A FAMILY-CENTERED APPROACH TO PRIMARY CARE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENT

By

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Cognitive impairment (e.g., dementia) presents challenges for individuals, their families, and healthcare professionals alike. It disproportionately impacts minoritized communities and often goes unassessed or undiagnosed, leaving missed opportunities for treatment and the use of supportive services for family caregivers. The primary care setting presents a unique opportunity to care for older adults living with cognitive impairment, who present with complex care needs that may benefit from a family-centered approach. An in-depth systemic review revealed that family-centered care and family engagement yields promising results including improved health outcomes, quality care, the patient experience, and caregiver satisfaction. Furthermore, it promotes and advances the core values of medical family therapy: agency and communion. An original quantitative study surveying 45 PCPs was conducted to better understand the influence of family engagement, race, and gender on primary care providers' (PCPs) diagnostic management and decision-making practices with older adults exhibiting cognitive impairment. Utilizing a vignette-based methodology, results revealed three main findings: (a) family engagement provides an opportunity for more efficient and accurate identification and diagnostic process for cognitive impairment, (b) family engagement allows for a clearer picture of patient symptoms and may present opportunities for PCPs to refer to specialists for diagnosis and treatment earlier, and (c) family engagement provides an opportunity to reduce health inequities by reducing variations in PCP perceptions of symptoms influenced by implicit bias. Recommendations for clinical care, training, and policies in primary care settings are provided using CJ Peek’s Three World View. This dissertation further advances the knowledge of family-centered primary care, and influence of provider bias, when designing systems of care for older adults with cognitive impairment and their families.

A FAMILY-CENTERED APPROACH TO PRIMARY CARE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENT

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By

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DEDICATION

Joshua, thank you for joining me on this adventure. I will never forget how supportive you have been of me pursuing this degree from day one when I called you from Indianapolis to tell you that I had found *my people*. You have encouraged me, pushed me, and held me through. I could not have done this without your unwavering support and love. Thank you for the sacrifices you have made as I have followed my dreams. I am so excited for our next chapter together.

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PREFACE

I have a passion for helping families through hurt and struggles, which I initially expected to do through private practice as a marriage and family therapist. However, I encountered several challenges both personally and professionally that led me in a different direction. Through a combination of watching my grandfather receive referrals from one specialist to another, my younger sister receiving a diagnosis of a chronic autoimmune disease, and my work in healthcare services research, I found that I was more passionate about improving the healthcare system than anything else. I became fervent about finding opportunities to enhance the delivery of mental and behavioral health services in traditional medical settings (e.g., primary care), increasing access to mental health care, and improving health equity for underserved populations. This is what led me to pursue a doctoral degree in medical family therapy at East Carolina University.

As I considered how I could have the most meaningful influence in the field of medical family therapy, I found Patient- and Family-Centered Care (PFCC; Johnson & Abraham, 2012). I experienced this approach to health care as both impactful and relatable. I deeply appreciated the core values of PFCC: dignity and respect, information sharing, participation, and collaboration. I found these values were directly aligned with the core values of medical family therapy (i.e., agency and communion; McDaniel, Hepworth, & Doherty, 1992) as well as my personal values of family, service, and advocacy. I knew that I wanted to find a way to improve how families were cared for and engaged by the healthcare system. I had seen opportunities for improvement through my family's experiences in primary, secondary, and tertiary care settings, and I wanted to help make a difference.

I learned through the early stages of the dissertation process that PFCC had been heavily researched in pediatrics and specialty services (e.g., cancer care), but there was a dearth of understanding about the engagement of families with older adults in the primary care setting. Furthermore, I found that the research that existed in this area had focused on engaging family members who were able to accompany older adults to their care visits. Yet, I knew from my family's experience that this was not always possible and that family members could still provide meaningful and helpful information from outside of the primary care visit.

Additionally, I observed how the lack of communicating with a family member could make identification of cognitive impairment more difficult for medical providers as I watched this unfold in a training setting with first-year medical students. During one of our small-group sessions with a standardized patient, the patient's spouse was not present and therefore their portion of the training script was omitted. This prevented the medical students from identifying the root cause of the symptoms described by the standardized patient (i.e., probable dementia) and led them astray to focus on other possible (yet incorrect) diagnoses. Through a discussion about this troubling event with my advisor and chair, Dr. Jennifer Hodgson, we realized this was a unique opportunity to demonstrate the usefulness of family engagement in the diagnostic, management, and treatment processes of older adults with cognitive impairment. I decided this was where I could provide the most help.

Through this dissertation process, I have focused on how to engage families in a manner that respects the agency of older adults and encourages communion by convening members of the support system and helping them to feel cared for, loved, and supported by the systems surrounding them. PFCC provides a vision of how this effort can succeed in the primary care setting. This body of work now provides evidence of the benefit of family engagement with older adults experiencing cognitive impairment. I also learned more about the difficult challenges presented by cognitive impairment and have provided evidence-based recommendations for primary care providers that will aid them in their deliver of care with this population. I hope my research provides an avenue for more effective and efficient care of older adults with cognitive impairment and their families.

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CHAPTER 1: AN INTRODUCTION TO FAMILY-CENTERED PRIMARY CARE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENT

Up to 20% of the older adult population (i.e., aged 65 and older) experiences at least mild cognitive impairment (Langa & Levine, 2014) and current threats to cognitive health (e.g., COVID-19) are leading to heightened rates of dementia diagnoses (Taquet et al., 2020). These increased concerns for cognitive impairment are worrisome, but diagnosing, managing, and treating cognitive impairment in older adults is not a new challenge for healthcare providers (Petersen, 2011). A cognitive impairment diagnosis (e.g., dementia, Alzheimer's Disease) leads to challenges with independently engaging in one's care compared to non-cognitively impaired peers (Wolff et al., 2016) and difficulties reporting accurate medical and psychosocial histories to one's healthcare provider (Adams et al., 2005). Therefore, older adults with cognitive impairment often rely on the support of family caregivers to help with these tasks, as well as daily activities and self-care needs. This can quickly become burdensome and difficult for caregivers (Wang et al., 2018). Consequently, it is important to attend to the needs of both patient and family in the care of older adults with cognitive impairment. Additionally, healthcare providers must be aware of the disproportionate impact of cognitive impairment on minoritized populations as not everyone experiences it equally; cognitive impairment rates and services received vary among social locations (Langa & Levine, 2014).

Health Disparities and Cognitive Impairment

It is increasingly important to understand how rates of cognitive impairment differ among social locations as the older adult population grows more racially and ethnically diverse (Schulz & Eden, 2016). The rate of cognitive impairment disproportionately impacts minoritized populations (e.g., African Americans; Katz et al., 2012). A recent study found that non-Hispanic

Black patients are twice as likely as non-Hispanic white patients to experience underdiagnosis of cognitive impairment (i.e., dementia; Gianattasio et al., 2019). Additionally, women are twice as likely to develop certain types of dementia (e.g., Alzheimer's Disease; Podcasy & Epperson, 2016; Seshadri et al., 1997) than men. Social factors, such as where patients live (i.e., rural areas) and education levels (i.e., fewer years of formal education) also increase the rates of developing cognitive impairment (Russ et el., 2012). It is at the intersection of these different social identifies (e.g., age, race, educational level, geographic location) where the devastating impacts become even more evident and innovations in care are essential.

Patients with intersecting social locations placing them at higher risk of developing cognitive impairment (e.g., Black women with lower levels of education) are vulnerable to experiencing multiple layers of systemic oppression in the healthcare system. Attention to the social location of demographics and rates of cognitive impairment through the lens of Intersectionality (Crenshaw, 1989) are valuable for healthcare providers to consider when caring for older adults with cognitive impairment and their families. An intersectional lens allows for examination of the complex and compounded interactions of social locations (e.g., race, gender, educational level) that is fluid and interrelated, rather than assuming a set level of aggregated discrimination (Heard et al., 2020). This lens has been used in previous health research to examine healthcare experiences of minoritized populations (e.g., sexual health of women with disabilities; Dean et al., 2017) and health inequities (e.g., higher risk for developing COVID-19 and less access to resources due to gendered racism; Laster Pirtle & Wright, 2021). Additionally, a family-centered approach to care provides an opportunity to attend to issues of power, context, and agency that influence the healthcare experience for patients and families (Ocloo et al., 2020).

Family-Centered Approaches to Care with Older Adults

Patient- and family-centered care (PFCC; Johnson & Abraham, 2012) is a healthcare strategy designed to improve the healthcare experience for patients with complex health conditions and their family members (Jennings et al., 2017). Based on the Institute of Medicine's (2001) emphasis on the value of relationships and family perspectives, this approach is particularly beneficial for vulnerable populations in which patients are unable to engage in their care or adhere to treatment plans to the same extent without the support of family caregivers (Kokorelias et al., 2019). Older adults with cognitive impairment are vulnerable patients as cognitive impairment inhibits patients' memories, thinking, and decision-making abilities (CDC, 2014).

Of note, researchers have primarily focused on the *family* engagement component of PFCC in pediatric settings in which the healthcare team partners with parents (Cené et al., 2016). A systematic review of family-centered care for children with complex healthcare needs (e.g., chronic health conditions, asthma) resulted in overwhelming support for family engagement: increased service use efficiency, improved patient health status, better access to care, enhanced communication, improved family functioning, and lower healthcare costs (Kuhlthau et al., 2011). However, few studies examined the family engagement component with older adults whose family members may include adult children, friends, neighbors, or other informants (Welch et al., 2021).

The Institute of Medicine (2012) recommended healthcare systems implement PFCC by partnering with patients and families to improve safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. This effort resulted in positive outcomes that included improved access to healthcare services, enhanced patient-provider communication, and higher-quality care (Lebrun-Harris et al., 2013). Over the years, PFCC has expanded beyond pediatrics (Clay & Parsh, 2016) and grown its presence in primary care settings (e.g., patient-centered medical home; Stange et al., 2010).

Primary Care Settings as a Landscape for Family-Centered Care of Older Adults

Older adult patients with cognitive impairment are frequently cared for in the primary care setting (Lugo-Palacios & Gannon, 2017; Wübbeler et al., 2017). However, primary care providers (PCPs; e.g., family physicians, physician assistants, nurse practitioners) have reported uncertainty regarding when and how to discuss cognitive impairment with patients and families (Brazil et al., 2015). Therefore, it is important for healthcare providers, policy makers, and researchers to better understand how to utilize PFCC in primary care for the benefit of older adults with cognitive impairment and their families.

Between 30-40% of older adult patients routinely bring a family member with them to their healthcare visits, particularly when they have more complex healthcare needs (Wolff & Roter, 2011). When families are engaged in care, PCPs provide more biomedical information and patients report feeling more supported (Wolff & Roter, 2011). Furthermore, when families are engaged in the care of older adults with cognitive impairment, there is improved satisfaction among patients and their caregivers (Adams et al., 2005; Schmidt et al., 2009; Shega et al., 2003). Despite these promising findings, evidence for the effectiveness of family engagement in primary care remains scant (Cené et al., 2016). Cené and colleagues (2016) argued for further exploration of family engagement as it has the potential to support favorable outcomes and be conducive to quality improvement in primary care settings.

According to the Institute for PFCC, primary care is an ideal landscape for the implementation of family-centered care and family engagement practices (IPFCC, 2016). PCPs who provide care at this level include physicians (i.e., general, family, internal, geriatrics, or gynecological medicine), nurse practitioners, and physician assistants. These providers are trained to address a variety of healthcare needs for patients and families across the lifespan. PCPs provide both diagnostic care and ongoing treatment of cognitive impairment and any comorbid conditions (Bunn et al., 2016). The following sections describe primary care as an ideal setting for addressing cognitive impairment with patients and their families and challenges presented within this context.

Cognitive Impairment among Older Adults in Primary Care

Most older adults are given a cognitive impairment diagnosis by a physician who does not specialize in dementia (e.g., family medicine doctor; Drabo et al., 2019). As an individual's cognitive impairment worsens, they lose their ability to conduct instrumental activities of daily living (IADLs; e.g., shopping, cooking) before basic ADLs (e.g., eating, bathing). Community-dwelling older adults with cognitive impairment are less active and engage in less positive health behaviors (e.g., receive influenza vaccination, breast or prostate cancer screenings) compared to individuals without cognitive impairment (Kang, 2018). Due to these complexities, providers who see patients with cognitive impairment more routinely (i.e., PCPs), and who practice from a family-centered approach, may be the best to address the needs of these patients and their families (Bayliss et al., 2020).

PCPs must be aware of common issues such as identifying and treating chronic conditions (e.g., dementia, diabetes), attending to safety (e.g., preventing falls), and managing ongoing care (e.g., complex medication regimens, polypharmacy) that impact older adults and their families (Thompson et al., 2016). Given that cognitively impaired older adults often first present memory or related concerns in primary care, PCPs are well suited to detect and address it

(Alzheimer’s Association, 2017). One study found that over 60% of older adults discussed memory concerns in initial primary care visits, while 30% of those who did not discuss memory concerns reported they would have liked to (Adelman et al., 2004). Additionally, Adelman and colleagues found that family engagement (i.e., caregiver accompaniment to the initial healthcare visit) was a predictor of having discussions with PCPs regarding memory concerns (2004). However, there are no known studies on the application of PFCC with older adults experiencing cognitive impairment in primary care settings and how patients’ social locations intersect and impact family engagement protocols and policies.

Dissertation Purpose

This dissertation was designed to better understand how PCPs deliver patient- and family-centered care with cognitively impaired older adult patients. A combination of PFCC (Johnson & Abraham, 2012) and Intersectionality Framework (Crenshaw, 1989) were used as theoretical foundations for the dissertation study. Researchers aimed to understand: (a) how family engagement influenced the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment, and (b) how the intersecting social locations (i.e., race and gender) of patients related to PCP diagnostic and decision-making processes. First, a systematic review was completed to understand known outcomes of family engagement with older adults exhibiting cognitive impairment in primary care settings (i.e., Chapter 2). Then, a critical review was conducted to further understand how PFCC (Johnson & Abraham, 2012) and intersectionality (Crenshaw, 1989) frameworks help advance what is known about the care of older adults experiencing cognitive impairment among various social locations (i.e., Chapter 3). These two reviews helped to guide the design of the original quantitative research study on how PCPs approach the care of older adults with cognitive impairment when family engagement and social location variables are introduced (i.e., Chapter 4). Findings from the original study were presented in the form of a publishable manuscript (i.e., Chapter 5). Results from this dissertation were utilized to inform and develop a guide for PCPs using Peek's Three World View (2008) which included evidence-based recommendations for engaging families when working with this population (i.e., Chapter 6). These contributions will help to improve the quality of care for older adults with cognitive impairment and their families.

This dissertation's purpose also aligned with the primary goals of the field of medical family therapy (MedFT): to promote agency and communion (McDaniel, Hepworth, & Doherty, 1992) and to assist MedFTs in implementing family-centered care models in primary care settings with older adults experiencing cognitive impairment. MedFTs promote agency and communion by eliciting the expertise of the patient and family regarding their illness experience. Agency helps patients and families to address health needs related to illness, the healthcare system, and their communities, while communion involves fostering relationships, convening members of the family's support system, and helping members of the system to feel cared for and supported by the systems surrounding them (McDaniel, Doherty, and Hepworth, 2014). MedFTs contribute to these goals and the adoption of PFCC models with this patient population through influential research, policy development, and training of PCPs from this family-centered approach. The dissertation presented has helped to expand the reach of MedFT values in primary care settings with cognitively impaired older adults.

Summary of Dissertation Chapters

This dissertation includes the following six chapters: (a) an introduction chapter to the family-centered approach to primary care for older adults, (b) a systematic literature review, (c) a critical literature review, (d) a methodology chapter describing the original research study, (e) results from the original study and a discussion of the contributions to the field with recommendations for future research, and (f) a guide for physicians offering practical recommendations for PCPs to advance the practice of family-centered care.

The second chapter is a systematic review of studies examining outcomes of family engagement practices in primary care for older adults with cognitive impairment. The three aims of this review were to: (a) identify the ways in which families of older-adult patients with cognitive impairment are engaged in primary care settings, (b) examine the outcomes of family engagement practices, and (c) organize and discuss the findings using Peek's Three World View (2008). Researchers searched PubMed, Embase, and PsycINFO databases through July 2019. The results included 22 articles out of 6743 identified in the initial search. Researchers provided a description of the emerging themes for each of the three aims. Findings of the review revealed favorable outcomes of family engagement in primary care when addressing cognitive impairment including improved satisfaction with patient care and reduced caregiver stress. It also exposed the inconsistent application of family-centered practices (e.g., communication with accompanying family in primary care visits, providing education, encouraging resource utilization) and the need for improved interprofessional education of PCPs to prepare multidisciplinary teams to deliver family-centered care.

The third chapter provides a review of the critical literature relevant to a diverse population of older adults with cognitive impairment in primary care settings and the potential of a family-centered approach to their care. This review was conducted through the lens of family-centered (Johnson & Abraham, 2012) and intersectionality frameworks (Crenshaw, 1989). Results from these reviews (i.e., Chapters 2, 3) highlighted the need for additional research regarding family engagement for this vulnerable population and laid the foundation for the development of an original research study.

The fourth chapter describes the design of a vignette-based methodology and analysis plan for an original quantitative research study. Researchers designed the study to answer the following research questions: (a) How does the inclusion of family-provided information influence the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment? (b) To what extent does the race and gender of patients influence the diagnostic and decision-making processes of PCPs? Researchers utilized a quantitative vignette-based survey methodology (Finch, 1987) and analyze data using various statistical analyses.

The fifth chapter includes the results of the original study and a discussion of the results, including evidence-based recommendations for future research. The purpose of the original research study was to expand knowledge of (a) how family engagement influences the way in which PCPs identify, diagnose, and manage cognitive impairment in older adults, and (b) whether patient race and gender influence these diagnostic and decision-making processes. Data were quantitatively analyzed using various statistical analysis of providers' decision-making and diagnostic pathways (e.g., identification of cognitive impairment, decision to communicate with family, referring to specialists). Three main findings were reported: (a) family engagement provided an opportunity for more efficient and accurate identification and diagnostic process for cognitive impairment, (b) family engagement allowed for a clearer picture of patient symptoms and presented opportunities for PCPs to refer to specialists for diagnosis and treatment earlier, and (c) family engagement provided an opportunity to reduce health inequities by reducing variations in PCP perceptions of symptoms influenced by implicit bias. The findings have improved understanding of how engaging families influences the diagnostic, management, and referral practices of PCPs. It has also helped to expose the possible influence of racial and gender biases in PCPs' perceptions of cognitive impairment symptoms. These findings aligned with the larger aim of the dissertation to promote quality care for older adult patients with cognitive impairment, their families, and to utilize the perspectives of PCPs to do so.

Finally, the sixth chapter includes a guide for family physicians centered on four major evidence-based arguments for engaging and communicating with family when caring for older adults with suspected or known cognitive impairment. It offers concrete and specific recommendations for primary care practices that may guide clinical, training, and policy improvements toward enhancing the care of this patient population and better engaging their families. These recommendations are presented using Peek's Three World View (2008) to attend to the clinical, operational, financial, and training worlds found in healthcare settings.

Conclusion

The purpose of this dissertation was to better understand the influence of family engagement on PCPs' diagnostic and decision-making practices when caring for older adults with cognitive impairment in primary care. The impact of this work will enable researchers and providers to collaboratively improve the care of older adults with cognitive impairment and their caregivers. It will also help to strengthen curriculum used to prepare providers for serving older adults with cognitive impairment and engaging with their families. It is hoped that the culmination of these efforts will lead to a more inclusive and patient- and family-centered healthcare system.

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CHAPTER 2: OUTCOMES OF FAMILY ENGAGEMENT IN PRIMARY CARE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENT: A SYSTEMATIC REVIEW

Older-adult patients with cognitive impairment (CI; e.g., dementia) utilize healthcare services more often than their non-cognitively impaired peers (St-Hilaire, 2016) and families frequently participate in their health care (Wolff et al., 2016). Unfortunately, families and healthcare providers have reported dissatisfaction with the quality of treatment and management of CI for decades (Boise et al., 1999; Caruana-Pulpan, 2014). This dissatisfaction includes frustration with poor communication and inefficient execution of assessment and diagnostic processes (Pathak & Montgomery, 2015). Providers identified insufficient time and support for these patients as primary concerns in their practice (Skibitsky, 2016) and suggested that improved standardized practice would be beneficial (Strivens & Craig, 2014). Existing literature has also emphasized the need for more effective assessment and improved diagnostic efficiency of CI (Seematter-Bagnoud & Büla, 2018). However, a thorough understanding of the care strategies that successfully facilitate these processes and their associated outcomes is missing.

The implementation of patient- and family-centered care (PFCC; Johnson & Abraham, 2012), may provide hope for improving the care of patients and families facing CI (Jennings et al., 2017). Yet, despite recommendations for healthcare systems to implement PFCC from notable organizations including the American Medical Association (AMA, 2015; Millenson et al., 2016), the absence of existing standard protocols results in providers engaging families according to their discretion (Sivananthan et al., 2013). Consequently, the way families are engaged (e.g., phone calls, in-person visits, decision making, care training) varies greatly across healthcare settings (e.g., primary care, nursing homes, hospitals) and among providers (e.g., family physicians, geriatric specialists, nurse practitioners). The development of clearly defined evidence-based standard practice requires an improved understanding of the evidence for PFCC with CI and its associated outcomes.

Patient- and Family-Centered Care (PFCC): A Vision

Researchers and policymakers identified PFCC as the future of healthcare delivery (Clay & Parsh, 2016). It is designed to ensure that family engaged health care becomes the rule, rather than the exception (as is currently the case). The practice of PFCC promotes collaborative and direct communication between the professional healthcare team, patients, and families (i.e., patient-identified support persons, which could include relatives, friends, neighbors, and/or caregivers). The PFCC vision of care builds upon four fundamental beliefs and values: (a) dignity and respect, (b) information sharing, (c) participation, and (d) collaboration (Johnson & Abraham, 2012). These concepts illustrate how to approach the treatment of patients and families in the healthcare system to improve experiences and outcomes of care (Institute for PFCC, n.d.). Stakeholders (e.g., patients, families, providers, administrators) achieve these values when they work collaboratively across the full continuum of care (Institute for PFCC, n.d.).

When compared to patient-only care, integrating families reduces unnecessary healthcare utilization, benefiting patients, families, and health systems alike (Crane, 2011). Researchers found significant benefits when implementing PFCC in hospital settings such as increased family satisfaction in adult intensive care units (Wong et al., 2019). Furthermore, the Agency for Healthcare Research and Quality (AHRQ, 2011) encourages family engagement to improve patient care quality across settings, including primary care. The Institute of Medicine (IOM, 2001) also identified PFCC as one of the ways to improve healthcare quality in *Crossing the Quality Chasm*, emphasizing the value of relationships and family perspectives.

However, two decades later, widespread implementation of PFCC remains uncommon. As the older adult population continues to rapidly grow, the prevalence of CI has also increased (US Census, 2018). This trend will impact healthcare system demands and the time to prepare is now. Recognizing the unique challenges that CI poses to patients, families, and healthcare systems provides a starting point for understanding the care necessary to effectively address and improve assessment, diagnosis, and treatment of CI in older adults.

Three World View Theoretical Framework

The Three World View (Peek, 2008) provides a foundation for conducting research in a way that honors the vision of PFCC and attends to the three worlds of successfully transforming healthcare practices: clinical, operational, and financial worlds. Viewing the research and outcomes of PFCC within a Three World View framework provides a way of building and implementing a PFCC strategy that will benefit all stakeholders. It is vital to understand the definition of *patient and family engagement* as patients, families, their representatives, and health professionals working together throughout the healthcare system to improve health outcomes and the system (Carman et al., 2013). The explicit use of “PFCC” and “family engagement” in our manuscript refer to care in which family members are actively and intentionally engaged.

Within our systematic review, health outcomes are examined and discussed using the three worlds: *clinical, operational, and financial*. These worlds provide a means for organizing the evidence for implementation of care strategies such as family engagement practices (Miller et al., 2009). We use a fourth world of *education* to discuss the preparation of medical providers and healthcare teams, which is equally necessary for successful implementation of PFCC. Peek’s lens also provides a shared language that can be used to bridge gaps between individual disciplines (e.g., business, family therapy, medical education) allowing for more successful knowledge sharing and advancement of related research (Peek et al., 2014). The Three World View has been used extensively in the research of integrated care, such as with the examination of operational factors that influence implementing mental health into primary care (Benzer et al., 2012), competencies for psychologists' practice in primary care (McDaniel et al., 2014), and payment reform (Miller et al., 2017). The lens is useful for these purposes as it provides a language communicable across levels within a healthcare system from clinicians to administrators.

Combining the vision of PFCC and the lens of the Three World View provides a systemic foundation and plan for reviewing the existing outcomes literature on family engagement practices with older adults experiencing CI. This is critical to the success of this review and the value of its results. Stakeholders must consider how outcomes of family engagement can influence their care delivery system within all four worlds. By examining the results from these multiple perspectives, it is possible to make better informed evaluations regarding implementation of such strategies. The resulting contribution to the literature will allow stakeholders to confidently make decisions regarding the implementation of PFCC and family engagement practices that could benefit their systems and patient populations.

Unique Challenges of Cognitive Impairment with Older Adults

Older adults (i.e., individuals aged 65 and older) with CI commonly struggle with memory, learning, concentration, and/or decision making (CDC, 2014). Additionally, they may struggle to describe their symptoms to healthcare providers and experience decreased comprehension of care instructions, which can negatively impact treatment and treatment adherence (Han et al., 2011). These communication challenges create a need for engaging support persons in the healthcare process, particularly when interacting with primary care providers (PCP) who need to also address other comorbid conditions (e.g., diabetes, high blood pressure, depression) that often accompany CI (Bunn et al., 2016).

Addressing CI in Primary Care

Individuals with CI often rely heavily on informal, unpaid caregiving from family members (Okura & Langa, 2011) and support with health care is no exception. This presents opportunities for healthcare teams to engage with family members of patients who have CI. It is important to note that most patients first discuss memory and thinking problems with PCPs (Alzheimer’s Association, 2017). Wolff and Roter (2011) found that more than 30 percent of older adults, particularly those who have more extensive health needs, bring a family member with them to routine primary care visits. This may facilitate family-centered treatment at earlier stages of care, which presents opportunities for improved health outcomes, reduced costs, and increased satisfaction of caregivers, patients, and providers.

Earlier detection of CI leads to improved patient satisfaction, greater medical treatment adherence, decreased utilization of unnecessary care, and lower healthcare costs (Lin et al., 2013). This is significant given that patients with CI generate higher treatment costs due to complex care within nursing facilities (Hurd et al., 2013) and elevated hospitalizations rates, which are more than tripled for individuals with CI compared to patients without cognitive problems (Alzheimer’s Association, 2009). Providing appropriate care to these patients and their families at the primary care level may help to alleviate these costs and negative health outcomes.

Assessment and Diagnostic Inefficiency

Researchers have suggested the areas of early detection and treatment of CI both need improvement (Kotagal et al., 2015). Researchers found CI goes unrecognized more than half the time in patients aged 70 or older (Kotagal et al., 2015) and patients experience an average delay of three years from the arise of dementia symptoms to the time of diagnosis (Alzheimer's Association, 2014). Reasons for this delay vary and although some family members may be reluctant to share their concerns when symptoms first develop, it is also likely that many families do not have opportunities to share their concerns with the healthcare team (Boise, 2006). Regardless, these problems persist, and a lack of effectively engaging family perspectives contributes to inefficient assessments, making CI difficult to diagnose.

Aims

Existing PFCC research primarily focuses on infant, child, and adolescent patient populations in settings such as hospitals and specialty care. There was an alarming gap in the literature regarding family engagement practices for older adults with CI in primary care where many of these patients are routinely treated (Wubbeler, 2017). To address this gap, we established three primary aims of this study: (a) identify the ways in which families of older-adult patients with CI are engaged in primary care settings, (b) examine the outcomes of family engagement practices, and (c) organize and discuss the findings using CJ Peek's Three World View (2008).

Methods

Design

The planning, conducting, and reporting of this review follows Cooper's (2017) seven-step model for conducting systematic reviews. It also adheres to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) standards of quality for reporting systematic reviews (Moher et al., 2009). Authors followed the PRISMA EQUATOR Checklist. This process involved the following steps: (a) formulation of the problem, (b) development of the research question, (c) systematic review of the literature, (d) data extraction, (e) quality appraisal of included studies, (f) analysis, and (g) synthesis of the findings.

Problem

Researchers followed the PICO (Population/Patient, Intervention, Comparator, and Outcome) format (Richardson et al., 1995) to help isolate the area in need of further review. This led to the development of the following research question guiding this systematic review: What are the clinical, operational, and financial outcomes (O) of family-centered primary care (I) with older-adult patients experiencing CI (P)? The comparator was not defined as the methods of relevant studies are diverse and some do not include comparisons between interventions.

Search Strategy

On July 23, 2019, authors comprehensively searched three databases (i.e., PubMed, Embase, and PsycINFO) for literature published at any date (up to the time of the search) that met the search criteria. The lead researcher collaborated with a library scientist to select databases that could identify national and international literature within health and social science disciplines. Databases were chosen primarily for the size of the databases in journal coverage. It is important to note that CINAHL was not used given the unlikely chance that CINAHL would result in unique studies compared to those found by PubMed, Embase, and PsycINFO. The library scientist has training in systematic reviews and assisted in defining key search terms, MeSH terms (medical subject headings in PubMed; e.g., “dementia” [mesh]), and syntax utilized within each database. Key terms included (a) Three World View, (b) family-centered care, (c) older adults, (d) primary care, and (e) cognitive impairment. A full list of search terms and syntax are available upon request.

Articles were included in this review if they met the following criteria: (a) original research, (b) published in the English language, (c) explicitly and clearly defined family engagement practice, (d) occurred within a primary care setting, (e) the patients had existing or suspected diagnosis of CI, and (e) the patients were aged 65 or older. Primary care settings included internal medicine and family medicine, as supported by previous research (Bertakis & Azari, 2011). Studies could be qualitative, quantitative, or mixed methods in nature. Omission of gray literature (e.g., conference and poster presentations, magazine articles, government reports) was necessary given the large-scale nature of the review and resource constraints. Gray literature also poses a challenge due to the lack of a formal peer-review process which can limit the quality of included studies. Final analyses did not include systematic reviews, meta-analyses, and literature reviews. The PRISMA diagram (Figure 1) illustrates the process used by co-researchers to identify and screen the articles admitted into the review.

Co-researchers screened titles and abstracts of all identified records using a triangulated approach in which at least two reviewers screened each article. To ensure reliability, the third reviewer served as a tiebreaker when necessary. A fourth researcher was available for discussions to assist in reaching consensus when disagreements between the three reviewers emerged. The lead researcher assessed full-text articles for eligibility and determined which articles to include in the qualitative synthesis with the assistance of two co-researchers.

Data Extraction, Analysis, and Synthesis

Upon the final selection of included articles (*n* = 22), the lead researcher extracted information to facilitate analysis and synthesis of the methods and results. Table 1 provides the following data for each study: author/date/country/quality appraisal score, aim/research question(s), sample/setting, and results/findings.

Co-researchers critically appraised methodological rigor of each study using a tool by Hawker, et al. (2002). Nine items were used in the appraisal process: (a) abstract and title, (b) introduction and aims, (c) method and data, (d) sampling, (e) data analysis, (f) ethics and bias, (g) findings/results, (h) transferability/generalizability, and (i) implications and usefulness. Items were scored using a scale from 1 (very poor) to 4 (good) with each score clearly defined by the assessment tool. Each study was then given a summative score that fell within four ranges: 1-9 is considered very poor, 10-18 is poor, 19-27 is fair, and 28-36 is good. Studies included in this review ranged from 21-36. All studies were scored as “good” with the exception of one rated as “fair”. However, no studies were excluded based on quality appraisal rating.

Co-researchers collaborated in the thematic analysis and synthesis of the data. The lead researcher categorized the data for each aim (i.e., engagement practices, outcomes, and associated worlds of health care) and then collaborated with co-researchers to group data into similar relationship patterns and themes. Theoretical frameworks (i.e., PFCC and Three World View) guided the thematic analysis and synthesis processes.

Results

Study Characteristics

The initial search identified 6743 articles, 6721 did not meet the review criteria (Figure 1), and 22 articles were admitted into this review (Table 1). All articles were published in peer reviewed journals. The earliest article was published in 1988 and most recent in 2018. The database search concluded on July 23, 2019. Study methodologies included quantitative (*n* = 12), qualitative (*n* = 5), and mixed methods (*n* = 5). Four studies were hypothetically based using case vignettes, rather than patient observations, which allowed for better understanding of provider preferences and ideal decision-making processes (Cheok et al., 1997; Fortinsky et al., 1995; Werner, 2006; Werner et al., 2004).

Most of the admitted studies were classified as taking place in general primary care contexts (*n* = 18), while four were specific to family medicine. Of the clinics identified as general primary care, two of them were also classified as a geriatric practice. None were classified as internal medicine. Four studies were specific to Veteran's Affairs (VA; Belmin et al., 2012; D'Souza et al., 2015; Judge et al., 2011; Nichols et al., 2011). The training and education of provider participants varied widely (shown in Table 1).

Studies included perspectives of families, patients, and providers to assess outcomes of family engagement practices. Interestingly, most studies (*n* = 11) included family member participants and perspectives. Five included family perspectives only, three included family and patient perspectives, and three evaluated family, patient, and provider perspectives. Nine studies evaluated provider only perspectives, and none considered patient only perspectives.

Both national (*n* = 13) and international (*n* = 9) studies were included, with a total of 8 nations represented in the review. Thirteen studies were conducted in at least eleven states within the United States. The United Kingdom and Israel were both represented in two studies each, while Canada, Japan, Germany, Belgium, and Australia were each represented in one study.

The terminology and definitions of families varied extensively in this review. Most studies referred to support persons as family (*n* = 8), caregivers (*n* = 7), or some variation of these two terms (e.g., family companion, informal caregiver, family caregiver). In most cases, studies included clear definitions of family (e.g., partner/spouse, adult children). However, terms such as "loved ones," "friend," "proxy," "lay carer," and "carer," were also used to describe support persons engaged in patient care. Additionally, only one study (Vick et al., 2018) noted that more than one family member was engaged in the patient's care and participated in the study.

Although almost all studies incorporated demographic characteristics of the studies' samples (e.g., race/ethnicity, rural/urban, age, gender, education), only two studies included explicit conversations regarding the influence of social locations on the studies' findings (Schmidt et al., 2009; Werner et al., 2004). However, in both cases, discussions focused on (a) age, gender, and educational background differences of providers or (b) gender differences of caregivers. Discussion of race and ethnicity variances were missing.

Health conditions comorbid to cognitive impairment were alluded to in four studies (Adelman et al., 2004; Callahan et al., 2006; De Lepeleire et al., 2004; D'Souza et al., 2015). However, the influence of comorbidities was not discussed at length. All studies specifically referred to the presenting condition as dementia, except for two studies that broadly referred to cognitive impairment (Adelman et al., 2004; Vick et al., 2018).

This review's results were organized according to its primary aims: (a) identification of family engagement practices, (b) examination of the outcomes, and (c) implications of the four worlds of health care. Then, using the theoretical frameworks (i.e., PFCC and Three World View) as a guide, researchers combed through extracted data and identified patterns and themes within each aim. Aim 1 resulted in three themes, Aim 2 resulted in three themes which were further divided into three subthemes each, and Aim 3 was organized into four themes in alignment with the Three World View (Peek, 2008).

Aim 1: Identify the Engagement Practices of PFCC in Primary Care with Older Adults Experiencing CI

Identification of family engagement practices was challenging given the various levels of specificity of the included studies. However, three themes emerged involving types and methods of PFCC engagement: (a) empowering and supporting patients and family caregivers, (b) gaining information about the patient for diagnostic and treatment purposes, and (c) standardizing communication through implementation of care coordination/management programs.

Empowering and Supporting Patients and Family Caregivers

The most robust theme emerged from 20 studies. It involved practices designed to empower and support patients and their caregivers. These studies focused on improving caregivers' emotional well-being through family counseling (*n* = 2; Callahan et al., 2006; Donath et al., 2010) and support groups (*n* = 8; Adams et al., 2005; Belmin et al., 2012; Callahan et al., 2006; Donath et al., 2010; D'Souza et al., 2015; Nichols et al., 2011; Teel, 2004; Werner, 2006). This also included engaging family members who accompanied patients to medical visits by including them in goal setting and treatment planning (*n* = 6; Adams et al., 2005; Brazil et al., 2015; Hansen et al., 2008; Judge et al., 2011; Teel, 2004; Werner et al., 2004), decision making (*n* = 2; Adams et al., 2005; Brazil et al., 2015), and advanced care planning (*n* = 2; Belmin et al., 2012; Shega et al., 2003). Ten studies also noted the value of healthcare team members providing caregivers with helpful information including education regarding patient's medical condition and caregiving (Belmin et al., 2012; Brazil et al., 2015; Callahan et al., 2006; Judge et al., 2011; Nichols et al., 2011; Philp & Young, 1988; Reuben et al., 2010; Sato et al., 2018; Shega et al., 2003; Teel, 2004).

Information Gathering

The second theme involved practices from 12 studies that routinely obtained information about the patient's condition from family members. This was primarily done when caregivers accompanied patients to medical visits. Studies focused heavily on the way in which providers gathered information about the patient from the family when present in routine healthcare visits (*n* = 9; Adelman et al., 2004; Cheok et al., 1997; Fortinsky et al., 1995; Hansen et al., 2008; Sato et al., 2018; Schmidt et al., 2009; Vick et al., 2018; Werner, 2006; Werner et al., 2004). For example, providers would listen to family members' concerns about patients exhibiting memory problems. Few studies focused on how to gain this information outside of the visit, such as through telephone visits (*n* = 2; D'Souza et al., 2015; Judge et al., 2011) or the utilization of a caregiver notebook (*n* =1; Nichols et al., 2011).

Standardized and Improved Communication

Finally, the third theme emerged in 14 studies. It entailed practices by which healthcare teams standardized and/or improved communication between patients, families, providers, and others involved in their care. Few studies included training providers and healthcare team members on how to care for and engage families (*n* = 3; Donath et al., 2010; Reuben et al., 2010; Sato et al., 2018), yet this was identified as a need in more than 36% of the studies reviewed (*n* = 8; Adams et al., 2005; Adelman et al., 2004; Brazil et al., 2015; Cheok et al., 1997; Donath et al., 2010; Fortinsky et al., 1995; Hansen et al., 2008; Teel, 2004). Six studies examined care coordination and collaborative care management as a way to employ PFCC (Callahan et al., 2006; Donath et al., 2010; D'Souza et al., 2015; Judge et al., 2011; Sato et al., 2018; Shega et al., 2003). Two studies included information from care management programs in the electronic medical records (EMR) and required the physician to cosign notes, ensuring that they would be aware of family information such as goals and concerns (Judge et al., 2011; D’Souza, 2015). It is worth noting that none of the included studies used the EMR to facilitate communication between family members and the healthcare team.

Aim 2: Examine the Outcomes of PFCC

Outcomes of family engagement practices were clustered by the review researchers into favorable, neutral, and unfavorable themes, and then sorted into subthemes. Favorable PFCC outcomes included three subthemes: (a) benefits to patients, (b) benefits to family, and (c) benefits to healthcare providers. Neutral observations also clustered into three subthemes: (a) communication patterns with engaged families, (b) preparing multidisciplinary teams to engage families, and (c) provider decision-making with engaged families. Unfavorable outcomes clustered into three subthemes as well: (a) patient agency; (b) documentation inconsistencies; and (c) resource underutilization. Favorable, unfavorable, and neutral outcomes of PFCC were elucidated from multiple perspectives (i.e., patient, family, provider) and are discussed in each theme.

Favorable PFCC Outcomes

Benefits to Patients. Five studies indicated multiple benefits of engaging families in the care of patients for the patients themselves. These benefits included reduction of problematic behaviors (Callahan et al., 2006), improved safety at home (Nichols et al., 2011), increased satisfaction with care (Adams et al., 2005; Shega et al., 2003), improved psychosocial symptoms (Callahan et al., 2006), and assisted in identifying goals for care (Judge et al., 2011). It is important to note that none of the included studies measured benefit to patients in the same way.

Benefits to Family. Thirteen studies measured benefits of PFCC to family members. Family engagement was shown to reduce caregiver stress (Callahan et al., 2006; Nichols et al., 2011; Philp & Young, 1988; Sato et al., 2018), increase service utilization of support groups and family counseling (Callahan et al., 2006; Donath et al., 2010; D'Souza et al., 2015; Nichols et al., 2011), and increase satisfaction with care (D'Souza et al., 2015; Schmidt et al., 2009; Shega et al., 2003; Vick et al., 2018). A common way of measuring family member benefit was through education about CI and its influence on patients and families. Family education led to better understanding and knowledge of CI that enabled caregivers to provide better care to patients (Brazil et al., 2015; Hansen et al., 2008; Nichols et al., 2011; Teel, 2004; Vick et al., 2018) and reduced the number of unmet needs (Judge et al., 2011; Philp & Young, 1988). Caregivers reported feeling more supported (Hansen et al., 2008; Philp & Young, 1988), and prepared (Brazil et al., 2015). Family engagement practices also benefited families by helping them to identify care goals (Judge et al., 2011). Active involvement of families also led to increased caregiver satisfaction of the provider's treatment of the patient (Schmidt et al., 2009). While one study noted that caregivers found it helpful to utilize alternative forms of communication with providers (e.g., communicating through the EMR; Vick et al., 2018), none of the studies evaluated such practices.

Benefits to Healthcare Providers and Health Systems. Ten studies included a wide variety of outcomes related to healthcare providers and organizations. Providers frequently discussed the benefits of having additional information from family members during the diagnostic process (Hansen et al., 2008; Teel, 2004; Vick et al., 2018). Providers also highlighted viewing the family as essential to optimal care, particularly when diagnosed with a CI (Adams et al., 2005; Donath et al., 2010; Teel, 2004). Additionally, providers noted benefits when families were engaged as evidenced by (a) having "successful" cases (Teel, 2004), (b) preserving rapport with patients (Vick et al., 2018), and (c) saving time in care visits (e.g., not having to repeat instructions; Nichols et al., 2011). Five studies evaluated PFCC by considering (a) improved collaboration (Sato et al., 2018), (b) feasibility of implementation (Judge et al., 2011), (c) alignment with quality measures (D'Souza et al., 2015), (d) higher resource utilization rates (Donath et al., 2010; Shega et al., 2003), and (e) providers' increased conformity to drug therapy guidelines (Donath et al., 2010). Convenience of electronic communication was mentioned by providers (Vick et al., 2018), but not evaluated. Similarly, neither was cost savings (e.g., reduced hospital and emergency room admissions, along with decreased use of expensive technologies; Shega et al., 2003). None of the included studies specifically measured financial impacts of PFCC.

Neutral PFCC Observations

Communication Patterns with Engaged Families. The influence of PFCC on communication patterns between providers, patients, and family members, was one of the most common observations made in the studies reviewed. Researchers measured communication within care visits, such as (a) talking time (Schmidt et al., 2009), (b) initiation of conversations about CI symptoms and concerns (Adelman et al., 2004; Brazil et al., 2015), and (c) revealing of a CI diagnosis (Belmin et al., 2012; Fortinsky et al., 2995; Hansen et al., 2008; Teel, 2004). Communication outside of the visit was also studied (e.g., frequency of communication did not increase [Judge et al., 2011]; means of communication included written notes, speaking on the phone, and using a secure patient portal for electronic messaging in the EMR [Vick et al., 2018]). At least three studies evaluated potential barriers to communication between providers and patients and/or families (e.g., providers not wanting to increase unnecessary anxiety in patients and family members [Donath et al., 2010]; family not wanting to discuss concerns with/without patient present [Adelman et al., 2004]; providers avoiding the conversation due to stigma [Teel, 2004]; greater geographical distance between patients and family members [Teel, 2004]). While few noted differences in communication styles between providers caring for patients with CI (e.g., internists and family physicians were more likely to engage in extensive discussions about dementia symptom management with patients and family members compared to osteopaths and general practitioners [Fortinsky et al., 1995], physicians with more years of experience would interact less with patients and families [Werner et al., 2004]; male providers were more likely to inform patients of a CI diagnosis than female providers [Werner et al., 2004]), none examined in detail why such differences emerged.

The means of communication between healthcare team members were rarely examined (e.g., co-signing notes in EMR [D'Souza et al., 2015]; use of carer-held records [CHR; Sato et al., 2018]). The CHR were used to provide information about the patient's condition and improve collaboration between caregivers and healthcare teams (Sato et al., 2018). Furthermore, studies noted the importance of providers' communication skills and the critical need for developing these skills to effectively communicate with families (e.g., listening is better than an assessment tool [Teel, 2004]). However little attention is given to provider training and how these skills are developed. Additionally, Cheok et al. (1997) found that providers need more information about community resources and training for how to explain benefits of the resources to the family.

Preparing Multidisciplinary Teams to Engage Families. While a variety of professionals were included in these studies (e.g., care coordinators [Judge et al., 2011], nurse coordinators [Shega et al., 2003], counselors and family therapists [Donath et al., 2010; D'Souza et al., 2015; Judge et al., 2011; Werner et al., 2006], social workers [Belmin et al., 2012; D'Souza et al., 2015; Judge et al., 2011; Nichols et al., 2011; Shega et al., 2003]), the extent of collaboration between the professionals during family engagement varied widely. This makes it difficult to evaluate similarities or differences of multidisciplinary teams. Furthermore, medical providers identified the need for more training and standardization of PFCC at various stages of caring for a patient with CI (e.g., diagnosis and management [Brazil et al., 2015], end of life [Adams et al., 2005]).

Provider Decision-Making with Engaged Families. Four studies investigated what providers used to determine their next steps in caring for a patient with CI (e.g., prescription of medications; referral to specialist). Their responses varied based according to patient level of CI severity (Cheok et al., 1997; Fortinsky et al., 1995; Werner, 2006; Werner et al., 2004). However, none described how family engagement, or collaboration with other specialists, was used during the diagnostic process or treatment plan formulation.

Unfavorable PFCC Outcomes

Patient Agency. In two studies (Adams et al., 2005; Vick et al., 2018), providers and families expressed concerns about the focus of the medical visit turning from the patient to the family member and the ethical concerns that result (e.g., patient autonomy, decision making). Providers and caregivers both worried that increased engagement of the family member in the patient's care could lead to leaving the patient out (Adams et al., 2005) or the patient no longer being the primary focus of the visit (Vick et al., 2018). A third study (Werner et al. (2004) confirmed that providers do at times speak to family more than patients (e.g., older, more experienced physicians addressed caregivers more than patients when compared to younger, less experienced physicians). This led to a concern about conflict becoming an issue when engaging families. Conflicts could arise from differing goals or priorities for care between providers, family, and/or patients (Vick et al., 2018). Moreover, providers reported that families could be manipulative (Hansen et al., 2008) or unrealistic (Teel, 2004), which can impede care.

Documentation Inconsistencies. Belmin et al. (2012) found that the lack of addressing CI symptoms by providers and patients in care visits resulted in patients not receiving care that could help to reverse or improve symptoms. However, few studies acknowledged the cause of not addressing CI directly (e.g., stigma associated with CI [Teel, 2004]). Furthermore, the documentation of how providers, patients, and families addressed CI in care visits was also inconsistent. What family members and patients reported happening in care visits differed from what providers documented in the EMR (Belmin et al., 2012). The study found that family members often reported more happening in the visit than what providers noted in the EMR. This is important to know for future research aiming to evaluate family engagement using EMR data. This review highlighted the stark void in current literature regarding EMR use and family engagement with this population.

Resource Underutilization. Finally, multiple studies noted that despite PFCC, family members underutilized resources available to them. Providers voiced desire and value for resources in their communities (Cheok et al., 1997), but complained that resources are often unavailable or underutilized (Philp & Young, 1988; Teel, 2004). Reasons for lack of resource use included (a) lack of understanding (Shega et al., 2003), (b) inconvenience (Sato et al., 2018), and (c) geographical restrictions (e.g., adult children living in different states [Teel, 2004]). However, while studies captured the presence of these challenges, recommendations for implementing/improving PFCC are omitted.

Aim 3: Organize Findings According to Peek's Three World View

Researchers organized outcomes and implications of PFCC from the review according to the Three World View (Peek, 2008; see Figure 2). Clinical, operational, and financial outcomes, as well as training/educational implications of studies admitted into the review are discussed. Overall, all studies (*N* = 22) addressed clinical outcomes of family engagement. About half of the studies included operational outcomes and training world implications (*n* = 14 and 9 respectively). Four studies addressed the financial world of care. Figure 3 shows the number of studies that cover more than one world of health care.

Clinical Outcomes

All studies (*N* = 22) included in this review reported clinical implications of family engagement. Patient health outcomes included (a) reduced memory and behavior problems (Callahan et al., 2006; Shega et al., 2003), (b) improved detection of cognitive status (De Lepeleire et al., 2004), (c) increased patient satisfaction with PCP and care (Schmidt et al., 2009), (d) improved assessment of activities of daily living (ADL; Shega et al., 2003) and instrumental activities of daily living (IADL; Shega et al., 2003), (e) decreased perceived pain (evaluated by caregivers; Shega et al., 2003), (f) fewer bothersome patient symptoms (evaluated by caregivers; Shega et al., 2003), (g) improved quality of care (Shega et al., 2003), and (h) increased likelihood of patients dying in their desired location (Shega et al., 2003). These outcomes were mainly studied from the perspectives of caregivers and providers and not the perspectives of patients. Both providers and family members expressed concerns about diminishing the patient's agency through their communication, but none of these studies evaluated the patient's perspective on engaging family members in healthcare visits.

Studies also evaluated caregivers' health and wellbeing, primarily from their perspective. Most discussed what happened in care visits and what healthcare teams did to support them. Caregiver health outcomes as a result of PFCC included (a) improved mood (e.g., reduced depression [Callahan et al., 2006; Judge et al., 2011; Shega et al., 2003]), (b) lessened relationship strain (Judge et al., 2011), (c) reduced stress (Callahan et al., 2006; Philp & Young, 1988), (d) minimized patient's behavior disturbance and reduced caregiver burden (Sato et al., 2018), (e) decreased caregiver strain (Shega et al., 2003), and (f) increased caregiver satisfaction with PCP and care (Schmidt et al., 2009). It is important to note that none of the studies evaluated provider health and wellbeing outcomes (e.g., provider turnover, compassion fatigue).

Operational Outcomes

Fourteen studies examined operational outcomes. These included (a) improved provider workflow, (b) increased utilization of community resources, (c) collaborative documentation in the patient's medical record, and (d) varying levels of collaboration between healthcare team members. Providers noted that family members did not have a negative impact on provider workflow. For example, family members did not increase the frequency of phone calls to the healthcare team as expected in one study (Judge et al., 2011). Another study noted the useful nature of using the EMR to communicate but did not provide specifics about how this happens operationally (Vick et al., 2018). Two studies engaged the providers by having them co-sign notes of other team members in the EMR (D'Souza et al., 2015; Sato et al., 2018). However, it is unclear how often or to what extent the providers utilized the available information and how it impacted patient care. Similarly, while collaboration among multidisciplinary healthcare team members was found helpful (e.g., addition of a nurse coordinator viewed as essential to success of program; Shega et al., 2003), the level of collaboration was not evaluated.

Financial Outcomes

Four studies discussed possible financial benefits of PFCC, such as (a) decreased hospital admissions and (b) reduced expenses related to life sustaining technologies (e.g., feeding tubes [Shega et al. 2003]). However, none of them included an actual financial analysis or examined the financial impacts of engaging families. Rather, studies noted outcomes of PFCC such as (a) decreased cost of time spent on caregiving (Nichols et al., 2011), (b) increased cost of time spent in visits (Adelman et al., 2004), (c) no change in time to nursing facility placement and related expenses (Callahan et al., 2006), (d) avoidance of unnecessary testing expenses (Fortinsky et al., 1995), and (e) reductions in hospitalization rates and associated costs (Callahan et al., 2006).

Educational Outcomes

Nine of the articles in this review included training and educational opportunities for providers to learn more about the value of PFCC when treating CI. Researchers indicated trainings in communication skills would help to improve providers' ability to effectively engage families (Vick et al., 2018) while simultaneously making an effort to include patients with CI (Schmidt et al., 2009). Most studies acknowledged the need for additional training, direction, and support as it was a new skill and research on training outcomes related to family engagement and patient outcomes. To date, it is unclear what the best method is for training multidisciplinary teams to work together using PFCC and maintaining fidelity of the method practiced.

Discussion

The purpose of this study was to better understand the outcomes of engaging families in primary care settings when caring for patients with cognitive impairment. Utilizing PFCC (Johnson & Abraham, 2012) and Three World View (Peek, 2008), this systematic review provides healthcare administrators, policy makers, educators, and clinicians with information related to family engagement and how it can be implemented and enhanced in the care of patients with CI. The three aims for this systematic review were: (a) identification of family engagement practices, (b) evaluation of family engagement outcomes, and (c) discussion of the clinical, operational, and financial outcomes, as well as the educational implications of PFCC. Of the 22 studies reviewed, 12 quantitative, 5 qualitative, and 5 mixed-methods studies revealed favorable, neutral, and unfavorable outcomes of family engagement practices.

Implications of Family Engagement Practices

The inconsistent definition of family used across studies is an important outcome of this review. This study showed that patients include a variety of family members in their care (e.g., partners, children, friends). Most included family members identified as spousal caregivers. However, caregivers were also adult children and friends. Furthermore, studies typically only enrolled one family member per patient. This lack of consistency and underrepresentation of non-intimate partner family members was identified as problematic in other reviews (Woods et al., 2020). Future studies should be sure to explicitly define family, their roles, and include more than one member when possible. Special attention should be paid to studying successful methods of balancing family involvement and maintaining patient autonomy (Jazieh et al., 2018). Furthermore, while researchers highlighted the usefulness of obtaining information from family members, they noted the need for providers to have flexibility and training on the various methods of engagement (e.g., EMR, videoconferencing) since not all involved family members can attend medical visits with the patient.

Implications of PFCC Outcomes

PFCC has the potential to reduce barriers for family engagement in CI patient visits (e.g., geographical distance between patients and family) by engaging families through means beyond accompanying patients to healthcare visits (e.g., phone visits [D’Souza et al., 2015; Judge et al., 2011]; electronic communication [Vick et al., 2018]) and improved quality of dementia care (Reuben et al., 2010). Knowing what these barriers were requires more consistent and accurate documentation of efforts in the EMR (Belmin et al., 2012). A recent study revealed that EMR data collected during routine patient care (e.g., medical notes containing information from family) may help to identify dementia within one year of symptom onset (Miled et al., 2020) but nothing is known about what role family involvement plays in expediting or delaying this process. Future research is needed to evaluate how family engagement in the care of patients with CI influences the diagnosis and care experience and what methods are most beneficial for patients, families, and healthcare teams. This systematic review found no research on how the EMR could be useful in primary care settings to improve and increase family engagement. However, evidence exists that communicating through the EMR promotes patient and family engagement in other non-primary care settings (e.g., hospitals [Manias et al., 2020]).

Clinical, Operational, Financial, and Educational Implications

Engaging family members in the care of patients with CI is understudied. Forty-five percent of the studies reviewed incorporated information obtained from family members about the patient’s condition into the care of patients with CI. However, this review also revealed no standard practice or procedures for the family engagement practice of collecting and utilizing of that information. There is also a lack of research on clinical, operational, financial, and training/educational benefits of implementing family engagement practices. For example, knowing that the EMR provides opportunities for patient, family, and provider communication is helpful, but understanding what constitutes best practice is still lacking. Providers often rely on families to initiate conversations about cognitive concerns (Nicosia et al., 2018) but how both parties prefer to exchange information efficiently and effectively should be examined. Furthermore, it would be useful to know if EMR communication results in improved diagnostics, treatment plans, and health outcomes for patients and families, as well as improved work experiences for healthcare team members (e.g., reduced burnout rates, reduced turnover).

A critical gap in the literature revealed in this review is the lack of financial analysis of PFCC in primary care with CI. Recent literature suggests that utilizing new cognitive assessment codes in primary care may promote more robust planning and be financially beneficial (Eramo, 2018). Eramo explains that Medicare now financially rewards physicians for performing cognitive assessments and developing care plans to address symptoms of cognitive impairments (e.g., functional limitations), which can be reported using CPT code 99483. Families want to be part of the conversations that initiate cognitive assessments (Adelman et al., 2004). Thus, it would be of financial interest to healthcare systems to evaluate how PFCC can encourage appropriate use of such billing codes. Furthermore, PFCC results in decreased utilization of costly services which may result in cost savings for patients, families, and healthcare organizations (Shega et al., 2003).

Additionally, research is needed to understand how differences in social locations (e.g., race/ethnicity, gender, age) influence clinical outcomes. These studies included information regarding participant characteristics, but rarely were the influences of those characteristics analyzed or discussed. Seven studies noted that patients were primarily female (Adelman et al., 2004; Belmin et al., 2012; Callahan et al., 2006; De Lepeleire et al., 2004; Donath et al., 2010; Sato et al., 2018; Shega et al., 2003), while only three noted that patients were primarily male (all veterans; D’Souza et al., 2015; Judge et al., 2011; Nichols et al., 2011). However, all studies with caregivers noted they were primarily female. Except for one study (Schmidt et al., 2009), differences in caregiver and patient genders were not discussed. Callahan et al. (2006) and Shega et al. (2003) both made note that patients were mostly Black and African American, but how that influenced their care and experience was not evaluated. Additionally, provider descriptors for these studies were not included to assess for variations in outcomes when providers and patients are of similar or dissimilar race and ethnicity.

Furthermore, despite having some details of the programs included, there is still little understanding of the outcomes due to the level of family engagement specifically. For example, studies evaluated differences in care based on level of patient impairment, but none compared care with and without family engagement. Also missing from clinical outcomes are evaluations of the influence of diagnostic time (e.g., how length of time to receiving a diagnosis of CI influences patient, caregiver, and/or healthcare team health outcomes).

This review also identified provider education as a barrier to effectively engaging families in caring for patients with CI. Studies showed that providers experienced varying degrees of comfort and confidence when communicating with and engaging families. However, all studies, apart from one (Sato et al., 2018), most often referred to physician-only education and did not recognize the presence and role of multidisciplinary and integrated care teams (i.e., teams who work to provide healthcare services that incorporate biological, psychological, social, and spiritual components of health). Patients with CI have high health care utilization rates, and most are cared for by a variety of healthcare specialists (Lugo-Palacios & Gannon, 2017). Future studies should examine if and how family engagement is addressed within inter-professional education so that multidisciplinary healthcare teams are prepared to effectively implement PFCC.

Limitations

A limitation of this systematic review is the omission of gray literature given that it may have relevancy to PFCC as an understudied field. However, this was done to ensure a high level of quality of included studies given the rigorous peer-review process. Additionally, the inclusion of findings from multiple countries may present challenges to generalizability given global variations in healthcare systems. However, expanding the research frame to be more inclusive is important to being able to better examine differences and similarities of family engagement across countries and social locations. Given that the analysis of the influence of patients’ race and gender on PFCC practices and outcomes were omitted from the reviewed articles, discussion of such influences of identities between and among patients, families, and healthcare team members was limited.

Conclusion

Findings of this study revealed favorable outcomes of engaging families in primary care when CI was the primary concern. Engaging families by including them in primary care visits, providing families with education, and encouraging resource utilization, resulted in improved satisfaction with patient care (Adams et al., 2005; Shega et al., 2003) and reduced caregiver stress (Callahan et al., 2006; Nichols et al., 2011; Philp & Young, 1988; Sato et al., 2018). However, application of family engagement practices remains inconsistent and ambiguous across settings. This review supports the need for further research to better understand (a) how patients, families, and healthcare teams prefer to communicate (e.g., utilizing the EMR), (b) what the outcomes of that communication are (e.g., diagnostic efficiency), and (c) how to provide inter-professional education to prepare multidisciplinary healthcare teams to successfully implement such practices. This study reveals that while primary healthcare teams often interact with family members of patients with CI, the active, intentional, and effective engagement of those families is not yet standard practice.

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Table 1

Summary of Study Characteristics

Authors (date), country, quality appraisal score	Aim/research question(s)	Sample/setting	Results/findings
Adams et al. (2005), United States, Good (33)	Develop an in-depth understanding of the issues important to primary care physicians in providing care to cognitively impaired elders	Patient Dx: Dementia Family: "family, caregiver, friend" Providers: (*N* = 20), General internists (*n* = 10), Family physicians (*n* = 10), Fellowship-trained geriatricians (*n* = 2), White (*n* = 19), Hispanic (*n* = 1), Women (*n* = 7), Age: 32-70, Years in practice: *M* = 14 Setting: Urban areas (*n* = 18), Rural areas (*n* = 2)	• A patient's difficulty providing an accurate history and selfcare hindered the usual process of care, which led to greater medical uncertainty and physicians feeling inadequate or frustrated. • Physicians had trouble shifting the goal of care from ‘‘curing’’ the patient's illness to ‘‘caring’’ for the patient's quality of life. • The involvement of family changed the doctor–patient relationship, sometimes creating ethical dilemmas related to patient autonomy and decision making. • Physicians experienced significant loss and grief as the patients declined. • The current model of practice made it difficult to manage complex social and emotional presenting issues.
Adelman et al. (2004), United States, Good (32)	Examine perceptions of older patients and individuals who accompany them about discussions concerning cognitive impairment during a first medical visit	Patients: (*n* = 100) Dx: cognitive impairment Age: 65-94, *M* = 79.5 Female (76%), White (89%), Primarily highly educated Family: (*n* = 47), "accompanying individuals (i.e., relative, friend, hired caregiver)" Setting: Outpatient geriatric medical practice	• Patients indicated that memory was discussed in 62% of visits. • Almost 1/3 of patients who did not discuss memory stated that they wanted to. • Physicians were more likely than patients to initiate discussions about memory. • Patients who identified discussing cognitive function as a goal of the visit were more likely to have a discussion about memory than those who did not.
Belmin et al. (2012), United States,	Evaluate care provided by primary care physicians in	Patients: (*N* = 101) Dx: Dementia Age: 75+, *M* = 81	Among 34 patients presenting with a new cognitive problem:

Good (32)	community practice to older patients presenting with cognitive impairment and dementia	Primarily female, white, nearly 50% were married, 62% attended at least some college Family: “proxy, family member, caregiver” Providers: (*n* = 40), Primary care physicians (*n* = 39; general internists, general practitioners, family physicians, osteopaths), nurse practitioner (*n* = 1), additional geriatrics training (*n* = 3), fellowship completed (*n* = 1)	• 50% received a cognitive assessment (i.e., memory test and one other cognitive task), • 41% were screened for depression, • 29% were referred to a consultant. Of the 27 patients with new dementia diagnosis: • 15% received the components of a basic neurological examination, • 20% received basic laboratory testing and • the medical record reflected an attempt to classify the type of dementia for 33%. For the 101 patients with dementia: • Counseling was under-reported in the medical record compared to caregiver reports. • 50% or less received counseling about safety and accident prevention, caregiver support or managing conflicts. • Less than 10% were referred to a social worker.
Brazil et al. (2015), United Kingdom, Good (35)	Describe the attitudes and practice preferences of GPs working within the UK’s National Health System (NHS) regarding communication and decision-making for patients with dementia and their families	Patient Dx: Dementia Family: “family carer” Providers: (*N* = 133), general practitioners, 57% male Years in practice: *M* = 24.7 Age: *M* = 49.3 Setting: Northern Ireland	• 96.2% of providers viewed dementia as a terminal disease. • 37.6% of providers felt that palliative care applied equally from the time of diagnosis to severe dementia. • 61% thought early discussions would facilitate decision-making during advanced dementia. • Providers disagreed about whether advanced care planning should be initiated at the time of diagnoses. • Providers felt that GPs should initiate, introduce, and encourage advanced care planning and that there is a need for improved knowledge to involve families in caring for patients with dementia at the end of life. • Providers reported that a standard format for advance care planning documentation was needed.

Callahan et al. (2006), United States, Good (35)	Test the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer disease	Patients: (*n* = 153) Dx: Alzheimer disease Age: *M* = 77 Primarily female, 50% were black, Primarily diagnosed with multiple comorbid chronic conditions, socioeconomically disadvantaged Family: (*n* = 153); "Caregivers (i.e., spouse, child, other)" Age: *M* = 61 Providers: (*n* = 76); geriatric nurse practitioner (*n* = 2), primary care physicians (*n* = 74) Setting: 2 U.S. university-affiliated healthcare systems	• Initiated by caregivers' reports, 89% of intervention patients triggered at least 1 protocol for behavioral and psychological symptoms of dementia with a mean of 4 per patient from a total of 8 possible protocols. • Intervention patients were more likely to receive cholinesterase inhibitors (79.8% vs 55.1%; P=.002) and antidepressants (45.2% vs 27.5%; P=.03). • Intervention patients had significantly fewer behavioral and psychological symptoms of dementia as measured by the total NPI score at 12 months (mean difference, −5.6; P=.01) and at 18 months (mean difference, −5.4; P=.01). • Intervention caregivers also reported significant improvements in distress as measured by the caregiver NPI at 12 months; at 18 months, • caregivers showed improvement in depression as measured by the Patient Health Questionnaire-9. • No group differences were found on the CSDD, cognition, activities of daily living, or on rates of hospitalization, nursing home placement, or death.
Cheok et al. (1997), Canada, Good (30)	Examine the practice patterns of family physicians in diagnosing and managing patients with dementia	Patients: Dx: Dementia Age: 70, 75 (2 vignettes) Family: Son, wife Providers: (*N* = 20) Family physicians, general practitioners Age: < 30 - > 70 Setting: metropolitan Toronto family practices	• Participants were more comfortable with diagnosing dementia than with ongoing management issues, and • most physicians were not using standardized cognitive screening protocols. • Physicians were more oriented to immediate medical and psychiatric problems than to long-term psychosocial issues.

De Lepeleire et al. (2004), Belgium, Good (29)	Examine the diagnostic value of IADL evaluation in the detection of dementia in general practice	Patients: (*n* = 1003) Dx: Dementia Age: 65+, *M* = 75 Primarily women Family: 4/10 patients came with a family member “relative or other informant” Providers: (*n* = 21) Flemish general practitioners	• There was a large discrepancy between the family’s and the patient’s judgment on the presence of memory problems. • There was an inverse correlation between the IADL and MMSE: when the IADL score increased, the MMSE score fell. • The diagnostic value of the IADL for the diagnosis of dementia with Camdex-N as a reference standard could not be evaluated because the number of tested subjects was too small. • Against the MMSE, sensitivity was 0.81 (SE¼0.03), and specificity was 0.48 (SE¼0.05). • The evaluation of the IADL activities had some drawbacks as a detection method for dementia but the use of IADL data may still be clinically valuable in general practice. • The correlation between the general practitioner’s judgment and that of the specialist was very good.
Donath et al. (2010), Germany, Good (34)	Test whether special training of general practitioners alters the care of dementia patients through their systematic recommendation of caregiver counseling and support groups	Patients: (*n* = 390) Dx: Dementia (Alzheimer type, Vascular Dementia, mixed form, other) Age: *M* = 80.3 Primarily female Family: (*n* = 390) “informal caregivers (i.e., care-giving informal caregiver; marital partner, children/children-in-law, other” Age: *M* = 59.4 Providers: (*n* = 129) General practitioners	• The diagnostic behavior of the general practitioners conforms to relevant guidelines. • The procedure in newly-diagnosed patients does not differ from previously diagnosed patients with the exception of the rate of referral to a specialist. • About one-third of the newly-diagnosed dementia patients are given an anti-dementia drug. • The utilization of support groups and counseling increased five- and fourfold, respectively. • Utilization of other support services remained low (< 10%), with the exception of home nursing and institutional short-term nursing.

D'Souza et al. (2015), United States, Good (34)	Describe the Caring for Older Adults and Caregivers at Home (COACH) program in its first 2 years of operation, assess alignment of program components with quality measures, report characteristics of program participants, and compare rates of placement outside the home with those of a nontreatment comparison group	Patients: (*n* = 133) Dx: Dementia Age: 65+, *M* = 82.5; Veterans (*n* = 133) Primarily married, white, male Noted comorbid conditions: hypertension, depression, diabetes mellitus, ischemic heart disease, chronic obstructive pulmonary disease; average 4 chronic diseases each Family: (*n* = 133); “family caregivers (i.e., live-in caregiver; 60% wives, 25% daughters” Age: *M* = 70 Control group: (*n* = 29) Providers: Social worker (*n* = 1), registered nurse (*n* = 1), both had geriatric experience Setting: Durham Veteran’s Affairs Medical Center in Durham, North Carolina	• Results of the evaluation demonstrated that COACH aligns with nine of 10 clinical process measures identified using quality measures and that COACH delivers several other valuable services to enhance care. • Mean time to placement outside the home was 29.6 14.3 weeks for both groups (P = .99).
Fortinsky et al. (1995), United States, Good (32)	Examine how office-based PCP diagnose and manage dementia symptoms for patient and family	Patient Dx: Dementia Age: 72 (vignette) Family: daughter Providers: (*n* = 498); primary care physicians (family practitioners, internists, general practitioners, osteopaths, neurologists) Age: 29-84 Setting: 3 U.S. states	• Physicians more likely to order a variety of laboratory tests than to perform mental and cognitive status tests as part of a diagnostic workup. • Respondents also were much more likely to disclose a diagnosis of probable Alzheimer’s disease to the daughter in the vignette than to her mother. • Differences in reported dementia management behaviors were found according to physician specialty, number of years in practice, and experience with patients with dementia in actual practice.

Hansen et al. (2008), Australia, Good (36)	Elucidating the GP perspective and using it to better understand the process of diagnosing dementia and delays in diagnosing dementia	Patient Dx: Dementia Family: Not defined Providers: (*N* = 24); general practitioners Setting: Rural practices (*n* = 6), Large town (*n* = 8), Urban practices in a capital city (*n* = 10)	• Four major themes in GPs' accounts of the diagnosis of dementia: (a) 'recognizing dementia', (b) 'holistic viewpoint', (c) 'family members and patients' and (d) 'medication'. • Dementia is a complex condition that takes time to diagnose. • Diagnosis may involve conflict between GPs, family members/carers and the person with dementia (PWD). • GPs did not consider that diagnosing dementia early was particularly important and may in fact be harmful to some patients. • GPs are skeptical about the advantages of dementia medications. • GPs assess the need for a formal diagnosis of dementia within the broader context of their older patients' lives. • GPs are more likely to pursue a formal diagnosis in situations where they see it leading to benefits for their patient such as accessing dementia specific services.
Judge et al. (2011), United States, Good (33)	Describe a telephone-based care coordination intervention, Partners in Dementia Care (PDC), for veterans with dementia and their family caregivers	Patients: (*n* = 93) Dx: Dementia Age: 65+, *M* = 80 Primarily White Primarily male Veterans (*n* = 93) Family: (*n* = 90) "caregivers (i.e., family [spouse, daughter, son] or other [friend]" Age: *M* = 69.2 Providers: care coordinators, primary care clinicians, social workers, nurses, counselors Setting:	• Data from the assessments and goals indicated areas of need were not limited to any one issue or subset of issues, but were widely distributed across a variety of domains. • Findings for action steps suggested a primary focus on getting/giving information and action-oriented tasks to access services and programs. • Most action steps were assigned and completed by veteran's spouses and the majority were successfully accomplished. • On average, families had two contacts per month with care coordinators. • Few barriers were indicated by care coordinators in implementing PDC, highlighting the acceptability and feasibility of the PDC protocol.

		2 large cities in 2 U.S. states	
Nichols et al. (2011), United States, Good (35)	Describe the population and outcomes of the Research Resources for Enhancing Alzheimer's Caregiver Health (REACH) VA (Department of Veterans Affairs) translation of REACH II into the VA.	Patients: (*n* = 127) Dx: Alzheimer disease Age: *M* = 83 Primarily White Primarily male Veterans (*n* = 127) Family: (*n* = 127) "caregivers (typically wives; coresident family caregivers)" Age: *M* = 72 Providers: social workers, psychologists, nurses Setting: Department of Veterans Affairs home-based primary care	• From baseline to 6 months, caregivers reported significantly decreased burden, depression, impact of depression on daily life, caregiving frustrations, and number of troubling dementia-related behaviors. • A 2-hour decrease in hours per day on duty approached significance. • Caregivers (96%) believed that the program should be provided by the VA to caregivers..
Philp & Young (1988), United Kingdom, Fair (21)	Determine how well a primary care team supported lay carers of the demented elderly	Patients: (*n* = 17) Dx: Dementia Age: 76-93, *M* = 81.6 Family: (*n* = 17) "lay carer (i.e., the person [relative, spouse, or friend] who provided most support for the demented person at least on a daily basis, living with or separately from the demented person"	• The primary care team knew of the existence of all symptomatic demented elderly patients in the practice • Lay carers lacked knowledge about dementia and had unmet needs. • Giving lay carers a booklet about dementia and reporting their unmet needs to the primary care team led to improvements in standards 2 and 3. • Stress among lay carers was reduced. • In spite of a reduction in the number of carers' unmet needs, there was no overall change in the use of available resources following intervention.
Reuben et al. (2010), United States, Good (33)	Determine whether a practice redesign intervention coupled with referral to local Alzheimer's Association chapters	Patients: (*n* = 121) Dx: Dementia Age: 75+ Family: "families" not defined Providers: (*n* = 10); physicians, 50% male, 50% white Age: *M* = 44.3	• Based on 47 pre- and 90 post-intervention audits, the percentage of quality indicators satisfied rose from 38% to 46% with significant differences on quality indicators measuring the assessment of functional status (20% versus 51%), discussion of risk/benefits of

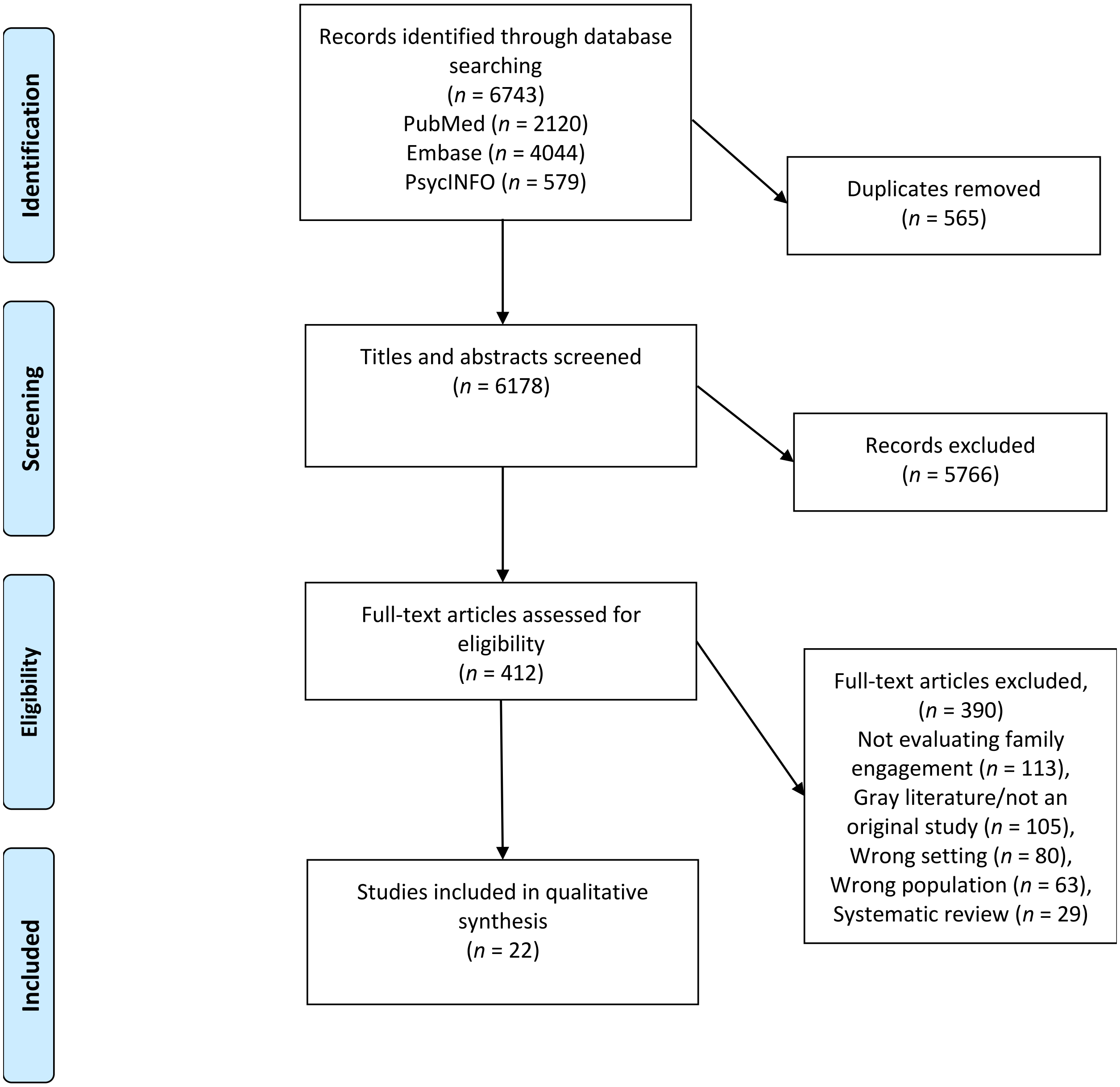
	can improve the quality of dementia care		antipsychotics (32% versus 100%), and counseling caregivers (2% versus 30%). • Referral of patients to Alzheimer's Association chapters increased from 0 to 17%. Referred patients had higher quality scores (65% versus 41%) and better counseling about driving (50% versus 14%), caregiver counseling (100% versus 15%) and surrogate decision-maker specification (75% versus 44%). • Some quality indicators related to cognitive assessment and examination did not improve.
Sato et al. (2018), Japan, Good (34)	Evaluate the usefulness of the carer-held records (CHR) for patients with dementia at the municipal level	Patients: (*n* = 74) Dx: Dementia (Alzheimer's disease, vascular dementia, Lewy bodies, semantic dementia, Parkinson's disease with dementia, idiopathic normal pressure hydrocephalus, other dementia) Age: 70-103, 84.5 median Primarily female Family: (*n* = 74); "carer, caregiver, informal caregivers (spouse, child, daughter-in-law" Age: 36-84 Providers: physicians, dementia specialists, care professionals, care service coordinators	• The information provision score significantly improved after CHR use for all informal caregivers. • The collaboration score significantly improved after CHR use only for informal caregivers whose care managers attended at least two collaborative meetings. • The Zarit Caregiver Burden Interview score significantly improved after CHR use for daughter-in-law caregivers. • The Dementia Behaviour Disturbance Scale scores did not significantly improve after CHR use.
Schmidt et al. (2009), United States, Good (35)	Understand the nature of each individual's verbal participation in triadic interactions in primary care visits of patients with Alzheimer's disease (AD) involving communication among	Patients: (*n* = 23) Dx: Dementia, Alzheimer disease Age: *M* = 79 Primarily white Family: (*n* = 23) "family caregivers (spouse or adult child; daughter)" Age: *M* = 68	• PCP verbal participation was highest at 53% of total visit speech, followed by caregivers (31%) and patients (16%). • Patient cognitive measures were related to patient and caregiver verbal participation, but not to PCP participation. • Caregiver satisfaction with interpersonal treatment by PCP was positively related to caregiver's own verbal participation.

	patients, family caregivers, and primary care physicians (PCPs)	Providers: (*n* = 20); primarily white and male, Age: *M* = 48	
Shega et al. (2003), United States, Good (28)	Assess the feasibility and effectiveness of offering primary care with a palliative approach to persons with dementia	Patients: (*n* = 150) Dx: Dementia (not limited to Alzheimer's disease) Age: *M* = 82.1, 75% women, 82% African American Family: "family, caregivers, proxy" Providers: Geriatric fellowship-trained physicians (*n* = 9), social worker (*n* = 1), clinical nurse specialists (*n* = 2) Setting: Chicago, Illinois	• Initial feedback suggests patients have adequate pain control, satisfaction with quality of care, appropriate attention to prior stated wishes, and death occurring in the patient's location of choice. • Families voiced similar high marks regarding quality of care.
Teel (2004), United States, Good (35)	Describe the experiences of primary care providers in non-metropolitan settings in diagnosing dementia and in initiating treatment for patients with dementia	Patients: Dx: Dementia, Alzheimer's disease Family: "family, loved ones (i.e., spouse, adult child)" Providers: (*N* = 19) Physicians (*n* = 17) Nurse practitioners (*n* = 2); primarily male, white Age: 31-67 Setting: Primarily rural areas of a midwestern U.S. state	• Participants estimated that the time from symptom onset to diagnosis ranged from several months to one year, largely dependant upon family recognition. • Limitations in access to consultants and limited or non-existent community support and education resources were major impediments to diagnosis and treatment, respectively. • Denial among family members, or families who were absent or uncooperative, created additional challenges for providers in making and communicating diagnoses and in supporting home-based or institutional care. • Supportive and motivated families played a central role in positive patient care experiences. • Participants agreed that support and education services were important for family caregivers, but generally had few resources to offer families, which constrained their ability to provide optimal care.
Vick et al. (2018), United States,	Understand how family companion	Patients: (*n* = 21) Dx: Cognitive impairment	• Family companions commonly facilitate communication by advocating for patients,

Good (36)	involvement affects the quality of primary care visit communication for older adults with cognitive impairment	Age: 65+, *M* = 83 Primarily Caucasian Family: (*n* = 21); "family companions (i.e., family member or unpaid companion; spouse/partner, adult child)" Age: *M* = 67 Primarily educated (college or higher) women Providers: (*n* = 10); primary care physicians, nurse practitioners, primarily female	ensuring the accuracy of information exchange and understanding, and preserving rapport. • Significant communication challenges include patient and companion role ambiguity, competing visit agendas, and primary care clinician confusion regarding the most accurate source of information. • Patients, companions, and clinicians each identified strategies to improve communication, chief among them being to identify, differentiate, and respect both patient and companion priorities and perspectives.
Werner (2006), Israel, Good (34)	Examine family physicians' recommendations for various pharmacological and nonpharmacological treatments for Alzheimer's disease (AD) and its correlates	Patient (vignette): 71 years-old male with Alzheimer disease Family: son Providers: (*N* = 395); family physicians, primarily female Age: *M* = 48.7	• Engagement in social activities and participation in support groups were the interventions most recommended by the physicians. • Isolation and physical restraints were the least recommended. • Recommendations about AD treatments were associated with the severity of the disease and the extent to which the person described in the vignette was perceived as dangerous. • Physicians' recommendations were very similar to those of the lay public
Werner et al. (2004), Israel, Good (35)	Examine the characteristics of physician-patient-caregiver encounters in the presence of dementia and how sociodemographic and professional characteristics of family physicians, and severity of symptoms in patients with dementia affect these encounters	Patients: Dx: probable Alzheimer's disease Age: 76 (vignette) Female Family: "family, caregiver" husband Providers: (*N* = 141) Family physicians Male (50%) Age: *M* = 48.6	• Physicians address the caregiver more than the patient (both with respect to questions, information, and involvement). • Physicians, who were older and had a higher number of years in the profession, address the caregiver to a higher degree (compared to the patient) than younger and less experienced physicians.

Figure 1

PRISMA Diagram



Note. PRISMA flow diagram (Moher et al., 2009).

Figure 2

Worlds of Care Addressed in Each Study

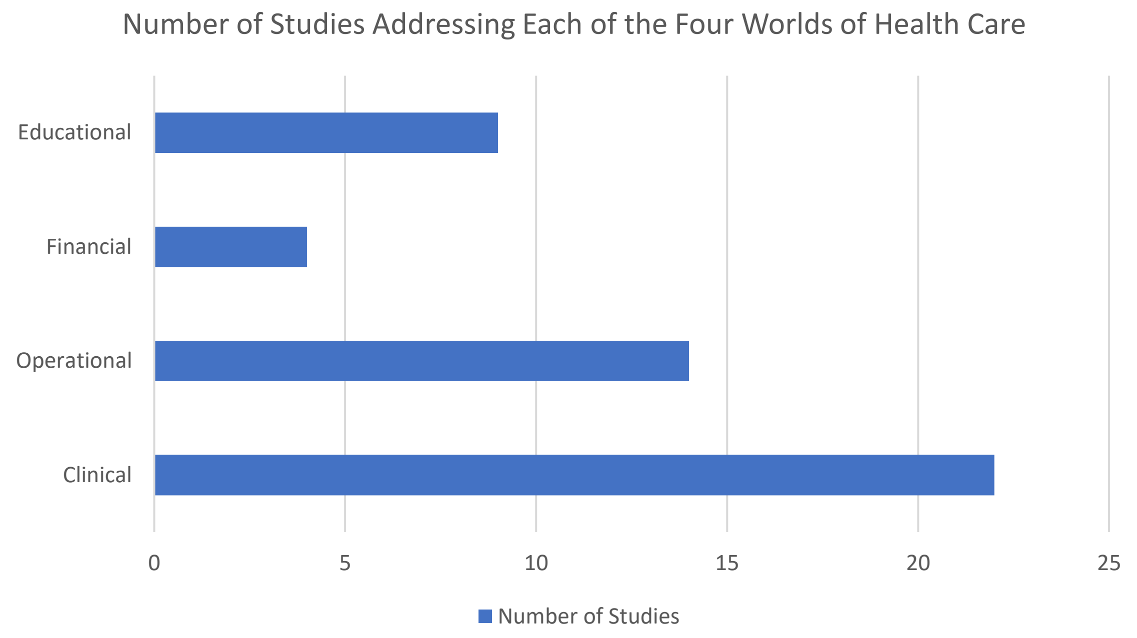
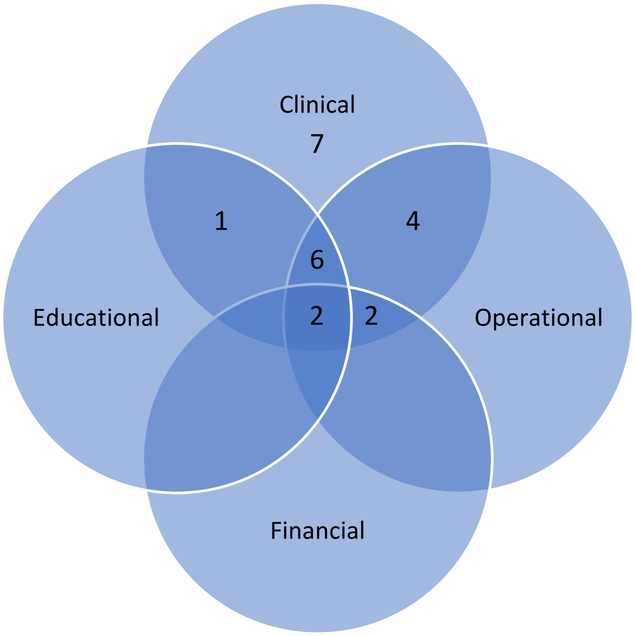


Figure 3

Number of Studies Addressing Multiple Worlds of Health Care



CHAPTER 3: THE UNACCOMPANIED OLDER ADULT WITH COGNITIVE IMPAIRMENT IN PRIMARY CARE: A FAMILY-CENTERED APPROACH

Cognitive impairment (CI) impacts more than 11 million Americans and their families (Alzheimer's Association, 2015). Patients living with CI may be diagnosed with mild cognitive impairment (i.e., more severe than normal aging but does not meet diagnostic criteria for dementia; Petersen et al., 1999) or various forms of dementia (e.g., unspecified, Lewy bodies; Molano et al., 2010). The number of individuals diagnosed with CI is expected to grow as the population ages over the coming decades and given that CI impacts older adults at increasing rates as they age (Corrada et al., 2010; Murman, 2015; U.S. Census Bureau, 2014). In addition, rates of detection and diagnosis of CI differ for individuals based on demographics including race, ethnicity, and sex (Katz et al., 2012), as well as social factors including geographical location (e.g., rural versus urban settings; Russ et al., 2012) and family involvement (Amjad et al., 2018). These variations contribute to health disparities in minoritized populations who often develop CI at an earlier age and live with impairment for a longer period of time, which presents heightened challenges for patients and their family caregivers (Hale et al., 2020). All these variables add to the complexity of caring for cognitively impaired older adults in healthcare contexts, such as primary care settings.

Primary care providers (i.e., PCP) contribute to the caring of patients with CI (Boise, 2006); however, the diagnosis and management of CI in primary care settings is challenging. PCPs have identified (a) patients' lack of disclosure regarding troublesome symptoms (Judge et al., 2019), and (b) stigma (e.g., perceived as dangerous drivers more at risk for vehicle accidents; Gove et al., 2016, Meuleners et al., 2016) as key barriers to timely diagnosis of CI. Compounded by difficulties recognizing symptoms and clinic workflow time constraints (Boise, 2006), these challenges lead to delayed diagnosis and unsatisfactory symptom management patterns (Paterson & Pond, 2009). A recent study found that only 20% of PCPs reported high confidence in their ability to interpret results of cognitive assessments and only 21% felt highly confident in their ability to make a specific diagnosis of CI (Bernstein et al., 2019). Perhaps these factors are connected to the frequent referral of patients to specialists and immense burden patients and caregivers experience when navigating a fragmented healthcare system (Parmar et al., 2014).

This critical review provides an overview of the current and relevant research regarding the identification, diagnosis, and management of CI in primary care settings using a combination of family-centered (Johnson & Abraham, 2012) and intersectionality (Crenshaw, 1989) theoretical frameworks. It helps to establish and define the need for the original study (Chapter 5). Attention will be drawn to variations in CI rates, care management, and family engagement based on the intersection of patient identities and characteristics including race, ethnicity, gender, and geographical location. A discussion of opportunities for further research in this critical area are also provided.

Theoretical Foundation

The theoretical foundation for this chapter is based upon a vision for what health care can be when it is focused on families as well as patients (i.e., Patient- and Family- Centered Care; Johnson & Abraham, 2012) and Intersectionality (Crenshaw, 1989) which provides a framework for these aspirations with consideration of how race and gender may be influential in the processes of identifying, diagnosing, and managing CI in primary care. This is critical as researchers have been encouraged to rapidly expand the scientific literature on Alzheimer’s disease and related dementias regarding intersecting identities, particularly ethnicity and race

(Babulal et al., 2019). Each of these frameworks and their contribution to this theoretical foundation are further described below.

Patient- and Family-Centered Care

PFCC envisions a healthcare system in which the patient and family members are active partners with the provider and healthcare team. It emphasizes that all parts of the system must work together at multiple levels (e.g., clinical, policy) to improve health care for older adults with CI and their families. The PFCC definition of family is any individual whom the patient identifies as a participant in their care (e.g., parent, adult child, neighbor, friend, hired caregiver). Collaboration with families in a PFCC-driven system takes place throughout the planning, delivery, and evaluation of care. The aim of PFCC is for all parts of the system to work together to improve care at clinical, program, and policy levels. However, PFCC does not acknowledge the importance of intersecting social locations that influence the implementation of family engagement with cognitive impairment.

Intersectionality Framework

Kimberlé Crenshaw's Intersectionality Framework (1989) provides a means for examining unique outcomes influenced by variations and intersections of provider- and patient-level characteristics. This framework has been utilized in research exploring the role of gender in the well-being of caregivers of patients with dementia (Chappell et al., 2015) and the social position of patients with dementia (e.g., experience of living with and viewing dementia as a disability; Thomas & Milligan, 2018). As the older adult population will be comprised of 27% racial and ethnic minorities by 2030 (Schulz & Eden, 2016), it is important for researchers to approach studying CI among older adults through a PFCC lens with cultural humility (Lewis et al., 2014) to produce science that attends to the intersections of patients', family members', and

PCPs' race and gender. This will provide opportunities to develop culturally informed treatments that are indicated for minoritized patients who have historically experienced poorer access to healthcare resources and beneficial interventions. The following section provides further description of the variations with cognitive impairment and the need for this theoretical foundation.

Cognitive Impairment: Cultural Variations in Prevalence

The prevalence of CI among older adults is somewhere between 10-20%, but the rates of it vary among social locations (e.g., race; Langa & Levine, 2014). For example, sex and gender variations among patients with CI can vary as a function of race and ethnicity (e.g., overtime, Black women experience steeper memory decline than Hispanic men and non-Hispanic white women; Avila et al., 2019). Given that the prevalence and progression of CI varies by sex and race/ethnicity, it is important to attend to such difference in research studies. Tracking population health data by social location helps PCPs to understand which populations in their practice may be at greater risk for worsening cognition (Sperling et al., 2011). Specifically, noting CI variations by social locations and the intersectionality of identities provides important information for PCPs to be mindful of when identifying and caring for patients who are at higher risk for developing it.

Racial and Ethnic Disparities

Given the expected growth of a diverse older adult population (Schulz & Eden, 2016), it is important to understand how CI varies among racial and ethnic groups to best equip healthcare teams to develop effective assessment practices and provide quality care. However, inconsistent findings have made it difficult to do so. For example, in one large study of nearly 2000 older adults (ages 70-101) in Bronx County, New York, researchers found that non-Hispanic Black patients were twice as likely to develop nonamnestic mild cognitive impairment compared to their white peers (Katz et al., 2012). However, Katz and colleagues also found that race was not a significant risk factor for developing dementia, Alzheimer's disease, or amnestic mild cognitive impairment (Katz et al., 2012). It is possible that higher rates of underdiagnosis are contributing to these inconsistences as research shows that non-Hispanic Black patients are twice as likely as non-Hispanic white patients to experience underdiagnosis of dementia (Gianattasio et al., 2019). These variations in research findings encourage further exploration of the intersections of patient-level characteristics including race and gender in the identification and management of CI with older adults.

Gender Differences

Both men and women experience rates of CI at similar rates until age 90, when women surpass men with a higher prevalence of CI (Corrada et al., 2010; Katz et al., 2012). Additionally, gender variations occur across dementia type (e.g., Alzheimer's disease, vascular dementia; Podcasy & Epperson, 2016). For example, women are twice as likely to develop Alzheimer's disease than men of the same age (Seshadri et al., 1997), but men are more likely to have a diagnosis of vascular dementia (Appelros et al., 2009) and dementia with Lewy bodies (Nelson et al., 2010). Podcasy and Epperson (2016) acknowledged that variations in rates of CI may be due in part to the societal factors that present opportunities for men to develop protective factors (e.g., advanced education) traditionally less available to women, which has resulted in documented disparities. This suggestion is supported by research showing that individuals with lower levels of education (i.e., fewer years of formal education) are at increased risk of developing CI, which has contributed to rate variations (Russ et el., 2012).

Prevalence in Rural Communities

In addition to race and gender, researchers found geography correlates with prevalence of CI (Nakamura et al., 2016; Russ et al., 2012). Russ et el. (2012) discovered that living in rural areas increases the likelihood that an individual will experience CI later in life. Similarly, Nakamura and colleagues detected higher incidence rates of CI in rural areas when compared to urban settings (2016). Residing in rural areas presents unique challenges including reduced access to supports and services (Paterson & Pond, 2009), and fewer available specialists and services beyond the primary care level (Powers et al., 2017). This makes it increasingly important that primary care practices caring for older adults are well trained and equipped to meet the needs of patients with CI.

Geographical limitations also present challenges for some families who engage in long-distance caregiving (Cagle & Munn, 2012). This is particularly challenging in America where older adults are less likely to live with their children/families as compared to older adults in other countries (Pew Research Center, 2019). Nearly 29% of the community-dwelling older adults in the Unites States are currently living alone and these rates increase to 50% for adults 85 and older (Kaplan & Berkman, 2019). The resulting lack of family engagement makes it more difficult for PCPs to gain information necessary to detect cognition issues and limits the support provided to patients and families (Philp & Young, 1988; Teel, 2004).

Cognitive Impairment in Primary Care Settings

Among medical specialists, PCPs and nurses are often the first to learn about a patient’s cognitive decline (Alzheimer’s Association, 2016; Islam et al., 2020); therefore, playing an integral role in the diagnosis and treatment of it. Caring for patients with CI in primary care practices, curtails the stress and expense of extending the diagnostic process to specialists (e.g., neurologists, psychiatrists) (Bunn et al., 2017). Retaining the care of patients with CI in primary care therefore allows the PCP to track cognitive declines alongside changes in any pre-existing or future comorbid conditions, decreasing the fragmentation of care. However, logistical barriers (e.g., brief and intermittent encounters) present challenges to effectively evaluate cognition in primary care and the presence of comorbidities increases the complexity of these challenges (Sabbagh et al., 2020).

CI and Other Comorbidities

Over 96% of community-living adults with a diagnosis of dementia had at least one comorbid condition (e.g., hypertension, arthritis; Griffith et al., 2016). In fact, adults with CI were more likely to have five or more comorbidities than individuals without (Clague et al., 2017). For example, patients may be at greater risk of cognitive decline when also living with conditions such as diabetes (Chatterjee & Mudher, 2018; Zheng et al., 2018), cardiovascular disease (Zhou et al., 2015), depression (Babulal et al., 2018), and inflammatory bowel disease (Fu & Yung, 2021). Multiple comorbidities in concert with CI may lead to exacerbations of each other (Santiago & Potashkin, 2021; Xu et al., 2015) and complex medication regimens (Johnell, 2015). Therefore, patients with a diagnosis of CI and another chronic health condition may experience poor self-care and greater dependence on others for adequate disease management (Babulal et al., 2018; Sinclair et al., 2000). Additionally, the presence of these comorbidities can create barriers to identifying and managing CI in a single primary care visit (Srikanth et al., 2020), leading to increased health service utilization (Griffith et al., 2016). PCPs can address issues such as deprescribing (i.e., the planned and supervised process of discontinuing or reducing unnecessary medications to improve a patient’s health and quality of life and reduce the risk of harm) and poor medication management by expanding their healthcare team and adopting a patient- and family-centered approach (Bayliss et al., 2020).

Family Engagement in Primary Care Visits

Over thirty percent of older adults (aged 60 years and older) attended routine primary care visits with a family member (Wolff & Roter, 2011). Such accompaniment presents opportunities to gain information regarding the patient's symptoms, cognitive performance, functional abilities, and related family concerns, which may lead to benefits such as earlier detection, diagnosis, and treatment (Wolff et al., 2016). Engaging families may also present challenges for PCPs (e.g., family members who disagree about patient symptoms or speak for the patient making it more difficult for the patient to engage in their own care; Adams et al., 2005; Vick et al., 2018). However, family members often (a) recognize the patient's symptoms sooner and (b) understand the severity of the patient's symptoms better than their PCP (Aufill et al., 2019). Furthermore, Amjad and colleagues found patients who are accompanied by a family member at their primary care visits are twice as likely to receive a diagnosis of CI compared to patients who attend medical visits alone (2018). Therefore, PCPs must be prepared to collaborate with families, caregivers, and other informants who are engaged in the care of older adults with CI.

A systematic review conducted by Welch at al. (2021) explored the engagement of families caring for older adults with CI. They found that, although rare, engaging families in the care of older adult patients with CI was beneficial to patients, caregivers, and providers. For example, PCPs reported engaging family members, particularly those who accompanied patients to medical visits, helped with the development of care goals and supported treatment plan adherence (Adams et al., 2005; Brazil et al., 2015; Hansen et al., 2008; Judge et al., 2011; Teel, 2004; Werner et al., 2004). Most often providers actively engaged them by: (a) asking for information regarding patient symptoms (Adelman et al., 2004; Cheok et al., 1997; Fortinsky et al., 1995; Hansen et al., 2008; Sato et al., 2018; Schmidt et al., 2009; Vick et al., 2018; Werner, 2006; Werner et al., 2004), (b) providing education regarding patient’s condition (Belmin et al., 2012; Brazil et al., 2015; Callahan et al., 2006; Judge et al., 2011; Nichols et al., 2011; Philp & Young, 1988; Reuben et al., 2010; Sato et al., 2018; Shega et al., 2003; Teel, 2004), and (c) initiating referrals to support services and resources (e.g., support groups; Adams et al., 2005; Belmin et al., 2012; Callahan et al., 2006; Donath et al., 2010; D’Souza et al., 2015; Nichols et al., 2011; Teel, 2004; Werner, 2006). These engagement practices resulted in increased patient and caregiver satisfaction (Adams et al., 2005; Shega et al., 2003), improved patient safety (Nichols et al., 2011), and reduced caregiver stress (Callahan et al., 2006; Nichols et al., 2011; Philp & Young, 1988; Sato et al., 2018). Unknown though are how these benefits look across various social locations. While available results are promising, documented barriers (e.g., inability of family members to accompany patients to in-person visits, inadequate availability of resources) prevent widespread adoption of consistent family engagement.

Limitations of Families to Attend Healthcare Visits In-Person

Lack of access to family is an ongoing barrier to identification, diagnosis, and management of CI in the primary care setting (Sabbagh et al., 2020). There is a dearth of information in the literature regarding how families are engaged in the care of older adults with CI when they do not accompany patients to healthcare visits (Welch et al., 2021). This is important to understand as many patients may not have the resources or ability to bring their family members with them to in-person healthcare visits, which creates additional challenges for all stakeholders.

Inadequate resources, such as lack of transportation, may also lead to a decreased ability to attend medical visits, disproportionately impacting patients and families from marginalized groups (Ruggiano et al., 2017). Despite access to resources, more than 60% of informal caregivers (i.e., family members or friends who provide regular help and support to those who are unable to function independently) are employed at least part-time (National Alliance for Caregiving & AARP, 2020). Work demands create challenges to balancing caregiving and employment responsibilities (Longacre et al., 2017), making it increasingly difficult to accompany patients to their primary care visits in person.

Patient preference may serve as another barrier as the patient may fear bringing their adult children with them to visits will result in less patient-centered communication and shorter visits (Wolff & Roter, 2012). While some family-engagement advocates encourage caregivers to email their concerns to the patient's physician (Abrahms, 2019; Jacobs, 2013), researchers have yet to examine PCP communication strategies (i.e., in person, telephone, video conference, written), what influence it has on successful patient and family-centered care practices, and how PCPs prefer to engage families to avoid potential challenges or frustrations (e.g., diminishing the patient's agency; Welch et al., 2021).

Discussion

The impact of CI is broad and far reaching as older adults are living longer (Commisso et al., 2017) and the number of individuals diagnosed with a CI continues to grow (New York University, 2018). Review of the literature demonstrated that patients commonly present with symptoms of CI to their PCPs first (Alzheimer's Association, 2016; Islam et al., 2020). However, providers are tasked with addressing CI symptoms in concert with other comorbidities, which may make it difficult to accurately diagnose CI in an efficient manner due to overlapping symptoms and exacerbating effects (Sabbagh et al., 2020). While it is well understood that the caregiver demands for CI are high (Wang et al., 2018), engagement of families in primary care is largely underutilized (Welch et al., 2021). Additionally, it is understudied how patient-level characteristics (e.g., race and gender) influence diagnostic practices. This review has provided an overview of the critical literature on this topic, exposing the need for attention to social locations and family engagement when diagnosing, managing, and treating CI in primary care.

Implications for Future Research

Further exploration is needed in multiple areas: (a) influence of social location on provider decision making regarding CI and (b) provider comfort level with diagnosing and treatment of patients with CI. As noted above, race and ethnicity of the patient have not been thoroughly studied regarding CI diagnoses (Callahan et al., 2006; Shega et al., 2003). There is an overall lack of attention to the demographics of patients with CI and the influence it has on the diagnosis and treatment process, as well as methods of family engagement practiced by PCPs. It is important that future researchers attend to the unique needs and social locations of and intersectionality (Crenshaw, 1989) with CI patients to ensure appropriate attention is given to patients' presenting symptoms and resources fit their indicated needs.

As the literature revealed, there are varying levels of comfort among PCPs regarding the identification, diagnosing, and management of CI (Pimlott et al., 2009), as well as limited evidence of the role that family communication and engagement play in their care plan and process (Welch et al., 2021). Some PCPs appear to engage specialists early in the diagnosis and treatment of CI (Kern et al., 2019). This may result in fragmenting the care process and making treatment more challenging for patients and their families. For example, a survey of 100 specialist physicians (e.g., neurologists) found that over 26% of referrals to specialists were potentially inappropriate (Kyruus, 2014). Of these inappropriate referrals, 17% did not require a referral at all and could have been adequately managed in primary care. Furthermore, patients who did require a referral, but were sent to the wrong specialist or subspecialist, were then re-referred to more appropriate providers. These unnecessary and inaccurate referrals resulted in wasted time and money (e.g., wages and co-pays) for patients and families as well as frustration for physicians. It is unclear if PCPs are feeling underprepared to meet the complex demands of this disease, or if there are other factors at play (e.g., time demands, lack of resources, perceptions of patients based on social locations). For example, the provider's perceived dangerousness of a patient's symptoms may influence the intensity of their treatment decisions (e.g., whether to prescribe medication; Werner, 2006). It would also be beneficial to understand if PCPs perceive issues such as symptom severity, disruptiveness, and dangerousness differently based on other patient-level social location identities (e.g., race/ethnicity, gender). Exploring these factors will enable stakeholders to better train and equip PCPs on how to diagnose and treat patients with CI and better engage their families who are extensions of their work outside of the medical visit.

Conclusion

Families are an untapped resource for PCPs in the care of older adults with CI. Prior to receiving an official diagnosis of CI, family members often have more familiarity with the patient's behavior and a better understanding of the severity of the patient's symptoms compared to their providers (Aufill et al., 2019). PCPs can gain greater understanding of the challenges that patients face by actively engaging families and soliciting their concerns. Furthermore, Amjad et al. (2018) found that (a) patients with probable dementia who attended medical visits alone were more likely to be undiagnosed than patients who had a family member accompany them to the visit, and (b) patients with a diagnosis of dementia were less likely to be aware of their diagnosis if they attended primary care visits alone. These concerns are important to consider when treating patients who do not have family members available to accompany them to their primary care visits (Welch et al., 2021). This can lead to problems such as under-detection of CI and poor communication between patients and providers. Engaging families in conversations about cognition better equips PCPs to detect CI in older adult patients and thus examining how and when this communication occurs is a crucial step leading to improved care for patients and families. Utilizing a theoretical foundation based on the PFCC (Johnson & Abraham, 2012) and Intersectionality (Crenshaw, 1989) will allow researchers to explore ways in which patients, families, and healthcare teams can work together to improve the care of older adults with CI.

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CHAPTER 4: EXPLORING FAMILY ENGAGEMENT USING A VIGNETTE-BASED SURVEY METHODOLOGY

This chapter describes the methodology of a quantitative study utilizing a vignette-based self-administered survey designed to explore family engagement practices of primary care providers (PCP) in the care of patients with cognitive impairment (e.g., dementia). The contributions of patient- and family-centered care (PFCC; Johnson & Abraham, 2012) and Intersectionality (Crenshaw, 1989) formed the theoretical foundation for this study. PFCC describes a vision of care in which patients and families are actively collaborating and communicating with the patient's healthcare team (Johnson & Abraham, 2012), while Crenshaw's Intersectionality framework (1989) was used to understand the complex interactions between various patient characteristics (e.g., race/ethnicity, gender) and how that may influence treatment decisions and the engagement of patients and families in care.

Researchers derived the methodology and research questions for the dissertation study from a recent systematic literature review (Welch et al., 2021) and focused critical literature review (see Chapter 3). Existing literature exposed a need for additional research to better understand the influence of family engagement on the diagnostic and treatment processes of older adults exhibiting cognitive impairment in primary care settings (Adams et al., 2005, Belmin et al., 2012, Brazil et al., 2015). For example, patients with cognitive impairment provided less accurate histories and were unable to care for themselves to the degree necessary (Adams et al., 2005). This created challenges in the typical care processes, resulting in several unfavorable outcomes: (a) greater medical uncertainty, (b) feelings of inadequacy in physicians, and (c) frustration for PCPs (Adams et al., 2005). Belmin et al. (2012) found that only half of the patients who presented with a new cognitive problem at a primary care visit were given a cognitive assessment which may have resulted in underdiagnosis and underutilization of available resources (e.g., counseling, or other support for patients and caregivers). Providers felt divided about when it is most appropriate to discuss cognitive impairment and intervention with patients and felt that improved knowledge of how to involve families of patients with dementia is needed to better support patients and caregivers (Brazil et al., 2015).

Of note, four of the studies included in the Welch et al. (2021) systematic review utilized a vignette-based methodology to examine providers' care for older adult patients with cognitive impairment (Cheok et al., 1997; Fortinsky et al., 1995; Werner et al., 2004; Werner, 2006). Findings revealed PCPs engaged family caregivers in their diagnostic and management practices to a small extent, but only when they accompanied patients to healthcare visits. As a result, Cheok et al. (1997) found: (a) PCPs felt more comfortable with diagnosing dementia than providing ongoing management of the disease, and (b) most PCPs did not utilize standardized cognitive screening protocols in their diagnostic practices. Similarly, Fortinsky et al. (1995) found that PCPs were less likely to consider the results of cognition status tests than other diagnostic measures (e.g., lab tests). It is unclear, however, if family engagement practices contributed to these patient care experiences.

The other two vignette-based studies looking at cognitive impairment and older adults focused on PCPs preference for disclosing a cognitive impairment diagnosis to a family member rather than to the patient directly (Werner, 2006; Werner et al., 2004). This positively correlated with PCPs' years of experience, extent of dementia care experience, and training in family medicine. Interestingly, in a diverse sample of family physicians (mean age of 48.6 years, SD = 8.3; mean of 22.2 years of experience, SD = 8.3), Werner et al. (2004) found older and more experienced PCPs (i.e., years of practice) spent more time interacting with accompanying family members than patients with cognitive impairment during primary care visits. In another study (Werner, 2006), PCPs were asked about management practices (i.e., treatment strategies) and reported frequently referring caregivers and family members to outside specialists and programs (e.g., support groups, social activities). However, it is still unclear in the literature if and how often PCPs prefer to collaborate with family members in the care of patients with cognitive impairment and if they are comfortable with treating cognitively impaired patients and their families or referring them to outside specialists.

Furthermore, while researchers reported differences in provider practices based on age and experience level (Werner et al., 2004), they failed to study how the intersection of patient characteristics such as gender and race may have influenced these outcomes. This is important to understand given that since 1956, social locations (e.g., race/ethnicity) were known to play a role in the diagnosis of cognitive impairment (Mannheim). For example, Weuve et al. (2018) found that Black patients are twice as likely to receive a diagnosis of Alzheimer’s Disease than their white counterparts even though Black and white patients do not differ in progression of cognitive decline. It is possible these disproportionate prevalence rates are related to assessments that are based on dominant culture and language, or other factors such as implicit biases (Braus et al., 2019; Gianattasio et al., 2019). How this transcends into family engagement is largely unknown.

Additional vignette-based studies would facilitate contributions to the literature and allow for improved understanding of PCP family engagement practices and underlying biases. Utilizing a vignette methodology to explore such issues allows researchers to ask questions in a concrete but less threatening manner due to the hypothetical nature of the study (Finch, 1987). This may help to explain why two separate systematic reviews found that the use of hypothetical scenarios (e.g., vignettes) is the most frequently utilized methodology in research studies to examine provider bias and medical decision making (Blumentahl-Barby & Krieger, 2014; Featherston, 2020).

Gaps throughout the literature indicated the need for (a) greater understanding of provider communication preferences for engaging family members, particularly when they are unable to accompany patients to primary care visits, and (b) increased attention to the influence of provider perceptions of patients with varying social locations on providers' practices and decision-making processes. There were also inconsistencies in the understanding of PCP's preferences for providing ongoing diagnostics and care or referring patients to specialists when families are engaged. Researchers designed this study to directly address these gaps with the aim to improve care for patients with cognitive impairment, their families, and healthcare providers.

Study Design

A vignette methodology (Finch, 1987) was employed as a part of the study design. Vignettes enable researchers to understand participants' perceptions and beliefs regarding particular phenomenon (Barter & Renold, 1999) and can be useful when exploring sensitive topics (Neale, 2002). Studies with vignette methodologies also assist with increased understanding of providers' preferred practices with older adults with cognitive impairment (Cheok et al., 1997; Fortinsky et al., 1995; Werner, 2006; Werner et al., 2004), as well as their implicit biases about race and gender (FitzGerald & Hurst, 2017). Furthermore, vignette methodologies contribute to the improvement of healthcare practice by allowing researchers to stimulate reflection and analyze hypothetical practices and clinical judgement-making of healthcare providers (Spalding & Philips, 2007). It enables researchers to safely achieve validity and generalizability without the risk of engaging actual patients (Evans et al., 2015).

The theoretical foundation for this study was based on Patient and Family Centered Care (Johnson & Abraham, 2012) and Intersectionality (Crenshaw, 1989). Utilizing these frameworks, researchers developed the following research questions:

a) How does the inclusion of family-provided information influence the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment?

b) To what extent does the race and gender of patients influence the diagnostic and decision-making processes of PCPs?

Researchers developed several hypotheses in response to these questions. First, researchers anticipated that the inclusion of family-provided information, which is included in the second phase of the vignette, would influence the provider's diagnosis (e.g., compared to the differential diagnoses made after phase one of the vignette, PCPs will more likely identify a cognitive impairment diagnosis after phase two upon receipt of family-provided information). This was based on recommendations for PCPs to include family or caregivers, when available, in their history taking of cognitive concerns as it is suggested to improve the PCP's evaluation process (Warrick et al., 2018).

Founded on previous literature suggesting that patient- and family-centered practice results in fewer referrals to specialists and diagnostic tests (Bertakis & Azari, 2011), participants were also expected to report reduced rates of referrals to outside sources once family was engaged (i.e., providing information regarding patient symptoms). Researchers measured this by comparing changes from Time 1 (pre-family engagement) to Time 2 (post-family engagement). Regarding the second question, researchers expected PCPs to be more likely to identify cognitive impairment in the vignettes describing white patients than African American patients. These hypotheses guided the analysis plan outlined below.

Participants

The target population included U.S. PCPs who were resident physicians or higher (PY1 residents and up), nurse practitioners, or physician assistants. PCPs could have been in training (e.g., residency, nurse practitioner program) or matriculated from training in medicine (i.e., general, family, internal, geriatrics, or gynecological medicine), nursing (i.e., nurse practitioners), or a physician assistant program. PCPs were required to self-report to have seen at least one older adult patient (i.e., 65 or older) in the past 12 months. Finally, participants must have been fluent in written and verbal English. It is worth noting the contextual impact and recency effect on the thought processes of PCPs that the COVID-19 pandemic may have had in this study. For example, providers may have viewed family engagement as more important within the context of the current pandemic compared to pre-pandemic contexts.

Researchers aimed to recruit a nationally representative and diverse sample of PCPs through the process described in the recruitment section below. The survey remained active until at least 10 participants were recruited for each of the 4 versions of the vignette (i.e., white male, Black male, white female, Black female). Participants were recruited one version at a time (first version one, then version two, and so on) but were unaware of the multiple vignette versions. Once a vignette version reached the minimum number of participants, the next version was opened.

Recruitment

East Carolina University IRB approval was obtained (number UMCIRB 20-002835) before engaging in any recruitment. This study was approved with an exempt certification.

Verification of approval is included in the appendices (Appendix A). Potential participants were contacted primarily through email and social media (i.e., the lead researcher shared study information via LinkedIn, Facebook, Twitter, and Instagram). An example of the language used in recruitment emails and social media posts is shown in Appendix B. Researchers have previously found recruitment of nonwhite physicians to be challenging with low participation rates (Asch et al., 2000). To promote a diverse sample of PCPs, dissemination of study information included groups which target populations of interest (e.g., social media accounts supporting Black and indigenous people of color in medicine). The lead researcher also distributed recruitment information to the Collaborative Family Healthcare Association's (CFHA) active listserv. The CFHA listserv had potential to reach over 1,500 CFHA healthcare professional members including physicians, nurses, and academicians across the country.

The recruitment process was continued until the ideal sample size was achieved (Burns & Grove, 2005). Using this purposive method of sampling known as snowball sampling or the chain method (Polit & Beck, 2006), researchers anticipated the survey would reach a representative sample of PCPs across the country from a variety of training, experience, and social locations. This sampling method was both efficient and cost effective for reaching a large sample that would otherwise be difficult to achieve (Magnani et al., 2005).

Consent and Research Administration Procedures

Researchers administered all assessment tools (i.e., consent form, questionnaire with vignette) through REDCap electronic data capture tools (Harris et al., 2009; Harris et al., 2019) hosted at East Carolina University. REDCap (Research Electronic Data Capture) is a secure, HIPAA-compliant, web-based application for developing and managing online research surveys and databases. No confidential participant information was collected. Participants were asked three pre-screening questions to ensure they met the inclusion criteria (i.e., at least 18 years old, cared for at least one older adult in the past 12 months, and received training in a relevant discipline). If participants met all three requirements, they were able to access the consent form.

Consent

Through REDCap (Harris et al., 2009; Harris et al., 2019), participants were asked to agree or disagree to consent for participation prior to starting the survey. Researchers wrote the consent document with language at the sixth-grade reading level to be as inclusive as possible for a variety of literacy abilities. Participants who agreed to take part in the research study had the opportunity to download and save a copy of the consent language for their records. Once participants completed the consent process, they were permitted to begin the survey.

Measures

Authors distributed a 56-item self-administered survey (Appendix C) to assess PCPs' knowledge, practices, and preferences for diagnostic and treatment processes of older adults with cognitive impairment, including items regarding family engagement practices (e.g., communicating with a patient's family member). The four-part questionnaire included a demographic section, survey questions (pre- and post- vignette), and a vignette (presented in two phases). All parts of the survey were self-administered (See Table 1). Pilot testing was conducted with four PCPs to assess the expected time to complete the survey, which researchers limited to 30 minutes. This was done to avoid the burden of an excessive time commitment for PCP participants (Herber et al., 2009).

To understand the role race and gender play in the diagnosing and treatment of cognitive impairment among older adults, four variations of the vignette were included (white male, Black male, white female, Black female). Researchers opened each version sequentially to randomize vignette variations among study participants. Participants were blinded to the use of multiple vignette versions. All other details of the vignette remained the same in each version. Participants were presented with one of the four vignettes versions describing an individual in their seventies presenting with symptoms of neurological deficits (i.e., tremors). Due to COVID-19 safety restrictions being practiced at the time of the study, participants read that the patient's partner was unable to accompany them to the primary care visit as they normally would.

Part One. The first part of the survey included a brief ten-item sociodemographic survey. Items measured provider-level characteristics such as age, race, and gender. Participants also indicated their professional role (e.g., physician, nurse practitioner), whether they completed a geriatric residency, the number of years they have provided patient care, the state in which they currently live and practice, and whether they practice in an urban or rural setting.

Part Two. In this part of the survey, participants received the first phase (pre-family engagement) of the vignette. The vignette used in this study was modified from a vignette (Appendix D) included in a medical education training series administered for use with standardized patients with first year medical students (Edwards, 2019). Authors obtained permission to use the vignette (see Appendix E). To better assess for how family engagement influences clinical decision making, modifications were made to the original vignette to separate out the one-to-one encounter between the patient and provider from family-obtained diagnostic information.

Phase one of the vignette involved a patient interaction at a routine primary care visit. Information provided includes presenting symptoms, medical history, family history, medications, and a basic review of systems. Immediately following the vignette, participants responded to 14 items assessing their initial impressions of the case and where participants were in their clinical decision-making process.

Part Three. Part three presented the second part of the vignette in the form of an email written to the PCP by a family member (i.e., the patient’s spouse). It was sent through the patient’s electronic health record (EHR) portal. This email contained additional information regarding symptoms, family concerns and observations (e.g., impaired memory) that the patient had not previously reported in the initial encounter. Participants then responded to 18 items assessing for changes in impressions of the case and any modifications to their clinical decision-making process or outcome.

Part Four. The fourth part included 14 items that assessed provider characteristics not previously collected in part one. These included: (a) the number of dementia cases seen in the past 12 months, (b) personal experience with cognitive impairment, and (c) training in how to engage families. Additional items assessed participant preparedness and preferences for communication practices with families. This section completed the survey.

Data Analysis

There were two research questions for this study: (a) How does family engagement (i.e., family-provided information) influence the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment? and (b) How do race and gender influence PCP diagnostic and decision-making processes when caring for white and African American patients? Researchers addressed these questions using a quantitative vignette-based methodology (Finch, 1987) and analyzed data using various statistical analyses.

Quantitative analyses of providers’ decision-making and diagnostic pathways (e.g., selection of tests/screeners, engaging family, referring to specialists) were performed using SPSS

(IBM, 2017). To address the first research question, paired-samples t-tests and a McNemar's Test (McNemar, 1947) were performed to evaluate the influence of family engagement. To address the second research question, researchers performed one-way repeated-measures analysis of variance (ANOVA) to determine the influence of patient race and gender on the various outcomes (e.g., perceived concern of patient symptoms, identification of cognitive impairment). This was an important step in the literature as previous studies have not analyzed the influence of patient race and gender. Finally, chi-square tests of independence were conducted to identify differences between vignette versions. Further details about the analysis of each question are described below.

Research Question 1

The first question focused on how family engagement (i.e., communication through email in the EHR) influenced PCP diagnostic, management, and referral practices. Researchers used paired-samples t-tests to determine if PCP responses to questions prior to family engagement (i.e., Time 1) were different from responses to the same questions post-family engagement (i.e., Time 2). This allowed researchers to evaluate if receiving communication from the patient's spouse changed the provider's perception of the patient's symptoms and their decision-making processes. Comparisons were made for PCP reports of perceived severity, disruptiveness, and dangerousness of symptoms, as well as their identification of a differential diagnosis. Of note, the terms "severity", "disruptive", and "dangerousness" were not explicitly defined for the participant but were intentionally left general and open to participant interpretation. These items were used in a similar fashion in a previous vignetted-based study exploring PCP care of patients with Alzheimer's disease (Werner & Giveon, 2008). Each of these three constructs were quantified using a single 5-point Likert-type scale item. For example, participants were asked to rate how disruptive they perceived the patient’s symptoms to be on a scale of 1 (not at all disruptive) to 5 (highly disruptive).

One open ended survey item was used to determine if family engagement influenced participants’ ability to accurately identify and diagnose cognitive impairment. An exact McNemar’s Test (McNemar, 1947) was used to compare the number of participants who identified it at Time 1 versus Time 2. A participant’s response was recognized as a correct and accurate diagnosis of cognitive impairment if it specifically mentioned cognitive impairment, dementia, or a closely related response (e.g., Alzheimer’s disease, dementia with Lewy bodies, mild cognitive impairment, vascular dementia, early cognitive deficit). Responses were only included in the analysis if the participant made a differential diagnosis at Time 1 and Time 2.

One 5-point Likert-type item was used to measure participant comfort level with ongoing care (i.e., 1 “definitely no” to 5 “definitely yes”). Additionally, one closed ended (i.e., “yes” or “no”) question was used to measure participant desire to communicate with family. Each of these items were measured at Time 1 and Time 2. Additionally, two items were assessed for participant decision to refer the patient to a specialist. First, participants responded to a closed ended (i.e., “yes” or “no”) item asking whether they would consider referring the patient to a specialist. Then they were asked to list the type of specialist they would refer to. A McNemar’s Test (McNemar, 1947) was used to determine the influence of family engagement on the PCP’s desire to communicate with the patient’s family and decision to refer the patient to a specialist.

Research Question 2

The second research question focused on how gender and race influenced the diagnostic and decision-making processes of PCPs. The same eight items used in the analyses for research question one were used in the analyses of research question two to determine differences between the four vignette versions. A mixed between-within subjects ANOVA was conducted to assess the influence of four different vignette versions (i.e., white male, Black male, white female, Black female) on participants' scores of perceived (a) severity, (b) disruptiveness, (c) dangerousness of symptoms, and (d) comfort level with ongoing care of the patient, across two time periods (pre-family engagement and post-family engagement). If the ANOVA revealed a significant difference between the vignette versions, a post-hoc comparison using the Tukey HSD test was conducted to identify which vignette versions significantly differed. Additionally, a Chi-square test for independence was used to identify associations between vignette versions and each of the following: identification of cognitive impairment, desire to communicate with family, and decision to refer to a specialist.

Summary

The purpose of this original research study was to expand knowledge of how family engagement and the intersection of race and gender influence the way in which PCPs identify, diagnose, and manage cognitive impairment in older adults. The analysis plan outlined in this chapter was designed to address two research questions: (a) How does family engagement (i.e., family-provided information) influence the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment, and (b) How do race and gender influence PCP diagnostic and decision-making processes when caring for white and African American patients? The study design allowed for improved understanding of the influence of explicit family engagement in a non-traditional format (i.e., communication with a patient's spouse via EHR) on PCPs' diagnostic, management, and decision-making processes when treating older adults with cognitive impairment. Researchers directly addressed these prominent gaps in the existing literature and helped to advance the knowledge in this important area.

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Table 1

Four Parts to the Questionnaire and Associated Items

Part	Phase of Vignette Included	Number of Items	Nature of Questions
One	n/a	10	Demographics
Two	Phase One/Time 1 (Patient-provider interaction)	14	Response to vignette phase one
Three	Phase Two/Time 2 (Email to PCP from family)	18	Response to vignette phase two
Four	n/a	14	PCP characteristics not previously addressed (e.g., experience and training)

CHAPTER 5: FAMILY-CENTERED PRIMARY CARE AS A PATH TOWARD IMPROVED CARE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENT

Cognitive impairment (e.g., dementia) in older adults can be a difficult and burdensome condition for patients, families, and their medical providers to address. A recent international study (Petrazzuoli et al., 2020) surveyed primary care providers (PCPs) to explore ways of reducing the burden of dementia on patients and their family caregivers. Not surprisingly, providers reported that identifying dementia burden was the first step in successfully assessing, diagnosing, treating, and managing it. Primary care is an ideal place for this identification process to start as PCPs are often the first to learn about patient symptoms from patients and their family (Bunn et al., 2012). However, identification of cognitive impairment is difficult for PCPs due to time constraints, uncertainty of how to best assess for cognitive concerns, and provider discomfort with diagnosis disclosure (Foley et al., 2017; Tang et al., 2018). Therefore, formal evaluation of cognitive impairment is often omitted (Kotagal et al., 2015) and it remains undetected by providers more than 40% of the time (Chodosh et al., 2004). This is especially true in populations who are underserved and have lower levels of education (Amjad et al., 2018), which perpetuates health disparities (Avila et al., 2019; Husaini et al., 2015). The Alzheimer's Association (2017) reported, in addition to a greater prevalence of dementia diagnoses among African Americans, there is also evidence of more frequently missed diagnoses of Alzheimer's and other dementias among older African Americans compared to older whites.

Family engagement in the primary care setting may help to resolve these concerns. Nearly 50% of older adults are accompanied to primary care visits by a family member, usually a spouse or an adult child (Wolff & Roter, 2011). Accompanied patients are more likely to be older, white, female, in poorer health, and have less formal education (Wolff & Roter, 2011).

Utilizing a patient- and family-centered approach to care (Johnson & Abraham, 2012) that is attentive to the intersection of patients' (a) social locations (Crenshaw, 1989), (b) agency (i.e., voice), and (c) communion (i.e., community of support) (McDaniel, Doherty & Hepworth, 2014), may be a way to detect and diagnose cognitive impairments earlier and more accurately. Researchers have already noted that reducing power imbalances between patients, family members, and the healthcare team results in better engagement of non-professional sources in the healthcare experience (Wolff & Roter, 2012).

In 2020, the U.S. Preventive Services Task Force acknowledged the importance of early detection of cognitive impairment (Owens et al., 2020). However, they stated there is insufficient evidence to recommend for or against routine screening for cognitive impairment in older adults (65+). Such ambiguity in the literature leads to confusion for providers to navigate in practice (Foley et al., 2017) and an overreliance on less desirable solutions such as antipsychotic medications (Jennings et al., 2018). Failure to evaluate and diagnose cognitive impairment leads to missed opportunities to treat the underlying condition, resulting in potentially unsafe situations for patients and their families (Bradford et al., 2009; McPherson & Schoephoester, 2012).

The purpose of this study was to explore the following research questions: (a) How does family engagement influence the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment, and (b) How do race and gender influence PCP diagnostic and decision-making processes when caring for white and African American patients? Researchers hypothesized that the inclusion of family-provided information would influence (a) the perception of patient symptoms (i.e., level of severity, dangerousness, and disruptiveness), (b) the provider's recognition of cognitive impairment and associated differential diagnosis (e.g., PCPs would be more likely to identify a cognitive impairment diagnosis after receipt of family-provided information), and (c) the PCP’s response to care (i.e., comfort with ongoing care, desire to communicate with family, and referral to specialists). Furthermore, research shows disproportionate rates of missed diagnosis of cognitive impairment among African Americans (e.g., non-Hispanic Black patients are twice as likely to experience underdiagnosis of dementia compared to white patients; Gianattasio et al., 2019), which may be related to implicit bias and/or discrimination. Therefore, researchers hypothesized that participants would be less likely to identify cognitive impairment in the vignettes describing an African American patient compared to the vignettes describing a white patient.

Methods

A vignette-based self-administered survey was designed to explore family engagement practices of PCPs in the care of patients with cognitive impairment. Cognitive impairment was defined as any diagnosis of a mental condition where a person loses their ability to think, remember, learn, make decisions, and solve problems. See Table 1 for a list of ICD-10 codes and diagnoses that were included in this definition. This study was approved by the IRB (number UMCIRB 20-002835) with an exempt certification.

Sample

A total of 49 PCPs from across the United States completed the survey. However, four participants were excluded for not meeting the inclusion criteria (i.e., one removed for not working with older adults, two removed for training requirements, and one identified as a pharmacist practitioner). An additional 63 participants initiated the online survey but did not complete it, so their data was not included. Thus, 45 records met the inclusion criteria and formed the final data set. Majority of participants were female (74%), white (76%), and practiced family medicine (78%) in urban areas (67%). This sample differed from national trends as it included primarily female and family medicine physicians, while national samples tend to have more male than female providers and slightly more physicians with internal medicine training than family medicine and general practice training (AAMC, 2021). The study sample also differed racially and geographically from the national sample as only 56% of active physicians in the U.S. are white (AAMC, 2019) and less than 15% practice in rural areas (Skinner et al., 2019). Participant demographic information is included in Table 2.

Measures

A 56-item self-administered questionnaire was developed for this study. It was designed to assess PCPs' knowledge, practices, and preferences for diagnostic and treatment processes of older adults with cognitive impairment and included items regarding family engagement practices. The four-part questionnaire included (a) a 10-item demographic section, (b) 46 survey questions (37 quantitative items and 9 open ended items) to assess PCP assessment and decision-making process (pre- and post- vignette), and (c) a vignette (presented in two phases to study the influence of family communication with PCP about patient's symptomatology) modified from a training manual for first year medical students. See Table 3 for a list of the eight items analyzed for research questions one and two. Of note, 14 items assessed at Time 1 were repeated at Time 2. Pre- and post- vignette questions were written to evaluate providers' perceived concern for the patient, which included a ranking of severity, disruptiveness, and dangerousness of symptoms. Each of these were measured by a single item using a Likert-type scale. For example, participants were asked to rank how disruptive they perceived the patient's symptoms to be from 1 (not at all disruptive) to 5 (highly disruptive). The constructs of severity, disruptiveness, and dangerousness were not defined, rather, they were left open to participant interpretation. Leaving the constructs open for general understanding was done to mirror a similar vignette-based study previously conducted to examine PCP behavior with older adults living with Alzheimer's disease (Werner & Giveon, 2008).

The clinical vignette described a face-to-face encounter with a patient in their seventies evidencing neurological deficits (i.e., tremors). To better assess for the influence of family engagement on clinical decision making, modifications were made to the original vignette (Edwards, 2019) so information exclusively obtained from the patient appeared in the first half of the vignette and information obtained from the family was in the second half. Due to COVID-19 safety restrictions being practiced at the time of the study, participants read that the family was unable to accompany the patient in-person and thus received the family-provided information regarding the patient's health via an electronic health record (EHR) system's patient portal instead. Four versions of the vignette were created to study influence of race on PCP decision making. Participants were randomly assigned one of four versions of the clinical vignette with varying combinations of patient race and gender (i.e., white male, Black male, white female, Black female). All other details of the vignette and survey remained the same. The survey measure was designed for this study. It did not include standardized items. To ensure face validity and determine length of the survey, four PCPs served as pilot testers prior to distribution. Modifications to the survey were made based on their feedback to limit the length to approximately 20-30 minutes.

Procedures

The target population had to meet the following inclusion criteria: (a) at least 18 years old, (b) U.S. based PCPs (i.e., general, family, internal, geriatrics, or gynecological medicine) in training or board certified to practice as physicians (PY1 residents and up), nurse practitioners, and physician assistants, and (c) cared for at least one older adult patient (i.e., age 65 or older) in the previous year. Recruitment was primarily conducted through email and social media (i.e., LinkedIn, Facebook, Twitter, and Instagram) using a purposive snowball sampling method also known as the chain method (Polit-O'Hara & Beck, 2006). As a result, researchers were able to reach a geographically diverse sample of PCPs with a variety of training, experience, and social locations (See Table 2 for participant demographics).

Researchers administered the consent process and survey through Research Electronic Data Capture (REDCap) electronic data capture tools (Harris et al., 2009; Harris et al., 2019). REDCap is a secure, HIPAA-compliant, web-based application for developing and managing online research surveys and databases. All responses were anonymous and no confidential information was collected.

Data Collection

The survey was open and accessible online between January and April 2021. The vignette versions were randomly assigned to each participant and participants were unaware of the multiple vignette versions (blinded to the independent variable). Each survey version remained open until a minimum of 10 participants had completed each of the four versions, and then the next survey version replaced it. This process continued until each of the four vignette versions had approximately the same number of participants (shown in Table 4).

Data Analysis

Researchers utilized SPSS (IBM, 2017) to perform all data analyses. To address research question one, researchers performed paired-samples t-tests to evaluate the influence of family engagement on the diagnostic, management, and referral practices of PCPs with older adults exhibiting cognitive impairment. This included an evaluation of scores for each of the following outcomes: (a) perceived severity, (b) perceived disruptiveness, (c) perceived dangerousness of the patient’s symptoms, and (d) comfort level with ongoing care. Additionally, a McNemar’s Test (McNemar, 1947) was conducted to evaluate the influence of family engagement on participants’ responses for identification of cognitive impairment in differential diagnosis, desire to communicate with family, and consideration of referring the patient to a specialist.

To address research question two and explore the influence of the patient’s race and gender on these outcomes, a one-way repeated-measures analysis of variance (ANOVA) test was conducted to evaluate the influence of vignette versions (i.e., white male, Black male, white female, Black female) for each of the outcomes: (a) perceived severity of patient symptoms, (b) perceived disruptiveness, (c) perceived dangerousness of the patient’s symptoms, and (d) comfort level with ongoing care. Additionally, to identify differences between each of the vignette versions, a chi-square test of independence was conducted for each of the following: (e) identification of cognitive impairment in differential diagnosis, (f) desire to communicate with family, and (g) referral to a specialist.

Results

Research Question 1: Exploring the Influence of Family Engagement

Researchers hypothesized that information obtained from the family would positively influence and enhance the perception of patient symptoms (i.e., perceived severity, disruptiveness, and dangerousness). It was also expected to influence PCPs ability to recognize and accurately diagnose cognitive impairment. Lastly, researchers expected that family engagement would increase PCPs’ comfort with providing ongoing care and decrease their referrals to a specialist (e.g., neurologist).

PCP Perception of Symptoms

Perceived Severity. Two participants indicated they were unable to assess the severity of the patient's symptoms at Time 1 and thus were not included in the analysis (participants could choose "cannot be determined"). For those who responded, there was a statistically significant increase in severity scores from Time 1 (M = 2.65, SD = 0.48) to Time 2 (M = 3.07, SD = 0.59), t (43) = -4.38, p < .001 (two-tailed). The mean increase in severity scores was -0.42 with a 95% confidence interval ranging from -0.61 to -0.23. The eta-squared statistic (0.31) indicated a large effect size. Severity was measured using one survey item with a 4-point Likert-type scale asking participants to rate how "severe" they perceived the patient's symptoms to be with 1 representing "not at all severe" and 4 representing "high severity". Severity was not defined for participants but was intentionally left open for participant interpretation. Increases in severity scores indicated an increased level of PCP concern about the severity of their patient's symptoms. Results are presented in Figure 1.

Perceived Disruptiveness. There was also a statistically significant increase in disruptiveness scores from Time 1 (M = 2.91, SD = 0.67) to Time 2 (M = 3.58, SD = 0.87), t (45) = -6.63, p < .001 (two-tailed). The mean increase in disruptiveness scores was -0.67 with a 95% confidence interval ranging from -0.87 to -0.46. The eta squared statistic (0.50) indicated a large effect size. Like severity, PCPs perceived the patient's symptoms to be more disruptive to the patient once they received information from the family than when learning about the symptoms from the patient alone. Disruptiveness was measured using one survey item with a 5-point Likert-type scale asking participants to rate how "disruptive" they perceived the patient's symptoms to be with 1 representing "not at all disruptive" and 5 representing "highly disruptive”. Disruptiveness was not defined for participants but was intentionally left open for participant interpretation.

Perceived Dangerousness. Once again, as hypothesized, there was a statistically significant increase in dangerousness scores from Time 1 (M = 1.87, SD = 0.79) to Time 2 (M = 3.42, SD = 0.87), t (45) = -12.41, p < .001 (two-tailed). The mean increase in dangerousness scores was -1.56 with a 95% confidence interval ranging from -1.81 to -1.30. The eta squared statistic (0.78) indicated a large effect size. This indicates that PCPs viewed the patient’s symptoms to be more dangerous after learning about concerning incidents (e.g., getting lost on a routine drive) from the family compared to when interacting with the patient independently. Dangerousness was measured using one survey item with a 5-point Likert-type scale asking participants to rate the patient’s symptoms from “1, very safe” to “5, highly dangerous”. Dangerousness was not defined for participants but was intentionally left open for participant interpretation. This approach has been used to measure PCP discriminatory behavior in a previous study (Werner & Giveon, 2008). Increases in dangerousness scores indicated an increased level of PCP concern about the dangerousness of their patient’s symptoms.

PCP Identification of Cognitive Impairment

All but two of the participants (n = 43) made a differential diagnosis at Time 1 and Time 2. Of those who made a differential diagnosis, only five participants identified some form of cognitive impairment at Time 1 prior to family engagement and 38 did not identify it. The number of PCPs who accurately identified and diagnosed cognitive impairment increased by 70% at Time 2, with 35 participants including cognitive impairment in their differential diagnosis after receiving family-provided information. Only eight PCPs (less than 19%) did not identify a diagnosis of cognitive impairment at Time 2. An exact McNemar’s Test indicated there was a significant change ($p < .001$) in the proportion of participants who identified cognitive impairment in their differential diagnosis following family engagement (81.4%) when compared with the proportion prior to the family engagement (11.6%). This finding confirmed the hypothesis that providers more accurately identified and diagnosed cognitive impairment after receiving information about patient symptoms from family.

PCP Response to Care

Comfort Level with Ongoing Care. At Time 1, over 95% of participants ($n = 43$) indicated they would feel comfortable with ongoing care of this patient, while only 4% ($n = 2$) reported feeling unsure or indicated that they would not. Conversely, only 87% of participants ($n = 39$) indicated comfort with ongoing care of this patient at Time 2, with 7% of participants ($n = 3$) indicating they would not. There was a statistically significant decrease in comfortability providing ongoing care to the patient from Time 1 ($M = 1.44$, $SD = 0.66$) to Time 2 ($M = 1.67$, $SD = 0.95$), t (45) = -2.49, $p = .017$ (two-tailed). The mean decrease in comfortability scores was -0.22 with a 95% confidence interval ranging from -0.40 to -0.04. The eta-squared statistic (0.12) indicated a large effect size. This indicates that overall, in contrast to the hypothesis, providers felt less comfortable with providing ongoing care to the patient after receiving more information about the patient's symptoms from the family.

Desire to Communicate with Family. A McNemar's Test indicated there was no significant change in the proportion of participants interested in communicating with the patient's family following family engagement (68.9%) when compared with the proportion prior to the engagement (80.0%). This means that PCPs were neither more or less interested in continued communication with the patient's family after receiving family-provided information as compared to Time 1.

Referral to Specialists. An exact McNemar's Test indicated there was a significant change (*p* = .008) in the proportion of participants (*N* = 45) who referred the patient to a specialist following family engagement (66.7%) when compared with the proportion prior to the family engagement (48.9%). This finding contradicted with the hypothesis that PCPs would be less likely to provide a referral to a specialist after family engagement. Table 5 shows the types of specialists that providers elected to refer to. Majority of referrals were made to neurologists at both Time 1 and Time 2. Of note, participants made referrals to specialists at Time 1 and Time 2 despite reporting an overall high rating of comfort with ongoing care.

Research Question 2: Exploring the Influence of Patient Race and Gender

In response to the second research question, researchers hypothesized that patient race and gender would influence the providers' responses to these various outcomes (e.g., PCPs would be less likely to make a diagnosis of cognitive impairment with African American patients compared to white patients given research findings of African Americans experiencing underdiagnosis of cognitive impairment twice as often as white patients; Gianattasio et al., 2019). The results suggested significant differences in perceived disruptiveness among the vignette versions (i.e., higher rating of perceived disruptiveness at Time 2 for white male vignette version compared to white female version at Time 2). However, there were no significant differences by race or gender among the other outcomes (i.e., perceived severity, perceived dangerousness, identification of cognitive impairment, comfort with ongoing care, desire to communicate with family, and decision to refer to a specialist). Each finding is presented below.

PCP Perception of Symptoms

Perceived Severity. A mixed between-within subjects ANOVA was conducted to assess the influence of four different vignette versions (i.e., white male, Black male, white female, Black female) on participants' scores of perceived severity of symptoms, across two time periods (pre-family engagement and post-family engagement). There was not a significant interaction between vignette version and time, Wilks' Lambda = .97, *F* (3, 39) = .41, *p* = .75, partial eta squared = .03. There was a substantial main effect for time, Wilks' Lambda = .68, *F* (1, 39) = 18.43, *p* < .001, partial eta squared = .32, with all four groups showing an increase in perceived severity scores across the pre- and post- time periods. This means that all four vignette versions experienced a significant increase in level of severity from Time 1 to Time 2. However, the main effect comparing the four versions of the vignette was not statistically significant, *F* (3, 39) = .80, *p* = .50, partial eta squared = .06, suggesting no difference in the influence of the four vignette versions.

The level of symptom severity was lower for both Black males and Black females compared to their white counterparts at Time 1 and Time 2, suggesting an influence of race on perceived severity. Additionally, the intersectionality of race and gender appears to have had an in influence on perceived severity for Black females as the slope of symptom severity from Time 1 to Time 2 is steeper for Black females compared to the other three demographics. This is a relationship that needs more research as there appears to be a relationship between perceived symptom severity, race, and gender. It is possible that the small sample size resulted in a lack of statistical power limiting the results from achieving statistical significance.

Perceived Disruptiveness. A mixed between-within subjects ANOVA was conducted to assess the influence of four different vignette versions (i.e., white male, Black male, white female, Black female) on participants' scores of perceived disruptiveness of symptoms, across two time periods (pre-family engagement and post-family engagement). There was not a significant interaction between vignette version and time, Wilks' Lambda = .94, *F* (3, 41) = .95, *p* = .42, partial eta squared = .07. There was a substantial main effect for time, Wilks' Lambda = .50, *F* (1, 41) = 41.48, *p* < .001, partial eta squared = .50, with all four groups showing an increase in perceived disruptiveness scores across the pre- and post- time periods. The main effect comparing the four versions of the vignette was statistically significant, *F* (3, 41) = 2.98, *p* = .04, partial eta-squared = .18, suggesting a difference in the influence of the four vignette versions.

A one-way between-groups ANOVA was conducted to explore the influence of vignette version on levels of perceived disruptiveness at Time 2. There was a statistically significant difference at the *p* < .05 level in disruptiveness scores at Time 2 for the four groups: *F* (3, 41) = 2.85, *p* = .049. The effect size, calculated using eta squared, was .17, which is considered a large effect according to Cohen's (1988) effect sizes. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for vignette version 1 (i.e., white male; *M* = 3.92, *SD* = .64) was significantly different from vignette version 3 (i.e., white female; *M* = 3.00, *SD* = .67). The other versions of the vignette did not differ significantly. No significant difference between vignette versions was found for Time 1. This result suggests there was a statistically significant difference in the perceived disruptiveness of symptoms based on gender, but not on race.

Perceived Dangerousness. A mixed between-within subjects ANOVA was conducted to assess the influence of four different vignette versions (i.e., white male, Black male, white female, Black female) on participants' scores of perceived dangerousness of symptoms, across two time periods (pre-family engagement and post-family engagement). There was not a significant interaction between vignette version and time, Wilks' Lambda = .92, *F* (3, 41) = 1.13, *p* = .35, partial eta squared = .08. There was a substantial main effect for time, Wilks' Lambda = .21, *F* (1, 41) = 151.18, *p* < .001, partial eta-squared = .79, with all four groups showing an increase in perceived disruptiveness scores across the pre- and post- time periods. The main effect comparing the four versions of the vignette was not statistically significant, *F* (3, 41) = .39, *p* = .76, partial eta squared = .03, suggesting no difference in the influence of the four vignette versions.

PCP Identification of Cognitive Impairment

A Chi-square test for independence indicated no significant association between vignette version and identification of cognitive impairment at Time 1, $\chi 2$ (3, *n* = 43) = 4.80, *p* = .19, *phi* = .33, or at Time 2, $\chi 2$ (3, *n* = 43) = 1.08, *p* = .78, *phi* = .16. Both tests violated the 'minimum expected cell frequency' assumption of chi-square. This finding suggests that the race and gender of the patient in the vignette did not influence the PCP's identification and diagnosis of cognitive impairment. This contrasts with the hypothesis that cognitive impairment would be identified and diagnosed more often in white patients than African American patients.

PCP Response to Care

Comfort Level with Ongoing Care. A mixed between-within subjects ANOVA was conducted to assess the influence of four different vignette versions (i.e., white male, Black male, white female, Black female) on participants' scores of comfortability with ongoing care of the patient, across two time periods (pre-family engagement and post-family engagement). There was not a significant interaction between vignette version and time, Wilks' Lambda = .94, *F* (3, 41) = .92, *p* = .44, partial eta squared = .06. There was a substantial main effect for time, Wilks' Lambda = .87, *F* (1, 41) = 6.00, *p* = .02, partial eta squared = .13, with all four groups showing a decrease in comfort level scores across the pre- and post- time periods. The main effect comparing the four versions of the vignette was not statistically significant, *F* (3, 41) = 1.47, *p* = .24, partial eta squared = .10, suggesting no difference in the influence of the four vignette versions. These findings reveal that comfort levels with ongoing care decreased for all four versions of the vignette. However, neither race nor gender had a significant influence on this outcome.

Desire to Communicate with Family. A Chi-square test for independence indicated no significant association between vignette version and desire to communicate with the patient's family at Time 1, $\chi2$ (3, *n* = 45) = .56, *p* = .91, *phi* = .11, or at Time 2, $\chi2$ (3, *n* = 45) = .22, *p* = .97, *phi* = .07. Both tests violated the 'minimum expected cell frequency' assumption of chi-square. This suggests that race and gender did not significantly influence the participants' desire to communicate with the family at Time 1 or Time 2.

Referral to Specialists. A Chi-square test for independence indicated no significant association between vignette version and referral to specialist at Time 1, $\chi2$ (3, *n* = 45) = 3.44, *p* = .33, *phi* = .28, or at Time 2, $\chi2$ (3, *n* = 45) = 4.48, *p* = .21, *phi* = .32. Both tests violated the 'minimum expected cell frequency' assumption of chi-square. Again, this finding suggests that race and gender did not significantly influence the participants' decision to make a referral to a specialist at Time 1 or Time 2.

Discussion

The purpose of this study was to expand knowledge of (a) how family engagement influences the way in which PCPs identify, diagnose, and manage cognitive impairment in older adults, and (b) whether patient race and gender influence these diagnostic and decision-making processes. Primary care is an ideal place for the care of cognitive impairment (Alzheimer's

Association, 2017); although, PCPs often feel unequipped or underprepared to do so (Foley et al., 2017; Tang et al., 2018). Patient- and family-centered care (Johnson & Abraham, 2012) provides an avenue for improving the care of cognitive impairment in primary care settings and supporting PCPs in this process by promoting team-based care which promotes effective communication between team members (e.g., PCP, patient, family) and provider wellbeing (Bodenheimer & Willard-Grace, 2016). Furthermore, studies have shown that patient demographics including race and gender influence health disparities including the detection rates of cognitive impairment (Avila et al., 2019; Husaini et al., 2015), but it is unknown if family engagement helps reduce these inequities. This study contributes to the literature with three main findings: (a) family engagement provides an opportunity for more efficient and accurate identification and diagnostic process for cognitive impairment, (b) family engagement allows for a clearer picture of patient symptoms and may present opportunities for PCPs to refer to specialists for diagnosis and treatment earlier, and (c) family engagement provides an opportunity to reduce health inequities by reducing variations in PCP perceptions of symptoms influenced by implicit bias. A larger sample with more diverse representation may have provided clearer findings and should be pursued in future research studies.

Although participants reported 80% interest in communicating with family at Time 1, as compared to 69% at Time 2, these findings were not statistically significant. This suggests that PCPs want to engage family members throughout the assessment, diagnosis, and treatment process. The 11% reduction observed may indicate that participants found electronic messaging sufficient for obtaining needed diagnostic and assessment information. Therefore, this study's findings support using electronic communication practices (e.g., email, EHR messaging) to actively engage patients' families versus only in-person appointment attendance as traditionally studied (Wolff et al., 2012). This study supports the understanding that availability of electronic methods of communication (e.g., EHR portals) facilitates patient- and family- centered care (Bouayad et al., 2017; Snyder et al., 2011). However, it is the first known study to confirm that EHR communication with family helps improve the diagnostic accuracy and care of patients. This was possible given the unique nature of the vignette method making it possible to capture changes in PCP decision making using family communication. This is not only a safer design but indicates promise for use in training purposes where they are able to immediately recognize the benefits of family engagement on the assessment, diagnosis, and treatment phases.

Future studies should focus on evaluation of various methods of engagement (e.g., in-person, email, phone calls) and identify which are best suited for different health conditions, settings, and literacy levels. These studies will also help to determine if alternative methods of family engagement (e.g., EHR patient portals) increase family engagement and improve health outcomes, decrease time to diagnosis, improve initiation of treatments that slow disease progression. Lastly, more studies are needed to demonstrate how family member advocacy and involvement may reduce health disparities and inequities of marginalized groups.

Consistent with previous research (Skibitsky et al., 2016), most PCPs reported feeling confident in their ability to care for patients with cognitive impairment. Findings suggest most PCP participants were comfortable with providing ongoing patient care. However, a fewer number reported comfort with ongoing care at Time 2 (87%) than Time 1 (95%). It is possible that PCPs felt less confident in their ability to manage the ongoing care once they understood the full picture of the patient’s symptomatology and severity, which lead to an increase in referrals to a specialist (i.e., neurologist) for diagnostic confirmation and care. Most participants reported wanting to make a referral to a specialist at Time 2 (67%), while fewer than half wanted to do so at Time 1 (49%). This suggests that the increase in level of concern for the patient's symptoms (i.e., increase in perceived severity), after receiving family input, led participants to make such a referral. This decision to refer patients to specialists may expedite the process to receiving an accurate cognitive impairment diagnosis and lead to improved and/or expedited management and treatment of the condition. However, this finding also implies that PCPs may not feel comfortable with caring for patients with cognitive impairment without referring to a specialist. Skibitsky and colleagues (2016) also found that fewer PCPs felt comfortable with treating dementia than making a diagnosis and over 60% of their participants reported a lack of time and support to manage these patients. It is possible that participants in this study felt similarly which may contribute to the decision to refer to specialists. This suggests a need for improved training for PCPs given the frequent nature of cognitive impairment in their practice. Additionally, given that PCPs feel the need to refer to specialists despite feeling comfortable with ongoing care, a team-based approach and family engagement may help to reduce the burden of needing to make additional appointments and improve care coordination.

This was the first study to analyze trends related to patient race, which was an important step in the literature. Although not statistically significant, rates of perceived severity amongst vignette versions by race varied more at Time 1 as compared to Time 2. For example, the rate of perceived severity for the white male patient was higher at Time 1 compared to that of the Black female patient. However, the difference in rating of perceived severity for these two groups was smaller at Time 2, after family member input, and rates of perceived severity for white males was closer (although still higher) to that of the Black female patient. The lack of statistical significance may be due to the small sample sizes of each group and low statistical power. Therefore, this trend should be explored further in future studies. It is possible that participants' perceptions of symptom severity were influenced by patient race and/or gender and this gap was minimized after receiving family-provided information. This observed trend may suggest that family engagement could reduce the negative influence of racial and gender bias, leading to greater equity in the evaluation of symptom severity regardless of the patient's race or gender.

Additionally, results showed significant differences in rates of perceived disruptiveness of symptoms between vignette versions at Time 2 (i.e., white male patient perceived to have significantly higher rates of disruptiveness than the white female patient). Although this difference was not significant at Time 1, this observed trend may suggest that the influence of family engagement can reduce gender bias, raising rates of perceived disruptiveness for females at Time 2 to that of males at Time 1. To the authors' knowledge, this is the first study to explicitly suggest family engagement is beneficial to reducing health inequities among African American patients with cognitive impairments. Future studies could expand on this finding by including additional social locations (e.g., (dis)ability, language), measures of implicit bias, and different forms of family member engagement (i.e., in person, electronic).

Strengths and Limitations

This study achieved significant results despite the small sample size of the group as a whole and within each vignette version. This should be viewed as a strength and further evaluation of these trends is warranted in future studies. It should also be noted that the completion rate for the survey (44%) is comparable to other studies attempting to survey PCPs (Fukuma et al., 2018; Zhu et al., 2019).

A potential limitation of the study is that results should be considered within the context of the COVID-19 pandemic and the potential of a cohort effect. It is possible that participants were acutely aware of the need to engage family members given the unique circumstances of the pandemic. Another limitation of this study is the small sample size and limited diversity of the sample demographics. Most of the participants were white women practicing in urban areas. The location of the participants is significant given that patients living in rural areas are at greater risk of developing cognitive impairment (Nakamura et al., 2016; Russ et al., 2012). Future studies should make an effort to recruit PCPs in rural areas and examine differences among PCPs practicing in rural versus urban areas. Given the small sample, researchers were unable to compare PCP racial and gender identity with that of the patient. This could be addressed in future studies to allow for greater understanding of the influence of intersecting patient and provider social locations.

Conclusion

Patients experiencing cognitive impairment require family member/support person involvement in their daily lives. Healthcare appointments are no exception. Utilizing PFCC (Johnson & Abraham, 2012) with attention to the intersection of patients' social locations (Crenshaw, 1989) provides a means for engaging and partnering with families in the care of older adults with cognitive impairment that reduces power imbalances between patients, families, and the healthcare team. This study examined the role of family engagement in the assessment, diagnostic, and management of cognitive impairment among older adults in primary care. Participants reported increased concern for patient symptoms after communicating with family members, which resulted in decreased comfort with ongoing care of the patient and increased rates of referral to specialists. Most importantly, this study displayed the importance of providers communicating with family to identify cognitive issues more accurately (e.g., memory problems) and make a correct diagnosis of cognitive impairment. PCPs may have concern about family engagement lengthening time with patients or increasing provider burden but communicating with family who accompany patients to a primary care visit adds fewer than 4 minutes to the visit length (Wolff et al., 2015) and results of the present study suggest it would be worth the small increase in time to receive helpful information about the patient (e.g., medical history and symptoms), leading to accurate identification of cognitive impairment. Furthermore, the results of this study suggest possible racial and gender bias in the perception of severity and disruptiveness of cognitive impairment symptoms, which is consistent with previous studies (Braus et al., 2019; Gianattasio et al., 2019; Teresi et al., 2012). The encouraging finding from this study is that family engagement may help to reduce the influence of such biases and promote more equitable health care. To the authors' knowledge, this is the first study to suggest such a benefit of family engagement.

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Table 1

Diagnoses and Responses Recognized as Cognitive Impairment

ICD-10 Code	Diagnosis	Participant responses included in this category (if different from main diagnosis label)
G30	Alzheimer’s Disease	Alzheimer’s, Alzheimer's Dementia, Early Alzheimer's Dementia
G31.83	Dementia with Lewy Bodies	Early Lewy Body Dementia, Lewy Body, Lewy Body Dementia, Parkinson’s Disease with Dementia, Parkinson's Dementia, Early Parkinson’s Dementia
G31.84	Mild Cognitive Impairment	Cognitive Impairment
F01	Vascular Dementia	Early Vascular Dementia, Multiple Infarct Dementia
F02.81	Dementia in Other Diseases Classified Elsewhere with Behavioral Disturbance	Other Dementia with Motor Features
F03.90	Unspecified Dementia without Behavioral Disturbance	Dementia, Senile Dementia
R41.84	Other Specified Cognitive Deficit	Early Cognitive Deficit

Table 2

Study Participant Characteristics (N = 45)

Age, years (±SD)	25-77, *M* = 42.53 (±13.85)
Patient Care Experience, years (±SD)	1-46, *M* = 12.66 (±13.04)
Gender	
Female	33 (73.3%)
Male	12 (26.7%)
Ethnicity	
Not of Hispanic, Latino, or Spanish origin	41 (91.1%)
Mexican, Mexican American, Chicano	1 (2.2%)
Another Hispanic, Latino, or Spanish origin	3 (6.7%)
National Origin/Race	
Asian	5 (11.1%)
Asian Indian	1 (2.2%)
Black or African American	3 (6.7%)
Chinese	2 (4.4%)
Other Asian	2 (4.4%)
White	34 (75.6%)
Unknown	1 (2.2%)
Middle Eastern	1 (2.2%)
PCP Profession	
Family Medicine	35 (77.8%)
Internal Medicine	3 (6.7%)
Geriatrics Medicine	5 (11.1%)
Gynecological Medicine	1 (2.2%)
Physician Assistant	4 (8.9%)
Nursing	4 (8.9%)
PCP Role	
Physician (board certified or board eligible)	22 (48.9%)
Resident Physician	12 (26.7%)
Physician Assistant	4 (8.9%)
Nurse Practitioner	7 (15.6%)
Completed a residency, fellowship, or certificate in geriatrics	
Yes	17 (37.8%)
No	28 (62.2%)
Area of Practice	
Rural	15 (33.3%)
Urban	30 (66.7%)

Table 3

Survey Items Used to Analyze Research Questions 1 and 2

Survey Item	Response Options
On a scale of 1 (none) to 4 (high), how severe do you perceive the patient's symptoms to be?	1 (not at all severe) 2 (low severity) 3 (moderate severity) 4 (high severity) Cannot be determined
On a scale of 1 (not at all disruptive) to 5 (highly disruptive), how disruptive to the patient's daily life do you perceive the patient's symptoms to be?	1 (not at all disruptive) 2 (slightly disruptive) 3 (fairly disruptive) 4 (disruptive) 5 (highly disruptive)
On a scale of 1 (very safe) to 5 (highly dangerous), how safe/dangerous do you perceive this patient to be to self and others?	1 (very safe) 2 (somewhat safe) 3 (neither dangerous nor safe) 4 (somewhat dangerous) 5 (highly dangerous)
With the information you have available to you currently, what diagnosis are you considering?	Open-ended
At this point, would you want to communicate with any family members, caregivers, or other informants?	Yes No
At this point, would you consider referring this patient to a specialist?	Yes No
If yes, which specialist?	Open-ended
Would you feel comfortable providing ongoing care to this patient?	Definitely yes Likely yes Unsure Likely no Definitely no

Note. All items in this table were asked at both Time 1 and Time 2.

Table 4

Participants by Vignette Version

Vignette Version	Patient Description	Number of Participants (*n*, *%*)
1	white male	13 (28.9%)
2	Black male	11 (24.4%)
3	white female	10 (22.2%)
4	Black female	11 (24.4%)

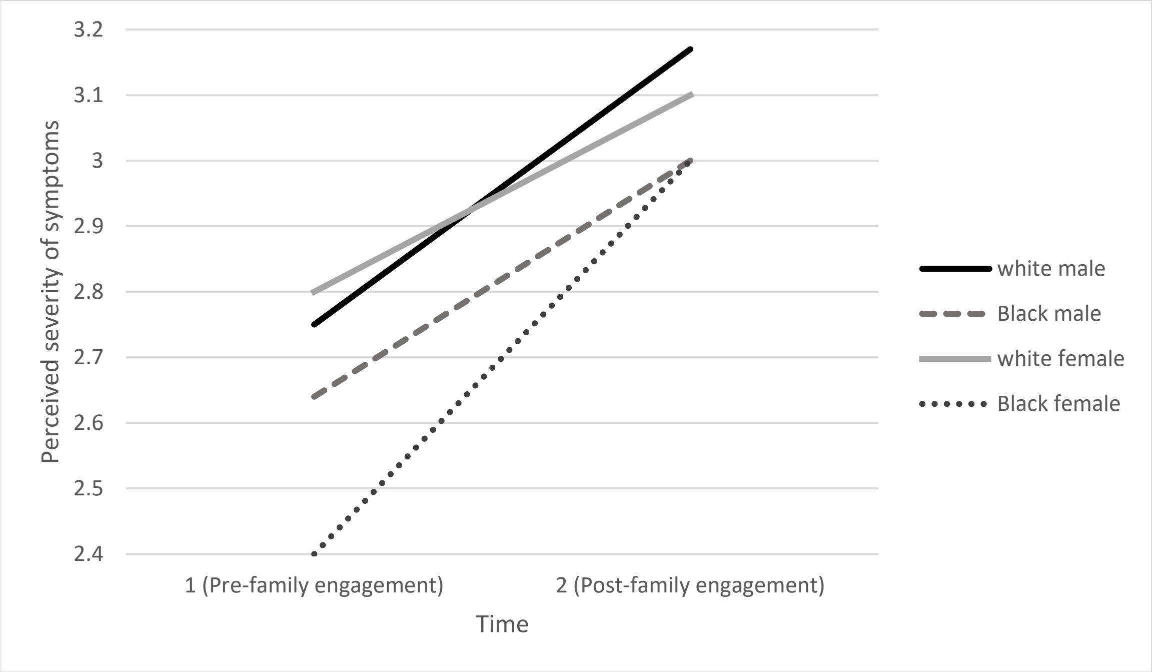
Table 5

PCP Referrals to Specialists at Time 1 and Time 2 (N = 45)

Specialist	Time 1	Time 2
Neurologist	21	23
Geriatrician	1	3
Psychiatrist	0	1
Physical Therapist	0	1
Neuropsychologist	0	1
Total referrals (%)	22 (49%)	30 (67%)

Figure 1

Influence of Family Engagement on PCP Perception of Symptom Severity by Vignette Version



Note. Participants rated the level of severity of symptoms on a four-point scale from 1 (not at all severe) to 4 (high severity). All versions of the vignette (i.e., white male, Black male, white female, Black female) resulted in significant increases in ratings of perceived severity from Time 1 to Time 2. However, there were no statistically significant differences in ratings among the vignette versions.

CHAPTER 6: A PHYSICIAN’S GUIDE TO ENGAGING FAMILY OF OLDER ADULTS WITH COGNITIVE IMPAIRMENT[1]

To provide the best care for older adult patients with suspected or known cognitive impairment, engaging the family is critically important. Here are some strategies for increasing one’s understanding of patient symptoms and promoting equitable care for older adults exhibiting cognitive impairment without spending excessive amounts of time doing so.

Family physicians play a key role in the care of patients with cognitive impairment (e.g., dementia). They achieve this through early identification of symptoms, accurate and timely diagnosis, and ongoing care of the cognitive impairment along with other comorbid conditions (Moore et al., 2018). Given the unique challenges presented by impaired cognition, collaboration with the patient’s family is important to providing high quality patient care (Scott et al., 2020). However, the means used to engage families as a part of the healthcare team is practiced inconsistently (Welch et al., 2021) and physicians have expressed interest and desire to learn more about how to foster family engagement when detecting signs of cognitive impairment (Foley et al., 2017). Likewise, families may not understand when or how to become an active contributor to the patient’s care. For example, it may be difficult for family members to feel comfortable with making decisions about the patient’s care or attend an appointment out of respect for the patient’s autonomy (Cené et al., 2016). However, through family education, providers can help families to recognize the benefits of actively participating in their loved one’s care and facilitate non-traditional forms of communication with patient families (e.g., phone and

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[1] This article is not in APA format as it is uniquely formatted to meet the requirements of the destination journal (Family Practice Management).

electronic communication). Family engagement helps providers improve the care of older adults with cognitive impairment, which is described in more detail below, and create a more welcoming experience for families in the care process.

Recently, a vignette-based study was conducted with 45 primary care providers (PCPs; 78% were family physicians) from 11 states (Welch, 2021). PCPs were assessed pre- and post-family engagement to determine the influence of family engagement on the diagnostic decision-making process (i.e., perceptions of symptom severity, disruptiveness, and dangerousness). Participants received a vignette in two parts (i.e., Time 1 and Time 2). Part 1 included information provided only by the patient (in person) and part 2 was information provided by a patient's family member (via email). Four different versions were constructed only modifying the patient's race and gender (Black male, Black female, white male, white female). Each participant only received one version, administered through random assignment.

The Welch (2021) study found family engagement improved PCPs' diagnostic accuracy of cognitive impairment by 70%. These results are important to care as achieving an accurate diagnosis earlier in the diagnostic process provides opportunities for patients and families to receive medical and mental health intervention, as well as support services sooner rather than later. The study also found gender significantly influenced PCP perceptions of patient symptoms of older adults exhibiting cognitive impairment (i.e., white males perceived to have more disruptive symptoms than white female patients) and similar trends emerged for differences in African American and white patients (see Figure 1). Although not statistically significant, researchers observed trending differences in providers perceptions of the severity, disruptiveness, and dangerousness of patient symptoms among vignette versions. All patients (i.e., Black male, Black female, white male, white female) were rated more similarly after providers received information from the family about the patient's symptoms compared to their ratings of concern when receiving patient-provided information alone. Thus, family engagement may help to reduce health inequities influenced by implicit bias.

Prior to this study, the Alzheimer's Association (2017) reported that African American patients were twice as likely to develop cognitive impairment compared to white patients and more likely to be underdiagnosed. Minoritized groups often view familism (e.g., an emphasis on family interdependence) and health as critical partners (Chiang et al., 2019). Combined with what is now known about the merits of family engagement for the care of patients with cognitive impairment (Vick et al., 2018; Welch, 2021), engaging families in the care experience may help reduce racial disparities by honoring the patient's culture, addressing implicit biases, and improving the care experience for all. However, doing this in a way that maximizes resources and does not add stress to an already stretched healthcare system, is important to consider.

There is a way to efficiently include family in the care process through the use of Peek's Three World View (2008). This framework provides an avenue for creating change to patient care that attends to the clinical, operational, and financial worlds critical to the healthcare setting infrastructure. This article applies the Three World View while outlining four major reasons for engaging and communicating with family when caring for older adults with suspected or known cognitive impairment. It concludes with specific evidence-based recommendations for primary care practices that may guide clinical, training, and policy improvements toward enhancing the care of this patient population and better engaging their families.

Reason One: Increase Understanding of Patient Symptoms

PCPs may not have the full picture of a patient's symptoms and symptom severity without talking to the family. Welch (2021) found that once PCPs obtained family input, their concerns for their patients' symptoms rose. More specifically, receipt of family-provided information resulted in statistically significant increases in the rates of perceived severity, disruptiveness, and dangerousness (Shown in Figure 2). Previous studies also highlighted the significance of collecting information from family members during routine primary visits (Judge et al., 2011; Judge et al., 2019), and comparing patient reports to family observations to ensure information accuracy (Vick et al., 2018). Family input is important as patients experiencing cognitive declines may struggle to provide all relevant information, leading to delays in diagnosis, treatment, and/or referrals. Family engagement may be a way to prevent lapses in care and help identify more realistic and effective patient- and family-centered treatment plans.

Reason Two: Promotion of Racial and Gender Equity

Research confirms the occurrence of disproportionate rates of cognitive impairment diagnoses among minoritized populations including African Americans and Hispanics (Alzheimer's Association, 2017). In fact, Braus et al. (2019) found care discrepancies largely influenced by race and gender unconscious biases. These unconscious biases play a role in determining how seriously medical providers take patients' complaints (Harris et al., 2018). The culmination of this negatively deepens healthcare inequities and results in a lower quality of care (FitzGerald & Hurst, 2017). However, family-engagement may help to reduce gender inequities as it levels the ratings of concern (i.e., perceived disruptiveness) of symptoms for female and male patients (Welch, 2021). Similar trends were also observed with race among African American and white patients but did not reach statistical significance due to sample size.

Reason Three: Accurate Diagnosis, Appropriate Management, and Beneficial Treatment

The Welch (2021) study found that prior to communicating with family, PCPs were more likely to consider diagnoses unrelated to cognitive impairment and were headed down the wrong path or wasted time exploring alternative options. Figure 3 displays the noteworthy finding that 70% more PCPs accurately identified cognitive impairment and made an appropriate differential diagnosis after receiving information from the family. Similarly, Amjad and colleagues (2018) found that patients who had dementia were less likely to receive a diagnosis of dementia when they attended healthcare visits alone compared to those who were accompanied to the visit by a family member. Furthermore, another study revealed that patients with cognitive impairment underestimated their deficits while their informants provided a more accurate representation of concerns including memory problems (Edmonds et al., 2014). Failing to communicate with a patient’s family may contribute to missed identification of problematic symptoms, resulting in an inaccurate or delayed diagnosis and care.

Reason Four: It is a Quick and Simple Practice

Providers identified lack of time as a barrier to effective and efficient diagnosis of cognitive impairment (Skibitsky, 2016). PCPs will be relieved to know that engaging family can be efficient, and it does not have to be an unrealistic time commitment (Welch, 2021). Wolff and colleagues (2015) found that visits with accompanying family members last fewer than four minutes of additional time compared to visits in which patients attend alone. Furthermore, family engagement can include more than inviting the patient to bring family into the medical visit (i.e., family accompaniment). Rather, families can provide vital information in an email, electronic health record (EHR) message, phone call, or other form of written communication (e.g., letters). This can be particularly helpful when barriers to accompaniment are present (e.g., limited visitor protocols, geographic restrictions, inability to get time off work).

The recommendations below provide family physicians with evidence-based strategies for promoting efficient family engagement and equitable care for older adults with cognitive impairment. Approaches to clinical care, provider training, and clinical and financial policy are provided as each of these attends to the clinical, operational, financial, and training worlds of healthcare systems (Peek, 2008). These recommendations may guide clinical, training, and policy improvements toward enhancing the care of older adults with known or suspected cognitive impairment and improving family engagement. Implementing these changes at the clinical, operational, financial, and educational levels promotes the reduction of health disparities and creates a more dynamic team-based, patient and family-centered approach to care.

Evidence-Based Recommendations for Clinical Care

Implement an interprofessional and team-based approach that features the distinctive strengths of each team member and optimizes primary care (Osbaugh et al., 2020). Expanding the primary care team (e.g., behavioral health providers, geriatricians, pharmacists) is one way to address patient and family needs without adding to the PCP workload. Team members using shared documentation systems and collaborating to develop treatment plans allow each member, including the patient and family to maximize their strengths. Ultimately, this allows PCPs to focus on the diagnosis and management of cognitive impairment with the confidence that the team is sharing detection of and addressing other patient and/or caregiver concerns.

Talk to family members early in the process to learn more about the patient and their symptoms. Communicating with the patient’s family is an important component of patient-centered communication (American Geriatrics Society, 2016). Researchers found patients reported higher levels of satisfaction with care when healthcare providers spoke with family members throughout the care process (Guan et al., 2018; Wong et al., 2019). Here are three tips for talking with family members:

(a) Ask open ended questions about symptoms (e.g., What concerns do you have about your mom's health?).

(b) Ask specifically about memory concerns (e.g., Have you observed any changes in your partner's memory?).

(c) Ask about any difficulty with medications (e.g., Has your loved one had any trouble with medications including side effects or problems with getting prescriptions filled?).

Incorporate electronic forms of communication to engage families who may not be able to accompany patients to the primary care visit. The EHR may be a useful means to communicate with patients and families in primary care (Vick et al., 2018). Most EHRs have a secure messaging platform available to facilitate communication between providers, inpatients, and family members (Manias et al., 2020).

Explore at home care options that enable people living with cognitive impairment to remain in their homes for as long as possible. Considering less than 25% of individuals with cognitive impairment live alone (Fazio et al., 2018), bringing health care into the patient's residence increases access and support to family members and can provide valuable information to healthcare providers (Jacobs, 2021). Furthermore, the increase in availability of telehealth services has demonstrated the value of providing a way for individuals with cognitive impairment to receive health care in the safety of their home, reducing the stress of the commuting to the healthcare setting for patients and caregivers (Goodman-Casanova et al., 2020).

Evidence-Based Recommendations for Provider Training

Use vignette-based training that incorporates information from the patient and the family. The hypothetical nature of the vignette methodology allows for the exploration of topics such as family engagement and implicit bias with PCPs in a tangible but nonthreatening manner (Finch, 1987; FitzGerald & Hurst, 2017). Vignettes can be delivered in multiple formats including written or video and provide practical and affordable methods for delivering and measuring provider knowledge (Banuri et al., 2018).

Use standardized patients and caregivers to practice family-engagement skills in a low-risk experiential learning context. This evidence-based learning method is helpful for medical students and residents to feel better prepared when placed in actual patient scenarios (Spalding & Rudinsky, 2018). It is beneficial to train a diverse group of standardized patients and caregivers to also help educate providers on any implicit biases that are impacting their patient care. Welch (2021) observed that providers responded differently to patients of different genders and races, and family engagement helped to reduce disparities in care.

Train medical providers to disclose cognitive impairment diagnoses in a culturally appropriate patient- and family-centered way. PCPs identified delivering diagnoses as one of their top five training needs (Foley et al., 2017). Researchers demonstrated that utilizing patient-centered communication in difficult conversations resulted in higher ratings of health care quality (Finney Rutten et al., 2015). Thus, learning how to deliver bad news (e.g., giving a dementia diagnosis) in a respectful and culturally sensitive and appropriate manner is an important skill for medical providers to possess. Using small group workshops to hone these skills (e.g., asking questions and inviting input, practicing good manners, and using appropriate self-disclosure; Hoffman et al., 2020) has proven to be beneficial (Foley et al., 2017).

Additionally, behavioral health providers with cultural humility and relational training can help prepare PCPs to disclose difficult information (e.g., dementia diagnosis) or accompany PCPs when doing so to help process with the patient and the family.

Evidence-Based Recommendations for Clinical and Financial Policy

Integrate mental and behavioral health professionals into residency programs and primary care by changing hiring and practice policies that support integrated care. Integrated care can help to reduce health disparities, improve health outcomes of the family unit, and reduce healthcare costs (Blount, 2003; Delbridge et al., 2017). Furthermore, integrated primary care has shown to improve the overall quality of care for community-dwelling older adults (Vestjens et al., 2019). Behavioral health providers can help to expand the system of care through inclusion of family members into the healthcare delivery process. For example, medical family therapists are trained and equipped to promote the inclusion of family perspectives into health care. Primary care providers can help to advocate for integrated behavioral health professionals in their training and clinical settings to increase access to family perspectives and support.

Cognitive impairment should be viewed as a chronic condition and PCPs should be able to bill for services appropriately so that they have the time to dedicate to caring for these patients and their families. Effective January 2021, providers can bill Medicare (using CPT code 99483) for a visit, either in-person or via telehealth, to thoroughly assess for cognitive functioning and develop a care plan (U.S. Centers for Medicare and Medicaid Services, 2021). Such assessments can be billed by physicians, nurse practitioners, clinical nurse specialists, and physician assistants and should be standard practice for patient populations who are at increased risk for developing cognitive impairment and/or who experience inequities in care.

Establish methods to pay caregivers for what they do at home. For example, due to state-level policy changes, some caregivers are now able to receive pay as certified nursing assistants (Jacobs, 2021). In some states, Medicaid now provides an avenue through adult foster care for informal caregivers to receive payment for their services (American Council on Aging, 2021). The influence of these financial incentives for caregivers should be further explored and pursued to reduce the financial burden on patients and families living with cognitive impairment.

Conclusion

Family physicians play an important role in caring for older adults with cognitive impairment. As evidenced in this article, the family can help providers to fulfill that role more effectively and efficiently. Additionally, the recommendations for family-centered care presented here can help providers engage family in a meaningful and beneficial manner. It is imperative for family physicians to receive training in a manner that ensures opportunities to recognize, address, and work through biases about cognitive impairment with diverse patient populations. Utilizing vignette-based exercises and standardized patients provide such opportunities and allow PCPs to practice engaging families through non-traditional in-person formats, such as communication through the EHR. This article provides an avenue for strengthening family medicine curriculum through the implementation of these approaches to medical education and training. Changes at the clinical, operational, financial, and educational levels put the healthcare system one step closer toward reducing health disparities and creating a more fluid team-based, patient and family-centered approach to care.

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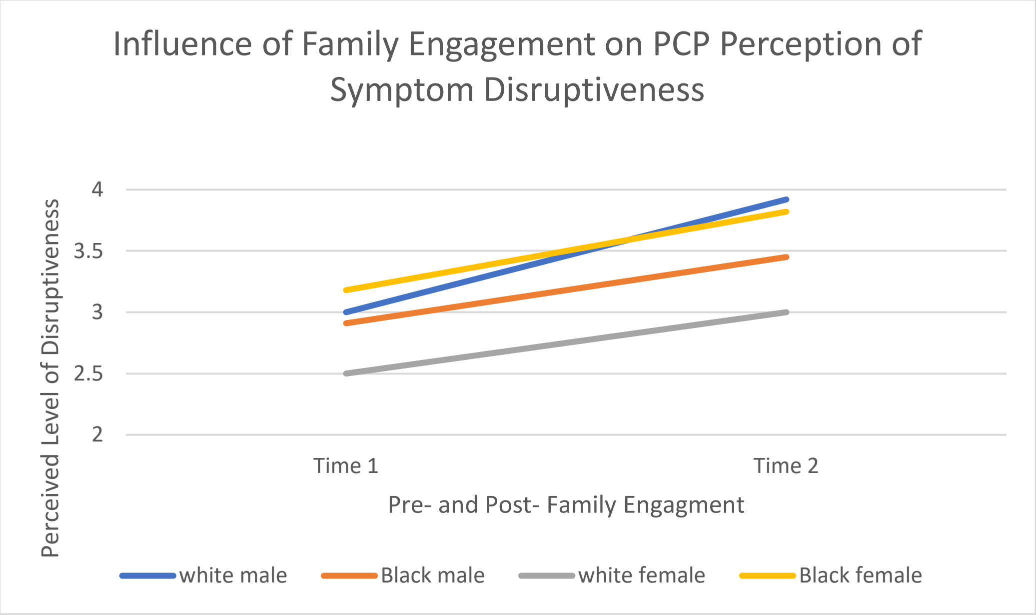
Figure 1.



Note. Participants rated the level of disruptiveness of symptoms on a five-point scale from 1 (not at all disruptive) to 5 (highly disruptive). All versions of the vignette (i.e., white male, Black male, white female, Black female) resulted in significant increases in ratings of perceived disruptiveness from Time 1 to Time 2. Additionally, at Time 2, the level of disruptiveness for vignette version one (i.e., white male) was significantly higher than that of vignette version three (i.e., white female), suggesting a higher level of perceived disruptiveness for the male versus female patient among white patients. There were no statistically significant differences in perceived disruptiveness based on race.

Figure 2.

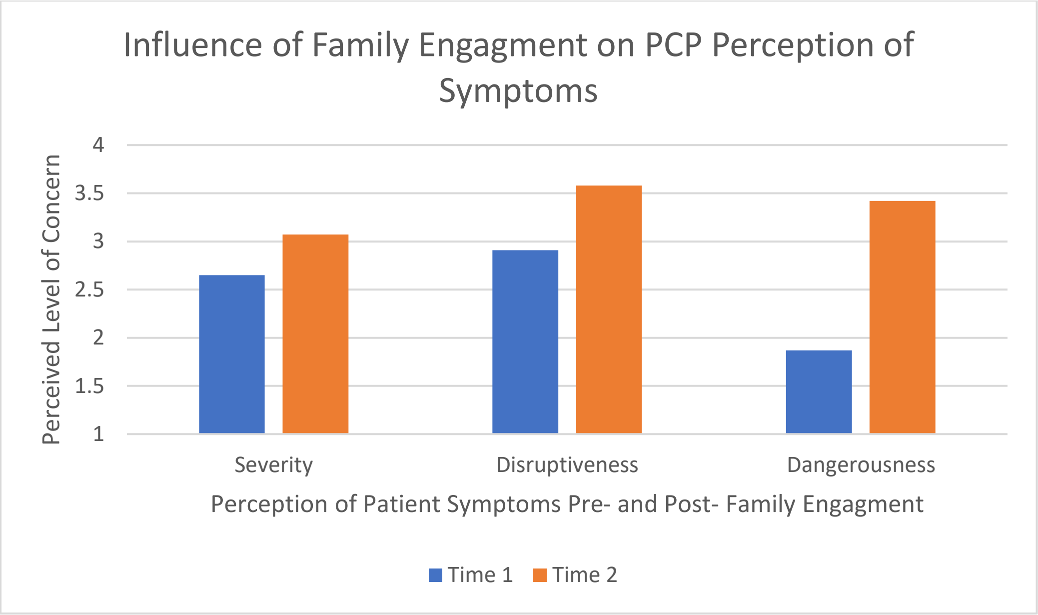
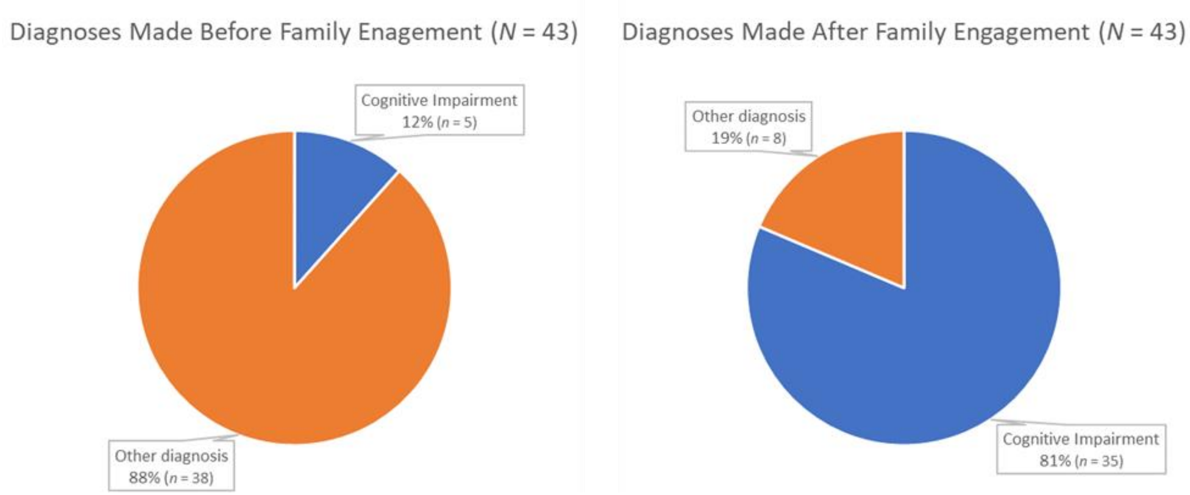
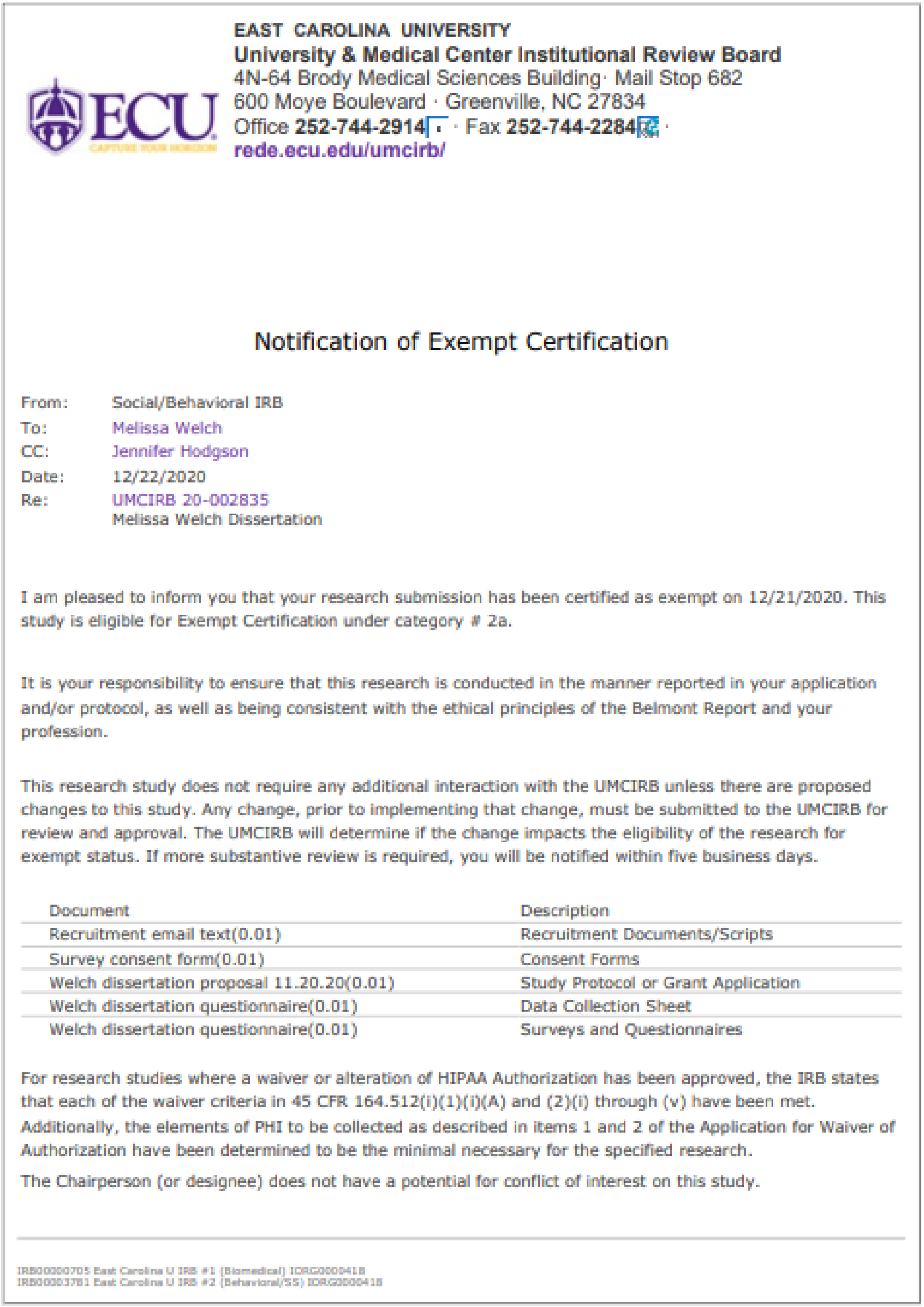

Influence of Family Engagment on PCP Perception of Symptoms
Perceived Level of Concern
4
3.5
3
2.5
2
1.5
1
Severity
Disruptiveness
Dangerousness
Perception of Patient Symptoms Pre- and Post- Family Engagment
Time 1
Time 2

Figure 3.

Diagnoses Made Before and After Family Engagement



APPENDIX A: IRB APPROVAL



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
rede.ecu.edu/umcirb/

Notification of Exempt Certification

From: Social/Behavioral IRB
To: Melissa Welch
CC: Jennifer Hodgson
Date: 12/22/2020
Re: UMCIRB 20-002835
Melissa Welch Dissertation

I am pleased to inform you that your research submission has been certified as exempt on 12/21/2020. This study is eligible for Exempt Certification under category # 2a.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
Recruitment email text(0.01)	Recruitment Documents/Scripts
Survey consent form(0.01)	Consent Forms
Welch dissertation proposal 11.20.20(0.01)	Study Protocol or Grant Application
Welch dissertation questionnaire(0.01)	Data Collection Sheet
Welch dissertation questionnaire(0.01)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: RECRUITMENT LANGUAGE FOR EMAIL AND SOCIAL MEDIA

Hello,

I am recruiting primary care providers (PCPs) to participate in a study about caring for older adult patients (65+) in primary care settings. If you have cared for a patient meeting that description in the past 12 months, and have **20-30 minutes** to complete this survey, I would greatly appreciate your time and support.

Who qualifies to take this research survey?

- PCPs currently practicing in the United States:
    - Physicians (matriculated from training in general, family, internal, geriatrics, or gynecological medicine)
    - Resident physicians (PY1 residents and up)
    - Physician assistants
    - Nurse practitioners
    - PCPs currently enrolled in a training program must be providing patient care.
- PCPs who have seen at least one older adult patient (65+) in the past twelve months
- Participants must be fluent in written and verbal English.

What to expect:

- You will be asked to read and respond to a brief vignette depicting a patient-provider encounter.
- You will be asked about your demographics and clinical setting.
- No identifying or confidential information will be collected.

Who is conducting this research?

- My name is Melissa Welch, and I am completing this research project as part of the requirements for my doctoral degree in Medical Family Therapy at East Carolina University. I am incredibly grateful for your willingness to contribute to the body of research on caring for older adults in primary care settings, as well as your support toward helping me to meet a degree requirement.

Thank you for your willingness to support this research and for your time.

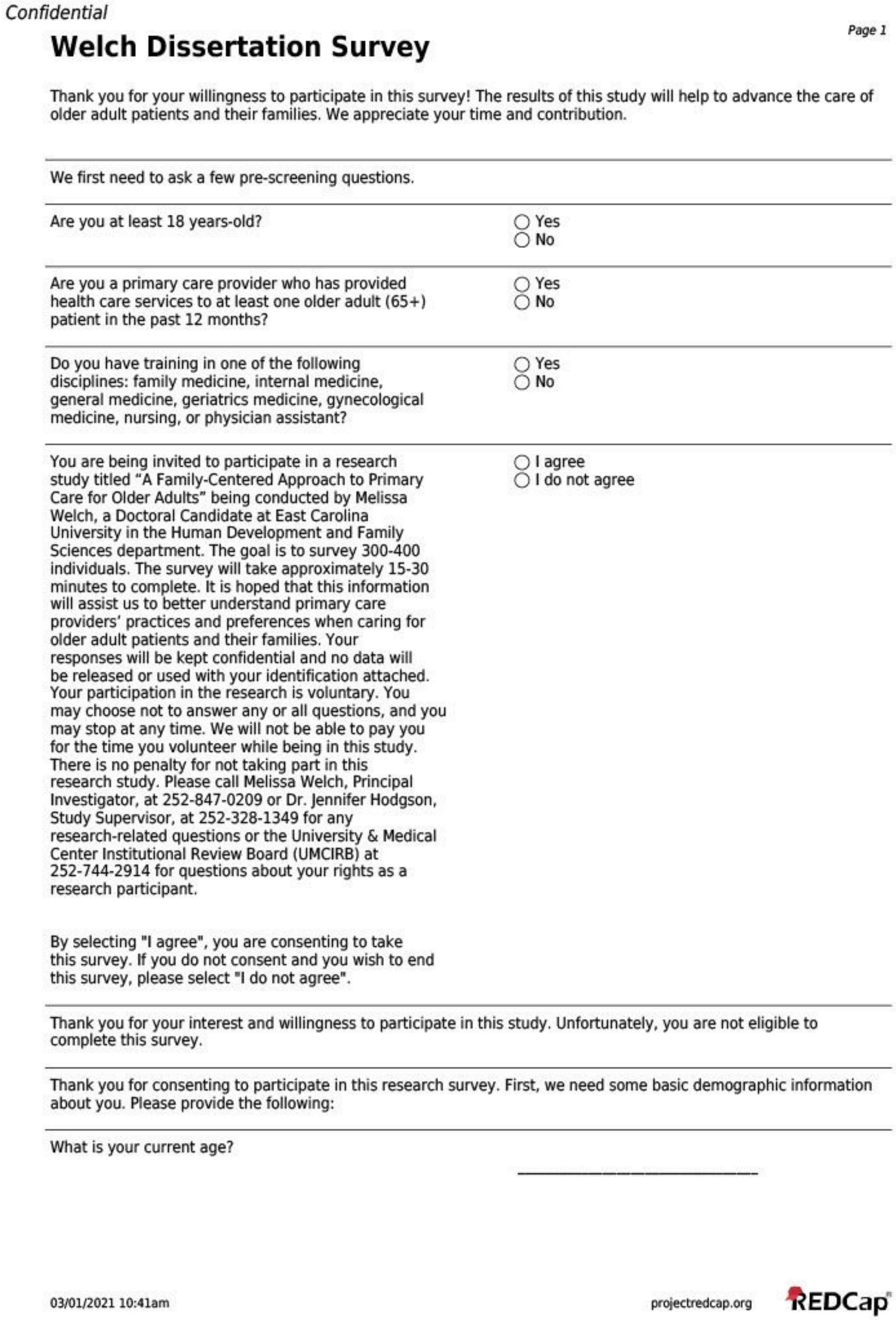
Click here to take the survey: [INSERT SURVEY LINK]

Kind regards,

Melissa

Melissa L. Welch, MA, LMFT
Doctoral Candidate, Medical Family Therapy
East Carolina University
Welchme18@students.ecu.edu

APPENDIX C: REDCAP SURVEY



Confidential

Page 1

Welch Dissertation Survey

Thank you for your willingness to participate in this survey! The results of this study will help to advance the care of older adult patients and their families. We appreciate your time and contribution.

We first need to ask a few pre-screening questions.

Are you at least 18 years-old?	○ Yes ○ No
Are you a primary care provider who has provided health care services to at least one older adult (65+) patient in the past 12 months?	○ Yes ○ No
Do you have training in one of the following disciplines: family medicine, internal medicine, general medicine, geriatrics medicine, gynecological medicine, nursing, or physician assistant?	○ Yes ○ No
You are being invited to participate in a research study titled “A Family-Centered Approach to Primary Care for Older Adults” being conducted by Melissa Welch, a Doctoral Candidate at East Carolina University in the Human Development and Family Sciences department. The goal is to survey 300-400 individuals. The survey will take approximately 15-30 minutes to complete. It is hoped that this information will assist us to better understand primary care providers’ practices and preferences when caring for older adult patients and their families. Your responses will be kept confidential and no data will be released or used with your identification attached. Your participation in the research is voluntary. You may choose not to answer any or all questions, and you may stop at any time. We will not be able to pay you for the time you volunteer while being in this study. There is no penalty for not taking part in this research study. Please call Melissa Welch, Principal Investigator, at 252-847-0209 or Dr. Jennifer Hodgson, Study Supervisor, at 252-328-1349 for any research-related questions or the University & Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 for questions about your rights as a research participant. By selecting "I agree", you are consenting to take this survey. If you do not consent and you wish to end this survey, please select "I do not agree".	○ I agree ○ I do not agree

Thank you for your interest and willingness to participate in this study. Unfortunately, you are not eligible to complete this survey.

Thank you for consenting to participate in this research survey. First, we need some basic demographic information about you. Please provide the following:

What is your current age? ______________________

03/01/2021 10:41am

projectredcap.org REDCap

Are you of Hispanic, Latino, or Spanish origin? (select all that apply)	☐ No, not of Hispanic, Latino, or Spanish origin ☐ Yes, Mexican, Mexican American, Chicano ☐ Yes, Puerto Rican ☐ Yes, Cuban ☐ Yes, another Hispanic, Latino, or Spanish origin ☐ Unknown ☐ Prefer not to say ☐ Not listed _____
What is your race or national origin (select all that apply)?	☐ American Indian ☐ Alaska Native ☐ Asian ☐ Asian Indian ☐ Black or African American ☐ Chamorro ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Native Hawaiian ☐ Other Asian ☐ Other Pacific Islander ☐ Samoan ☐ Vietnamese ☐ White ☐ Unknown ☐ Prefer not to say ☐ Not listed _____
What is your gender identity?	○ Female ○ Male ○ Trans-gender ○ Non-binary ○ Prefer not to answer ○ Not listed _____
Which type of primary care provider best represents your profession? (select all that apply)	☐ Family medicine ☐ Internal medicine ☐ General medicine ☐ Geriatrics medicine ☐ Gynecological medicine ☐ Physician Assistant ☐ Nursing (e.g., Nurse Practitioner) ☐ Not listed _____
Please select the provider type that best describes your current professional role. (choose one)	○ Physician (board certified or board eligible) ○ Resident Physician ○ Physician Assistant ○ Physician Assistant student ○ Nurse Practitioner ○ Nurse Practitioner student ○ Not listed _____
Did you complete or are you currently completing a residency, fellowship, or certificate in geriatrics?	○ Yes ○ No
How many years have you been providing patient care?	__________________________

Where do you currently live/practice? Please select your state from the drop-down menu. You may experience an error if your computer attempts to auto-fill your response.	○ Alabama ○ Alaska ○ Arizona ○ Arkansas ○ California ○ Colorado ○ Connecticut ○ Delaware ○ Florida ○ Georgia ○ Hawaii ○ Idaho ○ Illinois ○ Indiana ○ Iowa ○ Kansas ○ Kentucky ○ Louisiana ○ Maine ○ Maryland ○ Massachusetts ○ Michigan ○ Minnesota ○ Mississippi ○ Missouri ○ Montana ○ Nebraska ○ Nevada ○ New Hampshire ○ New Jersey ○ New Mexico ○ New York ○ North Carolina ○ North Dakota ○ Ohio ○ Oklahoma ○ Oregon ○ Pennsylvania ○ Rhode Island ○ South Carolina ○ South Dakota ○ Tennessee ○ Texas ○ Utah ○ Vermont ○ Virginia ○ Washington ○ West Virginia ○ Wisconsin ○ Wyoming
Which of the following best describes the area in which you practice?	○ Rural ○ Urban

The brief vignette below has been adapted for this study from a training vignette used in a foundations of doctoring course at a south eastern medical school (Edwards, 2019). The vignette describes a patient-provider encounter. Please read the vignette and then answer the questions that follow as if you were caring for this patient in your own practice.

Patient: Samantha Oakley, early 70's, married white female

Setting: Outpatient primary care clinic

History of present illness: Samantha Oakley is a 70-year-old who identifies as a white cisgender female. She presents today with complaint of indolent onset of tremor in the right hand. She is right-handed. The patient notes that she has "felt like my body was shaking on the inside" for several years but started to notice the hand tremor a few months ago. She cannot pinpoint exactly when the tremor started. It is mainly noticeable at rest and seems to improve when she is using the hand such as when eating or writing, although she notes her handwriting has gotten worse, or when using tools around the farm. She denies any vocal or head tremors.

Past medical history: Considers herself in good health generally. Hypertension diagnosed around age 40. Diabetes Type 2, diagnosed 20 years ago, takes insulin. Tobacco abuse, in remission. Chronic kidney disease, stage 3. Per old records, she has had a + PPD (tuberculin skin test) in the past due to BCG vaccination.

Past surgical history: None.

Past hospitalizations: Hyperglycemia at time of diagnosis of diabetes. Was not acidotic. Started on insulin at that time.

Allergies: Niacin (causes flushing).

Immunizations: States they are up to date.

Medications: Lisinopril 20mg orally once per day. Metoprolol 25mg orally twice per day. Insulin glargine (Lantus) 50 units subcutaneously at bedtime. Insulin lispro (Humalog) 15 units with each meal, three times per day subcutaneously. Aspirin 81mg orally once per day. OTC acetaminophen as needed. No herbal medications.

Family history: States she does not know much about her family history. Her father died in World War II and had some "heart trouble." Her mother was generally healthy but died of dementia. Her daughter Shirley has diabetes but is otherwise healthy. No known breast, colorectal or other cancers. Thinks her father had heart disease but is not sure what kind. No history of Parkinson's or other neurological diseases known to the patient.

Social history: Lives in a small, rural town in NC with partner Marty in a trailer home on land that belongs to Samantha's daughter and her husband. Does not smoke currently or use any alcohol or drugs. Formerly smoked about 1 pack per day of cigarettes, from age 14 to age 60.

Review of systems:

General/constitutional - no fever, no chills, no unintentional weight gain or loss. +excessive daytime sleepiness.

Head/ears/eyes/nose/throat - no nasal discharge, no sore throat.

Eyes - no visual blurring, no photophobia, no eye redness or drainage.

Neck - no neck masses, no problems swallowing, no goiter.

Cardiovascular - no chest pain, no shortness of breath, no palpitations, no orthopnea.

Respiratory - no paroxysmal nocturnal dyspnea, no chronic cough, no hemoptysis.

Gastrointestinal - no abdominal pain, no nausea, no change in bowel habits, no melena.

Neurological - no headache, no focal weakness, no seizure activity, no dizziness/lightheadedness. + tremor, +bradykinesia, no falls, no visual changes. No hypomimia (mask-like fasces), speech impairment, no festination or gait changes.

Musculoskeletal - no joint pain, no muscle wasting, no weakness.

Endocrine - no polyuria, no polydipsia, no changes in weight. Hematology/lymphatic - no easy bruising, no bleeding, no lymphadenopathy.

Extremities - no swelling of legs or ankles, no joint deformity.

Skin - no rashes, no skin lesions of concern,

Genitourinary - no dysuria, no hematuria, no vaginal discharge.

Psychiatric - No depression or suicidal thoughts.

On a scale of 1 (none) to 4 (high), how severe do you perceive the patient's symptoms to be?	○ 1 (not at all severe) ○ 2 (low severity) ○ 3 (moderate severity) ○ 4 (high severity) ○ Cannot be determined
On a scale of 1 (not at all disruptive) to 5 (highly disruptive), how disruptive to the patient's daily life do you perceive the patient's symptoms to be?	○ 1 (not at all disruptive) ○ 2 (slightly disruptive) ○ 3 (fairly disruptive) ○ 4 (disruptive) ○ 5 (highly disruptive)
On a scale of 1 (very safe) to 5 (highly dangerous), how safe/dangerous do you perceive this patient to be to self and others?	○ 1 (very safe) ○ 2 (somewhat safe) ○ 3 (neither dangerous nor safe) ○ 4 (somewhat dangerous) ○ 5 (highly dangerous)
With the information you have available to you currently, what diagnosis(es) are you considering? Place them in the order of greatest certainty. *to enter your response, you must select the first option	○ I am considering the following diagnosis(es): _____ ○ I have no working diagnosis based on the information provided.

What other information do you want to know about this patient in order to diagnose and treat effectively? Please list the type of information wanted, the source of that information, and whether you would want the information immediately or at a later date in the table below.

Information Type (e.g., medical records from previous provider) Source (e.g., patient, caregiver, other informant) Immediate or Later

_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____
_____ _____ _____

What additional tests would you want to run before making a diagnosis? (select all that apply)	☐ Blood tests ☐ Behavioral Health Screeners ☐ Other _____
Blood tests:	☐ Full Blood Count (FBC; hemoglobin and white cell count) ☐ C-reactive Protein (CRP) ☐ Electrolytes, Urea, and Creatinine (EUC) ☐ Calcium, magnesium, phosphate ☐ Liver function ☐ Fasting blood glucose ☐ Thyroid function ☐ Serum vitamin B12 ☐ Serum folate ☐ Other blood test _____
Behavioral Screeners:	☐ Mini-Mental State Exam (MMSE) ☐ Montreal - Cognitive Assessment (MOCA) ☐ Patient Health Questionnaire (PHQ-9; Depression) ☐ Geriatric Depression Scale (GDS) ☐ Other behavioral health screener _____

At this point, would you want to communicate with any family members, caregivers, or other informants?	○ Yes ○ No
If yes, how would you do so? Select all that apply, then rank your choices in order from most preferred (1) to least preferred (5) in the spaces provided.	☐ Use video conferencing technology to call family member during the current visit ______ ☐ Invite the patient to call family member during the visit ______ ☐ Call the family member after the current visit (without the patient present) ______ ☐ Speak to the family member in-person at next visit ______ ☐ Other ______
What would you want to ask/understand from that communication?	________________________________
If no, why not?	________________________________
At this point, would you consider referring this patient to a specialist?	○ Yes ○ No
If yes, which specialist(s) and why? Specialist Type Reason for Referral ______ ______ ______ ______	
If no, why not?	________________________________
Would you feel comfortable providing ongoing care to this patient?	○ Definitely yes ○ Likely yes ○ Unsure ○ Likely no ○ Definitely no

The patient's partner often accompanies them to their primary care visits, but due to safety concerns with the current COVID-19 pandemic, they were unable to join the patient at the visit this morning. However, you received an email from them through the EMR that afternoon (after your visit with the patient). Please read a summary of the email on the next page and answer the questions that follow.

The patient's partner reports the patient has had some very subtle periods of cognition change, but no overt mental status changes. For example, a few weeks ago the patient "got lost" driving home from a familiar place but eventually remembered the route. Another event happened where the patient missed a turn off the highway in their hometown that they've been driving for many years and seemed to forget where they were briefly. The patient's partner also noticed some slowing of the patient's physical movements and walking, but their gait has not changed (it is still normal). The patient's partner has recently started noticing the tremor, but the patient has not had any postural instability or falls.

On a scale of 1 (not at all likely) to 5 (very likely), how likely are you to incorporate this information from the patient's family member into your diagnostic decision-making?	○ 1 (not at all likely) ○ 2 (not likely) ○ 3 (unsure) ○ 4 (somewhat likely) ○ 5 (very likely)

Based on the additional information provided from the patient's family member, would you change your differential diagnoses?	○ Yes ○ No
Please list the primary reason(s) for this change:	______________________________
On a scale of 1 (not at all likely) to 5 (very likely), how likely are you to incorporate this information from the patient's family member into your treatment decision-making?	○ 1 (not at all likely) ○ 2 (not likely) ○ 3 (unsure) ○ 4 (somewhat likely) ○ 5 (very likely)
On a scale of 1 (none) to 4 (high), how severe do you perceive the patient's symptoms to be?	○ 1 (not at all severe) ○ 2 (low severity) ○ 3 (moderate severity) ○ 4 (high severity) ○ Cannot be determined
On a scale of 1 (not at all disruptive) to 5 (highly disruptive), how disruptive to the patient's daily life do you perceive the patient's symptoms to be?	○ 1 (not at all disruptive) ○ 2 (slightly disruptive) ○ 3 (fairly disruptive) ○ 4 (disruptive) ○ 5 (highly disruptive)
On a scale of 1 (very safe) to 5 (highly dangerous), how safe/dangerous do you perceive this patient to be to self and others?	○ 1 (very safe) ○ 2 (somewhat safe) ○ 3 (neither dangerous nor safe) ○ 4 (somewhat dangerous) ○ 5 (highly dangerous)
With the information you have available to you currently, what diagnosis(es) are you considering? Place them in the order of greatest certainty. *to enter your response, you must select the first option	○ I am considering the following diagnosis(es): _____ ○ I have no working diagnosis based on the information provided.

What other information do you want to know about this patient in order to diagnose and treat effectively? Please list the type of information wanted, the source of that information, and whether you would want the information immediately or at a later date in the table below.

Information Type (e.g., medical records from previous provider) Source (e.g., patient, caregiver, other informant) Immediate or Later

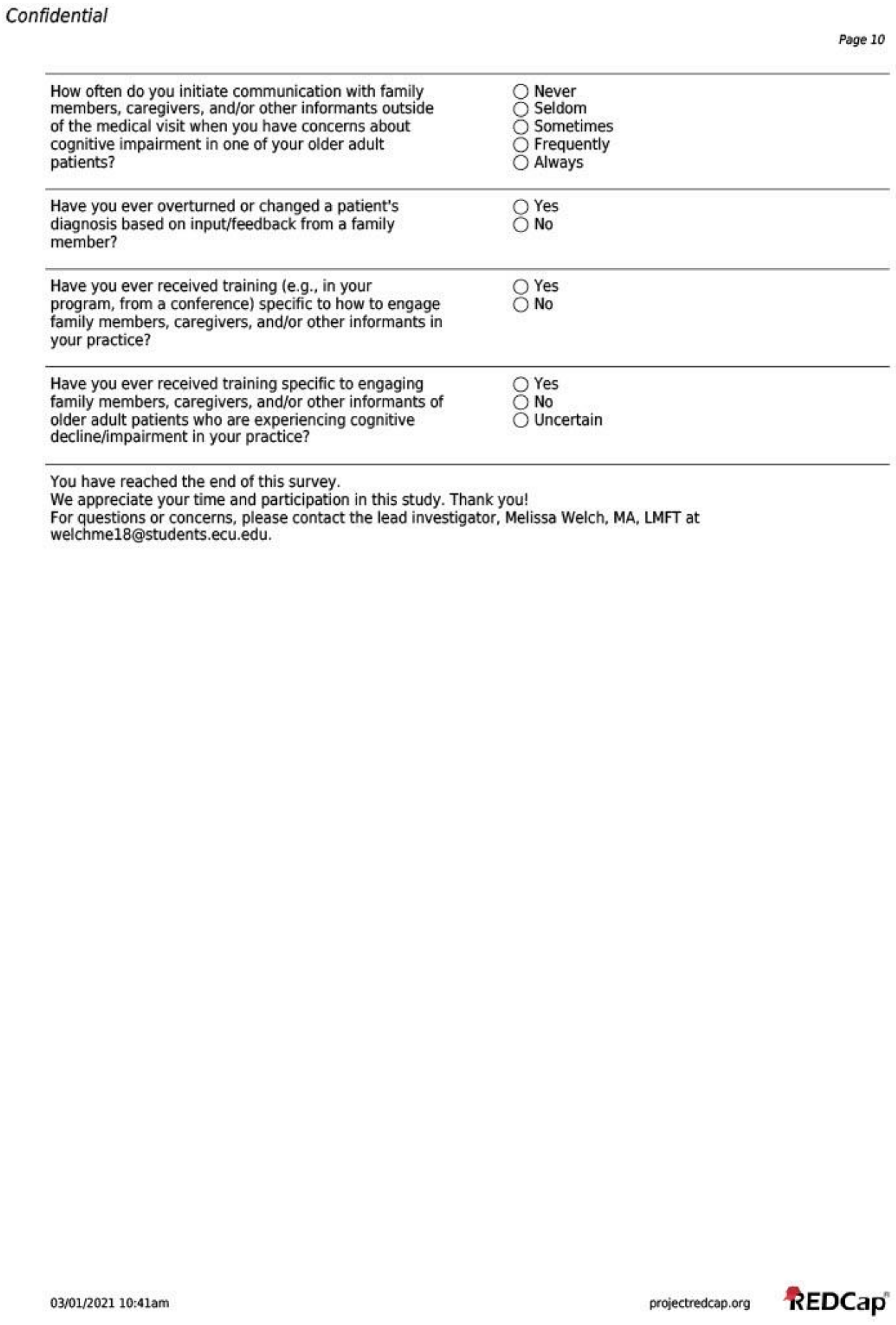
______ ______ _____
______ ______ _____
______ ______ _____
______ ______ _____
______ ______ _____

What additional tests would you want to run before making a diagnosis? (select all that apply)	☐ Blood tests ☐ Behavioral Health Screeners ☐ Other _____

Blood tests:	☐ Full Blood Count (FBC; hemoglobin and white cell count) ☐ C-reactive Protein (CRP) ☐ Electrolytes, Urea, and Creatinine (EUC) ☐ Calcium, magnesium, phosphate ☐ Liver function ☐ Fasting blood glucose ☐ Thyroid function ☐ Serum vitamin B12 ☐ Serum folate ☐ Other blood test _____
Behavioral Screeners:	☐ Mini-Mental State Exam (MMSE) ☐ Montreal - Cognitive Assessment (MOCA) ☐ Patient Health Questionnaire (PHQ-9; Depression) ☐ Geriatric Depression Scale (GDS) ☐ Other behavioral health screener _____
At this point, would you want to communicate with any additional family members, caregivers, or other informants?	○ Yes ○ No
If yes, how would you do so? Select all that apply, then rank your choices in order from most preferred (1) to least preferred (5) in the spaces provided.	☐ Use video conferencing technology to call family member during the next visit _____ ☐ Invite the patient to call family member during the next visit _____ ☐ Call the family member (without the patient present) _____ ☐ Speak to the family member in-person at next visit _____ ☐ Other _____
What would you want to ask/understand from that communication?	______________________________
If no, why not?	______________________________
At this point, would you consider referring this patient to a specialist?	○ Yes ○ No
If yes, which specialist(s) and why? Specialist Type Reason for Referral _____ _____ _____ _____	
If no, why not?	______________________________
Would you feel comfortable providing ongoing care to this patient?	○ Definitely yes ○ Likely yes ○ Unsure ○ Likely no ○ Definitely no

This final set of questions aims to understand more about your training, background, and experiences.

On a scale from 1 (not prepared at all) to 5 (fully prepared), how prepared are you to identify cognitive impairment (e.g., dementia) in your practice?	○ 1 (not prepared at all) ○ 2 (somewhat unprepared) ○ 3 (neither unprepared nor prepared) ○ 4 (somewhat prepared) ○ 5 (fully prepared)
On a scale from 1 (not prepared at all) to 5 (fully prepared), how prepared are you to diagnose cognitive impairment (e.g., dementia) in your practice?	○ 1 (not prepared at all) ○ 2 (somewhat unprepared) ○ 3 (neither unprepared nor prepared) ○ 4 (somewhat prepared) ○ 5 (fully prepared)
On a scale from 1 (not prepared at all) to 5 (fully prepared), how prepared are you to manage cognitive impairment (e.g., dementia) in your practice?	○ 1 (not prepared at all) ○ 2 (somewhat unprepared) ○ 3 (neither unprepared nor prepared) ○ 4 (somewhat prepared) ○ 5 (fully prepared)
On a scale of 1 (not prepared at all) to 5 (fully prepared), how prepared are you to engage family members, caregivers, and/or other informants of older adult patients with cognitive impairment (e.g., dementia) in your practice?	○ 1 (not prepared at all) ○ 2 (somewhat unprepared) ○ 3 (neither unprepared nor prepared) ○ 4 (somewhat prepared) ○ 5 (fully prepared)
Approximately what number of probable dementia cases have you had in your practice in the past 12 months?	○ None ○ 1-5 ○ 6-10 ○ More than 10
Do you have personal experience with cognitive impairment in older adults (e.g., caring for a loved one with dementia)?	○ Yes ○ No
How would you prefer to receive information from family members, caregivers, and/or other informants when they are unable to accompany patients to visits in your practice? Select all that apply, then rank your choices in order from most preferred (1) to least preferred (5) in the spaces provided.	☐ Email (using the EMR secure communication) _____ ☐ Email (secure work email) _____ ☐ By phone (e.g., office phone, patient phone) _____ ☐ By video (e.g., Facetime, Zoom, WebEx) _____ ☐ In person _____
How prepared are you to effectively engage family members, caregivers, and/or other informants who are unable to accompany patients to primary care visits?	○ 1 (not prepared at all) ○ 2 (somewhat unprepared) ○ 3 (neither unprepared nor prepared) ○ 4 (somewhat prepared) ○ 5 (fully prepared)
How often would you invite/welcome family members, caregivers, and/or other informants to accompany the patient in-person (not remotely) to the primary care visit when you have concerns about cognitive impairment in one of your older adult patients?	○ Never ○ Seldom ○ Sometimes ○ Frequently ○ Always
How often would you invite/welcome family members, caregivers, and/or other informants to accompany the patient remotely to the primary care visit when you have concerns about cognitive impairment in one of your older adult patients?	○ Never ○ Seldom ○ Sometimes ○ Frequently ○ Always



How often do you initiate communication with family members, caregivers, and/or other informants outside of the medical visit when you have concerns about cognitive impairment in one of your older adult patients?	○ Never ○ Seldom ○ Sometimes ○ Frequently ○ Always
Have you ever overturned or changed a patient's diagnosis based on input/feedback from a family member?	○ Yes ○ No
Have you ever received training (e.g., in your program, from a conference) specific to how to engage family members, caregivers, and/or other informants in your practice?	○ Yes ○ No
Have you ever received training specific to engaging family members, caregivers, and/or other informants of older adult patients who are experiencing cognitive decline/impairment in your practice?	○ Yes ○ No ○ Uncertain

You have reached the end of this survey.
We appreciate your time and participation in this study. Thank you!
For questions or concerns, please contact the lead investigator, Melissa Welch, MA, LMFT at welchme18@students.ecu.edu.

APPENDIX D: ORIGINAL VIGNETTE LANGUAGE

Original Vignette from Foundations of Doctoring 1, Case 7: Sam Oakley (Neurology case) by Justin Edwards, MD 6/11/2019

Case 7: Sam Oakley (Neurology case)

Age: late 70's married white male

Setting: Outpatient primary care clinic

Chief complaint:

History of present illness:

Sam Oakley is a 70-year-old male who is known to our clinic from previous visit for chest pain. He has done well since his last visit but today he presents with his wife with complaint of indolent onset of tremor in the right hand. He is right-handed. The patient notes that he has "felt like my body was shaking on the inside" for several years but started to notice the hand tremor a few months ago. He cannot pinpoint exactly when the tremor started. It is mainly noticeable at rest and seems to improve when he is using the hand such as when eating or writing, although he notes his handwriting has gotten worse. When using tools around the farm no vocal or head tremor. His wife reports he has had some very subtle periods of change in cognition that she cannot exactly put her finger on, but no overt mental status changes. For example, one day a few weeks ago he "got lost" driving home but was able to eventually remember where he was and get home. He missed a turn off the highway in Bethel that he's been driving for many years and seemed to forget where he was briefly. She has also noted some slowing of his movements and his walking. No gait changes per wife. Still has a normal gait. The patient's family has recently started noticing the tremor. He has not had any postural instability or falls.

Past medical history:

Considers himself in good health generally.

Hypertension diagnosed around age 40.

Diabetes type 2, diagnosed 20 years ago, takes insulin.

Tobacco abuse, in remission.

Chronic kidney disease, stage 3.

Per old records, he has had a + PPD (tuberculin skin test) in the past due to BCG vaccination.

Past surgical history:

None.

Past hospitalizations:

Hyperglycemia at time of diagnosis of diabetes. Was not acidotic. Started on insulin at that time.

Allergies:

Niacin (causes flushing).

Immunizations:

States they are up to date.

Medications:

Lisinopril 20mg orally once per day.

Metoprolol 25mg orally twice per day.

Insulin glargine (Lantus) 50 units subcutaneously at bedtime.

Insulin lispro (Humalog) 15 units with each meal, three times per day subcutaneously.

Aspirin 81mg orally once per day.

OTC acetaminophen as needed.

No herbal medications.

Family history:

States he does not know much about his family history. His father died in World War II and had some “heart trouble.” His mother was generally healthy but died of dementia. His daughter Shirley has diabetes but is otherwise healthy. No known breast, colorectal or other cancers. Thinks his father had heart disease but is not sure what kind. No history of Parkinson’s or other neurological diseases or dementia known to the patient.

Social history:

Lives in Bethel, NC with wife Mary Lou in a trailer home on land that belongs to his daughter and her husband (Shirley and Roy Jones).

Diet is “a typical Southern diet” most of the time. He eats fried foods that his wife cooks. Vegetables are from garden and often seasoned with pork meat and salt. Wife cooks something sweet several times per week. Likes sweet tea with meals but drinks water during the day. Does not do any formal exercise but is physically active around the home and farm.

Has 2 children, Shirley and Joe. Joe lives in a neighboring county and visits often. He works for the school system as a maintenance supervisor and has always been handy. He has several grandchildren (Samantha and Jeremy are Shirley’s children) and Joe and his wife Phyllis have an adopted son, Kevin who is 15. They fostered him when he was a baby and decided to adopt because Phyllis has “a problem with her ovaries and could never have children.” He has been having “trouble” in school but seems to be doing better.

He does not smoke currently or use any alcohol or drugs. Formerly smoked about 1 pack per day of cigarettes, from age 14 to age 60. He has not been sexually active in a long time because he and wife have lost interest in the physical aspect of their relationship. He considers this normal for them. He occasionally had trouble with erections in his 50’s before he quit smoking.

Review of systems:

General/constitutional - no fever, no chills, no unintentional weight gain or loss. +excessive daytime sleepiness

Head/ears/eyes/nose/throat - no nasal discharge, no sore throat.

Eyes - no visual blurring, no photophobia, no eye redness or drainage.

Neck - no neck masses, no problems swallowing, no goiter.

Cardiovascular - no chest pain, no shortness of breath, no palpitations, no orthopnea.

Respiratory - no paroxysmal nocturnal dyspnea, no chronic cough, no hemoptysis.

Gastrointestinal - no abdominal pain, no nausea, no change in bowel habits, no melena.

Neurological - no headache, no focal weakness, no seizure activity, no dizziness/lightheadedness. + tremor, +bradykinesia, no falls, no visual changes. No hypomimia (mask-like fascies), speech impairment, no festination or gait changes.

Musculoskeletal - no joint pain, no muscle wasting, no weakness.

Endocrine - no polyuria, no polydipsia, no changes in weight.

Hematology/lymphatic - no easy bruising, no bleeding, no lymphadenopathy.

Extremities - no swelling of legs or ankles, no joint deformity.

Skin - no rashes, no skin lesions of concern,

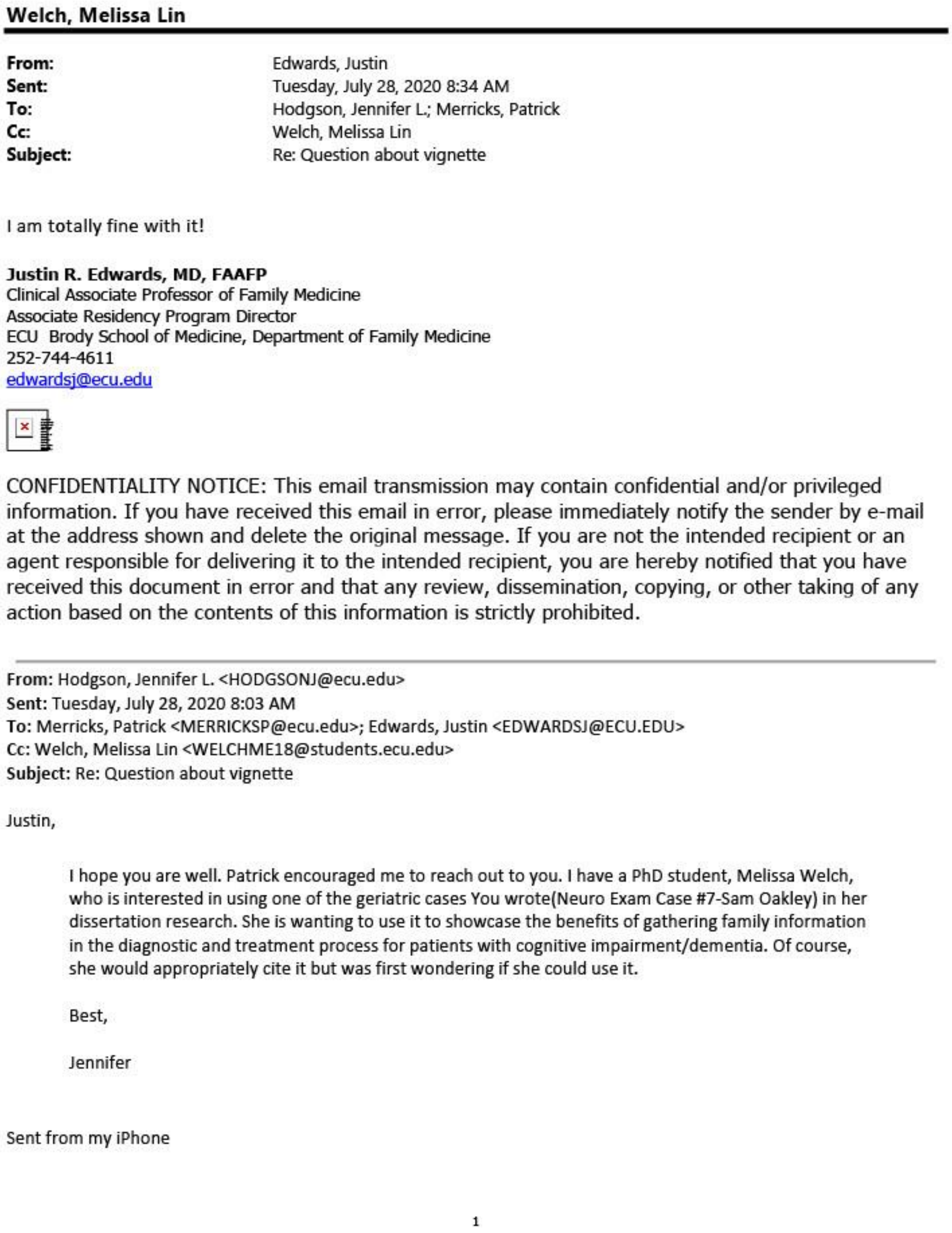
Genitourinary - no dysuria, no hematuria, no vaginal discharge.

Psychiatric - No depression or suicidal thoughts.

Optional discussion points:

- Tremor subtypes (focus on rest vs intention) e.g. Parkinson’s vs benign essential
- Symptoms of dementia (especially early)
- Symptoms of Parkinson’s - bradykinesia, festination, postural instability, tremor, rigidity

APPENDIX E: PERMISSION TO USE VIGNETTE



Welch, Melissa Lin

From: Edwards, Justin
Sent: Tuesday, July 28, 2020 8:34 AM
To: Hodgson, Jennifer L.; Merricks, Patrick
Cc: Welch, Melissa Lin
Subject: Re: Question about vignette

I am totally fine with it!

Justin R. Edwards, MD, FAAFP
Clinical Associate Professor of Family Medicine
Associate Residency Program Director
ECU Brody School of Medicine, Department of Family Medicine
252-744-4611
edwardsj@ecu.edu

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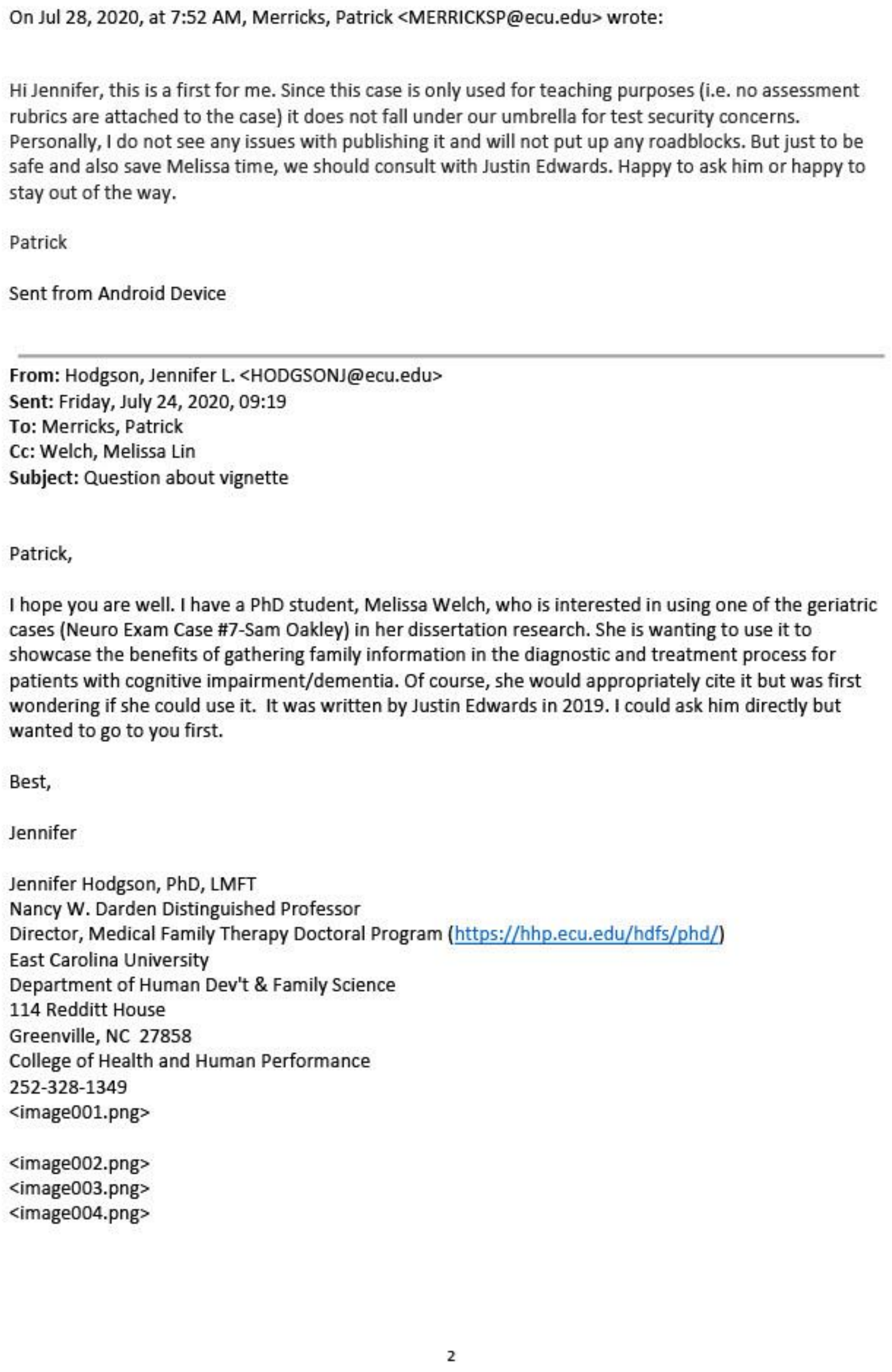
From: Hodgson, Jennifer L. <HODGSONJ@ecu.edu>
Sent: Tuesday, July 28, 2020 8:03 AM
To: Merricks, Patrick <MERRICKSP@ecu.edu>; Edwards, Justin <EDWARDSJ@ECU.EDU>
Cc: Welch, Melissa Lin <WELCHME18@students.ecu.edu>
Subject: Re: Question about vignette

Justin,

> I hope you are well. Patrick encouraged me to reach out to you. I have a PhD student, Melissa Welch, who is interested in using one of the geriatric cases You wrote(Neuro Exam Case #7-Sam Oakley) in her dissertation research. She is wanting to use it to showcase the benefits of gathering family information in the diagnostic and treatment process for patients with cognitive impairment/dementia. Of course, she would appropriately cite it but was first wondering if she could use it.
>
> Best,
>
> Jennifer

Sent from my iPhone



On Jul 28, 2020, at 7:52 AM, Merricks, Patrick <MERRICKSP@ecu.edu> wrote:

Hi Jennifer, this is a first for me. Since this case is only used for teaching purposes (i.e. no assessment rubrics are attached to the case) it does not fall under our umbrella for test security concerns. Personally, I do not see any issues with publishing it and will not put up any roadblocks. But just to be safe and also save Melissa time, we should consult with Justin Edwards. Happy to ask him or happy to stay out of the way.

Patrick

Sent from Android Device

From: Hodgson, Jennifer L. <HODGSONJ@ecu.edu>
Sent: Friday, July 24, 2020, 09:19
To: Merricks, Patrick
Cc: Welch, Melissa Lin
Subject: Question about vignette

Patrick,

I hope you are well. I have a PhD student, Melissa Welch, who is interested in using one of the geriatric cases (Neuro Exam Case #7-Sam Oakley) in her dissertation research. She is wanting to use it to showcase the benefits of gathering family information in the diagnostic and treatment process for patients with cognitive impairment/dementia. Of course, she would appropriately cite it but was first wondering if she could use it. It was written by Justin Edwards in 2019. I could ask him directly but wanted to go to you first.

Best,

Jennifer

Jennifer Hodgson, PhD, LMFT
Nancy W. Darden Distinguished Professor
Director, Medical Family Therapy Doctoral Program (https://hhp.ecu.edu/hdfs/phd/)
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Department of Human Dev't & Family Science
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