health conditions may be understated in this sample. Finally, although family caregivers of participants with complex medical conditions as well as cognitive impairment participated in the study, it is possible that many caregivers were not able to participate in the focus group sessions due to commitments with employment and caregiving. Indeed, there are opportunities for future research to build on this study in order to better understand the perspectives of older adults and family caregivers as they interact with the health care system.

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Chapter 3

Perceived Value of Geriatric Care Among Older Adults and Family Caregivers

INTRODUCTION

Organizations and policymakers are increasingly concerned with ensuring the provision of high quality health care to support our aging population.(Ferris et al., 2017; Gastfriend, 2018; Herdman et al., 2007; Ortman, Velkoff, & Hogan, 2014b; Osterman, 2017) The passage of Medicare in 1965 facilitated greater access to health insurance and subsequently, to health care for the elderly.(Berkowitz, 2005; Pham, O'Malley, Bach, Saiontz-Martinez, & Schrag, 2009) The Affordable Care Act, though primarily concerned with expanding health insurance coverage further, also sought to address the quality of care.(Blumenthal et al., 2015; Sommers et al., 2015) However, gaps persist at various levels of the health care system. For example, Medicare does not cover long term care services that older adults may need and these mechanisms for supporting older adults are under pressure with a growing elderly dependence ratio—i.e. a greater proportion of non-working older adults who depend on a smaller proportion of younger, working adults for system funding.(Grabowski, 2007; Vespa, Armstrong, & Medina, 2018) At the level of health care delivery itself, access to health insurance and to providers does not guarantee the provision of sufficient attention to the unique needs of older adults. While geriatric care offers individualized, team-based care for older adults that addresses many of the specific needs of older adults, little is known about how older adults think about geriatric care.(Bell et al., 2016; Wieland et al., 1996)

BACKGROUND

In 2002, older adults accounted for 30-40% of primary care visits and this proportion is growing along with increasing utilization of health services.(Adams et al., 2002; Herdman et al., 2007) Studies have shown that primary care physicians are overwhelmed with growing patient panels resulting in insufficient attention to their older patients who are more likely to have multiple complex conditions amidst complex social circumstances.(Altschuler et al., 2012) Primary care physicians may also have varying expectations, attitudes, and judgments when evaluating, diagnosing, and treating their older patients. For example in one study, roughly 15% of primary care physicians reported that depression is a normal part of aging and about 60% disagreed when asked if trouble remembering names is an accepted part of aging even though other data suggests that name recall declines with age.(Davis, Bond, Howard, & Sarkisian, 2011) With these inconsistencies in understanding of the aging experience, it is unsurprising, for example, that misdiagnosis of dementia is relatively common along with other issues in quality of care that can negatively impact health outcomes and quality of life.(Bynum & Langa, 2019; van Leeuwen et al., 2019) The population of older adults is also highly diverse—for example, in terms of race/ethnicity—and studies suggest striking prevalence of misdiagnosis and inappropriate treatments or therapies that consider the social and cultural context of older patients.(Gianattasio, Prather, Glymour, Ciarleglio, & Power, 2019; Yang & Park, 2019) Yet, older adults tend to stay with their primary care physicians for extended duration for reasons including a strong interpersonal relationship and concerns around building rapport with a new physician.(Mold, Fryer, & Roberts, 2004)

While this personal physician may be the primary point of contact for older patients, older adults are also more likely to see multiple physicians to manage different aspects of their care.(Vegda et al., 2009) As was described in Chapter 2, this requires greater coordination of care across multiple providers, potentially with conflicting care recommendations, that primary care physicians may not be adequately trained to do.(Boult et al., 2010) Geriatric medicine was established and then initiated formally in medical education during the 1980s as an approach to medicine for older adults to address these issues and to provide care that considers the circumstances and needs of older adults that may be different from the optimal health care for younger and middle aged adults. Geriatric medicine has demonstrated greater effectiveness when compared to primary care for older adults, particularly those with multiple chronic conditions and geriatric syndromes (e.g. frailty) in terms of medication management, diagnostic accuracy, shorter length of hospital stay, and lower costs per admission.(Baztan, Suarez-Garcia, Lopez-Arrieta, Rodriguez-Manas, & Rodriguez-Artalejo, 2009; Counsell et al., 2007; Eloniemi-Sulkava, Saarenheimo, & Laakonen, 2009; Grigoryan, Javedan, & Rudolph, 2014; Hogan, Fox, & Badley, 1987; Ward et al., 2016) Currently, however, utilization of geriatric care services remains low.(*Medical Expenditure Panel Survey (MEPS)*, 2015).

Still, societal pressures—namely population aging and a growing elderly dependency ratio— along with simulation models suggest that the demand for geriatric care will grow dramatically over the upcoming decades.(Cantor, 2017; Kottek, Bates, & Spetz, 2017; Sorbero, Saul, Liu, & Resnick, 2012; The American Geriatrics Society, 2017) Indeed, the workforce shortage in geriatrics may explain part of the low utilization of geriatric services today – particularly as care is streamlined to maintain manageable patient panels.(E. Flaherty & Bartels, 2019; Salsberg & Grover, 2006; Wasserman, 2015) However, little is known about how older

adults think about geriatric care. In order to better anticipate and even influence utilization of geriatric care in the future, we need to understand whether and under what circumstances older adults perceive value in geriatric care. Since family caregivers often support their older relatives in making decisions about different types of health care services, further insight is also required into their perspectives on the perceived value of geriatric care.

In order for geriatrics to endure as a field and for successful efforts to develop a geriatrics work force, there is a need for clarifying the value of geriatric care.(Tinetti, 2016) Yet, limited research has drawn upon the perspectives of older adults – and their family caregivers, who may support them in medical decision-making.(J. L. Wolff, Spillman, et al., 2016; Jennifer L Wolff & Spillman, 2014) Further, little is known about how specific experiences and perceived needs are related to how older adults' and family caregivers' perceive value in geriatric care.

THEORETICAL BACKGROUND

Perceived value of a service has been defined in the literature as a consumer's (or patient's) evaluation of the benefits of a service in relation to the sacrifices or investment they made in that service.(Zeithaml, 1988) For example, if a patient leaves their current physician, requiring them to drive further for care and sacrifice a well-established relationship, and enrolls in care with another physician, they may perceive high value in this new service if they experience better health outcomes; but, they may perceive low value if their perceive that their health benefits do not at least exceed their sacrifice and/or investment. Perceived value thereby influences satisfaction and loyalty in that a patient may be highly satisfied if the benefits of a service exceed the sacrifice they made, and they may be more loyal to that physician who they perceive is providing a valuable service.(Cronin, Brady, & Hult, 2000; Eggert & Ulaga, 2002)

In the literature on health services, however, perceived value has primarily been described and evaluated retrospectively—that is, by assessing a patient's perceived value of a service they have already received. In the case of geriatric services, perceived value is a challenging construct to assess due to current low utilization. Yet, perceived value is considered a dynamic construct that could change over time—indeed, a patient could perceive the anticipated value of a service before actually using it, and, their perceived value may change after using the service.(Ozer, Basgoze, & Karahan, 2017; Sanchez-Garcia, Fiol, Rodriguez-Artola, & Moliner, 2006) For example, the genomics literature offers a clinical context where patients may consider the value of the service upon discovering a potential clinical need for that service; yet, they may not be able to actually use the service until they have a clear diagnosis in the future.(Halverson, Clift, & McCormick, 2016)

In Chapter 2, older adults and family caregivers described specific experiences with providers, care delivery, and the health system, and related these experiences to needs that they perceive are important for high quality, patient-centered care for older adults. These experiences and perceived needs may influence their perceived value of geriatric care. Indeed, enrolling in care with a geriatrician may involve sacrificing a relationship with one's current physician, or perhaps even compromising one's resistance towards a field that has been promoted as being for those who are aging. However, in this study, I do not seek to evaluate or measure the sacrifices or investments that contribute to perceived value. Instead, in this study, I examine how different experiences and perceived needs of older adults and family caregivers may be related to the perceived value of geriatric care.

The specific objective of this study was to explore and examine how demographic characteristics, clinical complexity, caregiver characteristics, perceived characteristics of

providers, awareness of geriatrics, and health system experiences are related to the perceived value of geriatric care. I developed a survey informed by findings presented in Chapter 2 to explore these relationships and to generate hypotheses for future research. However, based on focus group discussions described in Chapter 2, I hypothesized that clinical complexity is particularly influential in whether older adults perceive value in geriatric care, while perceived characteristics of providers is influential in whether family caregivers perceive value in geriatric care for their older relative.

With the expected rise in demand for geriatrics in the coming decades, a better understanding of how older adults' experiences may be related to their perceived value of geriatric care could help us to determine the broader value of the field and develop educational and shared decision-making tools that could be used by patients who could benefit from geriatric care.(Tinetti, 2016) It could also help medical institutions develop their medical school, residency, and fellowship training curricula to reflect features of geriatric medicine that are aligned with patient needs.(Bensadon, Teasdale, & Odenheimer, 2013; McCrystle, Murray, & Pinheiro, 2010; Schapmire et al., 2018) In turn, we can design a health care system and policies that better respond to patient experiences and related patient needs, thereby becoming more patient-centered and better equipped to support an aging population.(V. Entwistle, Firnigl, Ryan, Francis, & Kinghorn, 2012)

METHODS

This was a cross-sectional survey of older adults and family caregivers across the state of Michigan and was the second phase of an exploratory sequential study design following focus groups described in Chapter 2. While findings described in Chapter 2 informed the development

of the survey described next, this study was also exploratory in nature with goals of continuing to generate hypotheses for future study.

Study design

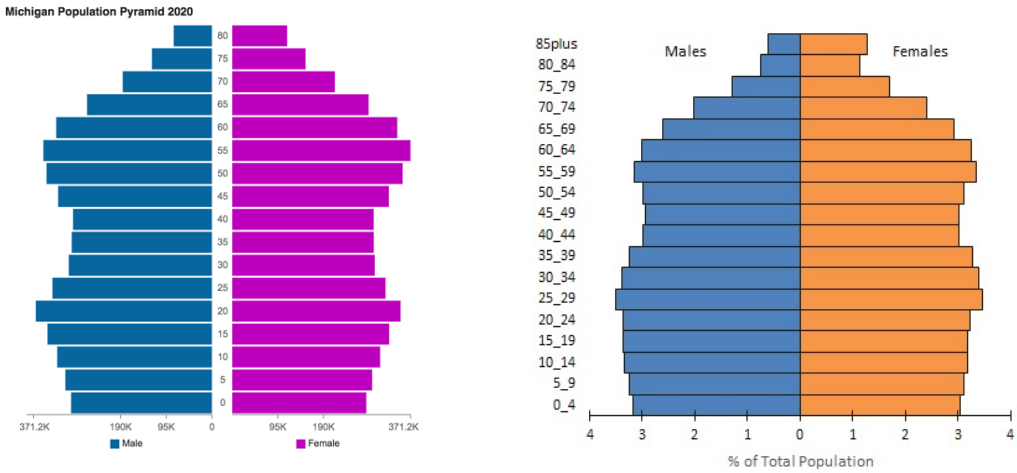
I developed two surveys – one tailored for older adults and the other tailored for family caregivers. Survey questions related to state level policies were specific to Michigan. Survey constructs were informed by Andersen and Colleagues' Behavioral Model of Health Services Use and were consistent with themes emerging from focus group discussions.(R. M. Andersen, 1995, 2008) Specific questions were adapted from existing surveys including the Consumer Assessment of Healthcare Providers and Systems (CAHPS), the Instrumental Activities of Daily Living Scale, and the Katz Index of Independence in Activities of Daily Living.(Bureau of Sociological Research, 2014; Katz, Down, Cash, & Grotz, 1970; M. P. Lawton & Brody, 1969) Survey questions given to older adults asked about their personal experiences, needs, and beliefs about the health care system and providers. Caregivers responded to questions about perceptions and observations of their older relative's experiences with the health care system and providers, along with questions about their role as a caregiver. This approach enabled me to understand both experiences and perceptions of older adults and caregivers.

Surveys were tested with a subsample of participants from each group (n = 12 total) using the "think-aloud" cognitive interview approach.(Daugherty, Harris-Kojetin, Squire, & Jael, 2001) Half of the cognitive interview participants had also participated in one of the focus groups and were asked to ensure that the survey (a) was functional, (b) comprehensive, and (c) reflective of their recollection of the focus group discussion. The survey was modified according to feedback (e.g. appropriate scales, wording).

Participants

Surveys were fielded to a Michigan sample. Older adults comprise roughly 20% of all adults across the state of Michigan and just over three-quarters of Michigan residents identify as white, non-Hispanic. Figure 3.1 illustrates the 2020 Michigan Population Pyramid, which shows that population aging in Michigan is similar to national population aging trends; demographic characteristics such as the proportion of individuals identifying as white, non-Hispanic and over age 65 are also similar when comparing Michigan and the U.S.(United States Census Bureau, 2017)

Figure 3.1 Michigan Population Pyramid (left image) and U.S. Population Pyramid (right image) (2020)



Participants were recruited using an online health research platform managed by a large academic medical center (Appendix A Figure A.3). The study was described as involving participation in a survey to understand health care needs of older adults from the perspectives of

older adults and unpaid, family caregivers (i.e. adult children, grandchildren, spouse/partners, or other extended relatives), along with how older adults and family caregivers select providers. Participants were recruited from across the state of Michigan.

Using a screening questionnaire, prospective participants self-identified either as an "adult 65 or older", "family caregiver of an adult 65 or older", or "both". Participants 65 or older who identified only as a caregiver received the caregiver version of the survey. Those who identified as "both" were asked which version of the survey they preferred to take and then received that version.

Older adults were included if they were at least 65 years old, comfortable with written English, and had received health care in the U.S. for at least one year. Individuals registered on the platform were not shown study information if they had a diagnosis of cognitive impairment (e.g. dementia). Family caregivers were included if they were at least 25 years old, actively providing unpaid care to a relative (parent/parent-in-law, aunt/uncle, sibling, grandparent, spouse/partner) 65 or older, and comfortable with written English. Family caregivers of older adults with cognitive impairment were included. The recruitment was conducted from March 2019 to August 2019 and identified 380 individuals expressing interest in the study. The study was granted permission by the University of Michigan Institutional Review Board.

Procedure

I contacted interested participants individually via messaging on the research platform or by email. A standard template was sent to participants with a brief overview of the study along with the URL for accessing the survey via Qualtrics (Appendix A Figure A.4). The first page of the survey provided relevant information for informed consent including an overview of the study; a

description of the potential benefits and risks of participating; reminders that participation was voluntary, that they could skip any question they did not want to answer; and a reminder that their responses were confidential and would not be shared with anyone outside the study team. Throughout the survey, participants were provided with definitions that were expected to assist them with answering questions. In Appendix A Figure A.5, terms and definitions that were provided in the survey are shown. Upon completing the survey, participants were asked to select a random number and enter it in the final field of the survey and send their number back to the study team in order to compensate them for their time. I then mailed $10 to participants.

Since surveys were tailored for older adults and family caregivers, I will first describe the measures used to analyze (A) the older adult perspective, and then describe the measures used to analyze (B) the family caregiver perspective.

Measures

A. Measures used for understanding older adults' perceived value of geriatric care

The objective of this part of the study was to examine how key demographic characteristics, clinical complexity, caregiver, perceived provider characteristics, and health system experiences relate to perceived value of geriatric care. Relevant variables were adapted from existing surveys as well as developed based on focus group analyses. The full survey for older adults is included in Appendix C Figure C.1.

Outcome variable

The outcome of interest was perceived value to self, which was measured using the question: *I am too healthy to see a geriatrician*. Possible responses included "Yes", "No," or "I'm not sure".

"No" and "I'm not sure" were combined resulting in a binary variable indicating high perceived value (No/I'm not sure) and low perceived value (Yes).

Independent variables

Demographic characteristics. Participants reported their sex (male or female), race/ethnicity (white, Non-Hispanic or Not white, or Hispanic), and age in years which I then categorized into age cohorts (65-69, 70-74, and 75+).

Clinical complexity. Older adults were asked to report their self-reported health status on a six-point scale ranging from *Very poor* to *Excellent*. For the current analysis, this was categorized into two groups (Very poor to Good, and Very good or Excellent). Participants were asked how many prescription medications they are supposed to take per day, and I classified this into two categories (0-3 and 4 or more).(Frazier, 2005; Steinman & Fick, 2019) These two measures were negatively, and weakly correlated (r=-0.27) suggesting that both should be included and may reveal different aspects of clinical complexity.

Caregiver support. To assess caregiver support, I asked respondents to indicate whether they receive support from a caregiver other than their health care provider(s) (Yes, No, or As needed). Participants who responded that they have a caregiver "As needed" were combined with "Yes" responses.

Perceived provider characteristics. I asked all participants fifteen questions about their perception of their current doctor's quality. Questions were drawn and adapted from the

Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, and other questions were developed based on focus group analyses. Expecting that many variables were likely highly correlated based on the thematic classification emerging from focus groups, I conducted a factor analysis in two stages as a method of dimension reduction. The goal was to identify dimensions that reflect dimensions of provider quality. A factor test using the Bartlett test of sphericity revealed a statistically significant chi-squared test rejecting the null hypothesis that the 15 variables tested were not intercorrelated, $X^2 = 1578.777, p < 0.001$. The Kaiser-Meyer-Olkin test, which evaluates whether the sampling for each variable is adequate to conduct a factor analysis, was 0.94. These are consistent with prior recommendations of a sample size of at least 100 to conduct a factor analysis.(Pearson & Mundform, 2010)

Prior to conducting the factor analysis, I classified the fifteen variables into two groups informed by the thematic analysis of focus groups and prior literature. These variables reflected technical and interpersonal characteristics of providers. Then, I conducted a principal components analysis to determine the number of underlying factors explaining the variance in each item. Two factors revealed Eigenvalues of greater than 1.(Gorsuch, 1983) In Appendix B Table B.1, I show results of principal components analysis for the full set of items tested. Then, to assess the items underlying each of the two factors, I conducted a factor analysis with orthogonal varimax rotation, which assumes that factors in the analysis are uncorrelated and thus somewhat forces the separation of underlying factors. To confirm the underlying factors, I then conducted factor analysis with oblique promax rotation, which assumes that factors in the analysis are correlated. I considered variables that had a factor loading of more than 0.4 to be related to each unique underlying factor.(Stevens, 2009; Yaremko, Harari, Harrison, & Lynn, 1986)

Final results of both analyses confirmed two dimensions reflective of perceived provider characteristics – technical quality and interpersonal quality. The items underlying each dimension were consistent with my initial classification.(Fung et al., 2005) Final results of the factor analysis with orthogonal varimax rotation are presented in Appendix B Table B.2. Cronbach's alpha of internal consistency for the nine items underlying the technical dimension was 0.93, and for the six items underlying the interpersonal dimension was 0.91. Results related to the technical and interpersonal quality of providers from factor analysis will be described in results from the multivariable analysis rather than described independently, since a factor score was predicted, generating an index to reflect dimension reduction.(Gorsuch, 1983)

Although studies have suggested that patients are better able to assess the interpersonal quality of their providers than the technical providers, I included both of these dimensions in the final analysis as they may contribute to insights, first, about how older adults think about each dimension of quality, and then, how their perception of these dimensions of quality relates to their perceived value of geriatric care.(McGlynn, 1997)

Health care system experiences. I asked participants to respond on a four-point scale from *Not at all true* to *Very true* to the prompt: "The current health system is meeting my needs". Through this question, I sought to understand whether there were larger system-level issues that may influence perceived value of geriatric care since concerns about the health care system (e.g. navigating Medicare, the capacity for the system to support older adults) was a theme emerging from focus groups.

Awareness of geriatrics. Finally, I asked participants to respond ("Yes" or "No") to the question: *Were you aware of what a geriatrician does prior to taking this survey?*

B. Measures used for understanding family caregivers' perceived value of geriatric care

The objective of this part of the study was to examine how key demographic characteristics, characteristics of caregivers, clinical complexity of older relatives, perceived provider characteristics, and health system experiences relate to family caregivers' perceived value of geriatric care for their older relative. Relevant variables were adapted from existing surveys as well as developed based on focus group analyses. The full survey for family caregivers is included in Appendix C Figure C.2.

Outcome variable

The outcome of interest was perceived value to older relative, which was measured using the question: *My older relative is too healthy to see a geriatrician*. Possible responses included "Yes", "No," or "I'm not sure". "No" and "I'm not sure" were combined resulting in a binary variable indicating high perceived value (No/I'm not sure) and low perceived value (Yes).

Independent variables

Demographic characteristics of caregivers. Participants reported their sex (male or female), race/ethnicity (white, Non-Hispanic or Not white, or Hispanic), and their age in years which I then categorized into age cohorts (25-39, 40-54, 55+). The purpose of categorizing family caregivers' age into groups was to assess if there were any differences between older family

caregivers who may have different perceptions based on their own experience of aging, and younger caregivers.

Characteristics of caregiver. Participants indicated their relationship with their older relative by specifying whether they are an adult: child/child-in-law, spouse/partner, grandchild, niece/nephew, sibling, or other relative. I created two categories to designate either adult child/child-in-law or spouse/partner/other relative. I also asked participants whether they live in the same household as their older relative ("Yes", "No" or "Part-time"). Part-time indicated that the older relative lives with different caregivers for various amounts of time (e.g. living with adult children for parts of the year). Therefore, I combined "Part-time" with "Yes" since these caregivers would have the opportunity to observe their relative in the same household at some point.

Clinical complexity of older relative. Participants were asked how many prescription medications their older relative is supposed to take per day, and I classified this into two categories (0-3 and 4 or more).(Frazier, 2005; Steinman & Fick, 2019)

Perceived provider characteristics. The perceived provider characteristics measures were identified using the same approach as described above for older adults. Caregivers were asked the same questions but were asked to respond in terms of their older relative's provider.

The Bartlett test of sphericity revealed a statistically significant chi-squared test rejecting the null hypothesis that the same 15 variables tested were not intercorrelated, $X^2 = 1821.712$, $p <$

0.001. The Kaiser-Meyer-Olkin test, which evaluates whether the sampling for each variable is adequate to conduct a factor analysis, was 0.94. These are consistent with prior recommendations of a sample size of at least 100 to conduct a factor analysis.(Pearson & Mundform, 2010) I used the same questions for the factor analysis and conducted orthogonal and oblique analyses. For this sample, there was only one underlying factor that was revealed in the principal components analysis. However, to be consistent with the analysis of the older adult survey and with insight from focus group analyses, I distinguished the two dimensions—technical and interpersonal quality. Results from principal components analysis are provided in Appendix B, Table B.3. Crohnbach's alpha test of internal consistency was 0.94 for items comprising the technical dimension of perceived quality, and 0.93 for items comprising the interpersonal dimension. Results related to the technical and interpersonal quality of providers from factor analysis will be described in results from the multivariable analysis rather than described independently, since a factor score was predicted, generating an index to reflect dimension reduction.(Gorsuch, 1983)

In addition, I asked participants to report on a four-point scale ranging from *Not at all true* to *Very true*, the following prompts: *I trust that my older relative's personal doctor has the skills and training to provide care for them as they grow older*, and *I trust my older relative's personal doctor to do what's best for them*. Trust is a construct that has been shown in the literature to be related to use and perceived value health services and two important dimensions of trust in providers include trust in provider competence and in their fidelity.(Musa et al., 2009; Pevec & Pisnik, 2018; J. E. Platt, Jacobson, & Kardia, 2017; Rowe & Calnan, 2006)

Health system experiences. To understand the role of experiences with the health system in predicting caregivers' perceived value of geriatric care for their older relative, I asked participants to indicate whether their older relative had ever experienced issues with any of the following in the previous six months using "Yes" or "No": *Did not get a medication their doctor prescribed due to cost*; *Could not get to an appointment or procedure because of transportation issues*; *Did not get doctor care that they needed due to cost*; *Had problems paying their medical bills*; and *They had to count on you to pay their medical bills*. I then created a new variable that indicated whether or not participants' older relative had experienced any of these issues with the health care system, and this binary variable was included in the analysis.

Awareness of geriatrics. Finally, I asked participants to respond ("Yes" or "No") to the question: *Were you aware of what a geriatrician does prior to taking this survey?*

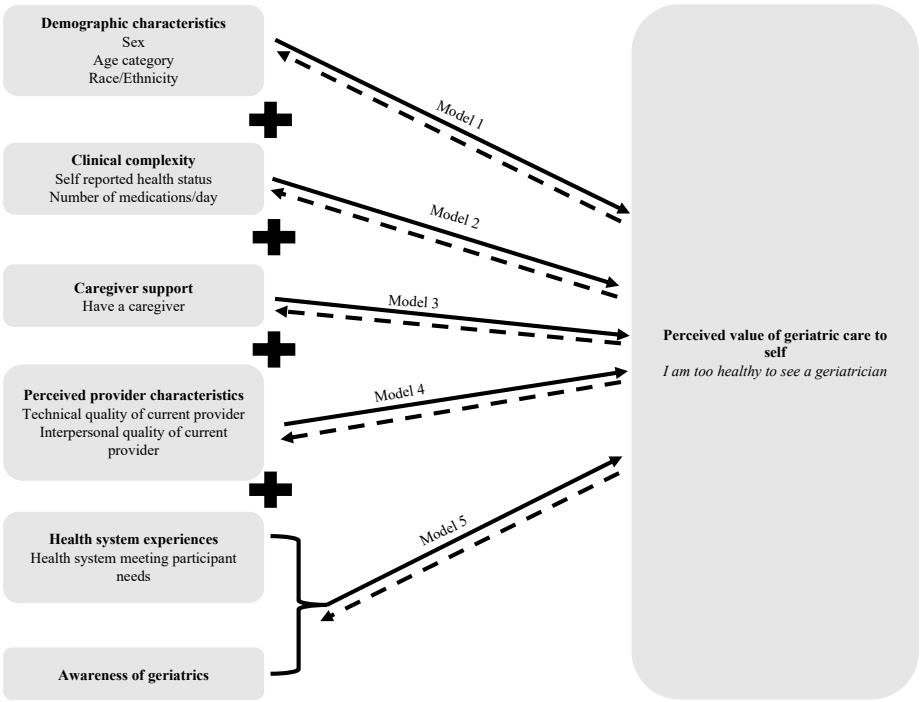
Analysis

The final survey included responses from 165 community-dwelling older adults and 153 family caregivers across the state of Michigan. My analytic plan included conducting both descriptive analyses as well as a multivariable logistic regression relating independent variables described previously, to the perceived value of geriatric care.

I conducted descriptive analyses on the full sample of older adults with complete demographic information (n=156) and for the sample of older adults with complete information for and independent variables of interest for the logistic regression (n=143). For the logistic regression examining older adults' perceived value of geriatric care, I used an analytic sample of only older adults who were not enrolled in geriatric care at the time of the survey (n=135) since

those who are enrolled in geriatric care may perceive higher value because of other factors such as loyalty that were not measured in the present analysis. I conducted hierarchical logistic regression models to examine the relationship between key characteristics and perceived value of geriatric care (Figure 3.2).

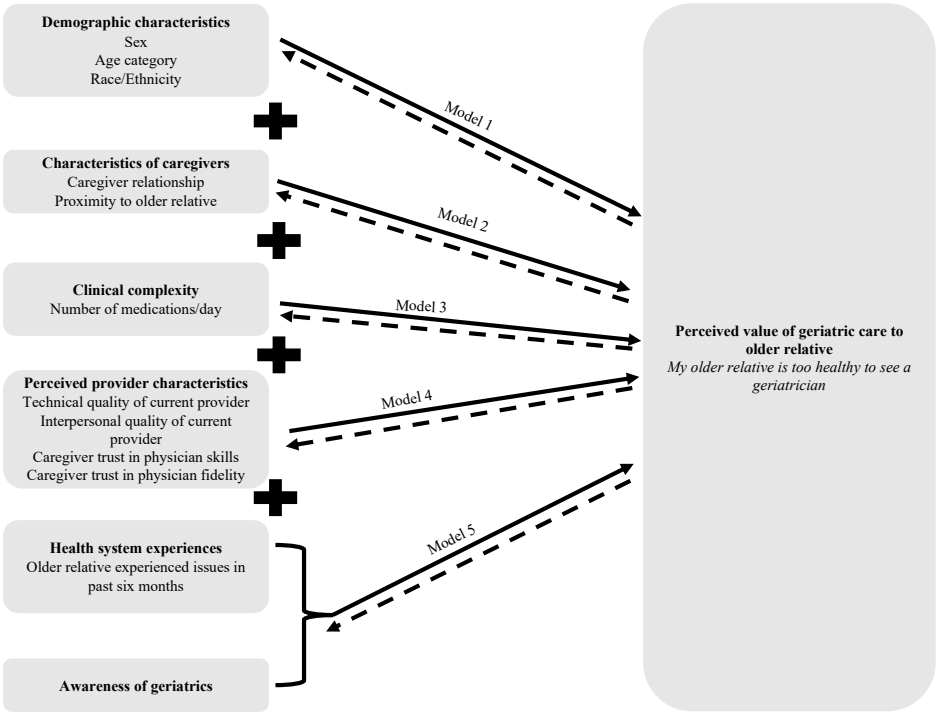
Figure 3.2. Hierarchical models examining perceived value of geriatric care among older adults (n=135)



For family caregivers, I conducted descriptive analyses on the full sample with complete demographic information (n=147). I then excluded observations with missing data for relevant variables for the multivariable logistic regression model and conducted descriptive analyses (n=139). For the logistic regression, I used this sample (n=139) which included caregivers of older adults who were enrolled in geriatric care. Since a caregiver's older relative may make

their own decision about enrolling in geriatric care, I expected that family caregivers may still have their own perceptions about the value of geriatric care that are unrelated to their older relative's actual enrollment in care. The correlation between these two variables—i.e., the perceived value to older relative and enrollment in geriatric care—was weak, though positive (r=0.03). I conducted hierarchical logistic regression models to examine the relationship between key characteristics and perceived value of geriatric care (Figure 3.3). For both analyses, I report odds ratios and consider statistical significance if $p<0.05$.

Figure 3.3. Hierarchical models examining perceived value of geriatric care among family caregivers (n=139)



Since this survey was informed by focus groups that provided me with a broader landscape of what older adults and family caregivers think are important in their care, and, to better understand some of the nuances of perspectives examined in this study, I conducted additional descriptive analyses that may inform areas for future research. Summaries of these findings are

provided in Appendix D. Specifically, for older adults I assessed duration of enrollment with current doctor for older adults and family caregivers' older relatives. I also examined reasons for not seeing a geriatrician among those not enrolled, and, descriptively analyzed caregivers' role in facilitating their older relative's care-seeking from a geriatrician. In addition, I examined prevalence of responses to other items measuring perceived value of geriatric care.

RESULTS

Older adults and family caregivers participated from across the state of Michigan. Demographic characteristics of older adults with (a) complete demographic information (n=156) and (b) complete responses for variables included in the logistic regression (n=143) are summarized in Table 3.1.

Table 3.1. Demographic characteristics of older adults with complete (a) demographic information (n=156) and (b) data for multivariable logistic regression (n=143)

	Full sample (n=156) *n (%)*	Complete responses for current analysis (n=143) *n (%)*
Age		
65-69	82 (52.6)	79 (55.2)
70-74	35 (22.4)	32 (22.4)
75+	39 (25.0)	32 (22.4)
Sex		
Female	105 (67.3)	96 (67.1)
Male	51 (32.7)	47 (32.9)
Race		
White, non-Hispanic	128 (82.1)	116 (81.1)
Not white, or Hispanic	28 (18.0)	27 (18.9)
Self reported health status		
Very poor – Good	66 (42.3)	61 (42.7)
Very good – Excellent	90 (57.7)	82 (57.3)
Number of prescription medications per day		
0-3	104 (66.7)	96 (67.1)
4 or more	52 (33.3)	47 (32.9)
Have a caregiver	46 (29.5)	40 (28.0)
See a geriatrician	10 (6.4)	8 (5.6)
Perceive they are too healthy to see a geriatrician		61 (42.7)

Just over half of older adults in the full sample were between age 65 and 69, and about two-thirds of respondents identified as female. About 58% of respondents reported being in very good to excellent health and 33% of respondents have been prescribed four or more medications per day. Almost one-third of participants have a formal or informal caregiver aside from their health care provider(s), and consistent with the Medical Expenditures Panel Survey estimate, about 6% of the full sample are enrolled in geriatric care.

Demographic characteristics of family caregivers with (a) complete demographic information (n=147) and (b) complete responses for variables included in the logistic regression (n=139) are summarized in Table 3.2.

Table 3.2. Demographic and support characteristics of family caregivers and clinical complexity of older relatives among caregivers with complete (a) demographic information (n=147) and (b) data for multivariable logistic regression (n=139)

	Full sample (n=147) *n (%)*	Complete responses for current analysis (n=139) *n (%)*
Age		
25-39	49 (33.3)	47 (33.8)
40-54	54 (36.7)	52 (37.4)
55+	44 (29.9)	40 (28.8)
Sex		
Female	125 (85.0)	119 (85.6)
Male	22 (15.0)	20 (14.4)
Race		
White, non-Hispanic	105 (71.4)	100 (71.9)
Not white, or Hispanic	42 (28.6)	39 (28.1)
Number of prescription medications per day		
0-3	53 (36.1)	48 (34.5)
4 or more	94 (64.0)	91 (65.5)
Older relative lives in same household	62 (42.2)	60 (43.2)
Relationship with older relative		
Adult child/child-in-law	92 (62.6)	88 (63.3)
Spouse/partner or other relative	55 (37.4)	51 (36.7)
Older relative enrolled in geriatric care	33 (22.5)	31 (22.3)
Responded that older relative is too healthy to see a geriatrician		16 (11.5)

About two-thirds of family caregivers in the sample were age 40 or older, and the majority of respondents identified as female. Almost two thirds of respondents were an adult child or adult child-in-law of the older adult they supported, and just under half live in the same household as their older relative. About 22% of respondents support older relatives who are enrolled in geriatric care.

Perceived characteristics of providers and health system experiences

As described earlier, results related to the technical and interpersonal quality of providers emerged from factor analysis resulting in a factor score reflecting dimension reduction. Family caregivers in the full sample had slightly higher mean trust when asked if their older relative's doctor had the skills to take care of their older relative as they grow older (mean=2.07, sd=0.95) when compared to their mean trust in their older relative's provider to do what is best for their older relative (mean=1.98, sd=0.93). Among family caregivers of older adults who are enrolled in geriatric care, mean trust in provider skills was slightly higher (mean=2.26, sd=0.93) as was mean trust in provider fidelity (mean=2.13, sd=0.92). The difference in mean trust in provider skills and provider fidelity were not statistically significant between caregivers of older adults who are and are not enrolled in geriatric care.

Almost three-quarters of older adult participants (71.3%) responded that it is fairly or very true that the health care system is meeting their needs. The majority of older adult participants (69.9%) were aware of what a geriatrician does prior to taking the survey. Over half of family caregivers (59%) responded that their older relative had experienced any issue with the health care system. Most (67.6%) were aware of what a geriatrician does prior to taking the survey.

Older adults' perceived value of geriatric care

I used complete responses from 135 older adults who were not enrolled in geriatric care at the time of the survey, with complete information for multivariable logistic regression. Table 3.3 shows results from the hierarchical logistic regression examining predictors of perceiving value of geriatrics to self. Notably, responses from participants perceiving that they are too healthy to see a geriatrician are interpreted as perceiving low value to self (Table 2.3).

Table 3.3 Odds ratios from hierarchical models estimating predictors of perceived value of geriatric care to self *among participants who are not enrolled in geriatric care* (n= 135)

	Perceived value to self (I am too healthy to see a geriatrician) OR (SE)				
	Model 1	Model 2	Model 3	Model 4	Model 5
Demographic					
Gender					
Male	Ref	Ref	Ref	Ref	Ref
Female	0.59 (0.23)	0.39 (0.17)*	0.26 (0.13)**	0.24 (0.13)**	0.17 (0.11)**
Age Category					
65-69	Ref	Ref	Ref	Ref	Ref
70-74	0.50 (0.22)	0.47 (0.23)	0.52 (0.27)	0.50 (0.26)	0.33 (0.19)
75+	0.64 (0.30)	0.61 (0.32)	1.03 (0.60)	1.07 (0.63)	0.70 (0.45)
Race/Ethnicity					
Not white, or Hispanic	Ref	Ref	Ref	Ref	Ref
White, NH	2.32 (1.21)	2.10 (1.17)	1.74 (1.03)	1.83 (1.11)	2.24 (1.49)
Clinical complexity					
Self-reported health status					
Very poor – Good		Ref	Ref	Ref	Ref
Very good – Excellent		5.09 (2.19)***	4.95 (2.24)***	4.42 (2.09)**	3.35 (1.74)*
Number of prescription medications/day					
0-3		Ref	Ref	Ref	Ref
4 or more		0.56 (0.26)	0.55 (0.27)	0.53 (0.26)	0.43 (0.24)
Caregiver support					
Have a caregiver			0.11 (0.70)***	0.14 (0.09)**	0.15 (0.09)**
Provider characteristics					
Technical quality of current provider				0.94 (0.33)	0.75 (0.30)
Interpersonal quality of current provider				1.52 (0.61)	1.41 (0.61)
Health system experiences					
Health care system meeting my needs					1.96 (0.65)*

Awareness of geriatrics					4.72 (2.86)*
Pseudo R^2	0.04	0.16	0.22	0.23	0.32

** p<0.05; **p<0.01; ***p<0.001*

Respondents with a caregiver were significantly less likely to perceive that they are too healthy to see a geriatrician (OR=0.15, p<0.01), i.e. seeing high value of geriatric care to self, while respondents reporting very good or excellent health status were significantly more likely to perceive they are too healthy to see a geriatrician (OR=3.35, p<0.05). Those who were aware of geriatrics prior to taking the survey were also more likely to perceive being too healthy to see a geriatrician (OR=2.72, p<0.05) as were those who believe the health care system is meeting their needs (OR=1.96, p<0.05). Perceiving technical quality of current provider was associated with a lower likelihood of the perception of being too healthy to see a geriatrician (OR=0.75, p=0.471) while higher interpersonal quality was associated with a higher likelihood of the perception of being too healthy to see a geriatrician (OR=1.41, p=0.426). In other words, perceiving higher technical quality of current provider was associated with perceiving high value in geriatric care, while, perceiving higher interpersonal quality was associated with perceiving low value in geriatric care. Older respondents were less likely than younger respondents to perceive they are too healthy to see a geriatrician (age 70-74, OR=0.33, p=0.054; age 75+, OR=0.70, p=0.583).

Family caregivers' perceived value of geriatric care for older relative

Family caregivers living in the same household as their older relative were significantly more likely to perceive that their older relative is too healthy to see a geriatrician (OR=6.88, p<0.05) and higher mean trust in older relative's provider's skills and fidelity were both associated with a higher likelihood of perceiving low value in geriatric care for their older relative (OR=4.37, p=0.116; OR 1.47, p=0.594, respectively). Supporting older relatives who are prescribed four or

more medications per day was associated with a significantly lower likelihood of perceiving the older relative is too healthy to benefit from geriatric care (OR=0.13, p<0.01) and perceiving higher technical quality and interpersonal quality of provider were associated with a lower likelihood of perceiving low value in geriatric care (OR=0.46, p=0.281; OR=0.82, p=0.786, respectively). Results of multivariable logistic regression models are shown in Table 3.4.

Table 3.4 Odds ratios from hierarchical models estimating predictors of perceived value of geriatric care to older relative among family caregivers of older adults (n= 139)

	Perceived value to older relative (They are too healthy to see a geriatrician) OR (SE)				
	Model 1	Model 2	Model 3	Model 4	Model 5
Demographic characteristics of caregivers					
Sex					
Male	Ref	Ref	Ref	Ref	Ref
Female	0.42 (.28)	0.48 (0.33)	0.45 (0.33)	0.49 (0.39)	0.39 (0.33)
Age Category					
25-39	Ref	Ref	Ref	Ref	Ref
40-54	4.62 (3.77)	6.63 (5.69)*	6.35 (5.79)*	7.88 (7.87)*	11.06 (12.15)*
55+	3.08 (2.69)	2.70 (2.41)	2.34 (2.21)	2.15 (2.21)	2.24 (2.43)
Race/Ethnicity					
Not white, or Hispanic	Ref	Ref	Ref	Ref	Ref
White, NH	0.66 (0.38)	0.57 (0.35)	0.41 (0.29)	0.59 (0.48)	0.54 (0.45)
Characteristics of caregiving support					
Caregiver relationship					
Adult child or child-in-law		Ref	Ref	Ref	Ref
Spouse/partner/other relative		2.22 (1.43)	2.65 (1.90)	3.08 (2.41)	3.65 (2.97)
Proximity to older adult					
Older relative lives outside of household		Ref	Ref	Ref	Ref
Older relative lives in same household		3.27 (2.01)	4.18 (2.91)*	5.68 (4.58)*	6.88 (5.77)*
Clinical complexity of older relative					
Number of prescription medications/day					
0-3			Ref	Ref	Ref
4 or more			0.12 (0.08)**	0.11 (0.09)**	0.13 (0.10)**
Provider characteristics					
Technical quality of current provider				0.53 (0.37)	0.46 (0.33)
Interpersonal quality of current provider				0.82 (0.54)	0.82 (0.58)
Mean caregiver trust in relative's doctor's skills				4.44 (4.02)*	4.37 (4.10)
Mean caregiver trust in relative's doctor's fidelity				1.37 (0.95)	1.47 (1.08)
Health system experiences					3.24 (2.80)

Older adult has experienced issues					
Awareness of geriatrics					1.23 (0.98)
Pseudo R^2	0.07	0.14	0.26	0.35	0.37

** p<0.05; **p<0.01; ***p<0.001*

Comparing older adults' and family caregivers' perceived value of geriatric care

Although the models I tested to understand perceived value of geriatric care were tailored for the type of respondent, there are a few ways to compare the perspectives of each group. For both groups, polypharmacy, or the use of multiple medications per day (four or more in this case), was associated with a higher likelihood of perceiving value in geriatric care (i.e. a lower likelihood of perceiving that the older adult or relative is too healthy to see a geriatrician). Older adults with a caregiver were also significantly less likely to perceive that they are too healthy to see a geriatrician. In contrast, however, compared with caregivers who do not live with their older relatives, those who live in the same household were significantly more like to perceive that their older relative is too healthy to see a geriatrician. Although higher perceived technical quality of current provider was associated with a higher likelihood of perceiving value in geriatric care across both groups, the relationship between perceived interpersonal quality and perceived value was different for older adults versus family caregivers. While higher interpersonal quality was associated with a lower likelihood of perceiving value in geriatric care among older adults, it was associated with a higher likelihood of perceiving value in geriatric care among family caregivers. Finally, awareness of geriatric care prior to taking the survey, across both groups, was associated with a lower likelihood of perceiving value in geriatric care.

DISCUSSION

Attempts to define the value of geriatrics have been primarily pursued from a systems perspective of quality measurement—which is challenging when providing care to a population for whom traditional outcomes measures are less relevant—and from the perspective of physicians who practice geriatric medicine.(Tinetti, 2016) In her article, Tinetti asks who is expected to benefit from geriatric care – only the oldest old, or all older adults? Only older adults with frailty and geriatric syndromes, or anyone who wants to age in a healthful way? (Burton & Solomon, 1993; Friedman, Shah, & Hall, 2015; Reuben, Zwanziger, Bradley, & Beck, 1994; Tinetti, 2016; Yoshikawa, 2012) In this study, I begin to explore some of these questions using the perspectives of older adults. I additionally include the perspectives of family caregivers whose increasing role in decision-making and health care encounters position them to also contribute to how we understand the value of geriatrics, and who are increasingly involved in making care-seeking decisions, such as, about the use of geriatric care.

In a Michigan sample, less than half of older adults and less than a quarter of family caregivers responded that they, or their older relative, are too healthy to see a geriatrician. In supplementary analyses (Appendix D) I found that less than 5% of older adults and family caregivers perceive that only someone over age 80 can benefit from geriatric care; in fact, a majority of respondents perceived that even someone under age 65 could benefit from geriatric care. This suggests first, that older adults may not be resistant to geriatrics as a field and that indeed, continuing to clarify its value and its contribution may be critical for guiding older adults and their family caregivers to use geriatric care when they may benefit from it. Second, it reflects potential for geriatricians to become more involved in regular primary care teams as they may contribute to care for older adults in a transitional capacity (i.e. from middle to older age) as well as later in life.

In this study I found that older adults with a caregiver are more likely to perceive value in geriatric care for themselves. It is possible that having a caregiver in itself signals to older adults that they are not healthy – perhaps even regardless of their health status—which influences their perception that a specialized provider could help them. In contrast, caregivers living in the same household were less likely to perceive value in geriatric care for their older relative compared to those living in a different household. It is possible that caregivers who live in the same household believe that the support they provide actually takes the place of a geriatrician. However, it is also possible that caregivers who are in close proximity to their older relatives are in greater communication with their older relative's provider(s) and are actually doing some of the coordination work, and as such, they may not perceive a need for a geriatrician.

Having a skilled, competent doctor was associated with a higher likelihood of perceiving value in geriatric care for both older adults and family caregivers. This was a surprising finding as one might expect that if a provider demonstrates technical quality—i.e. skill and competence—a patient would be less likely to see a need to switch doctors. However, as prior research has indicated mixed evidence regarding patients' ability to assess technical quality, this finding requires greater exploration. Nevertheless, it is still possible that, for example, providers who are trained in providing care to older adults—one feature of technical quality—are also better equipped to refer older adults to see a geriatrician or even to recognize their own limits in practice. In fact, recent literature emphasizes that preparing individuals to make decisions for their future needs is an essential, but often neglected, aspect of clinical care.(Creutzfeldt & Holloway, 2020)

That perceiving higher interpersonal quality is associated with lower likelihood of perceiving value in geriatric care among older adults is less surprising. Older adults may feel

satisfied in their relationship and may see a risk in having to build rapport with a new doctor. Studies have suggested that medical encounters are themselves a therapeutic intervention for older adults, and that older adults tend to stay with the same primary care physician for a long time and are tend to be more favorable when reporting on their physician's quality and are also less likely to change doctors.(Mold et al., 2004; Williams, Haskard, & DiMatteo, 2007) This notion is consistent with comments participants made in focus groups suggesting that building a relationship with a new doctor would be challenging, presenting concerns about doctors retiring, moving away, or even passing away. In my sample, more than half of participants had been with their current physician for at least five years; roughly one-quarter of the full sample had been with their current physician ten or more years (Appendix D).

For family caregivers, interpersonal quality may function in a similar way as technical quality. Interpersonal quality included measures examining, for example, the extent to which older relatives' doctor respects them, listens, and explains things in a way they can understand. These features of shared decision making may increase perceived value and consideration of geriatric care among family caregivers. That awareness of geriatrics prior to taking the survey was associated with a lower likelihood of perceiving value in the service was striking. There are multiple explanations for this finding. First, it is possible that those with a prior awareness of geriatrics responded to questions about the value of geriatric care by drawing upon the definition I provided in the survey along with the information they had about geriatrics prior to taking the survey—their previous understanding of geriatrics was not assessed in this survey. Thus, it is possible that for example, participants were comparing themselves to friends who see a geriatrician and are more clinically complex; or, to educational materials they have seen about geriatrics that emphasize its value to individuals with MCC or cognitive impairment. Thus,

perceived value could have been influenced by how the value of geriatrics has been conveyed or communicated by the health care system. This suggests that educational materials for older adults and their family caregivers must not lead older adults to compare themselves to others who are using the service, when in fact, geriatrics is meant to be an individualized approach to care.

Implications for theory and areas for future research

This study suggests that perceived value may be studied prospectively – that is, the perceived value of a service need not be studied only if that service has been used. Although the tradeoffs participants made—i.e., the perceived sacrifice or investment of seeing a geriatrician—is not explicitly measured, we can still gain insight into the benefit that older adults and family caregivers may anticipate as they think about geriatric care as a service they might use someday. Future explanatory studies may seek to understand what older adults expect to be sacrifices if they enroll in geriatric care—based on prior literature, some of these sacrifices might include the disruption of a long-standing relationship with a primary care physician, or, a sacrifice in the belief itself that one is too healthy to see a geriatrician. Accepting or expecting that one is no longer "healthy" can itself be a tremendous loss.

This study informs several areas for future research and provides preliminary information for developing a survey that can be fielded nationally. First, there is a need for examining perceived value in multiple ways – first, to oneself, but also, to others, for example by using vignettes such as those described in Chapter 2 along with observational surveys like the one developed for this study. Notably, most studies consider perceived value in terms of a service that one has already invested in; since utilization of geriatric care is low, there is a need to continue developing theoretical frameworks for understanding and measuring anticipated perceived value of a service.

More broadly, there is a need for continuing to examining ways to measure quality of care for older adults—and how to include family caregiver perspectives—in order to begin to understand how geriatric care may contribute to improved quality of care from older adult and family caregiver perspectives. In Chapter 2, I sought to understand what patient-centeredness means to older adults and family caregivers, and in this study, I identified how various health care experiences and health and social circumstances may related to the perceived value of geriatric care. Yet future research should continue to examine how older adults make decisions about actually seeking and using geriatric care to better understand how perceived characteristics of providers along with perceived anticipated value of a service may inform utilization of geriatric care.

There is a need for future research to continue examining the perspectives of family caregivers, both exclusively as well as in dyads with their older relatives.(Riffin et al., 2018; Rivera, Soderstrom, & Uzzi, 2010) Dyadic research has been limited to date, but as family caregivers are increasingly involved in decision-making in the clinical context, we need to better understand how they make decisions with their older relatives. For example, what is their role in facilitating use of geriatric services? How does use of geriatric care influence family caregivers in their supportive activities outside of the health care context? Does geriatric care actually support family caregivers in their own health maintenance?(Wittenberg et al., 2019)

Implications for practice and policy

Geriatrics, as a field, has the opportunity to clarify its value not only from the perspective of providers, but also from the perspective of older adults and family caregivers who may consider and ultimately benefit from geriatric care. Robust evidence demonstrates clinical, evaluated

value of geriatric care for older adults; in this study, I find that older adults and family caregivers of older relatives also perceive value in geriatric care.(Butler, 1974; Collard, Bachman, & Beatrice, 1985; Hogan et al., 1987; Prestmo, Hagen, Sletvold, Helbostad, & Thingstad, 2015) I find that while measures of clinical complexity and social support are important predictors of the perceived value of geriatric care, perceived characteristics of providers are also important. Alongside educational materials to help older adults make decisions about geriatric care alone or with their caregivers, non-geriatrician physicians can also provide information to their older patients and integrate family caregivers into patient-centered and family-centered conversations that will ultimately become partnerships as they make care decisions together. In fact, perhaps physicians should have conversations with older adults and their family caregivers discussing the value of geriatric care to older adults in general and identifying the ways in which it may be beneficial for individual patients.

That older adults and family caregivers perceive value in geriatric care suggests that with increased awareness of the field both inside and outside of the clinical setting, demand for geriatric care may increase in the future as is consistent with simulated models of projected need for geriatricians.(The American Geriatrics Society, 2017) As will be studied in depth in Chapter 4, it is possible that with increasing demand for geriatric care, interest in the profession among trainees may also increase. Further, with the high cost of long-term care and the preference of older adults to age in place in their communities, the public may begin to recognize geriatric care as an avenue for supporting older adults as well as the family caregivers who support them. Policymakers may consider the possibility of incentivizing the health care workforce such as through loan forgiveness programs to generate a sustainable geriatrics workforce.(Collins & Casey, 2019; E. Flaherty & Bartels, 2019) They should also consider increasing support to

institutions for interprofessional training in order to ensure that other professionals such as nurses and social workers can support older adults and family caregivers in navigating the health care system and in addressing other social determinants of health such as transportation and independent living.(Mohler et al., 2014)

Although this study did not examine perceived value of geriatric care from dyadic perspectives, with more research in this area and continued exploration of how caregivers envision and practice their involvement in their older relative's care and decision-making, we can begin to develop policies for integrating family caregivers formally into health care teams. Family caregivers—particularly those who live in the same household as their relative or frequently interact with them—are optimally positioned to supplement formal medical care. Their observations can provide tremendous insights into their older relatives' needs and concerns that older adults may not express to their health care providers or even realize on their own. For example, policymakers should consider the possibility and implications of standardizing policies to give family caregivers access to their older relative's medical record so that caregivers can use this information, along with their own observations and insights, to determine whether their older relative could benefit from geriatric care.(Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013; J. L. Wolff, Darer, & Larsen, 2016)

If findings from this study, which indicate that a substantial proportion of older adults perceive value in geriatric care, reflect anticipated future demand for geriatric care, then there is subsequently a need to ensure that there is a sufficient workforce equipped to provide this specialized care. Here, I find that non-geriatrician physicians may have a critical role in influencing how older adults perceive value in geriatric care—both in terms of their technical and interpersonal quality which also encompasses their provision of information to patients. This

means that non-geriatrician physicians must also be well equipped to guide their older patients in making optimal decisions about care-seeking, for example, from geriatricians, which requires sufficient understanding of the field and its potential benefits to patients. In addition, it requires physicians to have insight into whether they are equipped to provide patient-centered care to their older patients given their growing patient panels. A primary care physician may perceive risk in losing patients by referring older patients to see a geriatrician. There is a need for medical training to ensure that physicians are insightful and reflective in determining whether the extent of their training enables them to provide high quality care for their older patients.

Limitations

This was a cross-sectional study asking older adults and family caregivers to express their perceived value of geriatric care given their health, health care, and social circumstances at the time of survey participation. As such, there is no way of determining causality between experiences and circumstances, and perceived value of geriatric care. There is also no way to know whether perceived value relates to actual future use of geriatric care—however, this is an expected area of future study, for example using a longitudinal study design. In addition, although individuals from across the state of Michigan participated, this study only reflects the perspectives of older adults and family caregivers in one state. There are multiple geriatrics clinics in southeastern Michigan, and so, awareness of geriatrics may be higher in this sample than in a national sample. Similarly, this was a fairly healthy sample of older adults and for the purpose of this study, I did not ask family caregivers to specify the health conditions of their older relatives and I cannot assume that having a caregiver implies poorer health status of the care recipient. In these ways, the sample is not necessarily generalizable, but suggests the need

for a larger nationally representative survey. In addition, older adults who participated in the survey lived in the community— i.e., not in long term care facilities. The perceived value of geriatrics may be different among older adults who require greater assistance or are residing in a facility that may make them feel that they are not independent. Finally, only about 12% of family caregivers responded that their older relative is too healthy to see a geriatrician. Although the logistic regression sought to understand variation in the perceived value of geriatric care, the much smaller sample may have led to inaccurate estimates of the likelihood of perceiving value of geriatric care. In the future, I plan to field this study using a nationally representative sample to minimize this limitation as well as potential limitations in generalizability of findings.

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Chapter 4

Influence of Cultural, Social, and Learning Entities on Trainees and Implications for Geriatric Medicine

INTRODUCTION

In order to fulfill the increasing population of older adults in the U.S., an additional 30,000 geriatricians will need to be trained by 2030.(The American Geriatrics Society, 2017) Despite the establishment of the Institute of Medicine (IOM) ad hoc Committee on the Future Health Care Workforce for Older Americans in 2007, there is little evidence that physician trainees are selecting geriatric medicine (GM) as a subspecialty.(Herdman et al., 2007) GM was first funded as a fellowship program in the 1970s followed by the inception of 36 programs in 1980.(Warshaw, Bragg, Shaull, Goldenhar, & Lindsell, 2003) The number of programs has continued to grow with 148 programs currently offering 419 fellowship positions. Yet, less than half of these positions were filled in 2016.(National Resident Matching Program, 2016) As a result, geriatric care is being provided primarily to older adults over 85 exhibiting frailty, geriatric syndromes, severe functional impairment, and clinical complexity, even when such care or early consultations may be beneficial for many more individuals between 65 and 85 years.(Warshaw, Bragg, Fried, & Hall, 2008) To ensure a sufficient and well-trained workforce to provide care for older adults, there is a need to understand how medical trainees think about geriatric care and how the institutions within which they are embedded may inform their interest in, and perceived value of the field.

BACKGROUND

Following medical school, trainees interested in primary care may pursue family medicine or internal medicine. Physicians trained in family medicine are equipped to provide care "from cradle to grave" and internal medicine physicians are trained to provide care to all adults over the age of 18. After completing residency training, typically for three years, trainees may commence fellowship training in a subspecialty of their choice. Subspecialty training could be disease or organ focused (e.g. cardiology) or population focused (e.g. pediatrics, geriatrics). In the 2006-2007 cohort of graduating medical residents, roughly 51% of IM residents continued to a subspecialty program, while just under 7% of FM residents continued on to a subspecialty program.(Byrne, Holt, Richter, Miller, & Nasca, 2010)

In 2018 the three most popular fellowship positions from internal medicine residency (i.e. those with the biggest volume of applicants per number of positions available) were cardiovascular disease, pulmonary disease and critical care medicine, and hematology and oncology; primary care was the least popular.(Murphy, 2018) Geriatric medicine is considered a subspecialty in the U.S. but has features of primary care (i.e. non-procedural, unlike most other subspecialties), yet trainee interest in the field resembles that of trainee interest in general primary care. Further, compensation for geriatricians remains lower than that of general internal medicine and family medicine physicians.(Bensadon et al., 2013; Fitzgerald, Wray, Halter, Williams, & Supiano, 2003; Golden, Xu, Wan, & Issenberg, 2017) Efforts to increase the geriatric workforce have taken many forms over the past few decades.

Studies from the early 2000s found that incoming medical students had minimal knowledge about aging and low interest in geriatric medicine with the exception of students who had cared for older adults; another study found that medical students, residents, and fellows

demonstrated positive attitudes towards geriatric patients, but only acquired knowledge about the specialty during residency(Fitzgerald et al., 2003; Kishimoto, Nagoshi, Williams, Masaki, & Blanchette, 2005). Minimum core competencies were developed for GM in 2008.(Leipzig et al., 2009; Lu, Hoffman, Hosokawa, Gray, & Zweig, 2000; Meiboom, de Vries, Hertogh, & Scheele, 2015) Subsequently, a longitudinal assessment of medical students found that a knowledge-based curriculum alone may not be as effective as empathy-building curricula at improving attitudes toward geriatric medicine.(De Biasio, Parkas, & Soriano, 2016; Leipzig et al., 2009). In recent years medical programs have increased mentorship capacity, emphasis on interprofessional learning, and have developed curricula that include oral history, narrative medicine, and dementia simulation modules to foster empathy and understanding of the aging experience. (Bensadon et al., 2013; Cravens, Campbell, & Mehr, 2000; McCrystle et al., 2010; Ni Chroinin et al., 2013; Schapmire et al., 2018; Smith & Cheng, 2018)

Health care professionals' reluctance to work with older adults as geriatricians additionally stems from perceived lack of compensation for the amount of additional training required and level of complexity and perceived challenges of providing care to older adults with MCC. Nurse practitioners have a net career earning over a lifetime comparable to that of geriatricians with shorter and less financially burdensome training which may explain the tendency of medical students' interest towards more lucrative medical specialties despite high career satisfaction among geriatricians.(Golden et al., 2017; Leigh, Tancredi, & Kravitz, 2009; Leigh, Tancredi, & Jerant, 2012; Shah, Aung, & Chan, 2006) In fact, studies using discrete choice experiments (DCE) and surveys have found that financial incentives influence specialty choice, with students even hypothetically choosing primary care if provided a financial incentive.(DeZee et al., 2011; Fitzgerald et al., 2003; Meiboom et al., 2015; Thornton, 2000)

While most programs to increase interest and competencies in geriatric medicine have involved curriculum development, leaders in geriatric medicine have advocated for broader policy changes—primarily in terms of changing the compensation and financial incentives for geriatricians.

In recent years, policies have considered incentivizing trainees to pursue geriatric medicine as well as improving institutional capacity to train physicians. In 2005, South Carolina passed the first bill nationally to forgive medical school loans for physicians pursuing geriatrics via the Geriatric Loan Forgiveness Program.(AARP, 2010) While other states have implemented similar policies, the programs are typically only applicable to states with health professional shortage areas (HPSAs); in the case of geriatrics, this is most of the country. As such, there is limited evidence demonstrating that these programs have been successful in generating interest in geriatrics. More recently, Senators Susan Collins (R-ME) and Bob Casey (D-PA) introduced the Geriatrics Workforce Improvement Act as a bipartisan legislation to increase the number of geriatric health professionals in two ways. First, it would support career development of individual junior faculty in geriatrics, and second, it would provide resources for transforming clinical training environments, integrating geriatrics approaches into other subspecialty training to foster interprofessional training, and support the training of non-geriatrics faculty who provide mentorship to trainees. (Collins & Casey, 2019; E. Flaherty & Bartels, 2019) While the progress of this legislation is unclear, its emphasis on developing the capacity for institutions to provide robust geriatrics training suggests that institutions may have a critical role in transforming the workforce, and that policymakers have an interest in the support and development of institutions to generate a sustainable geriatrics workforce.

THEORETICAL BACKGROUND

The case of geriatrics has been explored to a greater extent via surveys of medical trainees and physicians and cross sectional evaluations of institutional curricula, with little in-depth examination and comparison across medical training programs.(Bensadon et al., 2013; Fitzgerald et al., 2003; McCrystle et al., 2010) Institutional theory posits that a practice is "institutionalized" when it is widely accepted and enduring.(Zucker, 1987) Geriatrics is a young field of medicine; yet due to rapid population aging, institutions are at a crossroads of deciding whether to close down their geriatrics programs, combine with other units (e.g. palliative care), or to continue investing resources with anticipation that there will be more interest over time. While there is a possibility that the government will support such efforts via legislation such as the Geriatrics Workforce Improvement Act, the realization of these policies may take longer than the amount of time available to ensure that high quality care is available to older adults today.

Members of professional organizations such as the American Geriatrics Society suggest that the value of geriatrics as a field needs to be clarified in order for it to become sustainable.(Tinetti, 2016) While DiMaggio and Powell (1983) suggest that ambiguity in organizational goals leads to mimesis of successful organizations, in the case of geriatrics programs, limited research has sought to articulate how a "successful institution" looks, functions, and influences trainees.(DiMaggio & Powell, 1983) In fact, ambiguity in defining geriatric medicine could lead to evolution of geriatric medicine programs that begin to resemble primary care programs or palliative medicine programs to the possible detriment of both fields. For example, if geriatric medicine departments begin to function like palliative medicine departments, palliative medicine is at risk for evolving to focus on older adults when tenets of palliative medicine actually apply to all ages. While geriatric medicine could certainly benefit

from palliative care approaches—just as many other specialties may benefit from geriatric medicine approaches—there is a pressing need to first explicate the value of geriatric medicine on its own, and to identify what it looks like when successful within a medical institution.

Further, medicine as a broad field is highly professionalized—in fact medical trainees' rankings of prestige of various medical specialties is consistent with perceptions of practicing physicians despite the stark differential in experience, suggesting potential passage of values and norms of medicine through the learning environment.(Creed, Searle, & Rogers, 2010) For example, studies show that trainees who choose primary care, for example, are less interested in prestige—the relationship between interest in prestige and geriatrics is less known.(Bennett et al., 2010) Primary care, which also faces a workforce shortage, is expected to undertake the role of geriatricians in the circumstance that the geriatrics workforce shortage persists; yet the two fields are distinguished not only by the population served, but also by the skills needed to serve the older population. Little is known about how socialization and social support both outside of and within training environments influences trainee understanding of how work in geriatrics is distinct from other medical fields, and further, how these processes vary across institutions and influence perceptions of prestige.(DiMaggio & Powell, 1983) For geriatric medicine as a field to become enduring, institutional norms around geriatric care and the professional value of geriatricians should be consistent.

Moreover, we need a better understanding of institutions influence professional identity formation and meaning from work, which may also be related to trainee consideration of geriatrics.(Rodriguez et al., 2014; Sarangi & Roberts, 1999) According to Roberts (2005), professional image is constructed to demonstrate capabilities in the skill-based and social demands of one's job; this in turn builds one's reputation and legitimacy.(Roberts, 2005)

Professional image and professional identity are thus related, wherein image—which may be demonstrated—may then be passed along through social interactions, generating ideas about the responsibilities and tasks that a professional should accomplish to fit their role.(Rodriguez et al., 2014; Sarangi & Roberts, 1999) In the case of geriatrics, little is known about how those with an interest in geriatrics describe their professional identity and the role of institutions in this process. Further, little is known about how professional identity among those with an interest in geriatrics compares with professional identity of physicians who are not interested in geriatrics.

Medical training institutions not only expose students to curricula and experiences that shape their understanding of medicine and subspecialty interests, but they also represent a learning environment within which trainees are embedded and immersed for multiple years. The cultural (e.g. personal background) and social structures (e.g. family and peer) that trainees are embedded in prior to and during their medical training are also influence career decisions.(Hodkinson & Sparkes, 1997) These entities individually and in combination contribute to development of beliefs, values, identity, and perception of risks and benefits that ultimately guide career decision-making—for example including subspecialty decisions within the medical profession.(Banks et al., 1992; Bourdieu & Wacquant, 1992; Ginsberg, Ginsberg, Axelrad, & Herma, 1951; Krumboltz, 1979; McNeill, 1990; Osipow, 1990; Super, 1980; Zheng, Hall, Dugan, Kidd, & Levine, 2002)

In this study, I draw upon Hodkinson and Sparkes' (1997) framework of career decision-making to guide a qualitative exploration of how personal background, peer and social support, and institutional characteristics are related to professional identity, meaning from work, and interest in geriatrics. While I explore relationships between all three of these entities and interest in geriatrics, I select three institutional cases to focus on how institutional characteristics in

particular may be related to professional identity, meaning from work, and interest in geriatrics. This study contributes to the literature on institutional theory by using a case of medical specialty that faces tremendous societal pressure to expand its capacity, but whose sustainability may actually require it to differentiate itself from other fields. Moreover, by selecting three cases that are prestigious based on rankings, this study seeks to expand upon traditional institutional approaches to evaluating institutional "success". This is particularly important for other medical training institutions which may use highly ranked programs as role models to develop their own programs; with deeper insight into the processes—such as transfer of geriatrics values and norms to trainees—I expect that findings from this study can also guide the development and enhancement of programs that are at risk for closing fellowship positions.(Selznick, 1996)

METHODS

I conducted semi-structured interviews with internal medicine residents at three institutions to understand how personal background, peer and social support, and institutional characteristics influence their consideration of or interest in GM.(Brooks, Singer, Rosenthal, Chien, & Peters, 2017) I focused on internal medicine residents as residents in different specialties continue with subspecialty training at different rates. For example, in the 2006-2007 cohort of graduating medical residents, about 51% of internal medicine residents continued to a subspecialty program, while less than 10% of family medicine residents continued on to a subspecialty program.(Byrne et al., 2010) Since the study objective was to learn more about subspecialty selection, I focused on the internal medicine residency context.

In addition, I conducted interviews with geriatrics fellows and asked them to reflect on factors that influenced their decision to specialize in GM as an approach to validating findings from interviews with residents.

Context

I selected institutions with both allopathic internal medicine and geriatrics fellowship programs based on (1) prestige and (2) filled fellowship positions in GM, as these institutions may have resources to generate interest or recruit in geriatrics, and may also serve as role models for other institutions.(Zucker, 1987)

To assess *prestige*, I identified hospitals ranked in the top ten positions for "Adult Geriatrics Hospitals" based on the U.S. News & World Report (2018) Best Hospital rankings. ("Best Hospitals for Geriatrics," 2016) Rankings indicate excellence in treating complex patients within specialties and are a valued criterion among students in medicine to assess reputation and performance, likelihood of exposure to complex patients, and mentorship from experienced physicians.(Bitektine, 2011; Creed et al., 2010; Hall, 1992; Morphew & Swanson, 2011; Olmsted et al., 2017; Washington & Zajac, 2005)

Next, I used the National Resident Matching Program's Fellowship Match Data and Reports to identify schools that filled a majority of available geriatrics fellowship positions, signaling availability of resources (e.g., mentorship, clerkship opportunities) to support geriatrics fellows. I selected institutions that had filled more than 50% of their total available positions from 2014-2018.(National Resident Matching Program, 2016) Seven institutions met both selection criteria. I then contacted institutions individually to seek permission to conduct interviews. Two institutions did not respond via email or phone, and the other two institutions

apologetically explained that their residents are involved in too many time-consuming studies. One of these institutions has been very successful at filling geriatrics fellowship positions; however, it was somewhat surprising that the other institution did not participate as it seemed that they were struggling to fill positions. The three institutions that agreed to participate were actually interested in learning about findings from the study in order to improve their programs. The final sample thus included three geographically representative institutions (east coast, west coast, and Midwest).

Participants

I used multiple approaches to recruit residents. First, the chief resident of the internal medicine program at each institution sent an email to residents describing our interest in interviewing residents both with and without an interest in geriatrics. At Institution 1, 144 second- and third-year residents were contacted; 82 second- and third- year residents were contacted at Institution 2; and 54 first, second- and third- year residents were contacted at Institution 3.

At the first two institutions, no residents with an interest in geriatrics responded to the initial email. Therefore, I used a snowball sampling approach and asked residents who participated in the interview to suggest other residents with an interest in geriatrics. I verified that only one resident had expressed an interest in geriatrics at each institution with program coordinators and subsequently emailed and recruited these residents. At Institution 3, one resident emailed other residents with an interest in geriatrics who subsequently expressed an interest in participating. I directly emailed all eight geriatrics fellows who were training in the three institutions, and all eight agreed to participate. Although the low number of residents interested in geriatrics was surprising, it is reflective of the broader geriatrics workforce

shortage. I recruited with the intention of interviewing until saturation; i.e. once no new themes were emerging from the interviews. I also concluded interviews once the responses from interviewees were consistent across our full sample (i.e. among those without an interest, and among those with an interest also validated by responses from fellows).(Fusch & Ness, 2015; Guest, Bunce, & Johnson, 2006)

Procedure

I conducted in-depth, semi-structured qualitative interviews on-site at two institutions and via videoconferencing at the third. I developed an interview protocol (Appendix C Figure C.3) that covered five topics informed by the sociological framework of careership, or career decision-making, that proposes the role of cultural, social, and learning entities on career decisions.(Hodkinson & Sparkes, 1997) The five topics included: (1) journey to becoming a physician (i.e. early experiences and exposures to medicine); (2) experiences in current training program; (3) long-term career aspirations; (4) identity and meaning in medicine; (5) conceptualization of geriatrics and ideas for programs, policy, and society to generate interest in GM. Participants completed a demographics survey at the end of the interview. Interviews were 30-45 minutes in length and participants were compensated with a $35 gift card. The compensation amount was determined based on conversations with other researchers who had conducted interviews with medical trainees, as well as with chief residents of programs. I recorded interviews with permission from participants after providing standard information about confidentiality and anonymity.

Analysis

All interviews were transcribed professionally by Rev, and were coded using MAXQDA. I conducted a narrative analysis, which is a qualitative approach to interpreting the stories and experiences that participants narrate.(Feldman, Skoldberg, Brown, & Horner, 2004) Specifically, I asked participants about their personal background, social and peer support, and institutional characteristics to understand the contexts they are embedded in. I asked participants to discuss their professional identity and meaning from work, and to explain who or what influenced their conceptualization of identity and meaning. Participants were aware that the interview was being conducted to learn more about geriatric medicine and how to generate interest in the field. Since I asked about geriatric medicine specifically at the end of the interview, participants were able to reflect on previous topics discussed (i.e. personal background, peer and social support, and institutional characteristics) when responding to semi-structured questions about their perceptions of geriatric care and its value. By this point in the interview, participants had also become comfortable with the interview process which led to rich discussion conducive to a thorough narrative analysis.

RESULTS

A total of 15 IM residents and 8 current geriatrics fellows participated in this study seeking to understand how medical trainees think about GM. While personal background influenced exposure to older adults, peer and social support and characteristics of the institution in which participants were training influenced their professional identity and their meaning from work. Table 4.1 summarizes demographic characteristics of participants by institution along with their interest in geriatrics. The majority of residents interviewed at Institution 3 were interested in geriatrics; most residents at the other two institutions were not considering GM for fellowship.

Responses from geriatrics fellows were consistent with responses from residents with an interest in geriatrics, which suggests that the personal, social, and institutional characteristics that residents are experiencing were similarly salient and formative for geriatrics fellows during their own residency training.

Table 4.1 Demographic, personal, and professional characteristics of participants

	Institution 1 (n = 6)	**Institution 2 (n = 7)**	**Institution 3 (n = 10)**
Trainee Category			
Interested in geriatrics	1	1	6
Not interested in geriatrics	3	3	1
Geriatrics Fellows	2	3	3
Sex			
Female	2	4	9
Male	4	3	1
Age range	27-31	26-33	27-32
Exposure to grandparents	6	6	9

Personal characteristics

Participants with an interest in geriatrics in particular described, unprompted, that they had either grown up in a household in which their grandparents lived for at least a year or had provided unpaid support to their grandparents (e.g., during college). Many participants without an interest in geriatrics also mentioned that they had met or visited their grandparents during their childhood; however, these comments were only made after the interviewer asked.

Participants attributed their interest in medicine to either having close relatives who were physicians, a primary care physician of their own in whom they found inspiration and mentorship, or, a love for science. Many participants had volunteered in nursing homes, but most were overwhelmed by the complexity of nursing home residents and were turned away from

geriatrics. Only one participant who is planning to pursue geriatrics attributed this experience to her interest:

> *People say, "I want to help people," but there's so much that you can do beyond just [medicine]. So... I actually took four years off... Half of the time I was working with kids with autism... And then the other half, I volunteered at a nursing home. That's when I recognized my love for geriatrics, maybe even before I realized why I want to go into medicine… I realized that I wanted to reach people's disease. I want to help make them whole again… to make them better in terms of their physical health, their emotional health. That, not a lot of other professions are able to do or have the opportunity to do… I just remember looking forward to going there every single day and it's because of the people that I got to take care of.*

Participants doing their residency at Institution 3 had found mentors or early training opportunities at the institution with a focus on geriatrics and thus had entered residency with the intention of pursuing or at least considering geriatrics. Two participants Institution 3 said that they were pursuing geriatrics as a fellowship because it would be advantageous in caring for older adults in any setting and was a shorter program than other subspecialties.

Peers and social support characteristics

Participants felt their relatives supported their subspecialty interests and decisions. Residents considering geriatrics and fellows added that many of their relatives (e.g. parents) were excited that the participant would be able care for them as they age. Participants with parents who are physicians in other specialties recalled their parents initially expressing concerns about prestige

and sustainability of work-life balance; however, their parents eventually recognized the immense need for quality clinical care for older adults. Although those without an interest in geriatrics did not hypothesize their relatives' thoughts about geriatrics, many expressed that their relatives were delighted that they were pursuing medicine at all and that specialty would not make a difference.

Most participants interested in geriatrics—both residents and fellows— recognized a salient lack of support from colleagues and peers in their programs, and sometimes even from physician mentors in other specialties—particularly at Institution 1 and Institution 2. For example, participants would describe others making comments such as *"Wow, good for you, I would never want to do that but it's great that you do"* or *"Why do you want to do that?"* or *"We all do geriatrics because we all see older patients"* or even, *"Won't that be depressing?"*. In fact, participants who were not interested in geriatrics made similar comments expressing their apprehension towards the subspecialty during interviews. Participants pursuing geriatrics sensed this reluctant enthusiasm when their colleagues would say—seemingly more genuinely—*"That's awesome!"* to a peer pursuing another specialty such as cardiology, and then would have little to say about geriatrics. Only one participant briefly considered another specialty after hearing these comments. Most were not deterred despite feeling misunderstood, judged, and less supported by their social networks. In fact, participants described geriatrics as their "calling" and geriatrician as their "role" despite social challenges and perceptions.

At Institution 3, a higher number of residents were interested in geriatrics and pursuing geriatrics was actually seen as a norm, despite having similar experiences of limited support at their prior training institutions. As a result, participants at this institution felt more supported, or at least, understood, by peers. Thus, it became clear that peer support was driven in part by

institutional characteristics, further validating the critical role of the institution in generating interest in geriatrics.

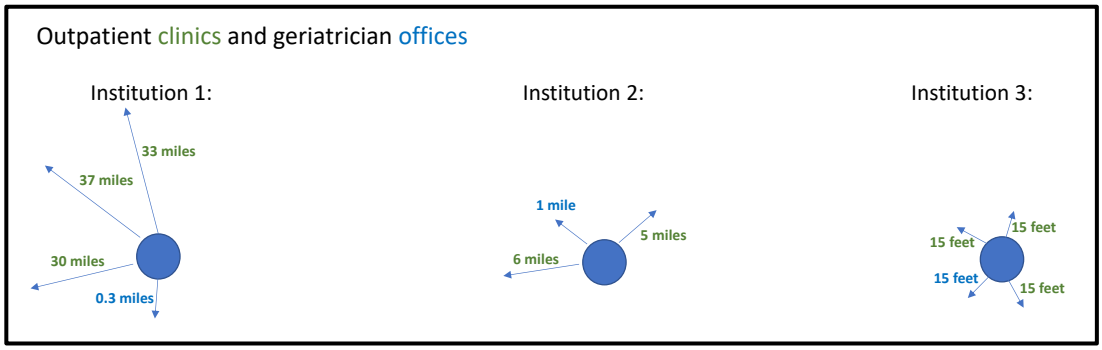
Institutional characteristics

Trainees described proximity and presence of geriatricians as well as prestige of geriatrics as being influential institutional characteristics with regard to generating interest in geriatrics. They also related these characteristics to the extent of peer support they received.

Proximity

At Institutions 1 and 2, the geriatrics rotation in residency primarily occurs in the inpatient setting. Participants explained that the patients they typically see in the hospital during the geriatrics rotation are very complex. As one fellow humorously reflected, *"We only deal with the train-wrecks in the hospital"*. They surmised that having the geriatrics rotation in the outpatient setting might expose trainees to a more balanced panel of older patients rather than exclusively seeing complex older patients. In these same institutions, geriatrics clinics and geriatricians' offices were primarily located off campus from other hospital and medical training facilities. In contrast, at Institution 3, geriatricians' offices are located within the same facility as other primary care training programs in a facility that is close to outpatient clinics. As a result, geriatricians at Institution 3 were also much more involved as leaders and mentors to trainees with varying specialty interests. Even residents without an exclusive interest in geriatrics at this particular institution felt that they had learned lessons from geriatricians that had made them comfortable and appreciative of the geriatrics approach to medicine. Figure 4.1 illustrates the physical distance between the main hospital campus where trainees spend the majority of their time and the geriatrics clinics and offices for each respective institution.

Figure 4.1 Proximity to geriatrics clinics and geriatricians



Presence

Presence of geriatricians also informed time of exposure to geriatrics. In two institutions geriatrics was introduced as a specific rotation during a specified time period; in the third, geriatrics was embedded throughout the training program because of ongoing involvement of geriatricians including in rounds for patients who were not necessarily older adults. All participants agreed that earlier exposure to geriatrics would be beneficial, fostering confidence when seeing older patients in other contexts such as cardiology. Participants also noted the importance of presence of geriatrics fellows serving as role models and mentors; fellows may be in the same age group and have similar training experiences as the residents and can offer a perspective that residents trust. Fellow responses aligned with these observations, describing that they recognize the value of having mentors and role models within geriatrics available, and themselves wanted to serve as mentors to current residents.

Prestige

Finally, prestige emerged as an additional theme that participants believed influenced their colleagues' lack of enthusiasm regarding geriatrics, but that could be modified by institutions and could subsequently strengthen peer support. Participants seemed to discuss ways

of conceptualizing prestige of a subspecialty—its perceived value to medical practice, its complexity, and the level of compensation.

For example, one participant explained that physician faculty from other specialties would comment that *"everyone does what geriatricians do without requiring additional training"*, creating skepticism around its value in medicine to new trainees. Some participants discussed that the medical school curriculum also emphasizes the value of acquiring depth of knowledge (e.g. specific organ systems or *"body parts"*) while neglecting the value of breadth. One participant explained that the first sessions of medical school involved learning about organ systems, and a later, much shorter section, covered activities of daily living and the health system. During coursework, the latter topics appeared simple; but when caring for an older patient with multiple conditions embedded within multiple fragmented systems (health, social, economic, family), the complexity was overwhelming. The transition from learning about *body parts* to *bodies* and *humans* appeared simple but was daunting in practice. Geriatricians were not seen as practicing prestigious medicine despite their breadth of knowledge and engagement with different types of complexity, and residents without an interest in geriatrics varied in their understanding of what geriatricians do across institutions. While residents without an interest in geriatrics at one institution speculated that the complexity of geriatrics may make it more challenging and thus more prestigious, others surmised that the perceived lack of complexity may lead to the compromise of prestige. Residents at another institution speculated that the salary or shorter duration of the geriatrics fellowship may reflect its differential prestige.

Prestige was also described in relation to compensation or financial incentives. Participants agreed that financial incentives and salary are a reflection of prestige, and are informed by perception of required skill and value. When discussing incentives such as loan

forgiveness programs, participants with an interest in geriatrics said that salary or financial incentives did not seem to be a barrier to their interest. They felt that trainees who want to pursue geriatrics will do it no matter the financial incentive, but that there are opportunities to attract others to geriatrics using financial incentives supplemented with more exposure to the specialty:

> *I think to some extent people just know that they don't want to work with that population. But I think people say that also about primary care generally. I would say, sure, there's going to be some people that you can draw no matter what. But just from my own experience… certainly [among] my colleagues… lifestyle and money have a huge draw... many of our highest test scores for instance are going to fields like dermatology. You're telling me that our 'brightest minds' are looking at acne all day or doing cosmetic procedures. That seems like a massive waste of human resources. So I think changing the incentive structure would draw people. Not all of them but more of them."*

Those who were not interested in geriatrics reflected that they themselves would not pursue geriatrics even if there were financial incentives. They explained that financial incentives would likely only generate interest in geriatrics if trainees also had a greater understanding of the nature of the complexity of older patients and of the work-life balance within geriatrics.

Of the characteristics examined – personal, support, and institutional – institutional characteristics, in particular via proximity to and presence of mentors and older patients, were especially critical in formation of professional identity and realization of meaning from work.

Professional identity and meaning from work

Nearly all participants commented that they had never thought about what it means to be a doctor, but described their thoughts based on lessons learned from influential mentors –

particularly during residency and fellowship – and from their own experiences. For example, one fellow explained:

> *It's ... we walk into a room and people have to tell us their life story in 30 minutes, and tell us their deepest secret, what kind of drugs they do, what kind of partners they do. It's really a privilege to be trusted with that kind of information. And yeah, so it's not just a job, like it is like a career ... it's a calling, it's a privilege, all those cheesy words, because it's true. It's very special, like not everyone is entrusted with that kind of knowledge, and then ... like, keep me alive. Like that's something that doesn't ... it's very special.*

Residents who were not interested in geriatrics tended to discuss medicine as a skill utilized to educate, advocate, counsel, and solve potentially debilitating problems. Those interested in geriatrics tended to describe their role in improving quality of life and enabling patients to do the things that are important to them in life:

> *For me, when I think about being a doctor, it is really about being someone who is present with the patient. Not even necessarily someone who has the answer to everything. If anything, I've learned that we very rarely have an answer, or even a good one. When I see my patients, I mean they come to me partly for expertise, sure, but half the time what I'm doing for them is talking with them about how their illness affects them and almost brainstorming like, "Well, what can we do to make this feel better for you?"*

Geriatrics fellows unanimously discussed being a doctor as the process of understanding and meeting patients' goals, and guiding them to health and overall wellbeing, while simultaneously respecting and recognizing patients as their mentors who teach the fellows about their needs and how to help. When I probed trainees interested in geriatrics to discuss how

trainees without an interest in geriatrics might define being a doctor differently, they speculated that others may be more interested in the procedural or diagnostic aspects of medicine and see their role as an extender of life while GM is focused on facilitating quality of life. This sentiment was aligned with participants without an interest in geriatrics who acknowledged the value of extending life; however, they were unsure of how those with an interest in geriatrics might define medicine and were more limited in describing value geriatricians add beyond caring for older adults. That is, they pragmatically described the role of a geriatrician but were unclear about how a geriatrician's identity expands beyond who they care for, to include what they do, why, and how.

When I asked what participants look forward to when engaging a patient, they typically discussed either the interaction with the patient (e.g., listening to their stories) or addressing their issues through a diagnosis and recommendation—the latter, exclusively among those without an interest in geriatrics. Participants with an interest in geriatrics were most drawn to hearing their patient's stories and using stories for insight into their values and preferences. This was tied strikingly to their meaning from work. Participants with an interest in geriatrics found meaning through these stories that led them to identify how to align their goals as care providers with the goals of their patients. Others were most gratified by being able to observe improvements or positive effects of treatments and therapies. These were described as different approaches to prestige – those without an interest in geriatrics described their achievements as being those that involve a diagnosis and accurate recommendation – i.e., addressing their patient's concern by *fixing the problem*. Those with an interest in geriatrics derived prestige from developing trust with their patients and inductively identifying patients' values, needs, and preferences.

Institutional characteristics – often comments and practices of peers, leaders, and mentors – influenced how trainees thought about and found meaning in their work as physicians.

Following the first interview, I added a question asking participants what type of cognitive activity they are most enthusiastic about or comfortable with. Participants without an interest in geriatrics were most enthusiastic in practice contexts wherein patient symptoms indicated a clear diagnosis and treatment or procedural option. One participant likened this to math problems wherein one acquires information on factors requiring attention and identifies a therapy with an expected outcome. Nearly all participants with an interest of geriatrics discussed an orientation towards "puzzles" (i.e., complex circumstances where task involves identifying all the factors requiring attention without certainty or expectation of a particular or known outcome) and "philosophy" (i.e., tasks oriented towards understanding and aligning recommendations with patient values and goals). Participants with an interest in geriatrics reflected that developing comfort with puzzles and philosophy is critical for providing care to older adults, but that it may, in general, be valuable for all physicians caring for patients with complex circumstances.

DISCUSSION

Recent literature suggests the need for generating interest in trainees to go into geriatrics, potentially in combination with another subspecialty, and to practice as part of interprofessional teams.(E. Flaherty & Bartels, 2019) Other studies suggest that a better approach may be to ensure that all medical trainees pursuing general primary care are equipped with the skills to provide high quality care to older adults. However, primary care physicians are overwhelmed with large patient panels and may not be able to offer older patients the time and the attention needed for high quality care.(Cantor, 2017; Denaro & Mudge, 2008; Ferris et al., 2017; Lehnert

et al., 2011) It remains critical to continue generating interest in geriatrics in order to ensure a sufficient workforce for clinical practice in communities as well as for leadership and clinical education positions. As one fellow reflected, continuing to work towards generating interest in GM sends a different message than training all residents to think like a geriatrician when they need to; the latter undermines the value of geriatrics and presents a risk of physicians underestimating the skill required to provide high quality care to older adults. One critical element to generating interest in geriatrics is defining its value and meaning, including from the perspectives of medical trainees .(Tinetti, 2016)

Our findings that exposure to grandparents and experience with providing care to older adults influence interest in geriatrics are consistent with previous literature.(Blachman, Blaum, & Zabar, 2019; Samra et al., 2017; Voogt, Mickus, Santiago, & Herman, 2008) While negative peer, family, and mentor support did not ultimately influence participants' choice to pursue geriatrics, participants were certainly affected by these comments and attitudes. Negative peer and social support at earlier stages (such as in medical school) may impact trainees' consideration of geriatrics. Participants in our study were highly influenced by their institutional training environment, i.e., faculty, resources, exposures, and daily experiences and their descriptions of what it means to be a doctor were informed by influential mentors – typically their program director or physician mentors. Limited presence of geriatrics mentors resulted in an inattention towards the values and norms offered by geriatricians and their unique style of medicine. Supporting geriatricians in leadership positions may be necessary for enhancing opportunities for them to serve as role models and mentors to trainees.(Barbarotta, 2010; Boult et al., 2010; Bragg, Warshaw, Meganathan, & Brewer, 2012; Kottek et al., 2017; Warshaw, Bragg, & Shaull, 2002; Wasserman, 2015) Further, increasing the presence of geriatricians can facilitate

passage of norms and values of geriatrics across interprofessional teams who may support older adults in various ways across the health system and health care organizations.

Institutions may influence development of professional empathy and understanding of the different facets of prestige in medicine. Particularly in an environment where financial incentives are closely tied to prestige, it is critical that we continue to examine the value of geriatrics and explore policies that recognize the complexity of the field and the nuanced approach to medicine taken by geriatricians. Participants pursuing geriatrics in our study described taking on a role of educating others about the profession. While this may garner peer support, a top-down approach of disseminating the value of geriatricians is also needed. Institutions may consider leadership training and leadership opportunities for geriatricians, along with expanding their mentorship role to include early-stage trainees.

Professional identity formation has been an imperative of medical training programs with the goal of generating "good physicians".(Cruess, Cruess, Boudreau, Snell, & Steinert, 2014) Although surprisingly few participants had considered the meaning of their profession prior to the interview, there were differences in identity between participants with and without an interest in geriatrics. Since this was a cross-sectional study, it is challenging to explicate whether professional identity informs subspecialty interest or vice versa. However, that differences in identity were salient across interviews suggests a need for institutions to foster reflection on what it means to be a physician and how trainees may find meaning in their work.(Snyderman & Gyatso, 2019) This may encourage trainees to recognize that they can be a physician by thinking about, and approaching, their work and their patients in different ways. There are opportunities for training institutions and perhaps even earlier education to encourage comfort with complexity—both clinical as well as at the system level.(Blachman et al., 2019)

There are some limitations of our study. I conducted interviews in person and via videoconferencing to build rapport and trust; although participant responses appeared to be candid, it is still possible that participants withheld or modified their responses as a result of desirability bias, or out of concern that their responses would be shared with their respective institutions. To ensure trustworthiness of findings, I recorded all interviews and documented a brief summary immediately following each interview.(Koch, 1994; Lincoln & Guba, 1985; Sandelowski, 1986; Tobin & Begley, 2004) Finally, I purposively sampled trainees at top institutions, and residents at other institutions (e.g., smaller academic medical centers) may have different experiences, exposures, and considerations, for example based on population size of older adults regionally. However, the in-depth insights I gained from this interview may inform future interviews or surveys that can be fielded at additional sites.

These insights are reflections of what trainees are experiencing and considering at highly ranked institutions; as a result, my findings can inform program and policy decisions at peer institutions as well as at other institutions who are striving for growth. Interest in geriatrics may be related to how trainees understand their role as doctors and the ways in which they find meaning in work, which are influenced by characteristics of their training institution. Defining who geriatricians are requires reflection among physicians and trainees in what it means to be a doctor and how geriatric medicine contributes to society. In Chapters 2 and 3, I supplemented this perspective with insights from older adults and family caregivers who shared their perceived value of geriatrics and how it may respond to their circumstances and experiences in health care.

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Chapter 5

Conclusion

In this dissertation I presented three studies examining perspectives of older adults, family caregivers, and medical trainees on geriatric care. In Chapter 2, I explored how older adults and family caregivers relate their experiences with the health care system to characteristics of providers, care delivery, and the health system that are important to them as they consider the needs of older adults. In Chapter 3, informed by findings from Chapter 2, I developed and fielded a survey to over 300 older adults and family caregivers across the state of Michigan to understand how perceived experiences within the health care system and clinical and social characteristics are related to the perceived value of geriatric care. In Chapter 4, I conducted semi-structured qualitative interviews with medical residents and geriatrics fellows to understand how personal, social, and training institution characteristics may be related to trainee interest in geriatric medicine.

Supporting older adults in their health care has become a priority at all levels of society. Indeed, each of us is aging every day; we may be caregivers or wonder if someday, an older relative will need our support. Daily interactions are reminders of age—at the bank, an older adult may be comforted by their life's savings or fearful of financial fraud. In the home, they may tell stories of their own childhood to their grandchildren. At the doctor, they may wonder whether the physical, cognitive, and emotional changes they are feeling are considered "normal" or whether they are cause for concern. Although policies through our history have supported

older adults in their social and physical environments and in their health care, there is more work to be done.(Berkowitz, 2005; Grabowski, 2007; Morley, 2004)

In recent years, there has been heightened attention to the needs of older adults and further, of the family caregivers who support them. Across headlines, titles urge: "Who will take care of the elderly?"; "America is running out of family caregivers, just when it needs them the most"; "'I Feel Very Torn Between My Child and My Dad'—Demands Intensify for the 'Sandwich Generation'"; and "Caring for Two Generations Almost Cost Me My Career". Attention has also turned to geriatricians, with articles asking: "As the population ages, where are the geriatricians?"; and "Older people need geriatricians. Where will they come from?"(Ansberry, 2018, 2020; Graves, 2014; Hafner, 2016; Span, 2020; Zigman, 2020)

A common theme across these popular articles as well as peer reviewed publications is the attention to supply side requirements for supporting an aging population—i.e. the need to generate a sustainable workforce.(Herdman et al., 2007; Wasserman, 2015) Yet, consideration of the perspectives of older adults themselves is also required, first, for designing care that is responsive to their needs and values, and second, for appreciation of the value of geriatrics as a field.

Aging has been considered a disease for example in the International Statistical Classification of Diseases and Related Health Problems (ICD) commonly used for diagnostic purposes.(Zhavoronkov & Bhullar, 2015) Yet perhaps aging cannot, and should not, be reduced to a symptom or a diagnosis. It is a complex, natural, normal process and medicalizing it, rather than considering it as more than a number and in fact, an entire experience, fundamentally undermines the value and purpose of geriatric care. I found through this dissertation that older adults and family caregivers do in fact perceive value in geriatric care—and more than age itself,

experiences with the health care system and providers, along with social and clinical circumstances may be influential in the perception that geriatric care may be beneficial.

This perceived value of geriatric care is related to two imperatives. First, it indicates the need for acute attention to health care quality for older adults in general—regardless of the type of provider they see. That older adults and family caregivers experienced or observed a loss of dignity or dismissal of their concerns is troubling. That consistently, participants described and reported instances of misdiagnosis or medical errors along with issues in care coordination, is also troubling—particularly given the recent decade's concerted efforts to improve quality of care starting with medical errors related to patient safety and evolving to include patient-centeredness and effectiveness of care.(V. A. Entwistle, Mello, & Brennan, 2005; McGlynn et al., 2003) That older adults receive poorer quality of care and are underrepresented in research critical to the improvement of care, presents an issue of health equity.(Dahlgren & Whitehead, 1991) Collectively, these point to a second imperative.

Perceived value in geriatric care from the demand perspective as reflected by older adults and family caregivers tells us that there is a need for ensuring that there are enough geriatricians both practicing in communities and serving as mentors, instructors, and leaders in medical institutions and other facilities (e.g. long-term care facilities). Chapter 4 reflected that trainees who are not interested in geriatrics – including at institutions highly ranked in geriatrics – are unclear of what geriatricians do; however, they still desire information and instruction on how to provide care to older adults. This in itself reflects that they value the field. Trainees with an interest in geriatrics, and geriatrics fellows, have taken it upon themselves to share knowledge, values, and norms of geriatrics with their peers. Yet this may be beyond their call of duty. Institutions must begin to think about how to redesign not only their curricula, but also their

culture, thereby reframing aging within the training setting as well as reframing medical practice and what it means to be a doctor.(Cruess et al., 2014)

Implications for practice

Starting with medical education, there is a need for reframing the meaning of medical practice. Implications extend beyond training in geriatrics, and non-geriatrician physicians may benefit from additional short-term fellowship training in geriatrics as they are likely to see more older patients in coming decades. One important shift that must occur in order to ensure the provision of high quality care—regardless of population subset—is attention to patient values. Continuing to understand what patient-centeredness means is essential and developing curricula that equip physicians and other providers to assess what patient-centeredness means and to align their practice with patient values is critical. An orientation towards enhancing quality of life rather than exclusively attempting to extend life may be more valued among older adults. Indeed, outcomes are typically measured in terms of survival and improvement; however, older adults' values and preferences should be considered and respected. Still, it is equally important to not dismiss the concerns of older adults and family caregivers, or "give up" on them entirely.(Downey, Engelberg, & Curtis, 2009) Prioritization of concerns may be helpful here, in ensuring that pressing clinical issues are addressed along with concerns that impose on quality of life for older patients.(Ramaswamy, 2014) Medical training may benefit from greater inclusion of older adults as standardized patients and with greater representation in research in order to understand what quality of life looks like.

To do this well might also require training providers to more effectively use the electronic health record and inclusion of insights from family caregivers. Studies have

demonstrated that older adults underuse the patient portal with concerns about proficiency in use and privacy of the technology.(D. L. Anthony, Campos-Castillo, & Lim, 2018; Chen, Malani, & Kullgren, 2018) Yet, it is possible that effective provider use of the technology may nudge older adults to use technology if it means they will have more opportunities to interact with their doctor, and further, if it means that in-person visits will be more effective from the patient's perspective. Use of the EHR can be especially helpful for older adults who may receive care from multiple providers; in Chapter 2 it became clear that coordinating care is still fairly burdensome.

In fact, family caregivers do much of this work – as was reflected both in Chapters 2 and 3 as well as in prior literature.(J. L. Wolff, Spillman, et al., 2016; Jennifer L Wolff & Spillman, 2014) Health care providers can expect to practice in an environment that increasingly involves family caregivers. It is essential that providers understand the social support context of their older patients and are aware of the value of having a caregiver who can provide insights into the patient's situation and support recommendations such as medication management in the home. They must also recognize their potential to actually support caregivers by better supporting older patients.

Finally, providers will need to consider processes for referring patients to geriatricians. Given the current shortage of geriatricians, streamlining of patients is understandable. However, with rise in interprofessional education—equipping more types of providers to care for older adults—and the piloting of different types of training environments (e.g. short-term training in geriatrics for non-geriatricians), primary care physicians and other specialists should be insightful in referring older patients to others when beneficial. Older patients already demonstrate surprisingly high trust in their doctors; this makes it even more important that trust

is not violated and that physicians make optimal referrals and decisions with, and on behalf of, their older patients.(Dugan, Trachtenberg, & Hall, 2005; Musa et al., 2009)

Implications for policy

The Geriatrics Workforce Improvement Act (GWIA) is promising legislation for supporting institutional capacity to generate and train a geriatrics workforce as well as non-geriatricians in learning the skills to care for an aging population.(Collins & Casey, 2019) Based on findings from Chapter 4, GWIA may have more potential than loan forgiveness programs or other financial incentive programs to change compensation for geriatricians. It appears that generating a sustainable geriatrics workforce may not just be about the financial incentive of going into the field; trainees may not choose geriatrics even with higher compensation. Central to interest in geriatrics, according to trainees, is a better understanding of the field and validation that geriatric medicine is, indeed, true medicine. GWIA may provide a tremendous opportunity for institutions across the country to increase their capacity in equipping trainees with skills and in transforming the culture of medicine.

Increasing capacity of medical training institutions may involve curricula development, interprofessional education, and support of geriatricians in mentorship and leadership positions. However, policymakers should consider that in the case of geriatrics, institutional capacity may also include the physical environment within which trainees learn about medicine and interact with older patients. In Chapter 4, I found that physical proximity to geriatrics clinics and geriatricians' offices may be related to social proximity to the norms of geriatrics, as well as to the presence of geriatricians in the training environment. Subsequently, other than during the geriatrics rotation, trainees do not see geriatricians or see older patients who represent a

"balanced' patient panel. Medical institutions may consider inclusiveness of all subspecialties within a common campus environment. As was mentioned by participants in Chapter 2, transportation and mobility pose additional challenges for older adults in addition to having to go to multiple locations for different aspects of their health care. Designing age friendly health care facilities and designing facilities that are conducive to seeing and interacting with older adults and geriatricians may be beneficial for generating a geriatrics workforce.

In addition, there is a need for policies that facilitate integration of family caregivers in the health care setting—both within and outside of formal health care environments. In Chapter 3, I found that family caregivers were involved in facilitating use of geriatric care for their older relatives. In a few cases as described by older adult participants, caregivers were reluctant to support care-seeking from a geriatrician. This dyadic decision-making or sharing of information at the very least suggests that formalized, or at least greater formal involvement of caregivers in health care for older adults may be beneficial. One approach to facilitating this integration is by using health information technology.(J. L. Wolff, Darer, et al., 2016)

One example of a policy that already exists in this regard is the Caregiver, Advise, Record, Enable (CARE) Act which identifies family caregivers of older patients during hospitalization and subsequently provides caregivers with information and discharge instructions.(Coleman, 2003) This policy has been implemented in 40 states and is a promising intervention to support caregivers in their efforts to support older relatives after discharge.

Policymakers should also consider the development and standardization of policies enabling caregivers' access to their older relatives' medical records. In supplementary questions in my survey, I found that family caregivers were sometimes using the portal on behalf of their older relative and found it helpful; yet in other cases, family caregivers could not gain access to

the record or their relative was concerned about privacy as is consistent in literature on patient portal use.(D. L. Anthony et al., 2018) However, family caregivers are often responsible for communicating with providers and access to the record may have bidirectional benefits both to providers, who may need insights from caregivers on aspects of follow up to care such as medication management, as well as caregivers, who may benefit from instructions and cautions that may only be available on the health record.

Of course, a policy like this must be approached with caution. It is important that access to the record is granted following conversations involving all members of the triad (older adults, family caregivers, and providers) so as not to violate older adults' trust, potentially damaging the patient-provider relationship or family dynamics. Health care providers often act as brokers of trust, and they may be ideally positioned to lead these conversations; but, providers should also reflect on potential risks of integration in this form.(J. Platt, Raj, & Kardia, 2019)

With access to the medical record, caregivers may also have access to information about their own risks, especially if they are caring for a biological relative such as a parent or grandparent. Policymakers at the institutional, state, and federal levels must begin to consider the integrated nature of older adults and their family caregivers beyond a social relationship. For example, workplace policies related to caregiving leave distinguishes between employee leave for the employee's own health versus employee leave for care of a relative, despite the health of both being related in many cases.("Family and Medical Leave Act," 2019; Gifford & Jinnett, 2014) Caregiver stress resulting from support of older adults is well established in the literature, yet, policies continue to consider their health and wellbeing as being separate from the health and wellbeing of older care recipients.(Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Garlo, O'Leary, Van Ness, & Fried, 2010; Pinquart & Sorensen, 2003; Schulz et al., 1997) In fact, as

part of discussions in focus groups described in Chapter 2, being a caregiver prompted participants to consider their own future. They expressed concerns about who would care for them, and also, about how they can begin to engage in health behaviors to maintain their mobility and functioning, and subsequently, their independence. In this way, health care organizations are themselves a social determinant of health and must recognize their role in addressing point of care concerns of older adults, as well as in promoting the health of caregivers. This could involve training family caregivers to support their relatives in the home, or, it could involve addressing family caregivers' needs.(Rabow et al., 2004) It is possible that the role of geriatricians will expand in this way to support caregivers. Perhaps, for example, geriatrics clinics can function as a "family centered medical home" modeled after the patient-centered medical home.(Kern, Edwards, & Kaushal, 2014; K. M. Nelson, Helfrich, & Sun, 2014) Indeed, I found that family caregivers also perceive value in geriatric care for their older relatives. Even though the survey described in Chapter 3 asks family caregivers to reflect on the value of geriatric care for their older relatives, their observations and subsequent perceptions of value may give us some insight into how family caregivers anticipate the value of geriatric care for their own health care in the future.

Theoretical implications

Value is a complex concept used interchangeably with need and preference despite its distinctiveness. Health systems are under pressure to deliver "high value care" that is simultaneously patient-centered.(R. M. Epstein & Street, 2011; Porter, 2010) The latter, in particular, has been understudied with regard to the health care of older adults. In this dissertation, I examined perceived value—or the expression of the value of a service—first, from

the perspective of older adults and family caregivers who may consider using a service in the future. Then, I examined perceived value of geriatric care from the perspective of medical trainees who may or may not consider providing the service as a subspecialty.

Application of theoretical frameworks of health services use have primarily examined perceived need as well as the relationship between perceived need and subsequent health service use.(R. Andersen et al., 1986; Cohen-Mansfield & Frank, 2008; Demiris et al., 2008; Prins et al., 2010) Through this dissertation, I expanded the conceptualization of health services use to explore perceived value as a potential determinant of future health services use rather than as a retrospective evaluation of the service. In addition, I extended our understanding of patient-centeredness through participant reflections of how their experiences are related to their needs, values, and preferences in health care. Further, I emphasized the need for both supply and demand perspectives in order to clarify the value of a field.

The endurance of the field of geriatrics presents a conundrum because it challenges theoretical propositions that a highly demanded field or institution will become legitimatized through its use, and will become a role model that other institutions and fields try to mimic.(Selznick, 1996) Although geriatrics does not face scrutiny, and its existence is not questioned, its endurance is threatened because its value and definition lacks clarity. Geriatrics is a young subspecialty amidst growing demand and need for its services to support an aging population. In Chapter 4, I found evidence that institutions take different approaches to disseminating the value and norms of geriatrics. While one institution demonstrates its value of the field by involving geriatricians across all training activities, in the other institutions, some trainees could not recall ever interacting with a geriatrician. In this dissertation, I challenge the notion that institutions will become enduring simply by meeting an external demand. I

emphasize that the process of clarifying value of the field is essential to this legitimacy and endurance; and further, that this clarification of value requires the efforts of both those within and outside of the field.

Future research

The Chapters presented in this dissertation point to myriad opportunities for future research. Here, I have presented perspectives of older adults and family caregivers in a Michigan sample. While a limitation is the generalizability of findings, these findings also suggest the need for a larger, nationally representative survey to understand the perceived value of geriatric care. Moreover, these surveys capture insights into broader health care decision-making, needs, and concerns of older adults and family caregivers that have been previously studied to a limited extent. Amidst population aging and the pressing need to also address the health and health care needs of family caregivers, this survey is can be disseminated broadly.

Future research should also continue using qualitative methods to understand the experiences and needs of older adults and family caregivers. The use of dyads as participants is a growing methodology particularly in studies related to aging, and identifying approaches to integrating caregivers into health care for older adults will benefit tremendously from this approach.(Quinn, Staub, Barr, & Gruber-Baldini, 2019)

The integration of family caregivers and older adults should be studied further. The use of technology comprises one important area of study—for example, the effectiveness of the CARE Act and the access and use of the patient portal by family caregivers. These studies can facilitate the design of EHR systems that are conducive to use by either older adults or family

caregivers. These studies may also yield insights into policies for protecting the privacy of patient health information while still helping caregivers to support their older relatives.

However, there is also a need for studies of how the integration of caregivers—either formally or informally—changes the nature of teamwork and professionalization within health care organizations. For example, studies have examined how patients build trust in physicians, but, how do family caregivers build trust in their older relative's physician? To what extent do older adults' physicians trust family caregivers, and does a lack of trust explain some of the dismissal of caregiver insights that were described in Chapter 2? Does involvement of family caregivers fundamentally change professionalization and teamwork in health care organizations, when now, a caregiver—albeit lacking professional training—has critical supplementary information to help providers? Examining the differences in integration of caregivers in geriatric care versus usual primary care presents another area for future study that may contribute further to an understanding of family-centeredness in health care.

The use of qualitative methods will continue to be important given the renewed efforts of institutions to generate interest in geriatrics. Quantitative research has provided important information about attitudes and knowledge of trainees regarding geriatrics, and now, there is a need to understand how institutional efforts influence trainees. This is especially important given the changing nature of medical training, for example, with the expectation of using the medical record and the increasing frequency of provider interactions with older adults. Further, institutions are evolving in different ways—for example, some geriatrics departments have combined with palliative care while others remain separate. As a result, institutions may not respond to "one size fits all" recommendations to generating interest in geriatrics, or even, to

equipping all providers with the skills to support older patients. Qualitative methods can be especially valuable for capturing these complexities.

There is an urgent need to develop and explore novel methods for involving older adults and family caregivers in research.(Bartlett, Milne, & Croucher, 2018; Cruz-Jentoft et al., 2013; Lewis et al., 2003) Their limited representation or even exclusion reflects a tremendous barrier to progress. Indeed, the experience and circumstances of aging are one that researchers and practitioners may empathize with but may not truly understand until they experience their own old age. Following their participation in Chapter 3, I was struck by participants' enthusiasm and willingness to continue participating in subsequent research, explaining their desire to contribute to the improvement health care for older adults. When reading debrief feedback from participants in Chapter 2, I was surprised by how many participants indicated their appreciation for having a chance to interact with others and to share a sense of solidarity about their experiences. From a methodological perspective, we should continue identifying ways to engage older adults in research in a way that limits burden and perhaps additionally serves as an intervention to promote social connectedness and promote health. Future research must also garner the insights of multiple disciplines. Supporting the health care needs of older adults requires an understanding of space and place, emotion, cognition, relationships, and history, among other disciplines. It also requires empathy—as the agriculturalist George Washington Carver urged, *Resolve to be tended with the young, compassionate with the aged, sympathetic with the striving, and tolerant of the weak and the wrong… Sometime in life you will have been all of these."* Only then, can we develop robust health care policies and practices to support our aging population.

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Appendices

Appendix A Chapter 2 Supplementary Material

Figure A.1 Andersen and colleagues' Behavioral Model of Health Services Use

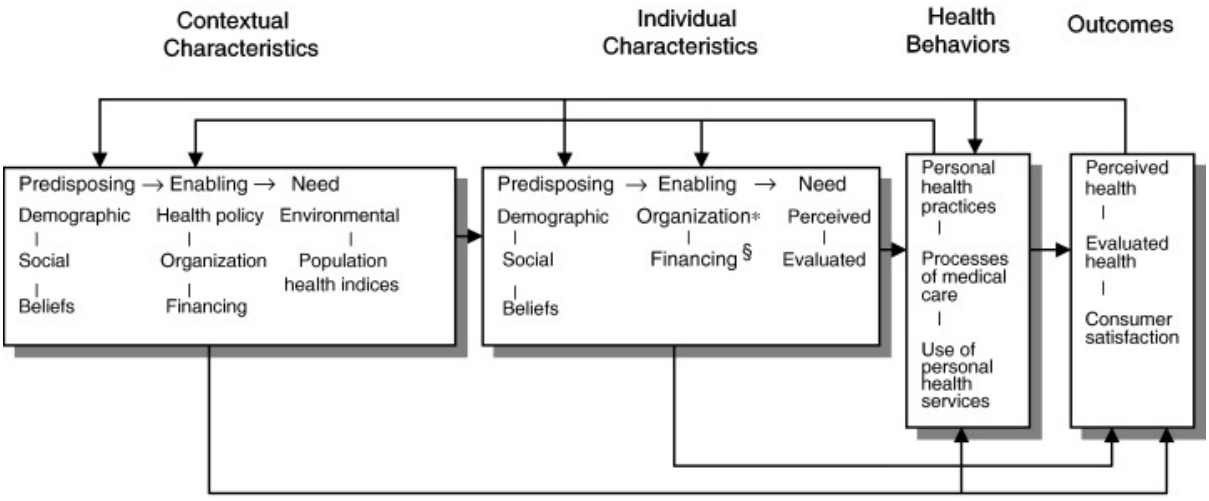


Figure A.2 Share of total health spending by age group (Kaiser Family Foundation)

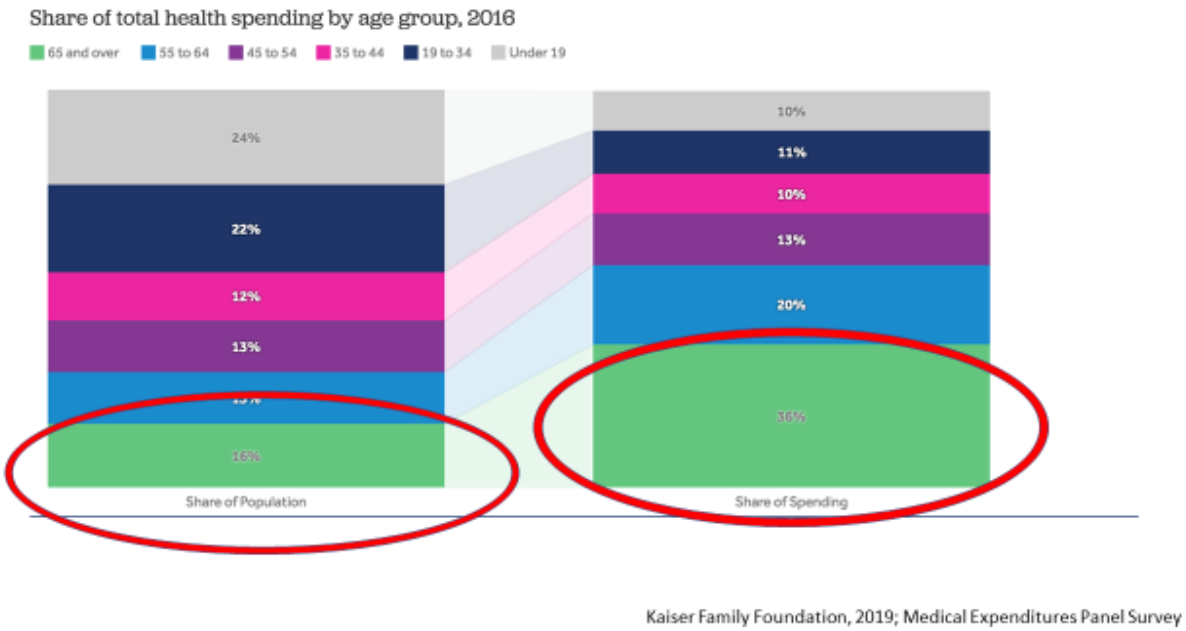


Figure A.3 Participant recruitment platform

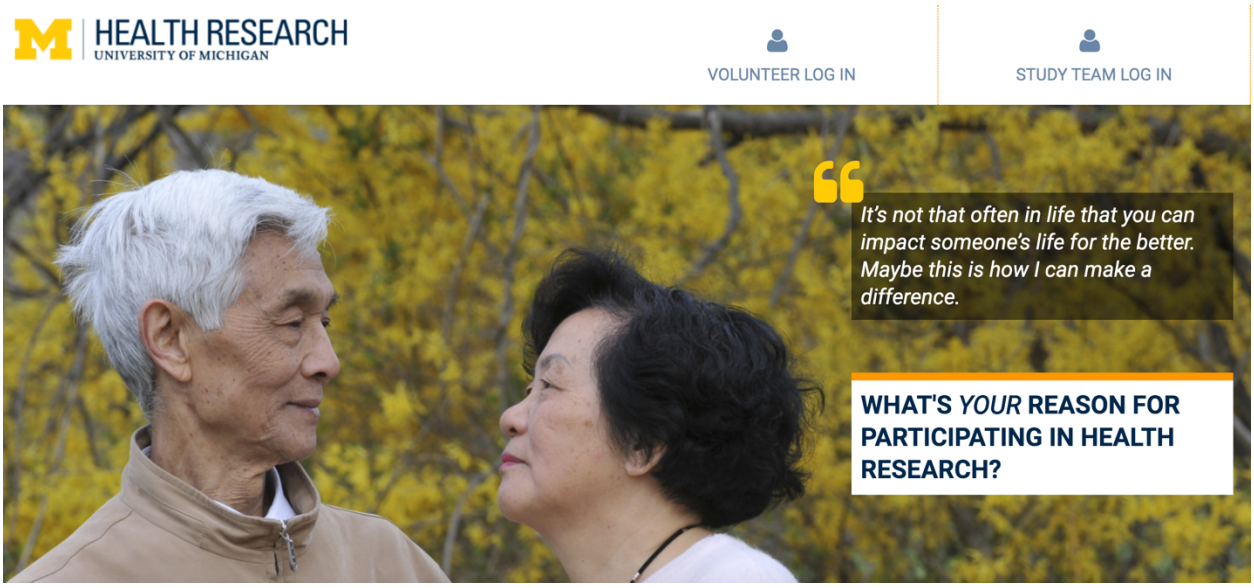


Figure A.4 Invitation template for survey recruitment

Dear [Participant],

Thank you for your interest in this study!

The URL to the survey is at the end of this message. At the end of the survey in the very last question, you will be asked to enter a random number. Please take note of that number so you can send it back to me in a message when you complete the survey, along with your address. This is so we can compensate you.

I would recommend taking the survey on a computer or iPad (rather than a phone) because it is easier to see the response choices on a larger screen. Since you said you are participating by yourself (not with a caregiver), you will answer "no" to the question that asks if you received a "link code".[a]

URL: https://umich.qualtrics.com/jfe/form/SV_d1lolDynrOv7XJX

Please feel free to contact me if you have any questions.

Thank you so much, again, for your willingness to participate. Your perspectives are so valuable.

Figure A.5 Terms and definitions provided in survey

Types of doctors

When we go to see a doctor **outside of a hospital, emergency room, or urgent care**, we usually see either a general doctor or a specialist doctor.

General doctor: a doctor who treats **many** different types of problems. This doctor is also sometimes called a primary care doctor, primary care physician, family doctor, or general practitioner.

Specialist doctor: a doctor who focuses on **one** major area or condition. Some examples are a cardiologist, who focuses on the heart, or a dermatologist, who focuses on the skin.

Personal doctor: the doctor you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Your personal doctor could be either a general doctor or a specialist doctor, and they are the doctor you see the most regularly.

Patient portal and electronic health record

Electronic Health Record (EHR): This is a system that has your health information online instead of on paper. Using the electronic health record, or EHR, your doctor can learn about your health and communicate with your other doctors about your health. When you visit the doctor, you might see them using a computer to enter information about you into the electronic health record.

Patient portal: This is a website with a password that gives you access to your health information on the electronic health record from your home, or anywhere with connection to the Internet.

Medications

When we ask about prescription medications, we're wondering how many different bottles or types of medications you have, with a doctor's label on them.

When we ask about vitamins, we are asking about vitamins that your doctor has prescribed and that you have decided to take on your own. Some examples include Vitamin D and Vitamin B.

When we ask about over the counter medications, we're asking about medications like Tylenol or Advil, which you can get without a doctor's prescription.

When we ask about pills total, we're asking about the number of tablets you take. For example, if you take 1 Tylenol in the morning and 1 in the evening, this would count as 1 over the counter medication and 2 pills.

Geriatricians

A geriatrician is a doctor who focuses on the health care of older adults. A geriatrician may do many of the same things as a general doctor, may work with a specialist doctor, or may even be a specialist doctor (such as a geriatric psychiatrist, or a geriatric oncologist). Your personal doctor, who we asked you some questions about before, could be a geriatrician.

Is your personal doctor a geriatrician, OR do you receive regular care from any of the following centers?

Turner Geriatric Clinic (Ann Arbor)
Rosa Parks Geriatric Center (Detroit)
Henry Ford Allegiance Senior Health Center (Jackson)
Hurley Medical Center Geriatric Clinic (Flint)
Veterans Administration Geriatrics Clinic (Ann Arbor)
Veterans Administration GeriPACT (Ann Arbor)

Appendix B: Chapter 3 Supplementary Material

Table B.1 Principal components analysis of full set of 15 variables (older adults)

Factor	Eigenvalue	Difference	Proportion	Cumulative
1	8.88	7.66	0.59	0.59
2	1.22	0.48	0.08	0.67
3	0.73	0.11	0.05	0.72
4	0.62	0.06	0.04	0.76
5	0.56	0.11	0.04	0.80
6	0.45	0.02	0.03	0.83
7	0.43	0.04	0.03	0.86
8	0.38	0.05	0.03	0.88
9	0.34	0.03	0.02	0.91
10	0.30	0.02	0.02	0.93
11	0.28	0.03	0.02	0.95
12	0.25	0.02	0.02	0.96
13	0.23	0.06	0.02	0.98
14	0.17	0.01	0.01	0.99
15	0.16		0.01	1.00

$Chi^2 = 1590.37$, $p<0.001$

Table B.2 Results of factor analysis (older adults)

Variable	Factor 1	Factor 2	Uniqueness
Empathizes	0.78	0.14	0.38
Trained	0.77	0.36	0.28
Has skills	0.76	0.25	0.35
Understands needs	0.74	0.40	0.29
Knows important information to share with other providers	0.69	0.43	0.35
Addresses mental and physical health	0.67	0.33	0.45
Gives resources	0.65	0.38	0.43
Right diagnosis	0.62	0.54	0.33
On the same page as other doctors	0.62	0.58	0.28
Shows respect	0.17	0.84	0.26
Listens	0.28	0.83	0.23
Explains	0.24	0.81	0.28
Spends time	0.44	0.69	0.34
Gives information	0.46	0.68	0.33
Responsive	0.46	0.67	0.33

Table B.3 Principal components analysis of full set of 15 variables (family caregivers)

Factor	Eigenvalue	Difference	Proportion	Cumulative
1	9.67	8.72	0.64	0.64
2	0.96	0.25	0.06	0.71
3	0.71	0.05	0.05	0.76
4	0.66	0.20	0.04	0.80
5	0.46	0.06	0.03	0.83
6	0.40	0.02	0.03	0.86
7	0.38	0.05	0.03	0.88
8	0.33	0.04	0.02	0.91
9	0.30	0.02	0.01	0.92
10	0.28	0.05	0.02	0.94
11	0.23	0.03	0.02	0.96
12	0.20	0.03	0.01	0.97
13	0.17	0.03	0.01	0.98

14	0.14	0.02	0.01	0.99
15	0.12		0.01	1.00

$Chi^2 = 1835.50$, $p<0.001$

Appendix C: Surveys and Interview Protocol

Figure C.1 Survey for Older Adults

Health Care Needs and Preferences of Older Adults

We are asking adults over 65 to complete a survey so we can learn more about their health care needs, how they choose different types of doctors, and how they make decisions about their health care. We expect the survey to take about 25 minutes to complete. You will receive $10 for completing the survey.

Your participation involves answering survey questions. Participating is voluntary, and you can skip any questions that you don't want to answer or stop at any time. By submitting this survey, you are providing consent to participate in the study. To keep your information confidential, your survey will be assigned a random ID number, and the survey team will never have access to any identifiable information, such as your name or contact information.

There are no "right" or "wrong" answers to this survey. Your participation won't necessarily benefit you directly, but your responses will help us learn how to improve training of doctors and how to design health care in a way that will help others in the future. The results of this study could be published in an article, but will include only summarized data. Your responses will be destroyed at the end of the study.

Once you have completed the survey, please mail it back in the envelope provided. Once we receive the packet, we will mail your compensation back to the same address.

If you have questions, concerns, or would like to find out more about the study, you can contact:
Mina Raj
miraj@umich.edu
1420 Washington Heights, Ann Arbor, MI 48109
734-763-5968

If you wish to participate in this study, please fill out and return or submit the survey. You may circle your responses or check the boxes to the left of the choices. Sometimes, we will have arrows with instructions to let you know if you need to skip to a later question based on the response selected. These instructions will be in **BOLD AND CAPITAL LETTERS**.

Thank you very much for your help.

☐ **I understand what I am asked to do in this research study and agree to participate.**

1. Do you have a "link code"? You would have received this code only if you specified that you and your caregiver live in the same household, and that they will participate as well.

☐ No

☐ Yes (please write the code): _____

At different points in the survey, we will provide some definitions to help you answer questions. Please feel free to read through these definitions and refer back to them if you need to.

In this section, we'll ask you some questions about the types of doctors you regularly see, how you communicate with them, and how you pay for your health care.

Here are a few definitions that might be helpful as you answer the next few questions.

When we go to see a doctor **outside of a hospital, emergency room, or urgent care**, we usually see either a general doctor or a specialist doctor.

General doctor: a doctor who treats **many** different types of problems. This doctor is also sometimes called a *primary care doctor, primary care physician, family doctor, or general practitioner*.

Specialist doctor: a doctor who focuses on **one** major area or condition. Some examples are a *cardiologist*, who focuses on the heart, or a *dermatologist*, who focuses on the skin.

Personal doctor: the doctor you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Your personal doctor could be either a general doctor or a specialist doctor, and they are the doctor you see the most regularly.

3. In the last 6 months, how many different types of doctors did you see? This includes your general doctor, any specialist doctors, and doctors like dentist (teeth), ophthalmologist (eyes), and podiatrist (feet).

☐ 0 ☐ 1-3 ☐ 4-6 ☐ 7-9 ☐ 10 or more

4. Does your response above include appointments that you had with other providers (e.g. nurse practitioner, physician's assistant, social worker?)

☐ Yes ☐ No

5. Is your personal doctor a general doctor or a specialist doctor?

☐ General doctor
☐ Specialist doctor
☐ I'm not sure

6. Approximately how many times did you visit your personal doctor in the last 6 months?

☐ 0 ☐ 1-3 ☐ 4-6 ☐ More than 6

7. How long have you been seeing this doctor?

☐ Less than 5 years ☐ 5 - 10 years ☐ 10 or more years

8. How did you choose your personal doctor? Please select all that apply.

☐ Referred by another doctor
☐ Referred by a friend, family, or caregiver
☐ Health plan recommended him / her
☐ Only doctor who would take my insurance
☐ Only doctor who had an appointment available
☐ My doctor is one of my friends
☐ Quality ratings (e.g. US News, Online ratings)
☐ My previous doctor retired, moved away, or passed away
☐ I was assigned to my doctor
☐ Other

9. How do you usually pay for health care? Please select all that apply.

☐ Medicare
☐ Medicaid
☐ Private health insurance (e.g. Blue Cross Blue Shield)
☐ Indian Health Service
☐ Out of pocket
☐ Veterans Administration
☐ Other

10. How satisfied are you with the different types of doctors you are able to get care from through your health insurance?

- ☐ Not at all satisfied
- ☐ Somewhat satisfied
- ☐ Fairly satisfied
- ☐ Very satisfied
- ☐ I don't have health insurance

11. Please pick your favorite color from the following list:

- ☐ Red
- ☐ Orange
- ☐ Yellow
- ☐ Green
- ☐ Blue
- ☐ Pink
- ☐ Purple

12. Please name something in nature or an object that is the color you selected.

_____

Now, we'd like to learn more about your thoughts on the patient portal and electronic health record. Here are some definitions that might be helpful:

Electronic Health Record (EHR): This is a system that has your health information online instead of on paper. Using the electronic health record, or EHR, your doctor can learn about your health and communicate with your other doctors about your health. When you visit the doctor, you might see them using a computer to enter information about you into the electronic health record.

Patient portal: This is a website with a password that gives you access to your health information on the electronic health record from your home, or anywhere with connection to the Internet.

13. What do you use the patient portal for? Please select all that apply.

☐ I don't use the patient portal at all ⟶ **PLEASE SKIP TO #15 IF YOU SELECTED THIS**

☐ To see my test or lab results

☐ To communicate with my doctor

☐ To refill medications

☐ To find my medications

☐ To review my doctor's advice

☐ To answer questions before my appointment

☐ To view or pay bills

☐ None of the above

14. How often do you use the patient portal?

☐ Rarely

☐ Only right before or right after appointments

☐ Only when I need to share information with another doctor

☐ Only when I get a notification

☐ Often

PLEASE SKIP TO #16 IF YOU ANSWERED #14

15. Why don't you use the patient portal? Please select all that apply.

☐ I was using it but stopped

☐ I don't know how to use it

☐ I don't have time

☐ I prefer to speak to my health care provider directly (in person or by phone)

☐ I don't have a computer

☐ I don't have an Internet connection where I live

☐ I don't know what this is

☐ I have a caregiver who uses the portal with / for me

☐ Other (please describe) _____

In your opinion, how true are the following statements about use of the Electronic Health Record and the patient portal by your personal doctor?

16. My personal doctor's use of the Electronic Health Record and the patient portal **makes me trust my doctor more.**

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

17. My personal doctor's use of the Electronic Health Record and the patient portal has improved my relationship with my doctor.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

18. My personal doctor's use of the Electronic Health Record and the patient portal has improved my health care.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

19. My personal doctor's use of the Electronic Health Record and the patient portal has improved my health.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

☐ Not applicable; I am already healthy

The next set of questions will ask you about your comfort with doing different daily activities, and how your doctor helps you manage any concerns you might have about these activities.

For the following questions, please select the appropriate box. Here is some guidance for these questions:

When we ask about prescription medications, we're wondering how many different bottles or types of medications you have, with a doctor's label on them.

When we ask about vitamins, we are asking about vitamins that your doctor has prescribed and that you have decided to take on your own. Some examples include Vitamin D and Vitamin B.

When we ask about over the counter medications, we're asking about medications like Tylenol or Advil, which you can get without a doctor's prescription.

When we ask about pills total, we're asking about the number of tablets you take. For example, if you take 1 Tylenol in the morning and 1 in the evening, this would count as 1 over the counter medication and 2 pills.

20. On a daily basis, how many of the following are you supposed to take:

	0	1-3	4-6	8-10	11 or more
Prescription medications for a medical condition	☐	☐	☐	☐	☐
Vitamins	☐	☐	☐	☐	☐
Over the counter medications	☐	☐	☐	☐	☐
Pills total (for all of the above)	☐	☐	☐	☐	☐

21. Do you actually take all the medications you are supposed to take?

☐ Yes ☐ No ☐ Sometimes

22. How comfortable are you, with managing your medications (for example, with taking all medicines each day at the right time, with meals as needed, and/or managing side effects)

☐ Not at all comfortable
☐ Somewhat comfortable
☐ Fairly comfortable
☐ Very comfortable

23. Do you have **concerns** about eating, dressing, bathing on your own in the next 5 years?
☐ I can't do this on my own ☐ Yes ☐ No **IF NO, PLEASE SKIP TO #25**

24. Does someone help you with eating, dressing, or bathing?

☐ Yes
☐ No **IF NO, PLEASE SKIP TO #25**

25. Do you consider this person to be your caregiver?

☐ Yes, a relative who is my caregiver
☐ Yes, a caregiver who is not related to me
☐ No _____

26. Do you have **concerns** about walking on your own in the next 5 years?
☐ I can't do this on my own ☐ Yes ☐ No **IF ~~NO~~ PLEASE SKIP TO #28**

27. Does someone help you with walking?

☐ Yes
☐ No → **IF NO, PLEASE SKIP TO #28**

28. Do you consider this person to be your caregiver?

☐ Yes, a relative who is my caregiver
☐ Yes, a caregiver who is not related to me
☐ No _____

29. Do you have **concerns** about driving on your own in the next 5 years?
☐ I can't do this on my own ☐ Yes ☐ No **IF NO, PLEASE SKIP TO #31**

29. Does someone help you with driving, or drive you wherever you need to go?

☐ Yes
☐ No **IF NO, PLEASE SKIP TO #31**

30. Do you consider this person to be your caregiver?

☐ Yes, a relative who is my caregiver

☐ Yes, a caregiver who is not related to me

☐ No _____

31. Do you have **concerns** about shopping on your own in the next 5 years?

☐ I can't do this on my own ☐ Yes ☐ No **IF NO, PLEASE SKIP TO #34**

32. Does someone help you with shopping?

☐ Yes

☐ No **IF NO, PLEASE SKIP TO #34**

33. Do you consider this person to be your caregiver?

☐ Yes, a relative who is my caregiver

☐ Yes, a caregiver who is not related to me

☐ No _____

34. In the past 2 weeks, how many days did you do the following activities on your own or with just a little assistance, if necessary?

	Less than 2	2-4	5-7	8-10	11 or more	Not applicable (I can't do this activity)
Walk for at least 30 minutes	☐	☐	☐	☐	☐	☐
Cook dinner (from scratch or reheating a prepared meal)	☐	☐	☐	☐	☐	☐
Socialize with friends or family by phone	☐	☐	☐	☐	☐	☐
Socialize with friends or family in person	☐	☐	☐	☐	☐	☐
Socialize with friends or family by email or social media	☐	☐	☐	☐	☐	☐

35. In the past 2 weeks, how many days did you...

	Less than 2	2-4	5-7	8-10	11 or more	Not applicable (I can't do this activity)
Seek new information (e.g. look something up on Google)	☐	☐	☐	☐	☐	☐
Wake up feeling rested (get enough sleep)	☐	☐	☐	☐	☐	☐
Read (e.g. a book, article, or the newspaper)	☐	☐	☐	☐	☐	☐
Manage stress (e.g. meditate)	☐	☐	☐	☐	☐	☐

36. Do you do any of the following completely on your own (please select all that apply):

☐ Use technology

☐ Manage my medications (e.g. taking the right medications at the right time)

☐ Socialize

☐ Make medical decisions with your doctor

☐ Get to the doctor or to and from procedures

The following prompt applies to #37- 49:
Do you have concerns about doing any of the following on your own, either now or in the next few years?

37. Using technology

☐ Yes ☐ No **IF NO, PLEASE SKIP TO #39**

38. Is your doctor aware of your concerns about using technology?

☐ Yes ☐ No ☐ I'm not sure

39. Managing my medications

☐ Yes ☐ No **IF NO, PLEASE SKIP TO #41**

40. Is your doctor aware of your concerns about managing your medications?

☐ Yes ☐ No ☐ I'm not sure

41. Finding ways to socialize (e.g. making new friends, seeing friends and family)?

☐ Yes ☐ No **IF NO, PLEASE SKIP TO #43**

42. Is your doctor aware of your concerns about finding ways to socialize?

☐ Yes ☐ No ☐ I'm not sure

43. Making medical decisions with your doctor?

☐ Yes ☐ No **IF NO, PLEASE SKIP TO #45**

44. Is your doctor aware of your concerns about making medical decisions?

☐ Yes ☐ No ☐ I'm not sure

45. Getting to the doctor or to procedures?

☐ Yes ☐ No

46. Finding a companion to take you to the doctor or to procedures when required?

☐ Yes ☐ No ***IF NO, PLEASE SKIP TO #48***

47. Is your doctor aware of your concerns about finding a companion to take you to the doctor or to procedures when required?

☐ Yes ☐ No ☐ I'm not sure

48. Falls?

☐ Yes ☐ No ***IF NO, PLEASE SKIP TO #50***

49. Is your doctor aware of your concerns about falls?

☐ Yes ☐ No ☐ I'm not sure

In the next questions, please indicate how much your doctor helps you with each activity, <u>even if you do not have any concerns.</u>

50. How much does your personal doctor help you <u>use technology</u>?

☐ Not at all ☐ Somewhat ☐ A lot

51. How much does your personal doctor help you <u>manage medications</u> (e.g. giving you instructions on when to take medications, giving you advice on managing any side effects)?

☐ Not at all ☐ Somewhat ☐ A lot

52. How much does your personal doctor help you <u>socialize (e.g. meet new friends, spend time with friends or family)</u>?

☐ Not at all ☐ Somewhat ☐ A lot

53. How much does your personal doctor help you <u>make medical decisions</u>?

☐ Not at all ☐ Somewhat ☐ A lot

54. How much does your personal doctor help you <u>get to the doctor or to procedures</u> (e.g. suggesting locations that are close to where you live, or making sure you have transportation)?

☐ Not at all ☐ Somewhat ☐ A lot

55. How much does your personal doctor help you <u>manage your mental health</u>?

☐ Not at all ☐ Somewhat ☐ A lot

56. How much does your personal doctor help you <u>reduce risk of falling</u>?

☐ Not at all ☐ Somewhat ☐ A lot

57. How much does your personal doctor help you <u>find a companion to take you to procedures when needed</u>?

☐ Not at all ☐ Somewhat ☐ A lot

58. On the previous set of questions, you were asked about how much your doctor does help you with various activities. How much **should** your personal doctor help you manage or prepare to manage:

	Not at all	Somewhat	A lot
Using technology	☐	☐	☐
Medications	☐	☐	☐
Falls	☐	☐	☐
Socializing	☐	☐	☐
Medical decisions	☐	☐	☐
Getting to the doctor or to procedures	☐	☐	☐
Mental health	☐	☐	☐
Finding a companion to take you to procedures when needed	☐	☐	☐

59. Does someone else in your doctor's office or clinic help you with these activities? If yes, what is their role (e.g. nurse practitioner, receptionist, social worker)

☐ Yes (please list their role) _____

☐ No

Now, we'd like to learn more about your interactions and relationship with your personal doctor. Please remember that your responses will not be linked to your name, address, or any other identifying information, and your responses will not change your treatment or medical care.

60. How often does your personal doctor do the following:

	Never	Sometimes	Usually	Always
Shows respect for what you have to say	☐	☐	☐	☐
Listens carefully to you	☐	☐	☐	☐
Explains things in a way that you can understand	☐	☐	☐	☐
Spends enough time with you	☐	☐	☐	☐
Is responsive to your concerns	☐	☐	☐	☐

61. Based on your experiences with your personal doctor, how true are the following statements in your opinion?

My personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Understands that older adults have unique concerns and needs	☐	☐	☐	☐
Is trained in care for older adults	☐	☐	☐	☐
Has been able to correctly diagnose my conditions	☐	☐	☐	☐
Is on the same page as any other doctors I may see	☐	☐	☐	☐
Is dismissive of my concerns because of my age	☐	☐	☐	☐

62. Based on your experiences with your personal doctor, how true are the following statements in your opinion?

My personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Gives me enough information so I can manage my conditions	☐	☐	☐	☐
Trusts me	☐	☐	☐	☐
Communicates with me too much using technology	☐	☐	☐	☐
Gives attention to both my physical and mental health	☐	☐	☐	☐
Knows what information is important to tell my other doctors	☐	☐	☐	☐

63. Based on your experiences with your personal doctor, how true are the following statements in your opinion?

My personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Probably gives me the same advice that she/ he gives everyone else	☐	☐	☐	☐
Has given up on me	☐	☐	☐	☐
Has the skills to provide good care to someone my age	☐	☐	☐	☐
Gives me resources to go to when I need help or information about my health	☐	☐	☐	☐
Empathizes with the experience of aging	☐	☐	☐	☐

64. How true are the following statements?

I trust my personal doctor to do what's best for me.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

65. *I trust that my personal doctor has the skills and training to provide care for me as I grow older.*

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

66. Have you ever thought about switching personal doctors because of any of the following? Please select all that apply.

☐ I have never thought about switching doctors **IF YOU SELECTED THIS, PLEASE SKIP TO #68**

☐ A health or medical related incident or error

☐ I felt your doctor was too young to understand my concerns

☐ My caregiver or relatives suggested it

☐ Another doctor recommended that I switch doctors

☐ My personal doctor retired, moved away, or passed away

☐ Other (please describe) _____

67. Did you actually switch personal doctors?

☐ No ☐ Yes **IF YES, PLEASE SKIP TO #69**

68. What has made you decide not to switch personal doctors?
Please select all that apply.

☐ I'm satisfied with my current doctor
☐ It would be impolite, rude, or disrespectful
☐ It would mean ruining a relationship
☐ It would be too hard to find a new doctor
☐ Even though it would be easy to find another doctor, I just don't want to
☐ It would be overwhelming
☐ I'm not sure a new doctor would be better
☐ Other

This section will ask you some questions about a specific type of doctor called a geriatrician.

A geriatrician is a doctor who focuses on the health care of older adults. A geriatrician may do many of the same things as a *general doctor*, may work with a *specialist doctor*, *or may even be a specialist doctor (such as a geriatric psychiatrist, or a geriatric oncologist)*. Your personal doctor, who we asked you some questions about before, could be a geriatrician.

69. Is your personal doctor a geriatrician, OR do you receive regular care from any of the following centers?
Turner Geriatric Clinic (Ann Arbor)
Rosa Parks Geriatric Center (Detroit)
Henry Ford Allegiance Senior Health Center (Jackson)
Hurley Medical Center Geriatric Clinic (Flint)
Veterans Administration Geriatrics Clinic (Ann Arbor)
Veterans Administration GeriPACT (Ann Arbor)

☐ Yes ☐ No, but I think one of my doctors is a geriatrician ☐ No **IF NO,**

PLEASE SKIP TO #73

70. Please select the response that best describes your interactions with your geriatrician:

☐ I would consider them my personal doctor

☐ I see a geriatrician AND another personal doctor, both more than once a year

☐ I consider another doctor my personal doctor, but I see a geriatrician for GENERAL care as needed (just once a year)

☐ I consider another doctor my personal doctor, but I also see a geriatrician for SPECIALIST care (e.g. a geriatric oncologist)

71. If you think your doctor is a geriatrician, why did you start going there?

☐ I felt that I needed to see a geriatrician **IF YOU SELECTED THIS, PLEASE CONTINUE TO #72**

IF YOU ONLY SELECT RESPONSES BELOW, PLEASE SKIP TO #74

☐ My caregiver suggested that I see a geriatrician

☐ My friend or other family member suggested that I see a geriatrician

☐ Another doctor suggested that I see a geriatrician

☐ My health plan/ health insurance suggested that I see a geriatrician

☐ A social worker or staff member where I live or receive care suggested that I see a geriatrician

☐ Other _____

72. Why did you feel you needed to see a geriatrician?

☐ I felt my regular doctor wasn't able to help me with my medical concerns

☐ I felt my regular doctor did not have enough time for me

☐ Other _____

73. Which of the following best describes why you don't seek care from one of these clinics or from a geriatrician:

☐ I was once evaluated by a geriatrician or at one of the four clinics, but was told I didn't need to see a geriatrician regularly

☐ I can't get an appointment

☐ I need more information about what a geriatrician does

☐ I don't want to

☐ I haven't considered it

☐ I'm satisfied with my current doctor

74. Were you aware of what a geriatrician does before taking this survey?

☐ Yes ☐ No

75. Please select the response that applies most to you, **in your opinion.**

	Yes	No	I'm not sure
I'm too healthy to see a geriatrician.	☐	☐	☐
It's easy for me to find a dentist where I live.	☐	☐	☐
It's easy for me to access a dentist through my insurance.	☐	☐	☐
It's easy for me to find a geriatrician where I live.	☐	☐	☐
It's easy for me to access a geriatrician through my insurance.	☐	☐	☐

76. Please select the response that fits best as you think about geriatricians and the type of care they provide to people in general. Remember, in these questions are asking about your opinion.

	Yes	No	I'm not sure
Someone should only see a geriatrician if their regular doctor isn't spending enough time with them.	☐	☐	☐
Someone has to be 80 in order to receive care from a geriatrician.	☐	☐	☐
Someone younger than 65 might benefit from seeing a geriatrician.	☐	☐	☐

The next set of questions will ask you about your opinion on how the health care system serves you and others. In these questions, we'd like to know about your thoughts based on your experiences and observations.

In your opinion, how true are the following statements?

77. The healthcare system is difficult to navigate.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

78. The current health system is meeting my needs.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

79. The current health system is meeting the needs of most people in my state.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

80. Did any of the following apply to you in the last 6 months? Please select all that apply.

☐ Did not get a medication your doctor prescribed due to cost
☐ Did not get doctor care that you needed due to cost
☐ Had problems paying your medical bills
☐ Had to count on a caregiver or relatives to pay your medical bills
☐ Could not get to an appointment or procedure because of transportation issues
☐ Could not get to an appointment or procedure because it required having a companion
☐ None of the above apply to me

Now, we'd like to learn about how you feel about aging.

81. In your opinion, how well do the following statements describe what aging means to you?

Aging:

	Not at all well	Somewhat well	Fairly well	Very well
Brings freedom	☐	☐	☐	☐
Requires being more cautious	☐	☐	☐	☐
Brings a loss of control	☐	☐	☐	☐
Is natural	☐	☐	☐	☐
Can be prevented	☐	☐	☐	☐
Brings respect	☐	☐	☐	☐
Is a burden	☐	☐	☐	☐
Could be made a better experience by society	☐	☐	☐	☐

82. In your opinion, how well do the following statements describe what aging means to you?

Aging:

	Not at all well	Somewhat well	Fairly well	Very well
Can be treated	☐	☐	☐	☐
Is misunderstood	☐	☐	☐	☐
Should be prevented	☐	☐	☐	☐
Is something you look forward to	☐	☐	☐	☐
Is something you worry about	☐	☐	☐	☐
Means relying on someone else	☐	☐	☐	☐
Is not a medical condition	☐	☐	☐	☐

83. In your opinion, how well do the following statements describe what aging means to you?
Aging means:

	Not at all well	Somewhat well	Fairly well	Very well
Losing dignity	☐	☐	☐	☐
Being outdated	☐	☐	☐	☐
Developing wisdom	☐	☐	☐	☐
Being lonely	☐	☐	☐	☐
Embarrassment	☐	☐	☐	☐
Being more aware of time	☐	☐	☐	☐

The next set of questions will ask you about others, like relatives or friends, who may support you in different ways.

84. Not including your doctor, do you have a primary caregiver?

☐ Yes
☐ As needed
☐ No **IF NO, PLEASE SKIP TO #87**

85. Do you live with your primary caregiver?

☐ Yes
☐ No
☐ Part-time (rotate with different caregivers)

86. What is your primary caregiver's relationship to you?

☐ Adult child ☐ Son ☐ Son-in-law ☐ Daughter ☐ Daughter-in-law
☐ Adult grandchild ☐ Grandson ☐ Granddaughter
☐ Adult niece/nephew
☐ Sibling ☐ Younger ☐ Older
☐ Spouse/partner/companion
☐ Friend/ neighbor
☐ Formal caregiver
☐ Other _____

87. Who most helps you make decisions about your health and medical care, other than your doctor?

☐ No one
☐ My primary or secondary caregiver who I mentioned earlier
☐ Adult child ☐ Son ☐ Son-in-law ☐ Daughter ☐ Daughter-in-law
☐ Adult grandchild ☐ Grandson ☐ Granddaughter
☐ Adult niece/nephew
☐ Sibling ☐ Younger ☐ Older
☐ Spouse/ partner/ companion
☐ Friend/ neighbor
☐ Formal caregiver
☐ Other _____

Now, we'd like to learn more about how you feel, in general.
88. How much do you agree with the following statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I enjoy my life overall	☐	☐	☐	☐	☐
I look forward to things	☐	☐	☐	☐	☐
I am healthy enough to get out and about	☐	☐	☐	☐	☐
My friends, family, or neighbors would help me if needed	☐	☐	☐	☐	☐
I have social or leisure activities/ hobbies that I enjoy doing	☐	☐	☐	☐	☐
I try to stay involved with things	☐	☐	☐	☐	☐

89. How much do you agree with the following statements?

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
I am healthy enough to have my independence	☐	☐	☐	☐	☐
I feel safe where I live	☐	☐	☐	☐	☐
I get pleasure from my home	☐	☐	☐	☐	☐
I take life as it comes and make the best of things	☐	☐	☐	☐	☐
I feel lucky compared to most people	☐	☐	☐	☐	☐
I have enough money to pay for household bills	☐	☐	☐	☐	☐

90. Overall, how would you rate your health in the past 4 weeks?

☐ Excellent☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Very Poor

This is the last section of the survey that will help us get a little more information about you.

91. What is your age (in years)?

_____

92. What sex do you identify with?

☐ Male ☐ Female ☐ Other

93. Are you of Hispanic, Latino, or Spanish origin?

☐ Yes ☐ No

94. What race do you identify with? Please select all that apply.

☐ White
☐ Black or African American
☐ American Indian or Alaska Native
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Multiracial

95. What is the highest degree or level of school you have completed?

☐ Less than a high school diploma
☐ High school degree or equivalent (e.g. GED)
☐ Some college, no degree
☐ Associate degree
☐ Bachelor's degree
☐ Master's degree
☐ Professional degree (e.g. MD, DDS)
☐ Doctorate (e.g. PhD, EdD)

96. What is your current employment status?

☐ Employed ☐ Full-time ☐ Part-time
☐ Retired from career, but returned to work
☐ Retired
☐ Veteran
☐ Unable to work

97. What is your current marital status?

☐ Married
☐ Living with partner
☐ Divorced/ separated
☐ Never married
☐ Widowed
☐ Prefer not to answer

98. How many children do you have?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 or more

99. How many grandchildren do you have?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 or more

100. What zip code do you live in?

_____

101. What type of place do you live in?

☐ House
☐ Apartment/ Condo
☐ Retirement community
☐ Assisted living facility
☐ Nursing home
☐ Other long term care facility
☐ Other _____

102. How many others are in your household (not including yourself)?

☐ I live alone ☐ 1 other ☐ 2 others ☐ 3 others ☐ 4 others ☐ 5 or more

Please indicate whether the following statements apply to you.

103. In the past 12 months:

	Yes	No
I worried whether my food would run out before I got money to buy more	☐	☐

104. To what extent does the following statement apply to you?

	Always	Often	Sometimes	Rarely	Never
I have money left over at the end of the month	☐	☐	☐	☐	☐

105. Please indicate how you completed this survey.

☐ Paper and pen/ pencil (in person)
☐ iPad (in person)
☐ Someone read the questions to me and circled my responses
☐ Computer
☐ Paper and pen/ pencil (mail)
☐ Phone

106. Do you have any comments you would like to share about your health care needs, or additional information you would like to provide about any of your responses?

_____

_____

107. Are there any terms used in this survey that you did not understand?

_____

_____

Thank you for participating in the survey! Once we receive your survey packet, we'll mail you compensation for your time!

Figure C.2 Survey for family caregivers

Caregiver Role in Health Care Decisions of Older Adults

We are asking informal caregivers (unpaid relatives) of adults over 65 to complete a survey so we can learn more about their role in making health care decisions with their older relatives. We expect the survey to take about 25 minutes to complete. You will receive $10 for completing the survey.

Your participation involves answering survey questions. Participating is voluntary, and you can skip any questions that you don't want to answer or stop at any time. By submitting this survey, you are providing consent to participate in the study. To keep your information confidential, your survey will be assigned a random ID number, and the survey team will never have access to any identifiable information, such as your name or contact information.

There are no "right" or "wrong" answers to this survey. Your participation won't necessarily benefit you directly, but your responses will help us learn how to improve training of doctors and how to design health care in a way that will help others in the future. The results of this study could be published in an article, but will include only summarized data. Your responses will be destroyed at the end of the study.

Once you have completed the survey, please mail it back in the envelope provided. Once we receive the packet, we will mail your compensation back to the same address.

If you have questions, concerns, or would like to find out more about the study, you can contact:

Mina Raj
miraj@umich.edu
1420 Washington Heights, Ann Arbor, MI 48109
734-763-5968

If you wish to participate in this study, please click below, and fill out and return or submit the survey. Please circle your responses. Sometimes, we will have arrows with instructions to let you know if you need to skip to a later question based on the response selected. These instructions will be in **BOLD AND CAPITAL LETTERS.**

Thank you very much for your help.

☐ I understand what I am asked to do in this research study and agree to participate.

1. Do you have a "link code"? You would have received this code only if you specified that you and your older relative live in the same household, and that they will participate as well.

No
Yes (please write the code): _____

At different points in the survey, we will provide some definitions to help you answer questions. Please feel free to read through these definitions and refer back to them if you need to.

First, we'd like to know a little bit more about the older adult you are a caregiver for, and the different types of support you provide.

2. How many relatives are you a caregiver for?

□ 1
□ 2
□ 3 or more

For the remainder of the questions, please refer to your role as a caregiver **for the individual for whom you provide most extensive care.** We will refer to them as "your older relative", or as "the older adult for whom you are a caregiver".

3. What is **your** relationship to the older adult for whom you are an informal caregiver?

□ Adult child or child-in-law → □ Son □ Son-in-law □ Daughter □ Daughter-in-law
□ Adult grandchild → □ Grandson □ Granddaughter
□ Adult niece or nephew
□ Spouse / partner
□ Other (please describe) _____

4. What types of support do you provide for the older adult you are a caregiver for? Please select all that apply.

- ☐ Eating / Feeding
- ☐ Preparing meals
- ☐ Dressing
- ☐ Bathing
- ☐ Toilet
- ☐ Shopping
- ☐ Driving / Transportation
- ☐ Technology
- ☐ Social engagement or socializing (in person)
- ☐ Social media
- ☐ Memory support
- ☐ Emotional support
- ☐ Financial support
- ☐ House cleaning
- ☐ Picking up medications from the pharmacy
- ☐ Managing medications (e.g. making sure they take medications at the correct time and correct dosage)
- ☐ Laundry
- ☐ Medical decision-making
- ☐ Using the electronic health record
- ☐ Communicating / translating
- ☐ Auditory / hearing
- ☐ Other (please describe what other types of support you provide):

_____

5. The following questions use a slider representing 0% to 100%. Please draw an "X" on each line to indicate how involved you are in providing support for the following activities. The remaining is how much they do on their own or with help from someone else.

Socializing	_____
Preparing meals (cooking or reheating)	_____
Medical decision-making	_____
Technology	_____

6. About how many hours per week do you work as a caregiver?

□ <7 □ 8-14 □ 15-25 □ 30-40 □ 40+

7. Does your older relative live with you?

□ Yes
□ No
□ Part-time (rotates living with other caregivers)

8. Does your older relative receive support from anyone else in addition to the support you and their doctors provide? Please select all that apply.

□ Yes, another informal (family) caregiver
□ Yes, a formal caregiver
□ No

9. Have you ever considered taking time off from full time work for responsibilities related to caregiving?

□ Yes
□ No ***IF YOU SELECTED THIS, PLEASE SKIP TO #13***
□ I don't work full time ***IF YOU SELECTED THIS, PLEASE SKIP TO #14***
□ I'm not employed ***IF YOU SELECTED THIS, PLEASE SKIP TO #PAGE 6***

10. Have you taken time off from work, including half days, for responsibilities related to caregiving?

□ Yes □ No → ***IF YOU SELECTED THIS, PLEASE SKIP TO #13***

11. What is the longest amount of time you have taken off from work to provide support as a caregiver?

□ Less than 1 week
□ 1 week to 1 month
□ 1 month to 3 months
□ 3 months to 6 months
□ 6 months or more

12. Was your time off from work paid?

□ Yes □ No □ I'm not sure □ I can't remember □ I'm self-employed

↳ ***IF YOU ANSWERED #12, PLEASE SKIP TO #14***

13. Which of the following explains why you decided not to take time off from work? Please select all that apply.

- ☐ I would not have been paid during my time off
- ☐ I would have lost my job
- ☐ It would have affected my reputation
- ☐ Someone else helped me with caregiving
- ☐ I felt I could manage
- ☐ I work from home

14. Does your employer have a policy related to caregiving of older relatives? Please select all that apply.

- ☐ Yes, the Family Medical Leave Act
- ☐ Yes, I can use my "sick leave" time
- ☐ Yes, another policy
- ☐ No
- ☐ I'm not sure
- ☐ My employer is flexible about my caregiving needs

In this section, we'll ask you some questions about the types of doctors the older adult you care for regularly sees.

Here are a few definitions that might be helpful as you answer the next few questions.

When we go to see a doctor **outside of a hospital, emergency room, or urgent care**, we usually see either a general doctor or a specialist doctor.

General doctor: a doctor who treats **many** different types of problems. This doctor is also sometimes called a *primary care doctor, primary care physician, family doctor, internist, or general practitioner*.

Specialist doctor: a doctor who focuses on **one** major area or condition. Some examples are a *cardiologist*, who focuses on the heart, or a *dermatologist*, who focuses on the skin.

Personal doctor: the doctor you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Your personal doctor could be either a general doctor or a specialist doctor, and is the doctor you see the most regularly.

15. In the last 6 months, how many different types of doctors did the older adult you are a caregiver for, see? This includes doctors like dentist (teeth), ophthalmologist (eyes), and podiatrist (feet).

□ 0 □ 1-3 □ 4-6 □ 7-9 □ 10 or more

16. Does your response above include appointments that your older relative had with other providers (e.g. nurse practitioner, physician's assistant, social worker?)

□ Yes □ No

17. Is their personal doctor a general doctor or a specialist doctor?

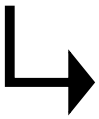
□ General doctor
□ Specialist doctor
□ I'm not sure

18. Do you go your older relative's personal doctor with them?

□ Yes, always
□ Yes, when I am able to
□ No, but I follow up with the doctor or a nurse after each appointment ***PLEASE SKIP TO #20***
□ No ***PLEASE SKIP TO #21***

19. Do you go to appointments with all the different types of doctors they see?

□ Yes
□ No, only with their "personal doctor"
□ No, I go to all appointments EXCEPT those with their "personal doctor"



IF YOU ANSWERED #19, PLEASE SKIP TO #21

20. Do you follow up with all the different types of doctors they see?

□ Yes
□ No, only with their "personal doctor"
□ No, with all doctors EXCEPT their "personal doctor"

21. Approximately how many times did they visit their personal doctor in the last 6 months?

□ 0 □ 1-3 □ 4-6 □ More than 6 □ I'm not sure

22. How long have they been seeing this doctor?

□ Less than 5 years □ 5 - 10 years □ 10 or more years

23. How did they choose their personal doctor? Please select all that apply.

- □ Referred by another doctor
- □ Referred by me
- □ Referred by another family member or friend
- □ Health plan recommended him / her
- □ Only doctor who would take their insurance
- □ Only doctor who had an appointment available
- □ Doctor is one of their friends
- □ Quality ratings (e.g. US News, Online ratings)
- □ Their previous doctor retired, moved away, or passed away
- □ I'm not sure
- □ Other

24. How do they usually pay for health care? Please select all that apply.

- □ Medicare
- □ Medicaid
- □ Private health insurance (e.g. Blue Cross Blue Shield)
- □ Indian Health Service
- □ Out of pocket
- □ Veterans Administration
- □ They are considered a "dependent" under my health insurance plan
- □ Other

25. How satisfied are you with the different types of doctors they are able to get care from through health insurance?

- □ Not at all satisfied
- □ Somewhat satisfied
- □ Fairly satisfied
- □ Very satisfied
- □ They don't have health insurance

Now, we'd like to learn more about your thoughts on the patient portal and electronic health record. Here are some definitions that might be helpful:

Electronic Health Record (EHR): This is a system that has your health information online instead of on paper. Using the electronic health record, or EHR, your doctor can learn about your health and communicate with your other doctors about your health. When you visit the doctor, you might see them

using a computer to enter information about you into the electronic health record.

Patient portal: This is a website with a password that gives you access to your health information on the electronic health record from your home, or anywhere with connection to the Internet.

26. Does the older adult you are a caregiver for use the patient portal?

- ☐ Yes, on their own
- ☐ Yes, with my assistance
- ☐ Yes with assistance from someone else
- ☐ No, but I use it for them on their behalf ***IF YOU SELECTED THIS, PLEASE SKIP TO #29***
- ☐ No, neither my older relative nor I use their patient portal ***IF YOU SELECTED THIS, PLEASE SKIP TO #31***

27. What do they use the patient portal for on their own or with assistance? Please select all that apply.

- ☐ To see test or lab results
- ☐ To communicate with their doctor
- ☐ To refill medications
- ☐ To find medications
- ☐ To review their doctor's advice
- ☐ To answer questions before their appointment
- ☐ To view or pay bills
- ☐ None of the above

28. How often do they use the patient portal?

- ☐ Rarely
- ☐ Only right before or right after appointments
- ☐ Only when they need to share information with another doctor
- ☐ Only when they get a notification
- ☐ Often

IF YOU ANSWERED THIS QUESTION, PLEASE SKIP TO PAGE 14.

29. What do you use the patient portal for on their behalf? Please select all that apply.

- ☐ To see test or lab results
- ☐ To communicate with their doctor
- ☐ To refill medications
- ☐ To find medications
- ☐ To review their doctor's advice
- ☐ To answer questions before their appointment
- ☐ To view or pay bills
- ☐ None of the above

30. How often do you use the patient portal for them?

- □ Rarely
- □ Only right before or right after appointments
- □ Only when I need to share their information with another doctor
- □ Only when they get a notification
- □ Often

31. Why doesn't your older relative use the patient portal? Please select all that apply.

- □ They were using it but stopped
- □ They don't know how to use it
- □ They don't have time
- □ They prefer talking to their doctor directly (in person or by phone)
- □ They don't have a computer
- □ They don't have an Internet connection where they live
- □ They don't know what this is
- □ Other (please describe) _____

IF YOU SELECTED IN #26 THAT YOU USE THE PORTAL ON THEIR BEHALF, PLEASE SKIP TO PAGE 14.

IF YOU DO NOT USE THE PORTAL FOR THEM, PLEASE CONTINUE TO #32.

32. Why don't you use the patient portal on their behalf?

- □ I don't have time
- □ I want to give them their privacy
- □ I prefer talking to their doctor directly (in person or by phone)
- □ I don't have a computer
- □ I don't have an Internet connection where I live
- □ I don't know what this is
- □ Other (please describe) _____

In your opinion, how true are the following statements about use of the Electronic Health Record and the patient portal by your older relative's personal doctor?

33. The doctor's use of the Electronic Health Record and the patient portal **makes me trust their doctor more.**

□ Not at all true □ Somewhat true □ Fairly true □ Very true

34. The doctor's use of the Electronic Health Record and the patient portal has improved my relationship with their doctor.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

35. The doctor's use of the Electronic Health Record and the patient portal has improved my older relative's relationship with their doctor.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

36. The doctor's use of the Electronic Health Record and the patient portal has helped me be a caregiver.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

37. The doctor's use of the Electronic Health Record and the patient portal has improved my older relative's health care.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

38. The doctor's use of the Electronic Health Record and the patient portal has improved my older relative's health.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true
☐ Not applicable; they are already healthy

The next set of questions will ask you about some of the activities your older relative may take part in.

For the following questions, please select the appropriate box. Here is some guidance for these questions:

When we ask about prescription medications, we're wondering how many different bottles or types of medications they have, with a doctor's label on them.

When we ask about vitamins, we are asking about vitamins that their doctor has prescribed and that they have decided to take on your own. Some examples include Vitamin D and Vitamin B.

When we ask about over the counter medications, we're asking about medications like Tylenol or Advil, which they can get without a doctor's prescription.

When we ask about pills total, we're asking about the number of tablets they take. For example, if they take 1 Tylenol in the morning and 1 in the evening, this would count as *1 over the counter medication* and *2 pills*.

39. *On a daily basis, how many of the following is your older relative supposed to take:*

	0	1-3	4-6	8-10	11 or more
Prescription medications for a medical condition	□	□	□	□	□
Vitamins	□	□	□	□	□
Over the counter medications	□	□	□	□	□
Pills total (for all of the above)	□	□	□	□	□

40. Do they actually take all the medications they are supposed to take?

□ Yes □ No □ Sometimes □ I'm not sure

41. How comfortable are you, with helping your older relative managing their medications (for example, with taking all medicines each day at the right time, with meals as needed, and/or managing side effects)?

□ I don't help with medications
□ Not at all comfortable
□ Somewhat comfortable
□ Fairly comfortable
□ Very comfortable

42. Which of the following activities does your older relative do completely on their own, or with minimal assistance? Please select all that apply.

- ☐ Walk for at least 30 minutes
- ☐ Cook dinner (from scratch or reheating a prepared meal)
- ☐ Socialize with friends or family by phone
- ☐ Socialize with friends or family in person
- ☐ Seek new information (e.g. look something up on Google)
- ☐ Wake up feeling rested (get enough sleep)
- ☐ Read (e.g. a book, article, or magazine)
- ☐ Manage stress (e.g. meditate)
- ☐ None of the above ***IF NONE OF THE ABOVE, PLEASE SKIP TO #45***

43. In the past 2 weeks, how many days did your older relative do the following activities either on their own or with just a little assistance, if necessary...

	Less than 2	2-4	5-7	8-10	11 or more	Not applicable (They can't do this activity)
Walk for at least 30 minutes	☐	☐	☐	☐	☐	☐
Cook dinner (from scratch or reheating a prepared meal)	☐	☐	☐	☐	☐	☐
Socialize with friends or family by phone	☐	☐	☐	☐	☐	☐
Socialize with friends or family in person	☐	☐	☐	☐	☐	☐
Socialize with friends or family by email or social media	☐	☐	☐	☐	☐	☐
Seek new information (e.g. look something up on Google)	☐	☐	☐	☐	☐	☐
Wake up feeling rested (get enough sleep)	☐	☐	☐	☐	☐	☐

Read (e.g. a book, article, or the newspaper)	□	□	□	□	□	□
Manage stress (e.g. meditate)	□	□	□	□	□	□

44. How much of a role do you have in encouraging their participation in these activities?

	I am not involved; they do this with someone else's help	I am not involved; they do this on their own	Somewhat involved	Fairly involved	Very involved; they wouldn't do this without my encouragement	Not applicable (they can't do this activity)
Staying active (e.g. walking)	□	□	□	□	□	□
Cooking dinner or preparing meals	□	□	□	□	□	□
Socializing by phone	□	□	□	□	□	□
Socializing in person	□	□	□	□	□	□
Seeking new information	□	□	□	□	□	□
Sleeping and getting rest	□	□	□	□	□	□
Reading	□	□	□	□	□	□
Managing stress	□	□	□	□	□	□

45. Earlier, we asked you what types of support you provide for the older adult you are a caregiver for.

Now, we'd like to know whether you have **concerns** about providing support for any of these activities either now or in the future. Please select all activities that you are concerned about.

- ☐ Eating or Feeding
- ☐ Preparing meals
- ☐ Dressing
- ☐ Bathing
- ☐ Toilet
- ☐ Shopping
- ☐ Driving / Transportation
- ☐ Technology
- ☐ Social engagement or socializing
- ☐ Memory support
- ☐ Emotional support
- ☐ Financial support
- ☐ House cleaning
- ☐ Picking up medications
- ☐ Managing medications
- ☐ Laundry
- ☐ Using the electronic health record
- ☐ Medical decision-making
- ☐ Communicating / translating
- ☐ Auditory / hearing
- ☐ Other (please describe) _____

46. Is your older relative's personal doctor aware of your concerns about providing support for these activities?

- ☐ Yes
- ☐ No ***PLEASE SKIP TO #48***
- ☐ I'm not sure ***PLEASE SKIP TO #48***

47. How did they find out?

- ☐ They asked me, and I told them
- ☐ They asked my older relative, and he/ she told them
- ☐ I told them on my own, without being asked
- ☐ They found out from another doctor

48. Have you tried telling them?

- ☐ Yes
- ☐ No

49. In what ways have they provided assistance? Please select all that apply.

- ☐ They suggested physical resources (e.g. support groups, social worker)
- ☐ They suggested online resources
- ☐ We talked about it extensively
- ☐ They have not provided assistance

50. How much does your older relative's personal doctor help your older relative manage or prepare to manage:

	Not at all	Somewhat	A lot
Medications	☐	☐	☐
Falls	☐	☐	☐
Socializing	☐	☐	☐
Mental health	☐	☐	☐
Medical decision making	☐	☐	☐

Just now, we asked you how much your older relative's personal doctor **does** help them manage various activities. The next question will ask you about how much their personal doctor **should** help them or prepare them to manage these activities.

51. How much **should** your older relative's personal doctor help them manage or prepare to manage:

	Not at all	Somewhat	A lot
Medications	☐	☐	☐
Falls	☐	☐	☐
Socializing	☐	☐	☐
Mental Health	☐	☐	☐
Medical decision making	☐	☐	☐

52. Who helps your older relative make decisions about health and medical care, other than their personal doctor?

☐ They make decisions completely on their own and with their doctor
☐ I'm the only other person who helps them
☐ Another caregiver or relative
☐ Friend or neighbor
☐ Another doctor

Now, we'd like to learn a little bit more about your thoughts on the relationship between your older relative and his or her personal doctor.

Please remember that your responses will not be linked to your name, address, or any other identifying information, and your responses will not change your older relative's treatment or medical care.

IF YOU GO TO THE DOCTOR WITH YOUR OLDER RELATIVE, PLEASE SKIP TO #54.

53. If you don't go to the doctor with your older relative, do they ever tell you about their appointment?

☐ Yes ☐ No ☐ Sometimes

54. **Based on your observations or from what your older relative has told you**, how often do you think their personal doctor does the following:

	Never	Sometimes	Usually	Always
Shows respect for what they have to say	☐	☐	☐	☐
Listens carefully to them	☐	☐	☐	☐
Explains things in a way that you they understand	☐	☐	☐	☐
Spends enough time with them	☐	☐	☐	☐
Is responsive to their concerns	☐	☐	☐	☐

55. **Based on your observations or on what your older adult has told you**, how true are the following statements **in your opinion**?

Your older relative's personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Understands that older adults have unique concerns and need	☐	☐	☐	☐
Is trained in care for older adults	☐	☐	☐	☐
Has been able to correctly diagnose their conditions	☐	☐	☐	☐
Is on the same page as any other doctors they may see	☐	☐	☐	☐
Is dismissive of their concerns because of their age	☐	☐	☐	☐

56. Based on your observations or on what your older adult has told you, how true are the following statements in your opinion?

Your older relative's personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Gives them enough information so they can manage their conditions	☐	☐	☐	☐
Trusts them	☐	☐	☐	☐
Trusts me	☐	☐	☐	☐
Communicates with them too much using technology	☐	☐	☐	☐
Gives attention to both their physical and mental health	☐	☐	☐	☐

57. Based on your observations or on what your older adult has told you, how true are the following statements in your opinion?

Your older relative's personal doctor:

	Not at all true	Somewhat true	Fairly true	Very true
Knows what information is important to tell their other doctors	☐	☐	☐	☐
Probably gives them the same advice that she/ he gives everyone else	☐	☐	☐	☐
Has given up on them	☐	☐	☐	☐
Has the skills to provide good care to someone their age	☐	☐	☐	☐
Gives them resources to go to when they need help or information about their health	☐	☐	☐	☐
Empathizes with the experience of aging	☐	☐	☐	☐

58. How true are the following statements?

I trust my older relative's personal doctor to do what's best for them.

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

59. *I trust that their personal doctor has the skills and training to provide care for them as they grow older.*

☐ Not at all true ☐ Somewhat true ☐ Fairly true ☐ Very true

60. Has your older relative ever switched personal doctors because of any of the following? Please select all that apply.

- ☐ A health or medical related incident or error
- ☐ They felt their doctor was too young to understand their concerns
- ☐ They felt their doctor was not addressing their most pressing concerns
- ☐ Another doctor recommended that they switch doctors
- ☐ Their personal doctor retired, moved away, or passed away
- ☐ They have not switched personal doctors to my knowledge

61. Have you ever encouraged your older relative to switch personal doctors because of any of the following:

- ☐ I have not encouraged them to switch ***IF YOU SELECTED THIS, PLEASE SKIP TO #63***
- ☐ A health or medical related incident or error
- ☐ You felt their doctor was too young to understand their concerns
- ☐ You felt their doctor was not addressing their most pressing concerns
- ☐ Another doctor recommended that they switch doctors
- ☐ Other

62. Did your older relative switch doctors following your encouragement?

☐ Yes ☐ No

63. To your knowledge, what has made your older relative decide not to switch personal doctors?

- ☐ They are satisfied with their current doctor
- ☐ They felt it would be impolite, rude, or disrespectful
- ☐ They didn't want to ruin their relationship with their doctor
- ☐ It would have been too hard to find a new doctor
- ☐ Even though it would have been easy to find another doctor, they just didn't want to
- ☐ It would have been overwhelming
- ☐ They weren't sure a new doctor would be better
- ☐ They didn't see a need to switch doctors
- ☐ Other (please describe):

_____

This section will ask you some questions about a specific type of doctor called a geriatrician.

A geriatrician is a doctor who focuses on the health care of older adults. A geriatrician may do many of the same things as a *general doctor,* may work with a *specialist doctor, or may even be a specialist doctor (such as a geriatric psychiatrist, or a geriatric oncologist)*. Your older relative's personal doctor, who we asked you some questions about before, could be a geriatrician.

64. Is your older relative's personal doctor a geriatrician, OR do they receive regular care from any of the following centers?

Turner Geriatric Clinic (Ann Arbor)
Rosa Parks Geriatric Center (Detroit)
Henry Ford Allegiance Senior Health Center (Jackson)
Hurley Medical Center Geriatric Clinic (Flint)
Ann Arbor Veterans Administration Geriatrics Clinic (Ann Arbor)
Ann Arbor Veterans Administration GeriPACT Clinic (Ann Arbor)

□ Yes □ No, but I think one of their doctors is a geriatrician □ No ***IF NO, PLEASE SKIP TO #67***

65. Please select the response that best describes your older relative's interactions with a geriatrician:

□ Their geriatrician is their personal doctor
□ They see a geriatrician AND another personal doctor, both more than once a year
□ They consider another doctor their personal doctor, but they see a geriatrician for GENERAL care as needed (just once a year)
□ They consider another doctor their personal doctor, but they also see a geriatrician for SPECIALIST care (e.g. a geriatric cardiologist)
□ I'm not sure how often they see a geriatrician

66. What made them decide to see a geriatrician?

□ I suggested it
□ They felt they needed to see a geriatrician
□ Another doctor suggested that they see a geriatrician
□ A friend or other family member suggested that they see a geriatrician
□ Their health plan/ health insurance suggested that they see a geriatrician
□ A social worker or staff member where they live or receive care suggested that they see a geriatrician
□ Other _____

IF YOU ANSWERED #66, PLEASE SKIP TO #68

67. Which of the following best describes why your older relative doesn't seek care from one of these clinics or from a geriatrician:

- □ They were once evaluated by a geriatrician or at one of the four clinics, but was told they didn't need to see a geriatrician regularly
- □ They couldn't get an appointment
- □ They need more information about what a geriatrician does
- □ They didn't want to
- □ I didn't want them to
- □ They haven't considered it
- □ They are satisfied with their current doctor

68. Have you ever encouraged your older relative to see a geriatrician?

□ Yes □ No

69. Have you ever made an appointment with a geriatrician on their behalf?

□ Yes □ No

70. Have you ever given them information about a geriatrician so they could decide whether to see one?

□ Yes □ No

IF YOU ANSWERED "NO" TO ALL OF THE ABOVE (# 68-70), PLEASE SKIP TO #72.

71. Why did you feel your older relative needed to see a geriatrician?

- ☐ I felt their regular doctor wasn't able to help me with my medical concerns
- ☐ I felt their regular doctor did not have enough time for them
- ☐ Other _____

72. Were you aware of what a geriatrician does before taking this survey?

☐ Yes ☐ No

73. Please select the response that fits best as you think about <u>your older relative.</u>

	Yes	No	I'm not sure
My relative is too healthy to see a geriatrician.	☐	☐	☐
It's easy for them to find a dentist where they live.	☐	☐	☐
It's easy for them to access a dentist through their insurance.	☐	☐	☐
It's easy for them to find a geriatrician where they live.	☐	☐	☐
It's easy for them to access a geriatrician through their insurance.	☐	☐	☐

74. Please select the response that fits best as you think about geriatricians and the type of care they provide to people in general. Remember, in these questions are asking about your opinion.

	Yes	No	I'm not sure
Someone should only see a geriatrician if their regular doctor isn't spending enough time with them.	□	□	□
Someone has to be 80 in order to receive care from a geriatrician.	□	□	□
Someone younger than 65 might benefit from seeing a geriatrician.	□	□	□

The next set of questions will ask you about your opinion on how the health care system serves you, your older relative, and others. In these questions, we'd like to know about your thoughts based on your experiences and observations.

75. **In your opinion**, how true are the following statements?

The healthcare system is difficult to navigate.

□ Not at all true □ Somewhat true □ Fairly true □ Very true

76. The current health system is meeting **my needs**.

□ Not at all true □ Somewhat true □ Fairly true □ Very true

77. The current health system is meeting the **needs of most people in my state**.

□ Not at all true □ Somewhat true □ Fairly true □ Very true

78. The current health system is meeting the **needs of my older relative**.

□ Not at all true □ Somewhat true □ Fairly true □ Very true

79. Did any of the following apply to your older relative in the last 6 months? Please select all that apply.

- ☐ Did not get a medication their doctor prescribed due to cost
- ☐ Did not get doctor care that they needed due to cost
- ☐ Had problems paying their medical bills
- ☐ They had to count on you to pay their medical bills
- ☐ Could not get to an appointment or procedure because of transportation issues
- ☐ None of the above apply

Now, we'd like to learn about how you feel about caregiving, or how you would describe what it means to be a caregiver.

---

80. How well do the following statements describe what being a caregiver means to you, based on your experience?

Being a caregiver means:

	Not at all well	Somewhat well	Fairly well	Very well
Sacrifice	☐	☐	☐	☐
Being a friend	☐	☐	☐	☐
Patience	☐	☐	☐	☐
Selflessness	☐	☐	☐	☐
Giving dignity	☐	☐	☐	☐
Responsibility	☐	☐	☐	☐
Being a translator	☐	☐	☐	☐

81. How well do the following statements describe what being a caregiver means to you?

Being a caregiver means:

	Not at all well	Somewhat well	Fairly well	Very well
Lifting spirits	□	□	□	□
Witnessing triumphs	□	□	□	□
Managing	□	□	□	□
Being a servant	□	□	□	□
Financial planning	□	□	□	□
Anxiety	□	□	□	□

82. How well do the following statements describe what being a caregiver means to you?

Being a caregiver means:

	Not at all well	Somewhat well	Fairly well	Very well
Being maternal	□	□	□	□
Coordinating	□	□	□	□
Doing the right thing	□	□	□	□
An obligation	□	□	□	□
Giving back	□	□	□	□
Cultural expectation	□	□	□	□

83. How well did these statements align with how you had thought about caregiving before taking this survey?

□ Not at all □ Somewhat well □ Fairly well □ Very well

84. Is there anything else you'd like to add to describe what it means to be a caregiver?

_____

85. When did you first realize you would be a caregiver? Please select all that apply.

□ During childhood (before 18 years old)
□ After age 18
□ Following my older relative's hospitalization
□ Following my older relative's medical diagnosis
□ Following a visit home
□ When my older relative asked me
□ When another relative suggested it
□ When a doctor suggested it
□ When their friend or neighbor suggested it
□ Cultural expectation
□ I felt responsible for my relative
□ No one else was available
□ It felt like the right thing to do
□ Other (please describe):

_____

86. How often did you engage in the following activities in the past two weeks?

	< 2	2-4	5-7	8 or more
Exercise	□	□	□	□
Prepare a meal from scratch	□	□	□	□
Manage my stress (e.g. meditate)	□	□	□	□

How well do the following statements apply to you?

87. Being a caregiver has motivated me to **exercise.**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

88. Being a caregiver has motivated me to **eat healthy**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

89. Being a caregiver has motivated me to **manage stress (e.g. meditate).**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

How well do the following statements apply to you?

90. Being a caregiver has prevented me from **exercising.**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

91. Being a caregiver has prevented me from **eating healthy.**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

92. Being a caregiver has prevented me from **managing stress (e.g. meditating).**

□ Not at all well □ Somewhat well □ Fairly well □ Very well

Now, we'd like to learn about how you feel about aging, or how you would describe what it means to age, in your opinion.

93. In your opinion, how well do the following statements describe what aging means to you?

Aging:

	Not at all well	Somewhat well	Fairly well	Very well
Brings freedom	☐	☐	☐	☐
Requires being more cautious	☐	☐	☐	☐
Brings a loss of control	☐	☐	☐	☐
Is natural	☐	☐	☐	☐
Can be prevented	☐	☐	☐	☐
Brings respect	☐	☐	☐	☐
Is a burden	☐	☐	☐	☐

94. How well do the following statements describe what aging means to you?

Aging:

	Not at all well	Somewhat well	Fairly well	Very well
Can be treated	☐	☐	☐	☐
Is misunderstood	☐	☐	☐	☐
Should be prevented	☐	☐	☐	☐
Is something you look forward to	☐	☐	☐	☐
Is something you worry about	☐	☐	☐	☐
Means relying on someone else	☐	☐	☐	☐
Is not a medical condition	☐	☐	☐	☐
Could be made a better experience by society	☐	☐	☐	☐

95. How well do the following statements describe what aging means to you?

Aging means:

	Not at all well	Somewhat well	Fairly well	Very well
Losing dignity	□	□	□	□
Being outdated	□	□	□	□
Developing wisdom	□	□	□	□
Being lonely	□	□	□	□
Embarrassment	□	□	□	□
Being more aware of time	□	□	□	□

Now, we'd like to learn more about how you feel, in general.

96. How much do you agree with the following statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I enjoy my life overall	☐	☐	☐	☐	☐
I look forward to things	☐	☐	☐	☐	☐
I am healthy enough to get out and about	☐	☐	☐	☐	☐
My friends, family, or neighbors would help me if needed	☐	☐	☐	☐	☐
I have social or leisure activities/ hobbies that I enjoy doing	☐	☐	☐	☐	☐
I try to stay involved with things	☐	☐	☐	☐	☐
I am healthy enough to have my independence	☐	☐	☐	☐	☐
I feel safe where I live	☐	☐	☐	☐	☐
I get pleasure from my home	☐	☐	☐	☐	☐
I take life as it comes and make the best of things	☐	☐	☐	☐	☐
I feel lucky compared to most people	☐	☐	☐	☐	☐

I have enough money to pay for household bills	□	□	□	□	□

97. Overall, how would you rate your health in the past 4 weeks?

□ Excellent □ Very good □ Good □ Fair □ Poor □ Very poor

This is the last section of the survey that will help us get a little more information about you.

98. What is your age (in years)?

_____

99. What sex do you identify with?

□ Male □ Female □ Other

100. Are you of Hispanic, Latino, or Spanish origin?

□ Yes
□ No

101. What race do you identify with? Please select all that apply.

□ White
□ Black or African American
□ American Indian or Alaska Native
□ Asian
□ Native Hawaiian or Pacific Islander
□ Multiracial

102. What is the highest degree or level of school you have completed?

□ Less than a high school diploma
□ High school degree or equivalent (e.g. GED)
□ Some college, no degree
□ Associate degree
□ Bachelor's degree
□ Master's degree
□ Professional degree (e.g. MD, DDS)
□ Doctorate (e.g. PhD, EdD)

103. What is your current employment status?

□ Employed □ Full-time □ Part-time
□ Student
□ Retired from career, but returned to work
□ Retired
□ Veteran
□ Unable to work

104. What is your current marital status?

□ Married
□ Living with partner
□ Divorced/ separated
□ Never married
□ Widowed
□ Prefer not to answer

105. How many children do you have?

□ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 or more

106. How many grandchildren do you have?

□ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 or more

107. What zip code do you live in?

_____

108. What type of place do you live in?

□ House
□ Apartment/ Condo
□ Retirement community
□ Assisted living facility
□ Nursing home
□ Other long term care facility
□ Other _____

109. How many others are in your household (not including yourself)?

□ I live alone □ 1 other □ 2 others □ 3 others □ 4 others □ 5 or more others

110. Please indicate whether the following statements apply to you.
In the past 12 months:

	Yes	No
I worried whether my food would run out before I got money to buy more	□	□

111. To what extent does the following statement apply to you?

	Always	Often	Sometimes	Rarely	Never
I have money left over at the end of the month	□	□	□	□	□

112. Please indicate how you completed this survey.

□ Paper and pen / pencil (in person)
□ iPad (in person)
□ Someone read the questions to me and circled my responses
□ Computer
□ Paper and pen / pencil (mail)
□ Phone

113. Do you have any comments you would like to share about health care needs of your older relative or your needs as a caregiver, or additional information you would like to provide about any of your responses?

_____

_____

114. Were there any terms used in this survey that you did not understand?

_____

_____

Thank you for participating in the survey! Once we receive your survey packet, we'll mail you compensation for your time!

C.3 Interview protocol for medical trainees

Internal Medicine Residents: Semi-Structured Interview Protocol

Introduction:
Thank you for taking time to meet with me. For my dissertation, I am studying geriatric care through three perspectives: patients, caregivers, and providers. As you may know, the population of older adults in the U.S. is rapidly increasing, but the supply of geriatricians is simultaneously approaching a significant shortage—over 20,000 relative to expected demand. As an internal medicine resident, you offer an extremely valuable perspective as a physician who is beginning to specialize in a particular area of medicine, and may choose to further sub-specialize. So, I would like to ask you some questions about your experiences during your residency training, with particular attention to your experience with selecting a subspecialty (or how you decided not to, if that is the case), what factors are especially important in influencing your selection as you think about subspecialties, and your perspective on geriatrics and models of care for older adults. This interview is voluntary, and you are free to end it at any time or to skip any questions you would prefer not to answer. With your permission, I will record and transcribe our conversation, but what you share will only be seen by myself and a professional transcription service; any quotations that may be used will not include your name, program, or any information that could be identifying. The interview will take about 45 minutes. Shall we begin?

Section 1. Past

- Can you tell me a little bit about your journey to becoming a physician?
    - What sparked your interest in medicine? When did you initially become interested?
    - What types of formal or informal experiences related to medicine or caregiving—e.g., volunteering, internships, family caregiving, etc.—did you engage in before joining medical school?
    - Were you supported in your pursuit of a career in medicine?
- Can you tell me a little bit about why you chose internal medicine for residency?
- Did you ever change your mind or consider another residency program (or other career) during medical school? Why?

Section 2. Present

I understand from our [email/phone] conversation that you are a [Xth] year resident.

- Can you tell me a little bit about why you chose internal medicine?
- How has your experience been in the residency program so far?
    - How would you describe the level of exposure you have had, to a variety of subspecialties?
    - How has being at [institution] shaped your exposure to patients across these subspecialties you mentioned above, as well as exposure to mentorship?
- Who are your top three mentors, and what makes them a good mentor for you?

Section 3. Future

- What are your plans for next year?
    - Do you plan to pursue a fellowship?
        - If so, which subspecialties are you considering and why?

- Who has been involved in your consideration of various subspecialties?
    - [E.g. may be family, peers]
- How supportive are your fellow residents as you consider these subspecialties? For example, maybe you have felt or feel peer pressure, or that others look down on the options you are considering?

Section 4. Medical Profession

- What does 'being a doctor' mean to you?
- Has your perspective on this changed drastically at any point?
- What and/or who has been most influential in your perception of what it means to be a doctor?
- How do you think your definition of being a doctor is similar to or different from those of your resident colleagues?
- What types of tasks, activities, or practices do you look forward to engaging in as a doctor?
- What types of outcomes do you expect for your patients? What types of outcomes, when you observe your patients, do you believe will make you feel most that you have fulfilled your definition of being a doctor?

Section 5. Geriatrics

Knowledge and Exposure

- Can you describe geriatrics in just a couple sentences, perhaps including the role or responsibilities of practicing geriatricians?
- Can you describe the training you have received thus far related to geriatrics, specifically; and care of older adults, more generally?
- What are the major distinctions between and considerations for caring for older adults versus caring for adults in general (i.e., anyone >18)?

Geriatrics Interest and Considerations

- Have you ever considered subspecializing in geriatrics? [Why or Why not?]
- If yes, were/ are you considering subspecializing in geriatrics to:
    - [Become a geriatrician and care exclusively for older adults
    - Become a primary care physician with an additional area of expertise in geriatrics
    - Become a hospitalist and care for older adults in an inpatient setting]
- Can you describe a few factors that have motivated your interest in geriatrics, and a few factors that have discouraged you from geriatrics?
    - [If it does not come up naturally, ask specifically about financial incentives]

Improving Programs, Policies, and Care

- What are some changes that [X INSTITUTION] can make to generate interest in geriatrics?
- What are some policies that will generate interest and greater consideration of geriatrics among physician trainees?
- What do you believe are some of the potential solutions to ensuring high quality care for older adults in the U.S.?

Is there anything I did not ask you about but should have?

Appendix D: Chapter 3 Supplementary Analyses

I conducted additional descriptive analyses to identify areas for future research. These statistics reflect responses from older adults (n=135) and family caregivers (n=139) with complete responses to items used in Chapter 2. There was still some missingness for items reported here; however, I report for purposes of exploring the different types of responses given. First, I examined *loyalty* using two measures. The first, was one item wherein older adults and family caregivers reported how long they had been enrolled in care with their current physician. The second item asked participants whether they had ever switched physicians, and if not, why not. Results are provided in Table D.1.

Table D.1 Assessment of loyalty among older adults and family caregivers' older relatives

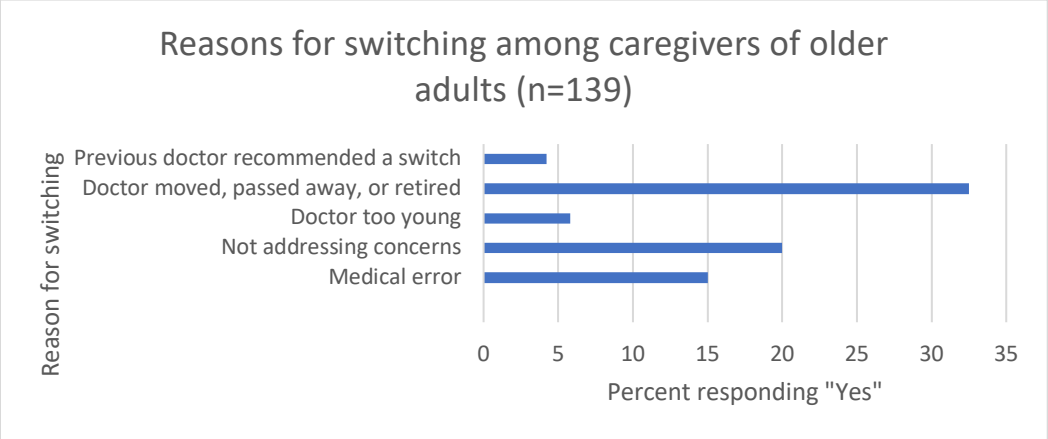
Item	Older adults (n=143)	Family caregivers responding about their older relative (n=139)
Duration of enrollment with current physician		
Less than five years	64 (44.8)	67 (48.2)
Five or more years	79 (55.2)	72 (51.8)
Switched doctors (ever)	65 (45.5)	69 (58.5)

Duration of enrollment with current physician. Among older adults, 55.2% had been under the care of their current physician for five or more years; just over half (51.8%) of family caregivers reported that their older relative had been enrolled in care with their current physician for five or more years. The proportion was the same just among caregivers' older relatives who are enrolled in geriatric care.

Reasons for considering switching physicians among older adults. I asked older adult participants if they had considered switching doctors to understand reasons even among those who had not actually switched. Though this was not an option in the given set of possible responses from which participants could select one or more reasons for considering switching, almost one quarter (n=31) of participants wrote comments in the subsequent open-ended response box describing reasons for considering switching that were consistent with issues participants described in Chapter 2 (e.g. feeling that their doctor did not respect or listen to them; trouble making diagnoses; challenges with using technology; and distance to their provider's office). Participants also reported reasons such as medical errors (n=9), not addressing the most pressing concern (n=4), doctor moving, retiring, or passing away (n=31), or a previous doctor recommending switching (n=4). Just two participants responded that they felt their doctor was too young, but one more wrote that their doctor primarily saw students as patients and that the doctor was not as comfortable with older patients. Three participants reported that a relative suggested they switch doctors.

Reasons for older adult switching providers, indicated by family caregivers. More than half of caregivers (58.5%) of caregivers responded that their older relative had ever switched doctors due to issues with their previous physician such as a medical error, their doctor moved or retired or passed away, or because they felt their doctor was too young or was not addressing their concerns. In Figure D. I illustrate the prevalence of reasons for switching doctors among older relatives of caregiver respondents. Among caregivers of older adults, the most common reason for switching doctors (at any point, not necessarily to a geriatrician) was a medical error (28%).

Figure D.1 Reasons for switching doctors among caregivers of older adults



Note: Respondents could select multiple reasons

Why not enroll in geriatric care? Among older adults, reasons for not enrolling in geriatric care included being satisfied with their current physician (n=82), not having considered geriatric care (n=35), needing more information about what a geriatrician does (n=10), being evaluated by a geriatrician and then told they did not need to see a geriatrician, or, not getting an appointment (n=5), and, not wanting to see a geriatrician (n=2).

Among caregivers who responded to the question asking why their older relative did not enroll in geriatric care, reasons for not older relatives not enrolling in geriatric care included being satisfied with their current physician (n=60), not having considered geriatric care (n=23), not wanting to see a geriatrician (n=13), needing more information (n=8), and, being evaluated and then told they did not need to see a geriatrician or, not getting an appointment (n=4). One caregiver reported not wanting their older relative to see a geriatrician.

Caregiver role in facilitating care-seeking from a geriatrician. I asked caregivers whether they had either: (1) encouraged their older relative to see a geriatrician; (2) made an appointment with a geriatrician on their behalf; or (3) given their older relative information about a geriatrician so

they could decide whether or not to see one. About one-quarter (25.9%) of caregivers had encouraged their older relative to see a geriatrician; 15.1% had made an appointment with a geriatrician on their behalf. Just under one-quarter (23%) had given their older relative information about a geriatrician.

Health status of caregivers. There is an imperative to support family caregivers, and while as a cross sectional study there is no way to know whether caregivers' self reported health status can be attributed to their caregiving responsibilities, I assessed health status of caregivers to explore potential for research and policy supporting the health of caregivers, for example, through integrated health care visits, or through geriatric service support or other programs for older adults with spillover effects onto caregivers. In this sample, 22.5% of family caregivers reported very poor, poor, or fair health; 31.9% reported good health status, and just under half (45.7%) reported being in very good or excellent health.

Additional measures of perceived value of geriatric care. I asked older adults and family caregivers three additional questions to assess for whom geriatric care may be valuable in addition to the item used as an outcome variable in logistic regression models in Chapter 3. First, I asked whether someone should only see a geriatrician if they are over 80. Only 2.9% of older adults and 7.2% of family caregivers reported "Yes" for this item.

Next, I asked if someone under 65 might benefit from seeing a geriatrician. Over half (59.9%) of older adults and nearly half of family caregivers (46%) reported "Yes" for this item. In addition, I asked if someone should only see a geriatrician if their current doctor is not spending enough time with them. To this, 13.6% of older adults and 20% of family caregivers responded "Yes".