THE INFLUENCE OF PATIENT-PROVIDER COMMUNICATION ON PATIENT CHRONIC KIDNEY DISEASE AWARENESS, RISK FOR KIDNEY FAILURE AND SELF-MANAGEMENT

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ABSTRACT

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Chronic kidney disease (CKD) is a global and national health crisis affecting 10% of the global population and 15% of Americans. These individuals often experience a diminished quality of life, an increased risk for cardiovascular disease, and have a markedly reduced life expectancy. Even with the significant costs and prevalence associated with CKD, 90% of adults in the United States are unaware of their diagnosis. Health care providers are key contributors to patient CKD awareness, yet the nature of CKD conversations between providers and patients is not well understood and the influence of provider communication on patient awareness and self-management of CKD has been significantly understudied. This dissertation explores how patient-provider communication impacts patients’ awareness and self-management of their chronic disease. This dissertation is composed of three papers and uses a multi-method study design to quantitatively investigate if provider communication style is associated with patient CKD awareness and risk for kidney failure. Qualitative methods are used to explore patient’s experiences communicating with their primary care provider’s (PCPs) and the influence it may have had on their self-management. Secondary data analysis revealed that age is associated with
patient awareness of CKD status, with older participants less likely to be aware of their CKD. Qualitative data analysis revealed that patients desire more information from providers regarding the self-management of their CKD. To fulfill this desire for information, participants describe how they build a relationship with their provider, come to clinic visits prepared with questions to facilitate communication and independently sought out information on CKD management. This is the first study to examine the link between provider communication style and patient CKD awareness and patient-provider communication and CKD self-management. Findings from this dissertation study showed an impact of patient-provider communication on patient self-management of CKD. Additional work is needed to evaluate the influence of provider communication style on patient CKD awareness and risk for kidney failure in a larger study population. Further qualitative investigation into the influence of patient-provider communication on patient self-management of CKD among marginalized and vulnerable populations is also warranted.
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CHAPTER 1: INTRODUCTION

Introduction

Nearly half of Americans suffer from at least one chronic disease, making it a way of life for many (DeHaven et al., 2020). Chronic illness contributes to approximately 70% of deaths worldwide and has led to nearly $4.1 trillion in annual health care costs, accounting for 90% of annual health care spending (Hardman et al., 2020; Raghupathi & Raghupathi, 2018; Tharani et al., 2021). Chronic illness affects both the health and quality of life for patients. These patients often use more health services and spend more time and money on health care resulting in a burden for themselves and the health care system (Buttorff et al., 2017; Raghupathi & Raghupathi, 2018). Moreover, due to the long-term nature and lifestyle factors associated with the management of common chronic illnesses, such as hypertension and diabetes, the focus of health care for these individuals has shifted towards a self-management approach, leaving the patient largely responsible for daily disease management (Hardman et al., 2020; Tharani et al., 2021). Health care providers are seen as mediators of self-management, as the disclosure of a diagnosis is a pre-condition for communicating self-management options from providers to patients (Daker-White et al., 2015).

In the United States, chronic illnesses such as hypertension and diabetes are among the leading causes of death and disability as well as the top two causes of chronic kidney disease (CDC, 2022). It is defined as kidney damage or a glomerular filtration rate less than 60 mL/min/1.73m² for three months or greater (Hoerger et al., 2015). If untreated, CKD can progress to end stage kidney disease (ESKD), an irreversible and fatal condition only treated with dialysis or kidney transplant (Ng et al., 2016). With an aging population and an increasing
incidence of chronic illnesses such as hypertension and diabetes, the number of individuals at risk for CKD will continue to rise (Szczech et al., 2014).

**Problem**

CKD is a global and national health crisis affecting 10% of the global population and 15% of Americans (CDC, 2021). The inequities and disparities in kidney disease are profound, with disproportionately high rates of kidney disease and kidney failure among people of color (Nicholas et al., 2013). It has been consistently documented that Black and Hispanic patients experience faster progression of CKD with several-fold greater incidence of end stage kidney disease (ESKD) when compared to their White counterparts (Chu, et al., 2021). These inequities are compounded by the widespread disparities in diagnosis and treatment (Brown & Elliott, 2021; Crews & Novick, 2020). The financial burden of kidney disease is immense with an annual estimated cost of $114 billion. But the cost of CKD is not limited to health care expenditures; there are also humanistic costs associated with CKD (Bieber & Gadegbeku, 2019). These individuals often experience a diminished quality of life, an increased risk for cardiovascular disease, and have a markedly reduced life expectancy; this burden is intensified for African Americans and Hispanic populations (Brown & Elliott, 2021; Jankowski et al., 2021).

Even with the significant costs and prevalence associated with CKD, 90% of adults in the United States with kidney disease are unaware of their diagnosis. Past studies on CKD awareness have largely focused on patient-level factors such as comorbidities, clinical markers, and language, which inadvertently devalues the influence of health care providers (Chu et al., 2021; Goro et al., 2019; Murphy et al., 2020; Nickolas et al., 2021).
1999; Tuot et al., 2013, 2019; Welch et al., 2016; Whaley-Connell et al., 2009). As most patients with CKD are predominantly managed in primary care settings, it is of paramount importance to explore the influence of primary care providers (PCPs) on patient CKD awareness (Bello & Johnson, 2022). The few studies that have investigated the role of providers have been limited by their focus on PCP recognition and knowledge of CKD and associated risk factors, PCP adherence to CKD care guidelines, or PCP reported structural barriers to providing optimal CKD care (Abdel-Kader et al., 2014; Boulware et al., 2006; Greer et al., 2012a; Ravera et al., 2011; Sperati et al., 2019; Szczech et al., 2014; Tiu et al., 2018). While these findings are valuable to our understanding of low patient CKD awareness, significant gaps remain in understanding the role of patient-provider communication in patient CKD awareness.

Intuitively, awareness is the first step to boost patient engagement and self-management; particularly since patients have expressed a desire to be informed about their CKD diagnosis and how to self-manage in the early stages despite their own fears of dialysis and death (Nunes et al., 2016; Tiu et al., 2018; Vassalotti & Boucree, 2022). PCPs are often the first point of care and can provide the most impact prior to or during the early stages of CKD. This places them in the optimal position to communicate information on the disease process and self-management strategies that prevent the progression of CKD (Prieto, 2016). Yet, little is known about the influence of patient-provider communication on patient self-management and awareness of CKD.

**Purpose**

The purpose of this dissertation was to assess the influence of patient-provider communication on patient self-management of chronic illness and to determine if there is a
relationship between provider communication style and patient CKD awareness and risk for kidney failure. Furthermore, this dissertation also qualitatively explored the patient’s experience communicating with providers about their CKD and the influence this may have on patient self-management of CKD.

Organization

This dissertation is in a three-paper format and includes a total of five chapters, with the first and fifth chapter serving as introductory and concluding chapters. Chapters 2-4 address each of the study’s aims. The first paper, *The Influence of Patient-provider Communication on Patient Self-management of Chronic Illness: A Mixed Studies Review*, used a results-based convergent synthesis approach to conduct a mixed studies systematic review investigating the influence of patient-provider communication on patients’ self-management of their chronic illness. Quantitative and qualitative studies were synthesized to reveal emerging themes from the literature. The second paper, *The Influence of a Participatory Decision-Making Communication Style on Patient CKD Awareness and 2-year Risk for Kidney Failure*, used secondary data analysis to determine if there was an association between provider communication style and patient CKD awareness or risk for kidney failure. The third paper, *Patient Experiences Communicating with Providers About Their Chronic Kidney Disease*, reports the findings of a qualitative descriptive study exploring how patients describe their experiences communicating with their provider about their CKD and the influence on their self-management. This dissertation concludes with a summary of the main study findings and a discussion of directions for future research. The author also presents how this dissertation contributes to the literature of both patient-provider communication and CKD awareness.
Background

Chronic kidney disease (CKD) is a growing national and global health burden described by data scientists as a “global killer hidden in plain sight” (IHME, 2020). In 2017, CKD was responsible for over one million deaths, and it currently affects approximately 15% of the United States adult population (CDC, 2021). To further characterize the growing incidence of kidney disease in the United States, it is important to note the 40% increase in the need for dialysis over the last 30 years, putting CKD on track to become the fifth global cause of death by 2040 (Carriazo et al., 2021). The Kidney Disease Improving Global Outcomes (KDIGO) criteria for CKD stages is determined by the estimated glomerular filtration rate (eGFR) and presence of the protein albumin in the urine, albuminuria. The stages are as follows: stage 1 (normal) with eGFR > 90 ml/min/1.73 m² and presence of albuminuria; stage 2 (mild CKD) with eGFR 60-90 ml/min/1.73 m² and presence of albuminuria; stage 3 (moderate CKD) with eGFR 30-59 ml/min/1.73 m² and presence of albuminuria; stage 4 (severe CKD) with eGFR 15-29 ml/min/1.73 m² and presence of albuminuria CKD; stage 5 (end stage kidney disease) with eGFR < 15 ml/min/1.73 m² and presence of albuminuria (Murphy et al., 2020). CKD is frequently asymptomatic in early stages which often results in a delayed diagnosis at the advanced stages of the disease (Stolpe et al., 2021). The societal and economic burden of CKD is immeasurable; it accounts for all the resources consumed in treatment and side effects of the disease as well as the time and financial costs incurred by patients, their caregivers, employers, and payers both health care related or non-health care related (Wang et al., 2016). In 2019, it cost $87.2 billion to treat Medicare beneficiaries with CKD and another $37.3 billion to treat those with ESKD (CDC, 2022).
CKD is common, serious, and costly but may be preventable (Luyckx et al., 2018). Though, tackling the burden of kidney disease will require a multilayered approach including policy change, aggressive public health initiatives and key stakeholder engagement; among these key stakeholders are patients and PCPs. Through adequate management in primary care settings and public health initiatives that raise awareness to CKD, its risk factors, and its complications, PCPs are best positioned to tackle the burden of CKD, especially since this population is likely to be managed in the primary care setting (Greer et al., 2012; Prieto, 2016; Vassalotti et al., 2016). This chapter will discuss the issues that influence CKD awareness and the important role of patient-provider communication to patient self-management. The author will also introduce the multimethod study that quantitatively investigated the role of provider communication style in patient CKD awareness and qualitatively explored the patient experience communicating with their provider about their CKD diagnosis and self-management.

CKD Awareness

A significant proportion of people with CKD are not aware of their declining kidney function (Bello & Johnson, 2022; Greer et al., 2012a; Szczech et al., 2014). Inadequate provider recognition and education about CKD are two proposed reasons for low patient CKD awareness (Tiu et al., 2018). The progression of CKD is unique in that the early stages are often asymptomatic but critical to disease trajectory. Without a working knowledge of risk factors and screening guidelines, the early-stage asymptomatic nature of CKD makes it difficult for providers to diagnose and patients to recognize (Szczech et al., 2014). Many patients with CKD receive a significant portion of their medical care in primary care settings; a place identified as being a launchpad for interventions that decrease the incidence and slow the progression of CKD
(Greer et al., 2012). Important interventions for CKD management in the primary care setting include hypertension management, diabetes control, and the use of cardioproteective medications (Vassalotti & Boucree, 2022).

Ninety percent of individuals with CKD are unaware of their diagnosis and 40% of individuals with advanced CKD are unaware of their status (CDC, 2021). Diagnosis of CKD is at times hindered by a lack of patient and provider awareness which is often intensified by systemic and structural health system barriers such as limited time for office visits, fragmented clinical information systems, and current payment models that disincentivize lengthy discussions (Luyckx et al., 2018; Sperati et al., 2019; Vassalotti & Boucree, 2022). Other contributors to low rates of patient CKD awareness include underutilized testing in at risk populations, failure to communicate a diagnosis, and a patient’s inability to fully understand the meaning of CKD and its relevance to health (Stolpe et al., 2021; Szczech et al., 2014). Our understanding of CKD awareness to date has focused on patient-level factors. There is a paucity of research that focuses on the forementioned provider level factors, particularly the role of communication in delivering a CKD diagnosis. The proposed study will contribute to our understanding and provide evidence for the role of patient-provider communication in patient CKD awareness.

Addressing persistent low rates of CKD awareness will require, at minimum, a detailed investigation of CKD-specific communication between patients and providers. Past studies have shown CKD awareness among PCPs to be as equally low as patient CKD awareness and lower for other chronic conditions (Hsiao, 2018; Velazquez et al., 2020)(Hsiao, 2018; Velazquez et al., 2020). Low CKD awareness among PCPs is often manifested in clinical practice as delivering a late CKD diagnosis, late nephrology referrals, and a wide variation in recognition and
management of CKD; all of which can result in adverse outcomes for patients (Hsiao, 2018; McBride et al., 2014). PCPs low levels of CKD awareness have been attributed to poor knowledge of CKD management guidelines and lack of skill to confidently educate and articulate the complexities of CKD to patients (Israni et al., 2009). PCPs also report a lack of reimbursement, educational resources, and time for CKD patient education as barriers to accommodating patient educational needs (Greer et al., 2011, 2012a; Nunes, 2013; Tuot, et al., 2016). These factors often serve as barriers to delivering optimal kidney care (Crear-Perry et al., 2021).

A main principle of health care is that informed patients have better outcomes (Nunes et al., 2013; Tuot & Plantinga, 2011). Patient-provider communication has been widely advocated as an important channel through which patients’ knowledge and awareness of CKD could be improved (Greer et al., 2011). Equipping providers with the strategies, techniques, and support needed to effectively communicate with patients diagnosed with CKD is a crucial part of improving patient CKD awareness. The proposed study will support the development of these strategies by exploring the influential factors and nuances associated with patient-provider communication and patient CKD awareness.

**Patient-Provider Communication and CKD**

Communication is a critical bridge between the provider and patient health outcomes. It is reasonable to suggest that patient CKD awareness may be directly linked to provider communication since patients cannot know their CKD status without a provider first communicating this information. Hence a lack of provider communication may serve as a structural barrier to patient CKD awareness (Tiu et al., 2018). Research on patient-provider
communication in the context of CKD has been limited to the identification of barriers, the delivery of educational interventions, and patient satisfaction studies (Dowen et al., 2017; Lederer et al., 2015; Nunes, 2013; Nunes et al., 2011). Very little has been written about the influence of provider communication on CKD awareness over the past several years and several fundamental questions remain such as, what aspects of patient-provider communication are most pertinent to patient CKD awareness? Or what topics of discussion are most important to help patients manage their CKD? The proposed study will begin to answer these questions by investigating the influence of patient-provider communication on patient self-management, CKD awareness and risk for kidney failure. PCPs play a key role in ensuring patients receive essential information regarding their overall medical care, risk factors and chronic illness diagnosis (Murphy et al., 2020; Schut, 2021). With CKD affecting approximately 15% of the United States population, equating to over 2,000 patients per nephrology provider, primary care providers are needed to support and provide the bulk of care for patients with early-stage CKD (Sperati et al., 2019). Previous studies have found that PCPs and at-risk patients rarely discuss the topic and low patient CKD awareness rates are partially due to lack of CKD-specific communication (Nunes et al., 2011; Stolpe et al., 2021). Results from earlier studies have reported that PCPs lack confidence and familiarity with CKD guidelines and have concerns about causing unnecessary stress on patients if the patient’s plan of care will not change. Providers also report that insufficient clinical support tools and educational material about CKD serve as a barrier to having CKD-specific conversations (Abdel-Kader et al., 2014; Burkholder et al., 2012; Kazley et al., 2014; Lederer et al., 2015; Nunes et al., 2016; Sperati et al., 2019). In a qualitative study with dialysis and clinic nurses and nurse practitioners from a university-based community clinic,
participants report feeling that patients do not receive the necessary education or information about their CKD diagnosis and are typically confused about its progression. These nurse clinicians also suggested that patients need more time with their provider to get this information as well as more support groups, rallies, and CKD information sessions to improve awareness (Kazley et al., 2014). These findings are particularly important as they represent the perspective of CKD care in the primary care setting and clinicians that take care of patients across the CKD spectrum.

There have been intervention studies to help moderate these barriers, such as Nunes and colleagues 2013 pilot study using a physician delivered educational tool to facilitate CKD communication which was shown to be feasible and effective at facilitating CKD communication (Nunes et al., 2013). Tzeggai and colleagues’ study implemented the use of a CKD-report card which was shown to increase patient knowledge and awareness of CKD while also helping facilitate patient-provider communication (Tzeggai et al., 2020). While these studies have been supportive to PCPs in having these conversations, these efforts may be premature, as the nature of CKD-specific communication between patients and PCPs is still not well understood. Further, it remains unclear how patients even become aware of their CKD and what phrases, or language used to describe CKD are most comprehensible by patients to accurately assess awareness (Tuot, et al., 2016; Velazquez et al., 2020). It is important to thoroughly examine the nature of these conversations before implementing such interventions. Further exploration of CKD-specific communication will also work to ensure future interventions embody the importance of how information is delivered and supports a level of patient understanding that can be translated into behavior change (Tuot et al., 2013). Patient-provider communication about CKD and its
importance to health may be more complex than other chronic illnesses, partly due to the complex and heterogenous nature of CKD and the need for tailored and individualized CKD care that is proportional to the adverse outcome risk for each patient according to pertinent clinical lab values (Stolpe et al., 2021; Vassalotti & Boucree, 2022). Provider’s use of technical terms and infrequent assessment of patient understanding of CKD concepts may also contribute to communication complexities and discourage patient involvement (Greer et al., 2011).

The first paper of this dissertation begins with a systematic examination of the literature concerning the influence of patient-provider communication on the self-management of chronic illnesses; a significant gap in the literature. This gap in knowledge provides a foundational understanding and grounds to further examine provider patterns of communication as an attempt to further disentangle the complexities within CKD-specific conversations. Just as effective patient-provider communication improves patient satisfaction, treatment adherence, and knowledge about risks and benefits of treatment; ineffective patient-provider communication can result in patients being less aware of their CKD, having lower satisfaction with provider communication and poorer health outcomes (Nunes et al., 2011). Effective communication is preferably bidirectional and can be enhanced when both the provider and the patient are equipped with the appropriate tools and strategies (Lederer et al., 2015). Shared decision making, similarly referred to as participatory decision making (PDM), is associated with improved health outcomes and increased patient satisfaction (Kaplan et al., 1996; Lederer et al., 2015). Patient engagement and provider communication is important in the management of chronic disease and patient self-management practices are predicated, to a significant extent, on open dialogue and discussion of the consequences of a chronic illness (Daker-White et al., 2015). Effective patient-
provider communication is essential to helping patients understand their disease and influencing their decisions. Research has illustrated that a combination of provider communication, provision of information and increased patient involvement improves physiological outcomes and patient self-report of health status (Heisler et al., 2002; Prieto, 2016). However, more research is needed to tease out which aspects of patient-provider communication are most influential on CKD patient outcomes, self-management and understanding of their disease and treatment plans (Heisler et al., 2002).

**Participatory Decision-Making Style of Communication**

Patients with kidney disease often have multiple comorbidities, making self-management complex and patient-provider communication about self-management strategies important. Additionally, being diagnosed with an often-asymptomatic condition can make it challenging for patients to comprehend a CKD diagnosis thereby adding to self-management complexities (Teasdale et al., 2017). Participatory relationships between patients and their providers have long been associated with better patient outcomes (Xu et al., 2004). Chronic disease experts recommend a more collaborative interaction style to facilitate patient self-management of chronic illness (Heisler et al., 2002). Having a greater degree of participatory decision-making (PDM) has been shown to improve numerous health-related outcomes in several chronic illnesses (Cho et al., 2007).

A PDM style of communication signifies a patient-centered style of making health care decisions in which providers routinely present patients with the best available evidence, unequivocally consider the patient’s own values, goals, and capabilities; offer options; and negotiate with patients to have a mutually agreed-on treatment plan (Cho et al., 2007; Kaplan et al., 1996). A PDM style of communication may help providers tailor information to most
effectively support patients’ self-management (Heisler et al., 2007). Furthermore, a provider’s use of a PDM style of communication has also been associated with more favorable patient outcomes and better physiological and functional status (Kaplan et al., 1995). Self-management has been found to be strongly associated with how well a provider communicates information about their illness and treatment to patients (Heisler et al., 2002). This association may be attributed to providers involving patients in their own care and fostering increased vigilance that may improve adherence to medications and other self-care behaviors (Cho et al., 2007).

**Significance**

There are important implications for investigating the influence of provider communication style in the context of CKD awareness and patient self-management. First, a new understanding of the importance of provider communication style is necessary for the development and refinement of new and current interventions that support effective patient-provider communication. Second, the proposed study will reinforce the notion of empowering patients to have the confidence and competence to actively participate in their health care. Third, findings from this study will help scientists and researchers in developing communication training and skills programs for all health care providers. Lastly, this study will be one of the first to begin quantifying the effect of patient-provider communication style on patient CKD awareness, which in turn, may be duplicated in other chronic illnesses with similar concerns around awareness.

Researchers of CKD awareness have called for foundational steps in developing new tools to help PCPs discuss kidney disease (Tuot et al., 2019). Information gained from this study can aid the development of awareness-building initiatives used by community or national
organizations, nurses, and PCPs (the most influential bodies in health care); and in turn improve CKD awareness and patient-provider relationships. Overall, this study will also add to the body of knowledge regarding participatory decision-making research, a growing area of interest in CKD.

Gaps in the literature, Conflicting findings and National issues and concerns

There is a substantial body of literature on patient-provider communication and a growing body of work on participatory decision making. However, important questions surrounding these phenomena as it relates to CKD remain unresolved. First, the assessment of CKD awareness in research studies is hindered by the ethical concerns of notifying patients of CKD before they are told by a provider. This may be a reason for the limited number of datasets available on CKD awareness and provider communication. Additionally, awareness of CKD has been shown to vary according to the language used and how participants are asked; indicating a need for more research on CKD-specific communication (Chu, et al., 2021; Tuot et al., 2019).

There is also the longstanding question of how patients even become aware of their CKD; although this likely hinges on provider awareness and disclosure of a CKD diagnosis, understanding this small part of patient CKD awareness can be instrumental to public health campaigns and future interventions to improve CKD awareness (Velazquez et al., 2020). Moreover, many patient-provider communication studies in the context of CKD have largely concentrated on patients with advanced stage kidney disease; it remains unclear how CKD specific conversations develop in patients with early-stage CKD. Critics of CKD awareness research argue that awareness of CKD is not as important as the management of chronic conditions such as hypertension and diabetes, the top two causes of kidney disease, and that
efforts should focus on the self-management of these chronic illnesses as a way of tackling the
growing prevalence of CKD (James et al., 2010; Van Buren & Toto, 2011). This thought process
mimics a paternalistic approach to care, where providers decide what is or is not important for
the patient to know (Abdi et al., 2012; Bugge et al., 2006; Thomasma, 1983). Further, this view
presupposes that being aware of CKD is not as important as other prominent chronic illnesses
which indirectly contributes to low levels of CKD awareness by underestimating its importance.
When providers communicate about the self-management and self-care of diabetes and
hypertension, instead of excluding CKD, it should be included in the conversation. This provides
patients with a comprehensive understanding of their risk for development of CKD, thereby
making them more informed and involved in their care. Furthermore, we know that patients
prefer early communication about their diagnosis (Nunes et al., 2016).

There are also conflicting findings as to whether CKD awareness is associated with
longitudinal health behaviors, disease progression and CKD management indicators
(Tummalapalli et al., 2020). This gap in knowledge is partially attributed to the lack of
longitudinal datasets and the complexities surrounding measuring and operationalizing CKD
awareness as well as factors that confound CKD progression and outcomes. Additionally, many
of the studies investigating CKD awareness are quantitative cross-sectional studies using data
from the National Health and Nutrition Survey (NHANES) (Iroegbu et al., 2021). While these
studies provide significant contributions to the literature because they are meant to be nationally
representative, they fail to provide context to study findings. Previous qualitative studies in CKD
awareness have focused on patient perception and knowledge and have underexplored the patient
experience communicating with providers, the center and origin of CKD awareness. The lack of
diversity in approaches and methods investigating CKD awareness reflects our limited understanding of CKD awareness as a whole and the many factors contributing to persistent levels of low CKD awareness.

Lastly, the importance of CKD awareness among older adults is not clear. There is an ongoing debate concerning decreased kidney function in older adults and differentiating between disease and the normal physiology of aging (Wonnacott et al., 2012). Data that help clinicians reliably distinguish between the two and identify which older adults will experience CKD progression is limited and research in this area is still evolving (Mallappallil et al., 2014; Tonelli & Rieilae, 2014; Wonnacott et al., 2012). This debate has implications for CKD disclosure and patient CKD awareness as there are some providers who have concerns about delivering a CKD diagnosis to older adults in whom they view are experiencing a normal part of aging (Abdi et al., 2012). Other providers express uncertainty in the usefulness of disclosing an early diagnosis of CKD in older adults and the potential of unnecessary referrals and outpatient appointments (Wonnacott et al., 2012). Given that older adults are at increased susceptibility for developing CKD because of age-associated physiological changes and higher incidence of hypertension and diabetes, CKD management and awareness in this population is of particular importance (Campbell et al., 2007).

Study Design

This dissertation employed a multi method research design using quantitative and qualitative inquiry. The quantitative study component used secondary data analysis to measure the association between a providers’ use of a PDM communication style and patient CKD awareness and risk for kidney failure by leveraging a rare dataset collected from participants at a public
health care delivery system from 2011-2012 in San Francisco, California. The sample population consists of patients under the care of PCPs with a diagnosis of CKD that were able to read or actively participate in a discussion with health care providers about their CKD. Qualitative methods were used to explore patient’s experiences communicating with providers about CKD via individual interviews with a different sample of participants. The qualitative and quantitative studies were conducted simultaneously, although this is not a mixed methods study, findings from the qualitative study helped provide more context to quantitative findings.

**Research Questions**

This multimethod study sought to answer three research questions: 1) Is a provider’s use of a PDM communication style associated with patient CKD awareness and risk for kidney failure based on the kidney failure risk equation? 2) How do patients with CKD describe their experience discussing CKD with their providers and 3) How do participants perceive these discussions to have influenced their self-management? The aim of the quantitative study was to measure the strength of association between a provider using a PDM communication style and patient CKD awareness and 2-year calculated risk for kidney failure. The aim of the qualitative study was to gain an understanding of how patients experiencing and managing the progression of their CKD described having CKD-specific discussions with their provider.

**Theoretical Frameworks**

*The Shared Decision-making Model*

The Shared decision-making (SDM) model was the overarching and guiding framework used for this study. The SDM model draws from the tenets of patient-centered care and rests on
the ethical principles that individual self-determination is an anticipated goal and providers need to support patients to achieve this goal when feasible (Elwyn et al., 2012). SDM also requires respect for the patient, their competence, and their autonomy. The SDM model (see Figure 1) consists of three steps: choice talk, option talk and decision talk. Choice talk involves presenting patients with information about their condition or disease process and treatment options. Option talk is about supporting patients as they consider their options, by providing more detailed information. Decision talk involves deciding on the best option by reviewing patients’ values and preferences then guiding them to a decision (Elwyn et al., 2012).

![Figure 1](image)

**Figure 1.** A three-step shared decision-making model for clinical practice.

The clinician supports deliberation throughout the process. *Choice talk* refers to the step of making sure that patients know that reasonable options are available. *Option talk* refers to providing more detailed information about options and *decision talk* refers to supporting the work of considering preferences and deciding what is best. ("Shared Decision Making: A Model for Clinical Practice - PMC")

**Assumptions, Limitations, and Scope**

The most important assumption of this study is that patients are truthful in their report of provider communication style and in describing their experiences communicating with their provider. Limitations of this study include the small sample size thereby limiting the ability to
generalize study findings and risk of a type 2 error (not finding an association when one exists). Conducting a secondary data analysis also presents limitations as the researcher has no control over what is contained in the data set (i.e. missing data) which can limit the analysis. Limitations of the parent study for the quantitative component of this dissertation include the inability to account for unmeasured confounders and the unavailability of specific kidney function clinical markers in the electronic medical record. Additionally, as it pertains to the qualitative component, participant recollection bias and the limited ability of the primary investigator to verify participants responses also serve as limitations.

Scope

The scope of the quantitative component of this study is restricted to the primary care clinics within a single public health care delivery system. Data for the quantitative portion of this study was collected between 2011 and 2012. The qualitative component of this study involves the perspectives of participants receiving care in the United States that had seen their PCP at least once in the previous two years, had a diagnosis of CKD, and were willing to share their experience. Exclusion criteria included patients who were not English speaking, unable to read or actively participate in a discussion with health care providers about their CKD. In summary, the scope of this study is limited to this country and more specifically to patients that are engaged in the health care system and under the care of a primary care provider.

Conclusion

This dissertation contributes to our understanding of the influence of patient-provider communication on patient self-management of their chronic illness, patient CKD awareness and
patient risk for kidney failure. The findings from this study are instrumental to the development of future interventions in the areas of patient-provider communication and CKD awareness. Study results also give providers and patients insight and understanding on how to facilitate and initiate CKD-specific conversations together. Additionally, study findings provide health care providers insight to information patients with CKD desire to know about their illness.
CHAPTER 2: THE INFLUENCE OF PATIENT-PROVIDER COMMUNICATION ON SELF-MANAGEMENT OF AMONG PATIENTS WITH CHRONIC ILLNESS: A MIXED STUDIES REVIEW

Introduction

Approximately six in every ten adults have a chronic illness (Centers for Disease Control National Center for Chronic Disease Prevention and Health Promotion [NCCDHPHP], 2022). Chronic illness is defined as a condition that lasts longer than one year, requires ongoing medical care and or limits activities of daily living (NCCDHPHP, 2022). Chronic illness is the main driver of annual health care costs and re-hospitalization of patients (Ivynian et al., 2020). Patients with chronic illnesses have complex needs, however, significant proportions of chronically ill patients are not receiving effective treatment, have poor disease control, and are unhappy with their care (Timpel et al., 2020; Vestjens et al., 2018; Wagner, 1998). One of the most difficult research questions to answer in health communication and chronic illness is how to improve patient’s self-management through patient-provider communication (Peltola et al., 2018). Since patients often rely on their health care providers to provide information that helps them manage their chronic illness, providers have a critical role in helping patients achieve optimal self-management (Ivynian et al., 2020).

Patients with chronic conditions self-manage their illness each day by deciding what to eat, if they will exercise and to what extent they will adhere to a prescribed medication regimen (Bodenheimer, Lorig, et al., 2002). For this review self-management is defined as the “ability of the individual, in conjunction with family, community, and health care professionals, to manage
symptoms, treatments, lifestyle changes, and psychosocial, cultural and spiritual consequences of health conditions” (Richard & Shea, 2011, p. 261). This is different from self-care which is defined in the literature as “a naturalistic decision-making process that influences actions that maintain physiologic stability, facilitate the perception of symptoms, and direct the management of those symptoms (Riegel et al., 2016, p. 226). Chronic disease self-management requires the patient to incorporate multiple strategies to meet their self-identified needs (Angwenyi et al., 2019). To optimize and make self-management as effective as possible requires a prepared health care team to not only empower patients, but to also ensure patients are aware of their chronic illness, have disease-specific knowledge, and a certain level of understanding of the process of their chronic illness (Angwenyi et al., 2019; Byrne et al., 2022; Piette et al., 2003). By providing patients with the information needed to self-manage their chronic illness, a realistic pathway to behavior changes and improved health outcomes is possible (Piette et al., 2003; Wagner, 1998).

Still, many patients remain confused about the basic aspects of their condition and its management (Ivynian et al., 2020). This places significant reliance on the provider to effectively communicate this information to patients in a way that minimizes gaps in knowledge and confusion while also emphasizing how to apply and incorporate this information to real life circumstances (Ivynian et al., 2020). The extent to which effective patient-provider communication influences how patients manage and care for their chronic illnesses is not well understood. Therefore, the purpose of this mixed studies review is to synthesize study findings on the influence of patient-provider communication on patient self-management of their chronic illness.
Patient-provider communication

The discussion of patient-provider communication in medicine can be traced back as early as 1950 with Osler insisting that physicians focus on and listen to the patient rather than the specifics of the disease (Platt et al., 2001). Since then, patient-provider communication continues to be studied in medicine, the social sciences, and nursing from various lenses. Traditional values of hierarchy and control in the patient-provider relationship are now being replaced with values such as equality and autonomy (Visse et al., 2010). A functional patient-provider relationship is built through communication and on the importance of listening and building an atmosphere of trust that enhances the patient-provider relationship (Peltola et al., 2018; Visse et al., 2010). Effective patient-provider communication has been linked to increased patient adherence to treatment regimens, reduced health expenditures and an overall improved patient experience (Verlinde et al., 2012). Ineffective patient-provider communication, however, can be a driver of health disparities and health inequities leaving groups of patients uninformed, unaware of their diagnosis, and with a heightened distrust in health care providers (Schut, 2021; Wilder et al., 2016). Additionally, studies investigating self-management support from providers serving disadvantaged populations have reported poorer outcomes and lower levels of adherence (Hardman et al., 2020). Furthermore, even if providers are effective at general communication, a lack in disease-specific communication may result in patients inefficiently managing their chronic illness (Piette et al., 2003).

A critical element in the delivery of health care services is directly related to the patient-provider relationship, which can directly or indirectly influence patient outcomes. The most critical component of this relationship is communication. In fact, Platt et al., (2001) suggest that
a therapeutic patient-provider relationship begins with good patient-centered communication. The provider’s role in providing support for patients to self-manage their chronic illness is complex and requires providers to consider the patient as a whole, in addition to providing helpful information (Kruse et al., 2013). Although, lack of time, poor reimbursement and difficulty changing habitual clinical practices often preclude providers from being able to adequately promote patient self-management during clinical encounters (Kruse et al., 2013). While there are many empirical studies that describe the positive or negative influences of patient-provider communication and several opinions and perspectives of what “effective” or “good” patient-provider communication entails, there has yet to be a systematic review of the literature on the influence of patient-provider communication on patient self-management of chronic illness.

**Patient-provider communication and self-management**

As the population continues to age and individuals progress to suffer from multiple conditions and comorbidities, self-care and self-management have become increasingly more important and essential to the management of chronic illness (Raghupathi & Raghupathi, 2018; Riegel et al., 2012). Self-management continues to be a highly contested issue among critics surrounding the beliefs of independence and control, as researchers in bioethics and medical sociology believe that self-management is more than just giving information to the patient; it requires relational, narrative, and communicative work between the patient and the provider (Visse et al., 2010). Good patient-provider communication provides patients with the understanding and tools to implement treatment options and increase patient trust and motivation. The responsibilities between providers and patients have shifted over the past
decades where providers have assumed a more objective and information-providing role; and patients are perceived as informed, autonomous experts, directing their life and care (Heisler et al., 2007; Visse et al., 2010). Patient-provider interactions within the clinical encounter are intended to create a partnership that will motivate patients to engage in their care; thereby patient-provider communication can serve as a mediator in some situations and a barrier in others, for the patient to self-manage their chronic illness (Riegel et al., 2012; Visse et al., 2010).

Historically, the conceptualization of self-management and decision making has consisted of health care practitioners “blaming” the patient for their disease-related problems (Paterson et al., 2001). This framing places much responsibility on the patient while limiting the significant role providers play in ensuring the patient has a complete understanding of how to appropriately manage their chronic illness. Self-management of a chronic illness is multifaceted and there are many factors that contribute to a patient’s ability or inability to successfully manage their chronic illnesses. However, one of the major contributors identified by the World Health Organization is health care system related factors, of which include patient-provider communication (Świątoniowska-Lonc et al., 2020)(Świątoniowska-Lonc et al., 2020). Patient-provider communication may not always result in agreement between both parties, but it should aim to ensure the patient understands their illness, benefits from consistent treatment, and leaves the patient with a sense of control over their illness and an ability to identify symptoms or changes in their condition (Świątoniowska-Lonc et al., 2020).
Aim

This review aimed to explore the influence of patient-provider communication on patient self-management of chronic illness while acknowledging that self-management can be defined and measured in diverse ways.

Design

A systematic mixed studies review using a results-based convergent synthesis approach was employed to examine the nuances of patient-provider communication and its influence on patient self-management of their chronic illness (Noyes et al., 2019; Pluye & Hong, 2014). This design was chosen for its ability to analyze and synthesize quantitative and qualitative results separately and then combine and synthesize both results together to gain a more comprehensive understanding of the influence patient-provider communication has on self-management (Noyes et al., 2019; Osokpo et al., 2021).

Search Methods

A literature search was conducted in collaboration with a university librarian in the following databases: CINAHL, EMBASE and PubMed. Medical subject headings (MeSH), key terms and concepts related to patient-provider communication and self-management were combined in the context of chronic illness and included the following search strategy:

“communication”[Mesh] OR communication*[ti], “interpersonal relations”[Mesh] OR "Professional Patient Relations") AND ("chronic disease"[mesh] OR "chronic disease*" OR "chronic illness*" OR "chronically ill" OR "chronically sick" OR "chronic sickness" OR

**Search outcomes**

Articles were included if they were peer reviewed, empirical data or original qualitative research that exclusively examined the relationship between patient-provider communication and patient self-management of a chronic illness. Articles that discussed the patient-provider relationship broadly, the use of electronic communication or were of an opinion perspective were excluded. Additionally, articles that discussed self-management outside of the context of patient-provider communication were also excluded. There was no limit on publication date and all articles included were published in English; articles without full text availability were also excluded.

**Data Extraction**

The following data extracted from the included studies consisted of the following: Author and year of publication; the type of chronic illness under investigation; Country where the study was conducted; Study aim; Design, methods, and sample characteristics; Outcomes of patient-provider communication on self-management for the patient; and the strengths and limitations of the study (See Table A.1).

**Synthesis**

Quantitative data were synthesized narratively (Hong et al., 2018). Due to the variability in methodological design and the limited number of quantitative studies included in this review, a meta-analysis was not performed. Qualitative studies were synthesized using thematic analysis.
and inserted into a matrix table (Hong et al., 2018; Thomas & Harden, 2008). This was done using a three-step approach, first, coding the text line by line for each study, second, developing descriptive themes from the included studies that reflected the aims of each study, and third, generating analytical themes that reflect and interpret the constructs of patient-provider communication and patient self-management. Data included in the matrix were reviewed iteratively and codes were generated (Hong et al., 2018). Generated codes were then grouped into categories to reveal emerging themes (Noyes et al., 2019; Pluye & Hong, 2014; Thomas & Harden, 2008). Following the analysis of quantitative and qualitative data, a combined synthesis of both data was performed to derive overarching themes from the integration of the data (Osokpo et al., 2021).

Results

A total of 375 articles were identified from PubMed, EMBASE and CINAHL. Four duplicates were removed and a total of 295 were excluded in title screening leaving a total of seventy-six articles for abstract screening. A total of sixty-five articles were excluded after abstract screening resulting in a total of 11 all of which are included in this review (see Appendix E).

Quality appraisal

The quality of each study was appraised using the Mixed Methods Appraisal Tool (Hong et al., 2018; Pluye & Hong, 2014). This tool is designed for methodological quality appraisal of systematic reviews. The author of this tool discourages the use of a total quality score and instead recommends the use of descriptive quality appraisal (Hong et al., 2018; Pluye, 2013;
Pluye & Hong, 2014). Therefore, the studies included in this review were based on a set of screening questions specific to qualitative or quantitative study designs. All quantitative studies (see Table B.2) and five of the qualitative studies included in this review have high methodological quality (see Table C.3). The remaining qualitative study included in this review had a low methodological quality due to its qualitative approach used to answer the research question, the inadequacy of the data analysis methods used, and the lack of coherency between the qualitative data source, collection, analysis, and interpretation (see Table C.3). The one mixed methods study included in this review is also of low methodological quality due to its lack of rationale for using a mixed methods design and lack of integration of qualitative and quantitative data (see Table D.4).

**Characteristics of the studies**

Studies included in this review were qualitative \((n = 6)\), quantitative \((n = 4)\) and mixed methods \((n = 1)\). All studies were published between 2003 and 2020 and were conducted in North America \((n = 6)\), Europe \((n = 4)\) and southeast Asia \((n = 1)\). Diabetes was the most frequent chronic illness studied and the primary focus of five studies; other chronic illnesses included heart failure \((n = 2)\), hypertension \((n = 1)\), COPD \((n = 1)\), and asthma \((n = 1)\); one study investigated diabetes and hypertension together.

Data was collected through surveys, individual interviews, observations, focus groups, survey instruments and electronic medical record review. All studies included adult men and women, but not all studies reported on race and ethnicity. Thematic, narrative, and qualitative descriptive methods were used in the qualitative studies. Quantitative studies used cross-
sectional analyses or survey results to describe the data and study outcomes. Sample sizes ranged from one to 104 in the qualitative studies and 752-1558 in quantitative studies.

Most studies sought to characterize the patient-provider communication encounter by describing the provider communication style, acquiring patient perceptions of their providers communication, or describing specific elements of the patient-provider clinical encounter. All studies explored or examined how these factors impeded, influenced, or improved the patient’s ability to manage their chronic illness. Self-management of chronic illness was described or specified in the included studies as performing specific self-care behaviors, measurement of a specific health outcome (ex. Hemoglobin A1c) or by a survey instrument score.

**Synthesis of quantitative studies**

Overall, quantitative studies found patient-provider communication to be influential on patient self-management of chronic illness. The quantitative studies included in this review focused on measuring the influence of patient-provider communication on key health outcomes. Outcomes measured for diabetes self-management were foot care, medication adherence, diet, and exercise (Claramita et al., 2020; Heisler et al., 2007; Kruse et al., 2013; Kumar, 2007; Peltola et al., 2018; Piette et al., 2003). Outcomes measured for heart failure included daily weight monitoring, consuming a low-salt diet, seeking medical attention when appropriate and medication adherence (Baker et al., 2005; Heisler et al., 2007; Piette et al., 2003; Świątoniowska-Lonc et al., 2020). Tools used to measure provider communication were the Communication Assessment Tool (CAT), the Interpersonal Processes of Care (IPC) questionnaire, a previously unpublished diabetes-specific communication scale, the Consumer Assessment of Health Plans
Study instrument, the Patient Assessment of Chronic Illness Care (PACIC) scale, and the American Board of Internal Medicine patient survey instrument.

Providers that embodied characteristics of a participatory communication style were correlated with better patient self-management of their chronic illness (Heisler et al., 2007; Piette et al., 2003). Providers that offered disease-specific information tailored to patients’ chronic illness were most influential on patients self-managing their chronic illness (Heisler et al., 2007; Piette et al., 2003). Patients that collaborated with their provider in a collaborative fashion found it easier to self-manage their chronic illness independently and effectively (Baker et al., 2005; Heisler et al., 2007). However, providers that did not deliver disease-specific information but received high communication scores, had patients that did not understand how to self-manage their specific chronic illness effectively (Baker et al., 2005). Additionally, studies involving the self-management of a respiratory chronic illness emphasized the importance of a therapeutic dialogue between patients and providers while diabetes studies tended to focus on how providers linking clinical measures to self-management strategies helped support patients in self-management (Claramita et al., 2020; Heisler et al., 2007; Kruse et al., 2013; Kumar, 2007; Newcomb et al., 2010; Peltola et al., 2018; Piette et al., 2003; Visse et al., 2010). This finding speaks to the importance of providers not only demonstrating effective general communication, but also delivering disease-specific information.

**Synthesis of qualitative studies**

Qualitative studies coincide with quantitative studies and support the notion that patient-provider communication does influence patient self-management of chronic illness. Patient perspectives in qualitative studies suggest that better patient-provider communication led to
better self-management. Data analysis from qualitative studies revealed the following themes: tailored information, patient engagement and provider collaboration, and knowledge translation.

**Tailored Information**

Patients preferred and found it more helpful to manage their chronic illnesses when providers delivered information specifically tailored and adapted for their illness (Ivynian et al., 2020). Patients were most satisfied when providers gave insights to how their disease process affects their ability to perform self-management behaviors and their overall quality of life; this also improved patient knowledge and understanding of their chronic illness (Kumar, 2007; Visse et al., 2010). When communication was not targeted to the patient’s chronic illness critical information was often missed and patients were left confused about matters concerning their illness (Newcomb et al., 2010). For example, patients who did not adhere to their asthma medication regimen reported not discussing their asthma medications with their provider and confusion surrounding these medications; on the reverse side, clinicians assumed that patients were taking their medication (Newcomb et al., 2010). This lack of communication surrounding the day-to-day management of asthma and asthma-related medications led to an increase in medication dose that may have not been warranted, had the provider known the patient had not been adhering to their medication regimen (Newcomb et al., 2010). Yet, when providers linked clinical measurements to patients’ symptoms and explained the etiology of patient’s specific chronic illness, patients better understood how to and the importance of managing their chronic illness (Ivynian et al., 2020; Kruse et al., 2013).

Information concerning patient self-management of their chronic illness is more powerful when it is linked and adapted directly to patients’ specific preferences, circumstances, and
behaviors (Heisler et al., 2007). It is this link that ultimately drives the improvement of clinical outcomes because patients are presented with realistic and practical solutions to apply to their everyday life. It is important for providers to be aware and understand patient’s social contexts as it often influences their decision making in managing their chronic illness.

**Patient Engagement and Provider Collaboration**

Patient involvement is crucial for patients to learn self-management skills and keeps the patient at the center of their care (Peltola et al., 2018). A patient centered approach is traditionally described as a philosophical orientation and defined through the relational communication behaviors between the patient and their health care providers (Gluyas, 2015; Peltola et al., 2018). It is the responsibility of the provider, as opposed to the patient, to place experiences, values, needs and preferences of the patient at the center of planning, co-ordination, and delivery of care (Gluyas, 2015; Peltola et al., 2018). When providers engage and communicate with patients respectfully and ensure their understanding, patients were in turn motivated to improve self-management behaviors (Peltola et al., 2018). When providers encouraged patients to share their experiences with illness as a story it provided a pathway for providers to provide practical support, advice, and solutions for patients to manage their chronic illness (Kumar, 2007; Visse et al., 2010). Additionally, promoting patient empowerment and engagement to improve awareness of their disease process helped patients prevent complications and, when patients were actively engaged in establishing goals for self-management by communicating their preferences and values, they were able to achieve successful self-management (Claramita et al., 2020; Kumar, 2007).
Considering a patient’s cultural background is a key part of patient engagement and can have significant implications for patient self-management and collaboration on a treatment plan. In Kumar’s (2007) case study, cultural background and beliefs influenced the patient’s management of her illness. It was through communication, with the nurse, that it was discovered that the patient believed things were not in their control but “in God’s hands” and they did not have the power or control to influence a health outcome. To address this, the patient and the nurse together developed a plan to improve the patient’s belief and perceptions of being able to influence their own health outcomes. Culture was also suggested to shape expectations and communication behaviors regarding how messages are sensed as well as subsequent reactions during the patient-provider clinical encounter (Peltola et al., 2018). This can serve as a barrier to patient-provider communication if providers have not achieved cultural competence when caring for specific populations. Yet, Claramita et al., (2020) found that a culturally sensitive communication style by providers included in their study, contributed to an increase in patient adherence to medication, physical exercise, and regular monitoring of their chronic illness.

Collaboration among providers and clinicians within the health care organization can serve to facilitate patient-provider communication. When a nurse and a physician or advanced care provider are both present in the clinic environment, they can collaborate to address and meet the patient’s needs (Kruse et al., 2013). For example, Kruse et al., (2013) found check-listing, a rapid review of several indicators, treatments, and practices specific to a chronic illness, to be a helpful strategy to ensure providers address important indicators of high-quality care and have in-depth conversation about patient self-management. This was achieved in collaboration with the nurse; while the nurse was responsible for addressing the medications, blood sugar testing
and values, testing supplies, laboratory tests and eye examinations, the physician was allowed more time to focus on discussing a treatment plan and other issues conveyed by the nurse during their patient assessment. This demonstration of collaboration among health care providers also maps onto the idea of interdisciplinary care where health professionals from different disciplines, along with the patient, work collaboratively as a team to optimize patient visits and provide self-management support.

**Knowledge Translation**

The expected goal of research is to embed research evidence into practice to improve and inform health care outcomes and decision making (Barac et al., 2014). Knowledge translation is described in the literature as bridging the gap between research and practice, where health care providers use research evidence to inform their decision making. Sharing this knowledge with patients, applying it to clinical practice, or using research to facilitate behavior or practice change are all examples of knowledge translation (Barac et al., 2014). Knowledge translation is particularly important to chronic illness and there is empirical evidence that suggests that many patients with chronic illness desire information about their illness process and treatment options (Costello, 2016; Manson, 2010). Additionally, the failure to optimally use evidence in clinical practice results in inefficiencies and reduced quality of life for patients (Straus et al., 2011).

Knowledge translation in this review concentrated on the way in which provider knowledge was communicated with the patient as how knowledge is translated to the patient has considerable influence on patient-self management of their chronic illness.

When sharing knowledge with patients, providers should opt to use plain language and develop a clear and concise action plan, in collaboration with the patient, to manage their
symptoms and chronic illness (Ivynian et al., 2020). Face-to-face communication as well as written material and visual aids were reported to be helpful for patients to self-manage their heart failure post hospitalization (Ivynian et al., 2020). Making eye contact, sitting down face to face, and active listening were significant nonverbal communication behaviors perceived by the patient as willingness of the provider to communicate and creating experiences of care conducive to their own self-management (Peltola et al., 2018). These nonverbal and verbal communication practices displayed by providers are central to interpersonal communication and are symbolic of a patient-centered approach to knowledge translation (Peltola et al., 2018).

Communication style was found to play an important role in knowledge translation and patient self-management. Provider’s thoroughness of information provision (PCOM) and participatory decision making (PDM) were two styles of communication measured in association with patients reported diabetes self-management among older adults (Heisler et al., 2007). Older adults were reported to prefer less of a participatory decision-making (PDM) communication style and valued spending more time discussing self-management and treatment options in detail; though both communication styles were associated with better self-management of their diabetes (Heisler et al., 2007). Lastly, when translating knowledge, it is important for providers to be cognizant of being too focused on the patient’s illness and other disease-specific quantitative measures as this can limit the transferability of information. This was evident in Kruse and colleagues’ study on patient-provider communication and diabetes self-management, where a difference in patient’s and provider’s views of measurable outcomes lead to a reduced interest in some self-management activities (Kruse et al., 2013). It is important for providers to embody a communication style that focuses on patient’s priorities, obstacles to self-management and
strategies for overcoming obstacles. This can be done by translating knowledge of how some clinical measures such as blood pressure and glycosylated hemoglobin are connected to how poorly or well a patient may feel.

**Synthesis of Findings from Quantitative and Qualitative Studies**

By integrating the quantitative and qualitative findings of the articles included in this review, an overarching theme emerged: *adaptive interpersonal communication*. Adaptive references tailoring or adapting communication content to the individual needs of the patient, incorporate their needs and circumstances, and linking clinical measures to physical symptoms the patient experiences or outcomes of self-management practices. For example, a decrease in hemoglobin A1c may be a clinical measurement linked to patient implementation of certain dietary practices or explaining to patient’s experiencing shortness of breath when lying down and swelling in the legs they may have fluid volume overload, a physical manifestation of their heart failure.

*Interpersonal* references the use of verbal and nonverbal communication to build a connection with patients and convey a willingness to communicate. It also references getting to know the patient outside of their illness, learning about their social circumstances and incorporating these matters into their communication about self-management strategies. All of which were shown to be significantly associated with improved patient self-management of their chronic illness. While attributes of interpersonal communication were described differently for various patient populations, patients overall wanted to communicate with providers about their specific disease process and learn how to effectively manage their illness in a manner that was conducive to their learning and inclusive of their lifestyle preferences and values.
Communication references the entire knowledge translation process that takes place in patient-provider discussions about their chronic illness and how that translation of knowledge is perceived by the patient. Providers can no longer communicate with a sole focus on the illness and biomedical measures. Instead, providers must meet patients where they are and engage in meaningful and empathic conversations that help them get to know the patient as whole and offer supportive self-management strategies. Adaptive interpersonal communication also considers the clinical encounter in which patient-provider communication occurs and acknowledges that there are health system and organizational barriers that may impede the knowledge translation process. Some of which can be addressed through acknowledgement and a willingness to change ingrained clinical practices. Part of this can be reflected in the collaboration amongst interdisciplinary providers and patients working together as partners in managing the patient’s care.

Discussion

Patient-provider communication is essential to patient self-management of their chronic illness. Effective chronic illness self-management requires following regimens for diet, medication, and exercise (Heisler et al., 2007). These are not new insights, there has been a substantive body of research examining these factors that support chronic illness self-management. There has not, however, been enough research to describe the influence of patient-provider communication on chronic illness self-management. Of the studies that have addressed this phenomenon, opinions are mixed about the importance of patient-provider communication as it pertains to age groups, communication styles and how information should be delivered (Heisler et al., 2007). However, it is clear that an adaptive and interpersonal approach to
communication when developing a self-management plan will lead to the most optimal outcomes. Given the importance of patient-provider communication for treatment outcomes, rigorous empirical evidence is needed to understand the effectiveness of different communication styles (Heisler et al., 2007). Additionally, more research is needed to understand how patient-provider communication affects clinical outcomes for minority and vulnerable populations (Heisler et al., 2007).

The chronic illnesses included in this study are among the most common in the United States and provide significant implications for clinical care and management of these conditions. However, CKD is a chronic condition not included in this review and frequently overlooked in discussions of patient-provider communication. Given that chronic illnesses such as diabetes and hypertension, that are included in this review are precursors to CKD, more research is needed to incorporate kidney disease in the patient-provider communication and self-management space. In this review, communication was evaluated in different ways including patient satisfaction with provider communication, perceived quality of patient-provider communication, provision of information and provider communication style (Baker et al., 2005; Heisler et al., 2007; Świątoniowska-Lonc et al., 2020). Additionally, various research and analysis methods and study designs were also employed in the studies included in this review. This is particularly important as we continue to build upon current knowledge to develop interventions that improve communication between patients and providers and patient self-management of chronic illness. Many of the studies included in this review were of good methodological quality as it pertains to the approach to answer the research question, data collection and analysis methods, interpretation, and coherence between all three of these factors. While this does provide solid
support for the findings in this review, there are only 11 studies included in this review which may impede the ability to make definitive conclusions and is indicative that more descriptive or intervention studies are needed.

While this review focuses on patient self-management of chronic illness as an outcome, specific measured outcomes included clinical measures (blood pressure, hemoglobin A1c), symptom and self-efficacy scales, and medication adherence. Though, it should not be ignored that to improve health outcomes, factors such as health care access and quality of care must also be addressed (Baker et al., 2005). Findings from this review have implications for individuals, health systems, and providers, to work on improving their communication skills and strategies. The clinical environment plays a direct role in facilitating patient-provider communication. Organizational and health system culture also play a key role in patient-provider communication, which indirectly affects patients and their ability to self-manage. In consideration of multiple competing demands during short office visits, it is important for providers to tailor communication to most effectively support patient’s self-management of their chronic illness (Heisler et al., 2007). However, when providers face barriers such as time constraints, poor reimbursement, and difficulty changing habitual clinical practices, it is difficult for providers to effectively promote self-management to patients (Kruse et al., 2013). Health systems and organizations should work to structure a clinical environment that intentionally supports knowledge translation between patients and providers and encourages patient engagement in decision-making (Heisler et al., 2007).

Relational communication, the Chronic Care Model, Orem’s self-care deficit theory, and patient-centered care (PCC) are among the guiding frameworks, models, theories or concepts for
many of the studies included in this review. This lends support to solidify the findings in this
review as they align with existing literature. However, the interaction of patient race, language,
culture in the context of chronic illness and patient-provider communication is poorly
understood, deeming these phenomena worthy of further investigation. Additionally, studies that
employ a health care equity lens or framework may lend support for investigations that consider
if patient expectations or perceptions of provider communication differs across race, age, gender,
and other sociodemographic variables. The lack of health care equity context in the studies
included in this review places boundaries for interpretation of findings.

Patients were variably successful in developing the skills needed to self-manage their
chronic illness (Claramita et al., 2020; Kruse et al., 2013; Kumar, 2007; Peltola et al., 2018;
Piette et al., 2003). In fact, patients often understand what they are supposed to do but are often
prevented from being able to do so because of external demands, such as caring for other family
members or work. When providers consider patients experiences, values, and needs it is also
important to take into consideration the social context of the patient, particularly when
developing a plan for self-management (Kruse et al., 2013; Peltola et al., 2018; Visse et al.,
2010). Providers should allow patients to share their life commitments, daily activities, and
various social circumstances. This helps patients and providers collaborate to develop self-
management strategies that work best for the patient (Visse et al., 2010). Failure to consider
patient’s social circumstances results in missed opportunities for providers to educate patients on
the significant role their home and social environment plays in their ability to effectively self-
manage their chronic illness. More importantly, when providers do not engage the patient in
discussing their social circumstances, patients often abandon general self-management strategies
they perceived as ineffective because they are not realistically applicable to their life circumstances (Kumar, 2007; Newcomb et al., 2010).

**Limitations**

There are limitations to this review, as only studies published in English and available in three databases (CINAHL, EMBASE, PubMed) were included. Although the search strategy was developed in collaboration with a librarian and varied combinations of search terms were employed, some relevant literature may have been missed. While there were a variety of chronic conditions included in this review, the findings cannot be generalized for all chronic conditions. Additionally, none of the studies included in this review included any health equity concepts, making generalizability and application to vulnerable and marginalized populations difficult. Lastly, articles were restricted to patient-provider communication and self-management only, articles that discuss the patient-provider relationship instead of just communication, may have yielded additional findings not included in this review.

**Conclusion**

Findings from this review can help patients and health care providers become more aware of the significance patient-provider communication has on patient self-management in the context of chronic illness. These findings may also assist patients and providers in developing more effective and appropriate communication in care relationships. Additionally, health policymakers and researchers can use these findings to help create a clinical environment that is more considerate of the time, effort and training needed to foster an environment for effective patient-provider communication and knowledge translation.
CHAPTER 3: THE INFLUENCE OF A PARTICIPATORY DECISION-MAKING STYLE ON PATIENT CKD AWARENESS AND 2-YEAR RISK FOR KIDNEY FAILURE

Introduction

Awareness of chronic disease is an important prerequisite for patient engagement and successful self-management of their chronic illness (Vassalotti & Boucree, 2022; Welch et al., 2016). Self-management is particularly important for individuals with CKD because the best way to slow CKD progression is through aggressive lifestyle and medical management (Tzeggai et al., 2020). Many public health organizations including the Center for Disease Control, the National Kidney Foundation, and the American Society of Nephrology, have made increasing CKD awareness a priority (Chu, et al., 2021; Tuot, et al., 2016). However, despite these efforts, incidence of CKD awareness has remained low among patients with and at risk for CKD for over two decades. While there are many factors that may contribute to reportedly low rates of CKD awareness such as the way in which patients are asked about their CKD and how awareness is assessed, there has been little investigation into the influence of patient-provider communication on patient’s awareness of their CKD.

To date, most research in CKD awareness has investigated provider and patient awareness separately. Studies that have examined the providers’ role in patient CKD awareness have been limited by their focus on assessing provider knowledge and awareness of CKD screening and management guidelines. While much has been learned from these studies, they fail to assess how this knowledge is translated into practice. Pilot intervention studies have concentrated on CKD screening and education as a way to improve CKD awareness, but these efforts have preceded our full understanding of the nature of CKD-specific conversations.
between patients and providers. Additionally, there are very few datasets that include information about provider communication that will enable the investigation of this phenomenon. Patient CKD awareness studies have largely reported on patient’s awareness of their diagnosis but are incomplete because they fail to connect patient awareness to the providers caring for these patients. While patients and providers are separate entities, the two are far from independent of each other and are integrally related (Tuot et al., 2012). Patients cannot be aware of their individual CKD status without a provider disclosing this information to them. The nature of these CKD-specific discussions between patients and providers is a significant gap in the literature (Plantinga et al., 2010; Tiu et al., 2018).

Many patients with CKD are cared for in primary care settings until their CKD has progressed to advanced stages and requires specialty care. Therefore, PCPs are often the first point of contact for patients with or at risk for CKD and are critical to patient CKD awareness and self-management. Primary care is the most fair, efficient, and accessible way for all people to enter the health care system and obtain the services they need (Rittenhouse et al., 2023). More importantly, access to a PCP provides important health benefits, including earlier detection and treatment and better management of chronic conditions. This is particularly important for patients with and at risk for CKD as patients rely on providers’ expertise and knowledge to guide their self-management choices and treatment plans (Prieto, 2016). Thus, communication that occurs during the patient-provider clinical encounter is a crucial aspect to our understanding of the possible reasons for persistently low rates of CKD awareness. Prevention, early detection, and well-targeted interventions are cost-effective strategies that can help slow the progression of CKD and meet the current public health efforts to improve CKD awareness rates (Levey et al.,
However, these cannot be fully implemented by providers alone, patients must be active participants in their own care and collaborate with providers to self-manage their chronic illness (Claramita et al., 2020; Novak et al., 2013).

Patient-provider communication is hinged to patient CKD awareness and instrumental to reducing the risk for kidney failure. This study links patients’ awareness of CKD status to the providers that care for them through communication. Providers that routinely involve patients in treatments options, discuss the pros and cons of those options, and elicit patient preferences are described as having a shared or participatory decision-making communication style (PDM) (Kaplan et al., 1996). Investigating the influence of a PDM communication style on patient CKD awareness and risk for kidney failure will provide a better understanding of how to effectively communicate and purposefully engage patients in their care; it may also assist providers in facilitating CKD-specific discussions. The proposed study seeks to answer the following research questions: (1) What is the relationship between a PDM communication style and patient CKD awareness? and (2) Assuming that the optimal management of comorbid conditions mediates PDM communication style and a patient's risk of kidney failure, what is the relationship between a PDM communication style and patient’s risk for kidney failure?

This study is driven by the underlying assumptions of the shared decision-making model and an integrative review on CKD awareness and the social determinants of health inequities (Iroegbu et al., 2021). Findings from the integrative review revealed that socioeconomic status, education, race, and gender are consistently associated with patient CKD awareness. These findings served as a basis for this dissertation and a rationale to further investigate the role of provider communication in patient CKD awareness. The shared-decision making model
describes an environment where clinicians and patients use the best available evidence to make decisions together; it is considered the most important part of patient-centered care (Elwyn et al., 2010; Légaré et al., 2008; Novak et al., 2013). The ability of providers and patients to make these decisions is operationalized through communication. Providers exercising this practice are said to have a PDM style of communication.

Research Methods

This study uses secondary data analyses to perform a new study investigating the association between a provider using a PDM communication style and patient CKD awareness and 2-year calculated risk for kidney failure. Accurately predicting kidney failure is a cornerstone of optimal CKD care as it facilitates targeted treatment and better conveyance of risks to high-risk patients (Ali et al., 2021). This study uses the Kidney Failure Risk Equation (KFRE) to calculate participants, with a CKD diagnosis, 2-year risk for kidney failure. To date the KFRE is the most well-validated risk predictions tool that predicts a 2-year risk for progression to end stage kidney disease in patients with CKD (Ali et al., 2021).

Study design, Setting, and Participants

This is a retrospective, cross-sectional study that leverages data collected from a prior study focused on patient awareness of CKD. The parent study surveyed a convenience sample of patients with chronic illnesses receiving primary care within one clinic in the San Francisco Health Network (SFHN) between August of 2011 and August of 2012 (Tuot, et al., 2016). The SFHN is an integrated public health care delivery system for San Francisco’s uninsured and publicly insured residents. Patients were eligible for the parent study if they were ≥ 18 years of
age, had seen their PCP at least once in the previous two years, spoke English, Spanish or Cantonese, had a diagnosis of CKD, hypertension, diabetes or hyperlipidemia in their electronic medical record, and were deemed appropriate for study participation by their PCP. Exclusion criteria included patients who were not able to read or actively participate in a discussion with health care providers about their CKD. For this study, the sample population was restricted to patients who had complete laboratory data to define kidney disease and ascertain risk for kidney failure (measurement of serum creatinine and urine protein). Written consent was obtained from all eligible participants and all study participants were blinded to the purpose of the research study. The Committee on Human Research at the University of California, San Francisco approved this study.

**Measurements**

**PDM Communication Scale**

A participatory decision making (PDM) communication style is defined as routinely involving patients in treatment decisions by presenting options, eliciting patient preferences, and reaching a mutually agreed-on treatment plan (Kaplan et al., 1996). To measure a PDM style of communication in the parent study, two different instruments were used: the 3-item PDM scale developed by Kaplan et al. and a modified 4-item PDM scale used by researchers assessing PDM and physician communication in diabetes self-management (Heisler et al., 2002; Kaplan et al., 1995). Both PDM scales measure the propensity of providers to involve patients in treatment decisions; a higher PDM score is indicative of a provider having a more participatory communication style (Heisler et al., 2002; Hercz, 2017; Kaplan et al., 1996). The 3-item PDM scale questions are: 1) “If there were a choice between treatments, would this doctor ask you to
help make the decision? (definitely yes to definitely no);” 2) “How often does this doctor make an effort to give you some control over your treatment? (very often to never);” and 3) “How often does this doctor ask you to take some of the responsibility for your treatment? (very often to not at all).” The score for the 3-item PDM scale ranges from 0-12, with a higher score representing a more participatory communication style, alpha Cronbach for the 3-item PDM scale is 0.62 (Kaplan et al., 1996). The 4-item PDM scale asks respondents how often their provider: 1) offered them choices in their medical care; 2) discussed the pros and cons of each choice with them; 3) asked for them to state which choice or option they would prefer; 4) took their personal preferences into account when making treatment decisions. These questions are rated on a 5-point Likert scale from 0 (none of the time) to 4 (all of the time) for a total score ranging from 0-16, with a higher number representing a more participatory communication style, alpha Cronbach for the 4-item PDM score was 0.68 (Heisler et al., 2002. Each participant had two different PDM scores, corresponding to the different instruments.

**CKD Awareness**

CKD awareness served as the outcome variable in the parent study and was determined by written questionnaire. Individual awareness of CKD was determined in five different ways using the same question stem: “Have you ever been told by a doctor or health care provider that you have…?” (1) weak or failing kidneys (excluding kidney stones, bladder infections or incontinence)” (2) “kidney disease”, (3) “protein in the urine” or (4) “a kidney problem” and (5) “kidney damage”. A patient was considered aware of their CKD status if they correctly answered any of these questions and a CKD diagnosis was confirmed using the electronic medical record as the gold standard (Tuot, et al., 2016). Awareness of CKD status was thus a
binary/dichotomous outcome (aware or not aware). Only patients with a diagnosis with CKD were included in the CKD awareness analyses.

**Risk for Kidney Failure**

The Kidney Failure Risk Equation (KFRE) is a validated equation that predicts the 2- and 5-year risk of kidney failure for a patient with CKD stages 3-5 using 4 variables: albuminuria, sex, age and GFR (Ali et al., 2021). We calculated patients’ 2-year risk for kidney failure using self-reported age and sex and GFR and albuminuria ascertained from the electronic medical record. GFR was estimated from serum creatinine using the 2009 CKD-EPI equation (Levey et al., 2009). Spot urine albumin-to-creatinine ratios (UACR) were used for albuminuria. For patients that were missing UACR, a predicted UACR was calculated using urine protein dipstick values and corresponding to ACR values as described in the empirically developed equation by Sumida and colleagues (Sumida et al., 2021). The 5-year risk for kidney failure was not calculated due to the prevalence of patients with early-stage CKD in this population.

**Demographics**

Self-reported demographic variables included age in years, gender (male or female), race/ethnicity (non-Hispanic white, Hispanic, Black, Asian and other), primary language (English, Spanish, or Cantonese), and educational attainment (did not attend, primary school, high school and college). Health literacy scores were calculated using two validated instruments, the single-item literacy screening (SILS) and Short Test of Functional Health Literacy in Adults (s-TOFHLA) screening questionnaire (Chew et al., 2008; Morris et al., 2006). Health literacy was determined by a score ≥ 6 out of a maximal score of 12 (Tuut, et al., 2016). Participants that
received a score of 6 or greater were considered to have limited or inadequate health literacy. Participants with a score less than 6 were considered to have adequate health literacy (Chew et al., 2008). For participants completing the s-TOFHLA screening questions, scores ranged from 0 to 100 and are categorized into inadequate (0-53), marginal (54-66) and adequate (67-100) (Chew et al., 2008). Other variables included the type of health insurance (Medi-Cal, Medicare, or none) and the number of times they visited their primary care provider in the past year.

**Data Analysis**

**Statistical Methods**

Descriptive statistics were conducted to describe the age, gender, race, level of education, primary language, health insurance, comorbidities (hypertension and diabetes), health literacy, and laboratory values of the sample population (see Table 1). To examine the strength and direction of the association between reported PDM score (continuous independent variable) and patient correct awareness of CKD status, logistic regression was used. The association between a reported PDM communication score and patients 2-year risk for kidney failure was examined using linear regression, with PDM score serving as a continuous independent variable and patient’s 2-year KFRE score serving as the continuous dependent variable. This was under the assumption that a more participatory communication style may lead to better patient self-management of comorbid conditions which in turn may result in a lower risk for kidney failure. All models were adjusted for age and sex. Analyses were performed using IBM SPSS statistical software.
Results

Study Population

Of the 81 participants, the mean participant study age was 56 years (range: 27-91 years) and 44.4% (n = 36) were females. The study population was racially/ethnically diverse: African Americans accounted for 40.7% (n=33), Caucasians accounted for 24.7% (n=20), Filipinos 3.7% (n=3), Chinese 3.7% (n=3), and Other Asian 2.5%, Over 50% (n=41) of the population reported English as their primary language, 12.3% (n=10) reported Spanish and 37% (n=30) reported other as their primary language. 69% (n=59) of the sample population had Medi-Cal for their insurance coverage, 22% (n=18) did not have insurance coverage, 3% (n=3) had Medicare, and 2.5% (n=2) had some other health insurance. 67.53% (n=52) of the population had adequate health literacy and 31% (n=24) had inadequate health literacy. A total of 34 (42%) participants had CKD and 47 (58%) participants did not have CKD (N = 81). A total of 76 participants that completed the PDM questionnaire were included in regression analyses. Regression analyses between PDM and KFRE, only included participants with a diagnosis of CKD.

Table 1. Patient Characteristics for Quantitative Study (N=81)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Mean (SD)</td>
<td>55.9 (11.4)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45 (55.6%)</td>
</tr>
<tr>
<td>Female</td>
<td>36 (44.4%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Caucasian or White</td>
<td>20 (24.7%)</td>
</tr>
<tr>
<td>African American or Black</td>
<td>33 (40.7%)</td>
</tr>
<tr>
<td>Chinese</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>Filipino</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>Other Asian</td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (16%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>7 (8.6%)</td>
</tr>
<tr>
<td>----------------------</td>
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</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>Primary School (finished around age 12)</td>
<td>17 (21%)</td>
</tr>
<tr>
<td>Secondary School (finished around age 18)</td>
<td>23 (28.4%)</td>
</tr>
<tr>
<td>Some College</td>
<td>20 (24.7%)</td>
</tr>
<tr>
<td>Finished College</td>
<td>15 (18.5%)</td>
</tr>
<tr>
<td>Attended and/or finished graduate school</td>
<td>4 (4.9%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td><strong>Primary Language</strong></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>41 (50.6%)</td>
</tr>
<tr>
<td>Spanish</td>
<td>10 (12.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>30 (37%)</td>
</tr>
<tr>
<td><strong>Health Insurance</strong></td>
<td></td>
</tr>
<tr>
<td>Medi-Cal</td>
<td>58 (71.6%)</td>
</tr>
<tr>
<td>Medicare</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>None</td>
<td>18 (22.2%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td><strong>Health Literacy</strong></td>
<td></td>
</tr>
<tr>
<td>Adequate</td>
<td>52 (67.53%)</td>
</tr>
<tr>
<td>Marginal</td>
<td>1 (1.3%)</td>
</tr>
<tr>
<td>Inadequate</td>
<td>24 (31.17%)</td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td>4 (5.19%)</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24 (29.6%)</td>
</tr>
<tr>
<td>No</td>
<td>57 (70.4%)</td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>75 (92.6%)</td>
</tr>
<tr>
<td>No</td>
<td>6 (7.4%)</td>
</tr>
<tr>
<td><strong>GFR</strong></td>
<td></td>
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<tr>
<td>Mean (SD): 72.47 (27.72)</td>
<td></td>
</tr>
<tr>
<td>Range: 8 - 119</td>
<td></td>
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<tr>
<td><strong>Creatinine</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD): 1.19 (0.71)</td>
<td></td>
</tr>
<tr>
<td>Range: 0.46 - 5.63</td>
<td></td>
</tr>
<tr>
<td>Participants with abnormal presence of proteinuria via dipstick or UACR</td>
<td>48 (62.33%)</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Missing</td>
<td>4 (5.19%)</td>
</tr>
</tbody>
</table>

**Association of PDM Score and Patient CKD Awareness**

**Three Item PDM Scale**

The study population only included participants that completed all questions for the 3-item (n=76) and 4-item PDM scales (n=75). To credit providers for correctly focusing on other aspects of care for participants without CKD, participants who were correctly answered being unaware of their CKD, of which they did not have, were also included in this population. Among those with a diagnosis of CKD that answered CKD awareness questions, 61.8% (n = 21) were aware and 38.2% (n = 13) were unaware of their diagnosis. The average 3-item PDM score was 8.26 (range: 0-12) and the average reported 4-item PDM score was 12.3 (Range: 0-16). Gender in the model is coded as follows: 0 = female and 1 = male. Logistic regression results revealed that on average when the 3-item PDM score increases by 1 unit, the odds of being correctly aware of CKD status increased by a factor of 1.033 CI [0.830-1.288]. This was not statistically significant. The odds of being aware of CKD are 3.762 CI [0.832-17.009] times higher among males as compared to females. This was also not significant. However, age (p-value 0.039) was a significant predictor of patient awareness of CKD status. For every one unit increase in age the odds of a patient being aware of their CKD status decrease by 0.064 units CI [0.884-0.997] while holding all other variables in the model constant. 12.8% of the variation in patient CKD awareness is explained by age and gender.
Four Item PDM Scale

For every one unit increase in 4-item PDM score the odds of being correctly aware of CKD status decreased by a factor of 0.897 CI [0.742-1.085]. This was not statistically significant. The odds of being aware of CKD were 2.022 times CI [0.467-8.749] higher among males as compared to females. This was not significant. Age (p-value 0.039) was a significant predictor of patient awareness of CKD status in this model. For every one unit increase in age the odds of a patient being aware of their CKD status decrease by 0.064 units CI [0.853-0.971] while holding all other variables in the model constant. 15.9% of the variation in patient awareness of CKD status is explained by age and gender.

**Table 2: PDM Score and Patient CKD Awareness (Logistic Regression Analyses)**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Model 1</th>
<th></th>
<th></th>
<th>Model 2</th>
<th>Beta Coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>aOR (95% CI)</td>
<td>Beta Coefficient</td>
<td>p-value</td>
<td>aOR (95% CI)</td>
<td>Beta Coefficient</td>
<td>p-value</td>
</tr>
<tr>
<td>Age</td>
<td>0.938 (0.884 – 0.997)</td>
<td>-0.064</td>
<td>0.039</td>
<td>0.910 (0.853 – 0.971)</td>
<td>-0.094</td>
<td>0.004</td>
</tr>
<tr>
<td>Male</td>
<td>3.762 (0.832 – 17.009)</td>
<td>1.325</td>
<td>0.085</td>
<td>2.022 (0.467 – 8.749)</td>
<td>0.704</td>
<td>0.346</td>
</tr>
<tr>
<td>3-item PDM Score</td>
<td>1.033 (0.830 – 1.288)</td>
<td>0.033</td>
<td>0.769</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-item PDM Score</td>
<td></td>
<td></td>
<td></td>
<td>0.897 (0.742 – 1.085)</td>
<td>-0.109</td>
<td>0.262</td>
</tr>
</tbody>
</table>

*Note: Model 1 references the 3-item PDM scale (N=76), Model 2 references the 4-item PDM scale (N=75). CI, confidence interval, aOR, adjusted odds ratio.*
Association of PDM Score and 2-year Risk for Kidney Failure (KFRE)

The mean KFRE score was 2.0% with a range from 0%-74%. Adjusting for age and gender, for each 1 unit increase in 3-item PDM score the average expected increase in risk for kidney failure decreased by 0.017 percentage points. The relationship between reported 3-item PDM scores and patients at 2-year risk for kidney failure is not statistically significant. Only 0.2% of variation in 3-item PDM score is explained by patients calculated 2-year risk for kidney failure (KFRE). For each 1 unit increase in 4-item PDM score the average expected increase in risk for kidney failure decreases by 0.016 percentage points. The relationship between reported 4-item PDM scores and patients at 2-year risk for kidney failure is not statistically significant. Only 0.1% of variation in 4-item PDM score is explained by patients calculated 2-year risk for kidney failure (KFRE).

Table 3: PDM Score and Patient’s 2-year Risk for Kidney Failure (Linear Regression Analyses)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Model 1</th>
<th></th>
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<th>Model 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Beta</td>
<td>Std. Error</td>
<td>t</td>
<td>p-value</td>
<td>Beta</td>
<td>Std. Error</td>
</tr>
<tr>
<td>(Constant)</td>
<td>4.007</td>
<td>6.873</td>
<td>0.583</td>
<td>0.562</td>
<td>4.112</td>
<td>6.820</td>
</tr>
<tr>
<td>Age</td>
<td>0.019</td>
<td>0.083</td>
<td>0.229</td>
<td>0.820</td>
<td>0.022</td>
<td>0.079</td>
</tr>
<tr>
<td>Male</td>
<td>-3.190</td>
<td>2.216</td>
<td>-1.440</td>
<td>0.155</td>
<td>-3.229</td>
<td>2.189</td>
</tr>
<tr>
<td>3-item PDM Score</td>
<td>-0.158</td>
<td>0.358</td>
<td>-0.441</td>
<td>0.660</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-item PDM Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.126</td>
<td>0.290</td>
</tr>
</tbody>
</table>

Model 1 references the 3-item PDM scale (N=76), Model references the 4-item PDM scale.
Discussion

In this secondary data analysis, we observed no significant relationship between provider communication style and patient CKD awareness or calculated 2-year risk for kidney failure (KFRE), although age was a significant predictor. This suggests that there may be other factors that could be influencing patient's awareness of CKD. Though, it is important to note that the 2-year average risk for kidney failure in this population was approximately 2%, which is quite low. These findings may suggest that providers are not communicating a CKD diagnosis to patients with such a low risk for kidney failure. This is consistent with prior studies that also found CKD awareness in older adults to be low (Chu et al., 2020; Giannelli et al., 2007). It may be argued that older patients are more likely to have a near normal creatinine, despite a reduced eGFR, so their CKD may go unnoticed by providers (Saunders et al., 2015). This would suggest that providers may be relying solely on creatinine as a measure of renal function and missing an opportunity to slow the progression of kidney disease (Giannelli et al., 2007). It is important for provider’s to accurately assess kidney function in older adults, especially given the asymptomatic nature of CKD and the natural progressive decline in renal function with age (Giannelli et al., 2007). Doing so may allow providers to introduce effective and appropriate treatments to help patients self-mange and slow the progression of CKD.

Even with appropriate recognition of CKD, Chu et al., (2020)have suggested that providers may have a higher threshold for disclosure of mild CKD in older adults. This may stem from the controversy concerning the distinction between loss of kidney function due to disease versus a normal part of aging, which may also speak to the lower likelihood of CKD awareness among older adults in this study (Wonnacott et al., 2012). Providers have reported that labeling
or disclosing a CKD diagnosis to older adults, may lead to undue anxiety and stigma for patients who may otherwise be well (Abdi et al., 2012; Chu et al., 2020.; Smekal et al., 2019). Other studies suggest that current guidelines may be over diagnosing CKD in older adults and suggest adopting a lower eGFR threshold for older adults to account for the normal aging process (O’Hare et al., 2021). Those of this view argue that labeling older adults with mild to moderate CKD exposes them to the potential harm of unnecessary medical tests, procedures, and treatments, while offering nothing in return. A study by Liu et al demonstrated that lowering the eGFR threshold for defining CKD in older adults did not have a meaningfully higher risk of death or kidney failure(O’Hare et al., 2021). Future research should continue to investigate the best approach to detecting, diagnosing, managing, and communicating about CKD in older adults.

Findings from this study may also suggest a shift from our hypothesis of provider communication style being influential on patient CKD awareness and risk for kidney failure toward other provider, patient, and community level factors that directly and indirectly influence patient CKD awareness. Plantinga et al (2010) urge researchers to be conscious and considerate of the interrelationships between patients, providers and the community when measuring and evaluating patient CKD awareness. Patient-level factors that have been suggested to influence patient CKD awareness include having comorbidities, a family history of CKD, and increased severity of CKD (Plantinga et al., 2008). Provider-level factors that are suggested to indirectly influence patient CKD awareness are recognition of patients CKD risk factors, practice characteristics (internists vs family practitioners, number of years in practice), and knowledge
surrounding patient counseling and management of CKD (Plantinga et al., 2008, 2010; Tiu et al., 2018).

This study is the first of its kind to investigate whether a participatory communication style being associated with CKD awareness and patient risk for kidney failure. While the findings from this study did not find an association between PDM score and CKD awareness or risk for kidney failure, we did find an association between age and patient CKD awareness. Given that the only relevant factors for CKD awareness in this study were at the patient/individual level, future research should explore other patient-level factors that contribute to CKD awareness. Findings from this study can provide preliminary data for hypothesis generation for future studies, particularly as it pertains to logistics and study design (Hayat, 2013). Lastly, we note differences in the associations between CKD awareness and the 4-item and 3-item PDM scores. In the logistic regression models for CKD awareness, an increase in 3-item PDM score was associated with a decrease in odds of CKD awareness. The association between CKD awareness and the 4-item PDM scale was in the opposite direction. While neither association was statistically significant, it is unclear which PDM scale is the better measure for communication style regarding CKD. Future research should consider exploring better tools to measure PDM or development of a new PDM scale; a CKD-specific PDM scale may also be helpful in examining this phenomenon.

Limitations

Limitations to this study include the relatively small sample size, the age of the data, and the skewed number of participants with a significantly low 2-year risk for kidney failure thereby limiting the ability to generalize study findings and risk of a type 2 error (not finding an
association when one exists). Additionally, these results are based on a single health care system which may limit generalizability to other settings. Replication of this study with a larger sample of patients from different geographical locations may yield different results. Missing data needed to calculate the KFRE led to the need to manually calculate an estimate of the urine proteinuria (uACR) for some patients which may have impacted the predicted KFRE scores. However, the conversion calculation used has been shown to be valid and effective with uACR calculations (Ali et al., 2021). Most importantly this study is cross-sectional and thus can only suggest associations and not causality.

Conclusion

In conclusion, through secondary data analyses we found a significant relationship between age and patient CKD awareness, however the relationship between a provider’s use of a participatory communication style and patient CKD awareness and risk for kidney failure was not statistically significant. While provider communication does play a role in patient CKD awareness, the style of communication a provider uses may not be influential. Acknowledging sample size limitations of this study, future research may explore other provider level factors that are influential on patient CKD awareness.
CHAPTER 4: PATIENT EXPERIENCES COMMUNICATING WITH PROVIDERS ABOUT THEIR CHRONIC KIDNEY DISEASE AND ITS INFLUENCE ON THEIR SELF-MANAGEMENT

Introduction

Chronic kidney disease (CKD) is a condition in which the kidneys progressively fail over time. It is identified and defined by the presence of abnormalities in the structure or function of the kidney for at least 3 months. The degree of renal dysfunction is classified in accordance with the Kidney Disease Improving Global Outcomes (KDIGO) organization staging system. CKD stage 1 is classified normal, whereas CKD stage 2-3a are classified as mildly decreased kidney function, Stage 3b is classified as moderately decreased kidney function, stage 4 is classified a severely decreased kidney function, and stage 5 is kidney failure (Fraser & Blakeman, 2016). CKD is often asymptomatic in its early stages, making early detection important to slowing the progression and reducing future risk (Fraser & Blakeman, 2016). CKD left untreated may lead to kidney failure or end stage kidney disease (ESKD); an irreversible condition only treatable with dialysis or kidney transplant (CDC, 2019, Nagib et al., 2021). The prevalence of CKD is expected to increase due to aging and the rising incidence of hypertension and diabetes (Van Dipten et al., 2018). Diabetes and hypertension are the two leading causes of kidney disease and the self-management of these two conditions in combination with lifestyle changes are important to slowing the progression of CKD (Van Dipten et al., 2018; Vassalotti et al., 2016). However, this heavily relies on patients and providers having meaningful conversations to make patients aware of their diagnosis and disease process, as well as the patient’s willingness to make lifestyle changes. It has been stated that patient-provider
communication is crucial to patients in learning self-management skills, but little research has been done to examine this phenomenon from the patient’s perspective in the context of CKD (Peltola et al., 2018). Caring for patients with CKD is complex and requires that a provider not only understand CKD guidelines and management but can communicate this information in a way that patients understand.

Collaboration and shared decision making between providers and patients are also important to self-management (Novak et al., 2013). Collaboration between patients and providers fosters a patient centered environment that enhances patient-provider communication and enables self-management. A systematic review on patient-provider communication preventing the progression of ESKD in primary care revealed a significant lack in valuable communication practices among providers as well as a great need for new communication techniques (Prieto, 2016). Investigating the way providers communicate and engage patients in critical CKD-specific conversations is essential to addressing the rising CKD crisis in the United States. However, our knowledge of how these conversations emerge, the details discussed during the clinical encounter and the patient’s experience being self-managers of their CKD is limited.

Materials and Methods

Study Design, Setting and Context

The aim of this study was to gain a deeper understanding of how patients with CKD describe communicating with their provider and if their communication had any influence on their self-management. This study also provides further context to the findings in paper 2 on the influence of provider communication style on patient’s risk for kidney failure. The research questions asked were: (1) “How do patients diagnosed with CKD describe communicating with
their health care provider about their CKD? and (2) how do they perceive their provider’s communication to influence their self-management?” Given the limited amount of research examining this phenomenon, a qualitative descriptive study design was employed using semi-structured individual interviews. Patients with a diagnosis of CKD and under the care of a primary care provider and/or nephrologist were asked to participate in individual interviews. Individual interviews took place either virtually via computer or phone, as decided by the preference of the participant.

**Participants**

IRB approval was obtained from the University of Pennsylvania to conduct this study and prior to participant recruitment. Written and verbal informed consent was obtained and reaffirmed throughout the interview process from study participants. Study participants were informed that the data they provided would be used for research purposes. The overall goals of this research study were communicated to all participants, as well as a description of the data collection procedures, and the expected time commitment at each point of contact. The benefits of participation in this research study were also conveyed and participants were assured that their privacy would be protected, that participation was strictly voluntary, and they had the right to withdraw from the study at will. Additionally, in the event of questions, comments or complaints, participants were provided contact information of whom they should contact. To protect the anonymity of participants, each participant was asked to provide a fictitious name to safeguard their identity. All data from participants was maintained in a locked file with restricted access to individuals only on a need-to-know basis.
Sampling

Participants were recruited from all areas throughout the United States via flyer, social media advertising, Research Match, emails, snowballing, and purposeful sampling in nephrology clinics. Participants were eligible if they met the following criteria: a) had a diagnosis of CKD as reported by the participant, b) had been seen by a primary care provider or nephrologist that had communicated the CKD diagnosis, c) were ≥18 years of age, d) able to communicate in English and e) had an established continuity of care with either a PCP or nephrologist over the last year. Patients were ineligible if they were on dialysis or did not have a reported diagnosis of CKD. A total of 51 individuals completed the screening survey but only 15 were eligible and three failed to respond to the primary investigator’s attempts to schedule an interview. As is consistent with qualitative descriptive studies, sampling continued until informational redundancy was achieved (Sandelowski, 1995). A total of twelve individual interviews were conducted.

Data Collection

Qualitative descriptive studies are founded in existing knowledge and careful linkages to the work of others in the field and clinical experience of the researcher. This approach offers a rich but honest description of an experience or event as the researcher is interested in the who, what, where and why of the experience (Neergaard et al., 2009). Therefore, data collection typically occurs through minimally to moderately structured individual interviews or focus groups (Sandelowski, 2000). For this study, individual semi-structured interviews were conducted by the primary investigator. All interviews were conducted in a virtual format on the Zoom platform with and without video. The audio of interviews was saved and uploaded to a secure cloud box accessible only to the primary investigator. The primary investigator verbally
re-consented each participant to ensure they were willing to participate in the interview.

Participants were also asked to answer brief demographic questions at the end of the interview.

Interviews lasted between 30 and 60 minutes and participants were asked to describe how they learned about their kidney disease, to describe elements of communicating with their provider and the influence these conversations have had on the self-management of their CKD. Participants were also queried about the role their sociodemographic factors, such as race, ethnicity or level of education, in how they communicated with their provider. Questions were closed and open-ended to elicit each participant’s experience, views, and reflections and probing was used to provide clarity on any aspects unclear to the primary investigator (See Appendix A). At the end of each interview participants were asked demographic questions including age, race, type of medical insurance, and level of education.

**Data analysis**

Analysis techniques typically used in qualitative descriptive studies are qualitative content analysis and thematic analysis methods (Sandelowski, 2010; Vaismoradi et al., 2013). For this study, the thematic analysis method was used to analyze individual interviews and elucidate themes (Vaismoradi et al., 2013). Thematic analysis is flexible and provides a rich, detailed, and complex account of the data; it is best used when the researcher wants to discover the actual behavior, attitudes, or real motives of participants, or to detect what has happened (Vaismoradi et al., 2013). A key characteristic of thematic analysis is the systematic process used to code, examine meaning, and provide a description of the social reality through the creation of a theme (Braun & Clarke, 2006; Vaismoradi et al., 2013, 2016).
The researcher used Zoom and Datagain transcription service to transcribe interview transcripts. The researcher then validated transcripts for accuracy with the audio recording. Next, the researcher read and re-read transcripts to become familiar with the data while simultaneously writing memos of initial ideas. The thematic analysis process began with the researcher reading transcripts line by line and highlighting meaningful words and phrases, identifying pertinent abstractions about communication of participants accounts, and writing reflective notes and initial ideas (Vaismoradi et al., 2016). Next, the researcher began developing initial codes by identifying interesting features systematically across the data set. The researcher then organized and compared codes, by identifying similarities and differences allowing codes to be grouped into larger categories of meaning that could possibly serve as potential themes (Braun & Clarke, 2006; Vaismoradi et al., 2016). After collating codes into potential themes, the researcher then collaborated with the Mixed Methods Research lab to review, refine and check if the themes aligned with coded extracts. This resulted in a thematic matrix that was then used to begin defining and naming themes. The process of defining themes included ongoing analysis and refining of the specifics of each theme and referring back to memos and transcripts to craft the overall story that the analysis sought to tell (Vaismoradi et al., 2013). These themes were then reviewed by a dissertation committee member for further refinement and to confirm that there was enough supporting data, if themes could be collapsed into one or needed to be broken down into two separate themes, and that the themes were a valid and an accurate reflection of the entire dataset (Braun & Clarke, 2006). This process is demonstrative of an inductive approach where themes are derived directly from the text data (Braun & Clarke, 2006; Vaismoradi et al., 2013).
The researcher did “distance” themself from the data for a period of time, as part of the rectification phase, to reappraise the analysis process. This is done to increase the researcher’s sensitivity and reduce any premature and incomplete data analysis (Vaismoradi et al., 2016). Lastly, the researcher ended with producing this report of the findings by constructing a concise, coherent, logical, and interesting story of the data within and across themes (Braun & Clarke, 2006).

**Rigor**

Trustworthiness and credibility were achieved in the data collection, sampling, analysis, and reporting phases. Since an inductive approach to analysis was used, data collection through individual interviews was as unstructured as possible to ensure the researcher was not biasing the participants answers (Elo et al., 2014). To ensure trustworthiness, the participant sample is comprised of participants that best represent and have the knowledge of CKD-specific conversations by using a purposive sampling strategy as described above. Credibility was established by ensuring the participants were described as accurately as possible (Elo et al., 2014). Methodological rigor, credibility, and conformability was maintained through a clear audit trail, peer debriefing, member checking and ensuring the data accurately represented the information that the participants provided, and the interpretation of those data were not devised by the researcher (Elo et al., 2014; Vaismoradi et al., 2013, 2016). Lastly to ensure trustworthiness of results, the use of quotations from the transcribed text is used and linked to each main concept (Elo et al., 2014).
Results

Demographics

Participants’ characteristics are summarized in Table 4. The median age for participants was 62.5 years and 66.66% (n=8) of participants were women. Participants self-identified as Caucasian (n=8), Black (n=3) and Biracial (n=1). Most participants were well educated with 66.66% (n=8) reporting educational attainment beyond a bachelor’s degree. There was a mixture of CKD etiology ranging from hypertension, hereditary or congenital conditions (i.e. polycystic kidney disease, ureteral reflux), autoimmune disease (i.e. lupus) and unknown etiology.

Table 4. Patient Characteristics for Qualitative Study (n=12)

<table>
<thead>
<tr>
<th>Variable</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Median (range)</td>
<td>62.5 (35-81)</td>
</tr>
<tr>
<td><strong>Gender N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (66.66%)</td>
</tr>
<tr>
<td><strong>Race N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>8 (66.66%)</td>
</tr>
<tr>
<td>Black</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>Biracial</td>
<td>1 (8.33%)</td>
</tr>
<tr>
<td><strong>Level of Education N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>1 (8.33%)</td>
</tr>
<tr>
<td>Associate degree</td>
<td>1 (8.33%)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>2 (16.66%)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>4 (33.33%)</td>
</tr>
<tr>
<td>Doctorate Degree</td>
<td>4 (33.33%)</td>
</tr>
<tr>
<td><strong>CKD etiology n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Hereditary/Genetic/Congenital</td>
<td>2 (16.66%)</td>
</tr>
<tr>
<td>Autoimmune Disease</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>1 (8.33%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2 (16.66%)</td>
</tr>
<tr>
<td>Unknown Etiology</td>
<td>4 (33.33%)</td>
</tr>
</tbody>
</table>
Themes

*A CKD Communication Playbook for Patients and Providers* was uncovered as the central theme unifying the patient’s experiences *building a relationship with the provider,* *preparing for the clinic visit,* and *taking charge of your health* (See Table 5). Participants described their experience communicating with providers about their CKD and the value they found in building and having a relationship with their provider. Additionally, to help facilitate communication with their providers during the clinic visit, participants described how they prepared for their appointments and when it came to self-management, participants describe their self-directed approach of how they decided to take charge of their health and seek out information on their own. When reporting findings, the source of each quote is identified by the participant’s pseudonym in parentheses.

A CKD Communication Playbook for Patients and Providers

A CKD Communication Playbook is a step-by-step plan of what navigating CKD is like for the patient and how patients and providers can work together to build a relationship that fosters an environment for interpersonal communication and empowers patients to take charge of their health. It would ideally include a description of the natural progression of CKD, how to slow down the progression and the best ways for providers to communicate with patients about their new diagnosis. This overarching theme was derived from the participant’s desire to receive more information from their provider about their CKD. Participants expressed a desire to learn about their CKD diagnosis early, often reflecting on the shock of receiving their CKD diagnosis...
without any warning. Because of this, participants describe wanting to know a step-by-step plan of care and specific details on how to be proactive in managing the progression of their CKD. Participants also spoke of learning about the cause of their diagnosis and the function and anatomy of the kidney to help them understand its importance. While receiving a CKD diagnosis may be overwhelming, participants still wanted information about CKD management and progression. Participants expressed an appreciation for their provider communicating the latest information, setting clear goals for the patients, and providing educational brochures or videos to help the patient learn more about their CKD.

“I hate to put anything more on providers plates, because I know, as time goes on with insurance they have less time and and everything. But I mean even just a brochure about nutrition when you're you, you know, when you have kidney disease and you know, or if you're on on dialysis, or what it is just something that somebody can take in their hands and take home and look at to kind of make them think about, you know, because the it's a lot of information when you're new to being sick. It it's so overwhelming you can't remember everything so even if they don't have time to talk about nutrition refer to a nutritionist, get a pamphlet something that's the biggest thing that I can say.”

(Participant Charlie)

“There should be a playbook, I mean, it sounds very boring. A doctor should say: Here we are, Miss. Do this. Here we are Matt, do that. We're not dealing with something that is necessarily resolvable, but you can slow down radically the illness”. And that is a very big expense to society, right?.... If you look at breast cancer, for example. how much better we've got at both diagnosing, treating, and resolving. If you look at even issues like knees and hips right there are clear prescriptive playbooks. There should be a prescriptive playbook for this”. (Participant Kizmet)

Building a Relationship with the Provider

The patient provider relationship is intricately connected to the communication that occurs between providers and patients. Participants understood this and described ways in which they built a relationship with their provider. These relationships helped foster an environment
where communication between both parties was easy, open, and free flowing, and participants described it as ‘friendly’, ‘rational’ and ‘comfortable’. There were different ways participants went about building a relationship with their providers and other ways that providers fostered that relationship. For both parties this was mainly through asking questions, expressing compassion, getting to know the other party outside of their ‘patient’ or ‘provider’ roles, and acknowledging the patients concerns in a respectful manner.

“\textit{Oh, he was wonderful! So, my partner was from London, and my nephrologist was from Scotland. So, you know, when we, when my partner would go with me to appointments. You know the two of them would start talking about. You know some of their history. It was it wasn't a very strict, you know, doctor-patient relationship. It was much more relaxed, and once my life partner died. it, you know it continued. We just had an easy relationship. It wasn't that boundaries were crossed. It was just that his style of communication was comfortable.}” (Participant Gabby)

“\textit{…Sometimes I ask kind of more personal questions to kind of get to know them, and with him it was he plays the violin. And so I brought in my violin. I I was given a violin. I don't know how to use it. One of the things broke, and so he restrung my violin for me. Yeah. So I mean, like he was a cool guy.}” (Participant Charlie)

**Preparing for the Clinic Visit**

Limited time is an ongoing issue for providers in the clinical setting. Participants acknowledged this is a barrier to communication and getting the answers to questions they had concerning their CKD. In an effort to get their questions answered and maximize their appointment time, participants describe preparing for their clinic visits in advance; some participants even described it as ‘studying’ before their appointment. Other participants view being prepared for their appointments with questions as a way of helping providers help them.
“I do my best to ask questions. Now I can access my labs and everything my results online. So, if I have a question about something that's high or low or whatever. Then I will, you know, ask about that like kind of being prepared for my appointments. I feel like that helps them take better care of me, you know. And then yeah, that's what I mean by that. Just just being aware of what's happening. And if I have questions asking, what what is this all about?” (Participant Charlie)

“….Of course but that again is planning. You know. It's like. I knew what my questions were when I went there and then he also worked with me on that, too. We got the stuff done immediately and out of the way, you know the going over the charts and everything, and then I I always had my questions ready before I got there.” (Participant B)

“Well, I think that it's really important, to ask questions. Ask what you don't know. Take your notebook in there and ask the questions, and if you don't feel like you're getting the answers, then then see if you're able to seek the person that's going to give you the answers” (Participant Kizmet)

Taking Charge of Your Health

Participants were asked how their providers communication style influenced their self-management. While some participants did receive some guidance on aspects of self-management, most participants report taking charge of their own health and self-directing their own management of CKD. Participants report leaning on their peers that had experienced chronic illness, joining online support groups and communities for kidney disease and reading books. The most common self-management strategy participants reported related to diet.

Although most participants sought this information on their own, they wished their provider would have communicated this information to them.

“So, he left a lot of it to me, and I really took took it by the reigns. I had a friend at the time who had a chronic condition. She had Crohn's disease, so she's the kind that would jump on things because she's familiar with what it's like to live with the chronic disease. So, she bought this cookbook called Cooking with David, and it was about a woman who cooked for her husband that had kidney disease, and how they changed their diet to turn things around. We bought, we bought the right foods, I ate the right things, I mean I I drank the right amount of water, and it's--just cleaned up my diet, majorly. It was like, oh, overhaul.” (Participant 01)
“And one thing that was valuable was a community of patients with kidney disease discussing it.”
(Gabby transcript, Pos. 116)

“...I found another group. It was more intimate, people who look like me. The person who ran the group, you could tell she was very, she was a very hard worker. She believed in what she was doing. She cared about what she was doing, but she's no longer here now. She passed away. But the whole energy of the group, it was knowledgeable based. She was making sure that you learn something when you were in the group, and they were trying their best to get the group I guess more exposure in terms of I guess others who may have the disease that this is where you could come to. I really enjoyed the vibe of the group.” (Participant Ms PJ)

When asked if their providers communication style had any impact on how they managed their CKD. Participant Mae responded:

“Not really I I kind of took that on myself....you won't believe this. I went to him, and I said, you know, I said, do you have any any books that that would be helpful to me that I could read or do you have any suggestions as far as diet is concerned, and he goes. No. no, he goes. Why would you? Why would you care about that, anyways? He said. Just wait until you get worse.” (Participant Mae)

Table 5. Definitions of Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>The CKD Communication Playbook for Patients and Providers</td>
<td>This is the central unifying theme of participants’ description of their experiences communicating with provider. It includes descriptions of what their ideal experience looks like and the type of information they would like to receive from providers.</td>
</tr>
<tr>
<td>Building a Relationship with the Provider</td>
<td>Building a relationship describes how participants approach building a relationship with providers that results in comfortable and open communication for the patient. Participants description of ways in which they established rapport with their providers.</td>
</tr>
<tr>
<td>Preparing for the Clinic Visit</td>
<td>Preparing for the clinic visit includes descriptions of how being prepared with questions for their provider in advance and reviewing lab results before their clinic visits supported their communication with their provider. Being prepared allowed participants to get the most out of their office visit and all their questions or concerns addressed.</td>
</tr>
</tbody>
</table>
Taking Charge of My Health

Includes references to how patients self-directed the management of their kidney disease and other chronic illnesses based on patient research, personal networks, online support groups and reading literature on CKD dietary management,

Discussion

Findings from these interviews suggest that patients were able to self-fulfill their desire for information about self-management from their providers, hence taking charge of their health. The participants openly and candidly described their experiences having CKD-specific discussions with their providers and how it related to their self-management of their CKD. Many participants report that while they did receive their CKD diagnosis from their providers, very little information about how to manage their CKD and future plans of care were discussed. This may support the findings from paper 2 of this dissertation where it can be interpreted that communication style isn’t as influential on awareness but may play a role when communicating with patients about their plan of care. Participants descriptions of provider’s communication style as is related to their communication, seemed to be important to building a relationship with the provider and communicating a step-by-step plan for CKD management. Because many providers did not provide participants with self-management strategies, participants in the sample took the initiative to retrieve information independently through online communities, support groups and reading. This self-directed behavior should be interpreted with caution as this may reflect the sample population of which most participants were college educated. Vulnerable and marginalized populations that may not be as educated and really depend on their provider for
self-management instructions may not be able to or know how to access online resources as easily as these participants.

Participants described how they built a relationship with their provider and what that looked and felt like to them. The relationships with their provider also supported their communication, making it feel more comfortable and easier to communicate with their providers during clinical visits. The patient-provider relationship has long been associated with and influential on patient provider communication as seen in paper 1, the literature review on the influence of patient provider communication on patient self-management, the theme *adaptive interpersonal communication* aligns with participants’ descriptions in this study. Interpersonal communication is defined as communication where two participants create verbal and nonverbal communication messages to generate shared meanings and accomplish situation-and relationship-related goals. This, it is not just communicating with another party, but entails addressing each other as unique human beings and acknowledging their personal and professional identities. This is supported by the findings in this study and participants descriptions of how they build relationships with their provider. Future research should investigate if this communication style is associated with patient CKD self-management specifically.

Many of participants’ experiences navigating their chronic illness led to them joining online communities, support groups, using personal relationships, and books to help them take charge of their health. Given that limited time and resources may impede on the providers ability to communicate self-management strategies to patients, online communities and support groups may be a way to supplement this void and provide access to the resources that patients need and
are already pursuing. Educational materials that are easily accessible and understandable are another potential way to support providers that have limited time while also providing patients with the information they desire. Providers previously reported access to quality educational material as a structural barrier to initiating CKD conversations with patients (Sperati et al., 2019).

Participants acknowledged time as a barrier to communication with providers. In an effort to mitigate this barrier, participants created a ‘work-around’ by preparing for clinic visits in advance. Given that time and limited resources are barriers expressed by patients and providers it is important to find ways to support both parties, without adding additional responsibility on providers (Ma et al., 2022; Simon et al., 2020). In summary, participant’s description of a CKD Communication Playbook embodies an ideal situation communicating with their provider. Participants expressed a desire for a clear prescriptive process of how to manage and slow the progression of their CKD as well as information about the nature of kidney disease. Continuing to acknowledge that providers time is limited and the shortage of primary care providers and nephrologists the impact on the ability of patients to receive answers to their questions and information needed to management their CKD progression is clear. Limited time to care for complex patients, such as those with CKD, poor reimbursement for delivering optimal CKD care, and insufficient clinical support tools are all barriers previously identified by primary care providers as compromising optimal CKD care and are manifested in study participant interviews (Sperati et al., 2019). It is imperative to advance clinical technology and interventions to support providers caring for this population. Additionally, it is important to
consider and advocate for policy and system level changes to improve CKD management in the primary care setting.

Limitations

There are several limitations to this study, the first being that this study only captures the patient’s perception of communication with their provider, therefore we cannot be certain of the specific details of what providers may or may not have communicated to patients. Recruitment of minority participants is an elusive goal for researchers as it was in this study, thereby limiting the generalizability of these study findings. Despite vast recruitment efforts many participants included in this study were Caucasian and highly educated. Additionally, volunteering to participate could reflect a strong opinion on the subject matter being discussed, which can be a limitation to research studies (Kennedy-Leon, 2022). As the researcher was a novice at conducting individual interviews, this can be considered a limitation of the study. To compensate for this limitation, the researcher familiarized herself with qualitative interviewing techniques and strategies which provided guidance and direction on conducting qualitative interviews. Finally, by employing a qualitative descriptive design, limitations of bias and challenges of coding schemes with the data analysis process are inherent (Baganz, 2022).

Conclusion

The purpose of this qualitative descriptive study was to understand how patients with CKD describe having CKD-specific discussions with their provider and how this may have influenced their self-management of their progression of CKD. The results of this study suggest that patients’ experiences communicating with their providers about CKD could be improved.
Participants described how they would like providers to ideally communicate with them and suggested ways in which this could be achieved. Participants also described how their relationship with their provider influenced their communication. Patients were able to seek out resources independently in a more self-directed approach to help them learn about and manage their CKD. This self-directed approach to self-management is described as a patient “taking charge of their health”. The quotations provided demonstrate the themes inductively generated through careful analysis of participants’ descriptions. A comprehensive discussion of the implications of this rich data is presented in Chapter Five. Chapter Five will also include explanations on the advancement of knowledge related to patient-provider communication in the context of CKD and recommendations for future studies.
CHAPTER 5: SUMMARY OF FINDINGS AND IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Summary of the Findings and Their Contributions

This dissertation contributes to the growing body of literature examining the influence of patient-provider communication on patient self-management of chronic illness and awareness of CKD. The mechanisms by which patient-provider communication influences patient CKD awareness and self-management of CKD were not well understood. However, this dissertation contributes to better understanding of the relationship between these two phenomena. Paper 1 reviewed the literature on the influence of patient-provider communication on patient self-management of chronic illness. Findings from this review revealed that patient-provider communication does influence patient self-management of chronic illnesses and particular communication characteristics contributed to this relationship. Although chronic kidney disease was not among those chronic illnesses studied, the literature provided empirical validation of the important role that patient-provider communication plays in patient self-management of a chronic illness. Paper 2, sought to build upon this evidence by investigating the influence of provider communication style on patient CKD awareness and risk for kidney failure using an existing dataset. The results showed no significant association between patient CKD awareness and provider’s use of a participatory communication style. However, when adjusted for age and gender, results revealed that an increase in patient’s age was associated with a decrease in odds of being aware of their CKD, holding PDM score and gender constant. This aligns with the literature and belief that a natural decline in kidney function occurs with age, of which providers may be hesitant to diagnose (Hodlmoser et al., 2020). Patient’s risk for kidney failure was not
significantly associated with a provider’s use of a more participatory communication style. These results do not support the hypothesis that a provider’s use of a more participatory communication style is associated with greater patient CKD awareness or risk for kidney failure. However, these results must be interpreted with caution as there were limitations to this study. Paper 3 sought to understand and explore the content of patient and provider’s discussions surrounding CKD by asking patients to describe CKD-specific discussions with their providers during individual interviews, in order to provide further context to the findings in Paper 2. Participants were also asked if these discussions had any influence on their management of their CKD.

This concluding chapter will serve as a review of this dissertation’s findings and will provide an overall discussion of this dissertation’s contribution to the science and advancement of CKD awareness, patient-provider communication, and patient self-management of chronic kidney disease. A brief summary of each paper will be provided within the context of established literature on CKD, patient self-management and patient-provider communication. Finally, the implications for all health care providers, policymakers, and researchers to improve patient-provider communication and CKD awareness will be presented. Suggestions on ways to support both providers and patients in CKD management will also be discussed.

Study 1

The purpose of this study was to empirically test the relationship between a provider’s use of a PDM communication style, and patient CKD awareness and 2-year risk for kidney failure. We did not find a relationship but did show a relationship between PDM score and patient CKD awareness in this secondary data analysis. These findings indicate that there may be other factors influencing patient CKD awareness. This is consistent with Plantinga et al’s (2010)
suggestion that patient’s CKD awareness status is not solely dependent on the communication exchange between patients and providers. Other provider, patient, and community-level factors that may influence patient CKD awareness include but are not limited to provider demographics and practice characteristics, public policy and screening programs, and patient socioeconomic, clinical and psychological factors (Plantinga et al., 2010).

While patients cannot be aware of their CKD without a provider communicating this information, a provider’s communication style did not appear to influence patient CKD awareness. The findings of this study suggest several new avenues for research into other provider-level factors such as the role of patient’s age in delivering a CKD diagnosis or the development of more refined PDM scales or communication measures. Additionally, the lack of association between PDM score and patient’s 2-year risk for kidney failure may reflect a provider’s belief that little is to be done in patients with early-stage CKD and preference not to discuss self-management until later stages (Mallappallil et al., 2014). Conversely, this may also be indicative of the limited literature and studies available on patients with early-stage CKD. However, in Study 2, when 81-year-old participant Mae asked her provider about information on the management of her CKD, to which he suggested she should wait until her CKD gets worse, lend support to the former.

**Study 2**

The aim of this study was to gain an understanding of how patients with CKD describe having CKD-specific discussions with their provider and its potential influence on their self-management. Acknowledging the limitations of study 1, if provider communication *style* is not a significant influence on patient CKD awareness or risk for kidney failure, it was useful to
explore the nature of CKD specific discussions with providers to gain insight and provide context to Study 1 findings. Although, the samples were different for both studies, individual interviews with CKD patients provided an inside look into the conversations between patients and providers about CKD. Thematic analysis identified that most providers are communicating a CKD diagnosis to patients, validating part of the findings from study 1. However, a provider communicating a CKD diagnosis was the extent of the conversation for some participants. Participants reported a desire for more information than just a diagnosis. Participants described a desire for a clear prescriptive process on how to manage or slow the progression of CKD. Similar findings were reported in a study on the self-management experiences of people with mild to moderate CKD which revealed that patients living with kidney disease want to self-manage their illness in collaboration with health care providers but wanted guidance and support from health care professionals to successfully achieve this (Costantini et al., 2008). Themes identified in Study 2 such as *The CKD Communication Playbook for Patients and Providers*, *Preparing for the Clinic Visit*, *building a Relationship* and, *Taking Charge of My Health*, embody descriptions of participants describing a desire for support and guidance from their providers and how they directed their own self-management. Study 2 also adds to our knowledge of CKD-specific communication between patients and providers by providing a glimpse of the content discussed between patients and providers and how patients perceive providers’ communication.

Furthermore, Study 2 enhances our understanding of how providers and the health system shape health outcomes (Leung et al., 2022). For example, the pressure on providers by the health care system to see high volumes of patients and manage electronic health records, significantly
reduces the time available to spend with each patient and provide necessary CKD management education (Leung et al., 2022). This is evidenced in the participant’s description of a need to prepare for clinic visits in advance just to ensure their questions are answered.

This section of Chapter Five has presented a summary of findings for the two studies conducted in this dissertation and the mixed studies review (Paper 1) as it relates to the established literature on CKD awareness and patient-provider communication. This chapter will continue with a discussion of implications and recommendations for future research.

**Implications**

This multi-method study was conducted to understand the influence of patient-provider communication on patient CKD awareness, risk for kidney failure, and self-management. First, a literature review was conducted to identify if patient-provider communication is in fact influential on patient self-management of chronic illness. This was to support the long-term goal of this research in identifying the provider and patient’s role in slowing the progression of CKD and preventing end stage kidney disease and the need for renal replacement therapy. The literature review revealed that patient-provider communication is indeed influential on patient self-management of chronic illness and particular characteristics of a participatory decision-making style of communication may contribute to this influence.

Quantitative analysis therefore was used to further investigate this relationship and uncover if a participatory decision making (PDM) style of communication influences patient CKD awareness and risk for kidney failure. This study was conducted under the assumption that providers communicate in more of participatory fashion with patients at a greater risk for kidney failure and that the providers use of this style is what increases patient CKD awareness. This
relationship was not supported by the secondary data analyses conducted, indicating that there may be other influential factors on patient CKD awareness beside provider communication style. A qualitative descriptive study provided more context to the quantitative findings by disclosing the content of CKD-specific discussions between patients and providers. Findings suggested that patients do become aware of their CKD from their providers, however, that may be the extent of what most patients learn from their providers. Participants describe learning about managing their CKD from other sources, peers and reading literature online and in books. These findings provide significant implications for the health care system, policymakers, and providers. The health care system can use findings from this study to implement supportive mechanisms that facilitate patient-provider communications, such as advancing in clinical support decision tools and quality educational materials. Policymakers can use findings from this study to advance policies that support providers caring for CKD populations, improve reimbursement and incentivizing preventive and primary care (Chin, 2016). Providers can use these study findings and implement suggestions from patients as it relates to building a relationship with patients and communicating in a more participatory fashion.

As it relates to professional practice, it is important for health care professionals to understand that with current technological advances patients can retrieve information from various sources. However, not all information is accurate. It is unreasonable to expect physicians alone to meet all the educational needs of their patients. This presents a unique and ideal opportunity for physicians, nurse practitioners, nurses, and other health care providers (ex. dieticians) to collaborate with patients to address unmet educational needs. Additionally, there is an opportunity for nurses to use their patient education skills to not only teach patients about
their diagnosis but also how to manage their diagnosis effectively. There is also an opportunity for nurse/health coaches, a virtually untapped resource, to assist patients in navigating the management of their CKD along with other comorbidities that often plague this population (Tuot et al., 2015).

**Implications for Future Research**

The results of this study suggest a number of new avenues for research, one being the development of collaborative models or frameworks that support self-management of CKD. Researchers can also use these findings to advance the development and evaluation of a CKD Communication Playbook, which would help facilitate communication between patients and providers by delivering on requests and desires of the patient. This playbook would differ from other previously developed instruments as it would not focus on one constituent; but it would connect the two by providing supportive information for both parties to work collaboratively and communicate effectively. To address the unmet educational needs of CKD patients, more research is needed to understand how other interdisciplinary professionals can contribute to increasing patient knowledge and understanding of CKD and self-management. Given that this study revealed provider communication style may not be associated with patient CKD awareness, more research into other provider-level influential factors should be explored specifically as it pertains to the clinical encounter. This may include research into the translation of CKD knowledge and guidelines from providers to patients and the development of interventions to address provider reported barriers to delivering CKD education. This may include how providers stay current with CKD guidelines or the development of electronic prompts and lab decision support tools for providers (Sperati et al., 2019). The need for research
on the implementation of educational programs for primary care providers to stay current on clinical guidelines is an effort that is supported by the WHO Global strategy on Human Resources for Health: Workforce 2030 initiative. This initiative provides strategic directions for workforce enhancement in primary care that can be used to develop broad based training programs to address several chronic conditions including CKD (Bello & Johnson, 2022)). This is salient to providers caring for patients with CKD as previous research has reported that providers perceive current CKD guidelines to be unclear, lack clarity, and are inadequate in dissemination to providers (Sperati et al., 2019).

Research that investigates innovative self-management support interventions is also needed, particularly given the qualitative study findings of this dissertation and participant’s desire for more information on self-management. Self-management support involves collaboratively helping patients acquire the skills and confidence to manage their chronic illness and routinely assess problems and accomplishments (Bodenheimer, Wagner, et al., 2002). Nurses, dieticians, and other non-physician personnel can support patient self-management by arranging routine periodic tasks such as lab tests, referring patients to community and online resources, and ensuring appropriate follow-up (Bodenheimer, Wagner, et al., 2002). Given the influence of patient-provider communication on self-management of their chronic illness, we can use findings from this study to support providers in delivering equitable care to all CKD. One way this can be done is by incorporating participant suggestions, such as having a step-by-step process for patient CKD management, into clinical practice. Prior research has reported that providers need help facilitating CKD discussions with patients. Considering findings from this study, future research should begin to think about interventions that support both patients and
providers in having CKD discussions (Bello & Johnson, 2022; Sperati et al., 2019; Vassalotti & Boucree, 2022). While supportive interventions may look different for providers than it does for patients, it may be imperative that future research explore system-integrated or coordinated interdisciplinary models of care of which patients have been shown to benefit from, particularly as it pertains to lifestyle modifications, a self-management strategy (Vassalotti & Boucree, 2022). Lastly, this dissertation does not assess the potential inequities in patient’s experiences communicating with providers, however, it does set the premise for this discussion and future research. Future studies should build upon the findings from this study and examine if there are explicit linkages between how providers communicate with patients of different genders, race, age, or other identifiers.

**Conclusion**

This dissertation illustrates that chronic kidney disease awareness and patient-provider communication are not independent of each other, as patients do become aware of their CKD status from their provider. The style of communication a provider uses, however, may not be as influential as other provider-level factors on patient CKD awareness. Furthermore, the content of CKD-specific conversations is important to patients and their self-management of their CKD. This dissertation highlights that patients desire to learn about their CKD and how to manage it from their respective health care providers. The two studies presented in this dissertation contribute to the growing literature regarding CKD awareness, patient-provider communication, and patient self-management of chronic kidney disease.
### Table A.1. Mixed Studies Review Table of Evidence

<table>
<thead>
<tr>
<th>Author, Year, Title</th>
<th>Type of Chronic Illness</th>
<th>Country where study conducted</th>
<th>Study Aims</th>
<th>Design/Methods</th>
<th>Sample</th>
<th>Study outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Ivynian et al., 2020) Patient preferences for heart failure education and perception of patient-provider communication.</td>
<td>Heart Failure</td>
<td>Australia</td>
<td>To explore perceptions of patient-provider communication and ascertain unmet educational needs and preferences.</td>
<td>Qualitative Semi-structured in-depth interviews. Thematic analysis.</td>
<td>N= 15 Male: 10 Median age: 55</td>
<td>Poor communication left patients without an understanding of how to identify and manage symptoms.</td>
</tr>
<tr>
<td>(Claramita et al., 2020) A partnership-oriented and culturally sensitive communication style of doctors can impact the health outcomes of patients with chronic illnesses in Indonesia</td>
<td>Diabetes and Hypertension</td>
<td>Indonesia</td>
<td>To test the effect of a communication skills training program for doctors on patient’s perception of doctor’s communication skills, doctor’s assessment of their communication skills,</td>
<td>Mixed Methods Longitudinal Focus Groups Surveys Paired t-tests Content Analysis Deductive Open coding</td>
<td>Doctors: Primary care N=30 Patients: N=96</td>
<td>Patients’ blood pressure or fasting blood glucose levels decreased significantly (p &lt; 0.05), except the two-hour blood glucose levels (NS). Patients expressed more satisfaction,</td>
</tr>
<tr>
<td>3</td>
<td>(Peltola et al., 2018) Patients' Interpersonal Communication Experiences in the Context of Type 2 Diabetes Care. Qualitative health research, 28(8), 1267–1282.</td>
<td>Type 2 DM Finland</td>
<td>To determine the relational communication characteristics of professional-patient communication situations that have either facilitated or impeded patients' self-management.</td>
<td>Qualitative Open-ended e-surveys and semi-structured interviews Descriptive Qualitative analysis</td>
<td>N= 16 Age range: 30-93 Gender: 13 Female 3 Males Race: not reported</td>
<td>Both positive and negative experiences described by patients were connected to four multidimensional relational communication characteristics: (a) building trust in the other party in the professional-patient relationship, (b) willingness to communicate, (c) emotional presence, and (d) appropriateness. Portrayal of trust/distrust, increased comprehension, and self-management, of their chronic illnesses.</td>
</tr>
</tbody>
</table>
Communicating an emotional presence can help patients understand the seriousness of managing their DM. Showing respect and understanding motivated patients to improve self-management behaviors.

| 4 | (Kruse et al., 2013) Communication during patient-provider encounters regarding diabetes self-management. | Type 2 DM | United States | To provide an in-depth analysis of how conversations of self-care emerge during clinical encounters. | Qualitative Direct observation Grounded theory Narrative analysis | N=30 Age range: 32-84 Gender: not reported Race: not reported | Clinicians often focused their communication on quantitative measures such as blood pressure and glycosylated hemoglobin, but... |
patients found it difficult to relate these measures to how they were feeling physically. Patients' social contexts influenced their self-management activities. Supporting self-management of patients with diabetes requires providers to link clinical measurements to patients' symptoms and likely outcomes. It is difficult for providers to know what support or assistance their patients need without knowledge of patients'
<table>
<thead>
<tr>
<th>5</th>
<th>(Visse et al., 2010) Dialogue for air, air for dialogue: towards shared responsibilities in COPD practice.</th>
<th>COPD</th>
<th>Netherlands</th>
<th>To examine the possibilities to enrich the notion of self-management in a dialectical circle between practical understandings and theoretical insights from ethics.</th>
<th>Qualitative Case-study Interviews (open and semi-structured) Narrative analysis</th>
<th>N=1</th>
<th>Patient-provider communication is a dialogical process that involves the provider exhibiting empathy, listening, and understanding of the patient and the patient being able to share their illness as a story. Providers and patients are then able to engage in meaningful conversations where providers can provide practical support, advice, and solutions for patients to manage their chronic illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>(Newcomb et al., 2010) Asthma United States</td>
<td>To describe</td>
<td>Qualitative</td>
<td>N=104 Patients</td>
<td>These findings</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Barriers to patient-clinician collaboration in asthma management: the patient experience.

What adult patients with asthma report about their experiences with their own self-management behavior and collaborating with their clinicians to control asthma.

- Semi-structured interviews
- Observational field notes
- Open and selective coding
- Grounded theory
- Post-hoc analysis
- Likert scale evaluation

Physicians and NPs emphasize the difficulties of establishing and maintaining a therapeutic partnership between patients and clinicians. The results underscore the need for system-wide interventions that promote the success of a therapeutic patient-clinician relationship to achieve long-term success in chronic disease management.

| 7 | Kumar C. P. (2007). Application of Orem's self-care deficit theory and standardized nursing | Type 2 Diabetes | United States | To illustrate the process of theory-based nursing practice by presenting a case study of a Qualitative Case-study | N=1 49yo Italian American Female | Nursing theory and standardized nursing language enhance communication among nurses and support a |
| 8 | (Piette et al., 2003) Dimension of patient-provider communication and diabetes self-care in an ethnically diverse population. | Diabetes | United States | To examine the impact of general versus disease-specific communication on self-management of diabetes among an ethnically diverse population within 3 separate systems of care. | Quantitative Telephone interview surveys IPC questionnaires Summary of Diabetes Self-care Activities questionnaire (modified) Predicted probability models | N= 752 Age: <50 – 9% (VA), 23.7% (County), 29.7% (University) 50-59-32% (VA), 30% (County), 27% (University) 60+ - 58% (VA), 45.8% (County), 43% (University) Gender (by clinic): 95%(VA), 47% (County), 42% (University) | General and diabetes-specific communication are independently related to improving DM self-management. Providers in these sites are communicating successfully with vulnerable patients. |
Race (by clinic):
White-
72%
(VA)
19%
(County)
35%
(University)
AA-
12.9%
(VA)
29.9%
(County)
20.9%
(University)
Hispanic
- 4%
(VA),
29%
(County),
14%
(University)

| 9 | (Baker et al., 2005) A telephone survey to measure communication, education, self-management, and health status for patients with heart failure: the Heart Failure United States | To measure the influence of patient-provider communication, patient satisfaction, patient education, knowledge and self-efficacy on patient self- | Quantitative Heart Failure Symptom Scale SF-12 PCS MCS scale Consumer Assessment of Health Plans study instrument Communication Scale N=781 Gender Female (52%) Race White (71%) | Mean communication score 4.0 (range 1-5). 76% of patients reported collaborating with a provider on a self-management plan. 66% of patient reported |
Improving Chronic Illness Care Evaluation (ICICE) education, self-management, and health status for patients with heart failure: the Improving Chronic Illness Care Evaluation (ICICE) management and health status

Knowledge of Heart Failure Physician and Nurse satisfaction scales
Self-efficacy scale

To assess the relative importance
Quantitative

N= 1558
Mean age: 69

Among these older adults, both

10 (Heisler et al., 2007)
Diabetes United States


A supplement al written self-managemen t plan improved patient knowledge about heart failure. Only 13% of participants knew how to effectively manage their heart failure independently. Even with a high communica tion score, patients poorly understood self-managemen t strategies.
Does physician communication influence older patients' diabetes self-management and glycemic control? Results from the Health and Retirement Study (HRS).

Cross-sectional PACIC scale
PCOM scale (Numerical rating)
Hemoglobin A1C

Gender: 46%
Male
Race: 70%
white
18%
African American
10%
Hispanic

Impact of satisfaction with physician–patient communication on self-care and hypertension in Europe

To evaluate the relationship between physician-patient communication and self-care and adherence
Quantitative Cross-sectional Communication Assessment Tool (CAT)
The Adherence to Refills and

N=250
Mean age: 61
Gender: 47%
Male
Race: not reported

Satisfaction with physician–patient communication has a significant impact on self-care and pharmacetical
| N= 11 | adherence in patients with hypertension: cross-sectional study | in patient with hypertension undergoing chronic treatment. | Medication Scale (ARMS) The Self-Care of Hypertension Inventory (SCHI) | adherence in patients with hypertension. The more satisfied the patient is with communication, the better their adherence and self-care. |
### APPENDIX B: Table B.2: Mixed Methods Appraisal of Quantitative Studies

#### Table B.2: Mixed Methods Appraisal of Quantitative Studies

<table>
<thead>
<tr>
<th>Author/Ye</th>
<th>Are there clear research questions?</th>
<th>Do the collected data allow to address the research questions?</th>
<th>Is the sampling strategy relevant to address the research question?</th>
<th>Is the sample representative of the target population?</th>
<th>Are the measurements appropriate?</th>
<th>Is the risk of the nonresponse bias low? OR Are the confounders accounted for in the design and analysis?</th>
<th>Is the statistical analysis appropriate to answer the research question? OR During the study period, is the intervention administered (or exposure occurred) as intended?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Piette et al., 2003)</td>
<td>Y</td>
<td>Y</td>
<td>Y, a clear justification for the sample frame is provided and the sampling procedure</td>
<td>Y, there is a clear description of the target population and of the sample, eligibility criteria is presented and eligible</td>
<td>Y, the variables are clearly defined and accurately measured. The measures are justified and appropriate</td>
<td>Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate</td>
<td>Y, Statistical analyses used are clearly stated and justified</td>
</tr>
<tr>
<td>(Baker et al., 2005)</td>
<td>Y</td>
<td>Y</td>
<td>Y, a clear justification of the sample frame used is provided.</td>
<td>Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; validated</td>
<td>Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; validated</td>
<td>Y, Statistical analyses used are clearly stated and justified.</td>
<td></td>
</tr>
</tbody>
</table>
and reliability tested measures of the outcome of interest are used. the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used.

<table>
<thead>
<tr>
<th></th>
<th>Y</th>
<th>Y</th>
<th>Y</th>
<th>Y, the source of sample is relevant to the target population and the sampling procedure is adequate.</th>
<th>Y, a clear description of the target population and of the sample is provided.</th>
<th>Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed</th>
<th>Y, appropriate methods to control for confounders are used.</th>
<th>Y, Statistical analyses used are clearly stated and justified.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Heisler et al., 2007)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| (Świątonio-
wska-Lonc et al., 2020) | Y | Y | Y, the source of sample is relevant to the target population and the sampling procedure is adequate. | Y, a clear description of the target population and of the sample is provided. | Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure. | Y, the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used. | Y, Statistical analyses used are clearly stated. |
### APPENDIX C: Table C.3: Mixed Methods Appraisal of Qualitative Studies

**Table C.3: Mixed Methods Appraisal of Qualitative Studies**

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Is the qualitative approach appropriate to answer the research question?</th>
<th>Are the qualitative data collection methods appropriate to address the research question?</th>
<th>Are the findings adequately derived from the data?</th>
<th>Is the interpretation of results sufficiently substantiated by data?</th>
<th>Is there coherence between qualitative data sources, collection, analysis, and interpretation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Ivynian et al., 2020)</td>
<td>Y, the qualitative approach used in a study and is appropriate for the research question and problem.</td>
<td>Y, the method of data collection and the form of the data are adequate. Clear justifications when data collection methods were modified during the study.</td>
<td>Y, data analysis methods used were appropriate for qualitative approach.</td>
<td>Y, the quotes provided to justify the themes is adequate.</td>
<td>Y, there are clear links between data sources, collection, analysis, and interpretation.</td>
</tr>
<tr>
<td>(Peltola et al., 2018)</td>
<td>Y, the qualitative approach used in a study and is appropriate for the research question and problem.</td>
<td>Y, the method of data collection and the form of the data are adequate. Clear justification of both data collection methods</td>
<td>Y, data analysis methods used were appropriate for qualitative approach</td>
<td>Y, the interpretation of results is supported by the data collected</td>
<td>Y, there are clear links between data sources, collection, analysis, and interpretation.</td>
</tr>
<tr>
<td>Study</td>
<td>N, the qualitative approach (grounded theory) used in a study is not appropriate for the research question and problem. For this study ethnography may have been a more appropriate approach/method.</td>
<td>Y, the method of data collection and the form of the data are adequate to answer the research question. Although there is mention of direct observation, there appears only to be audio recording and no video recording, or in-person observation or memos are noted.</td>
<td>N, the data analysis method used is said to be narrative analysis however, what is describe in the text is coding and theme development, which may align more with thematic analysis.</td>
<td>Y, the interpretation, and the quotes provided to justify the themes is adequate.</td>
<td>N, there are clear links between data sources, collection, analysis, and interpretation. There are discrepancies between the approach, data collection and data analysis.</td>
</tr>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Kruse et al., 2013)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Visse et al., 2010)</td>
<td>Y, the qualitative approach (case study) used in a study and is appropriate for the research question and problem. Clear justifications are presented when data</td>
<td>Y, the method of data collection and the form of the data are adequate. Clear justifications are presented when data are collected</td>
<td>Y, data analysis methods used were appropriate for a case-study approach.</td>
<td>Y, the interpretation of results is supported by the data collected</td>
<td>Y, there are clear links between data sources, collection, analysis, and interpretation.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Collection Methods</td>
<td>Analysis Methods</td>
<td>Interpretation</td>
<td>Links Between Data Sources, Collection, Analysis, and Interpretation</td>
<td></td>
</tr>
<tr>
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<td>---------------------------------------------------------------------</td>
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</tr>
<tr>
<td>(Newcomb et al., 2010)</td>
<td>Y, although the qualitative approach used in a study is not clearly stated, it is consistent with a qualitative descriptive approach and is appropriate for the research question and problem.</td>
<td>Y, the method of data collection (semi-structured interviews developed from questionnaire) and the form of the data are adequate</td>
<td>Y, the interpretation of results is supported by the data collected. The quotes provided justify the themes and are adequate.</td>
<td>Y, there are clear links between data sources, collection, analysis, and interpretation.</td>
<td></td>
</tr>
<tr>
<td>(Kumar, 2007)</td>
<td>Y, the qualitative approach used in a study is appropriate for the research question and problem.</td>
<td>N, data collection methods are not presented in this study.</td>
<td>Y, data analysis methods used were appropriate for a case-study approach.</td>
<td>Y, there are clear links between analysis and interpretation. Data collection and sources are not revealed in this study.</td>
<td></td>
</tr>
</tbody>
</table>
### APPENDIX D: Table D.4: Mixed Methods Appraisal Tool for Mixed Methods Studies

**Table D.4: Mixed Methods Appraisal Tool - Mixed Methods Studies**

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Is there an adequate rationale for using a mixed methods design to address the research question?</th>
<th>Are the different components of the study effectively integrated to answer the research question?</th>
<th>Are the outputs of the integration of qualitative and quantitative components adequately interpreted?</th>
<th>Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?</th>
<th>Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Claramita et al., 2020)</td>
<td>N, the reasons for conducting a mixed methods study are not clearly explained.</td>
<td>N, there is no information on how qualitative and quantitative phases, results, and data were integrated. Neither is there a discussion of how data gathered by both research methods was brought together to form a complete or when integration</td>
<td>N, there is no overall interpretations derived from integrating qualitative and quantitative findings as the qualitative and quantitative study are presented separately.</td>
<td>N, findings from these qualitative and quantitative components were not integrated, therefore divergence or inconsistencies were not addressed.</td>
<td>Y, Quant: clear description of the target population and of the sample (inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate is presented. The measurements reflect what they are supposed to measure, are justified and appropriate for answering</td>
</tr>
</tbody>
</table>
occurred. Results of the quantitative and qualitative studies are presented individually. The research question. The variables are clearly defined and accurately measured; Almost all the participants contributed to almost all measures. Almost all the participants contributed to almost all measures. Confounding bias is low. During the study period, the intervention was administered as intended.

<table>
<thead>
<tr>
<th>Qual: The qualitative approach was not clearly defined but appears to be qualitative descriptive, this is appropriate to answer the research question. Data collection method, including data</th>
<th>Qual: The qualitative approach was not clearly defined but appears to be qualitative descriptive, this is appropriate to answer the research question. Data collection method, including data</th>
<th>Qual: The qualitative approach was not clearly defined but appears to be qualitative descriptive, this is appropriate to answer the research question. Data collection method, including data</th>
</tr>
</thead>
</table>
sources used to address the research question were adequate. Data analysis methods were consistent with the qualitative approach. The interpretation of results is supported by the data collected and quotes provided. There are clear links between data sources, collection, analysis, and interpretation.
APPENDIX E: PRISMA Diagram Figure 2

Figure 2. PRISMA diagram selection process of included articles

Identification of studies via databases

Records identified from:
Databases (n = 375)

Records removed before screening:
Duplicate records removed (n = 4)

Records screened (n = 371)

Records excluded (n = 295)

Reports assessed for eligibility (n = 76)

Reports excluded:
- Discussed patient-provider relationship broadly (n = 25)
- Discussed the use of electronic communication (n = 14)
- Non-empirical/Opinion perspective (n = 17)
- Discussed self-management outside of the context of patient-provider communication (n = 9)

Studies included in review (n = 11)
APPENDIX F: Interview Guide

Study Title: The Influence of Patient-Provider Communication on Patient Chronic Kidney Disease Awareness and Patient Risk for Kidney Failure

Purpose: To investigate if provider communication style is related to patient CKD awareness and risk for kidney failure in patients with early-stage CKD.

Specific Aims:
Quantitative Aim: To determine the association between PCP communication style and patient’s CKD awareness and risk for kidney failure, defined by the Kidney Failure Risk Equation.

Qualitative Aim: To gain an understanding of the influence of patient-provider communication from the perspective of those experiencing and managing the progression of their CKD.

<table>
<thead>
<tr>
<th>Instructions for Interviewer</th>
<th>Question</th>
<th>Follow Up/Probe</th>
<th>Comments/Field Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction for the participants:</td>
<td>Thank you for agreeing to talk to me today. We are doing this study because we would like to learn about how patients with early-stage CKD came to learn about their kidney disease diagnosis, how to manage the progression and how their provider’s communication style may have influenced their self-management. Since you are a person with CKD, we consider you an EXPERT and we would like to learn more about your experience.</td>
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</table>

CKD Awareness

These are general assessment questions to open dialogue and identify how participants learned about their CKD and who delivered the diagnosis.

<table>
<thead>
<tr>
<th>Question</th>
<th>Follow Up/Probe</th>
<th>Comments/Field Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell me how you came to learn about your kidney disease</td>
<td>How long have you had kidney disease?</td>
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<tr>
<td></td>
<td>Do you have any related chronic illnesses such as diabetes or hypertension?</td>
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<td></td>
<td>How did you receive your diagnosis?</td>
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<td></td>
<td>Who delivered the diagnosis?</td>
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<td></td>
<td>How long had you been seeing that provider?</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Was this provider a doctor, nurse practitioner, physician’s assistant, nurse, or someone else?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you know anyone with kidney disease prior to your diagnosis?</td>
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</tbody>
</table>

**Provider Communication Style**

<p>| Participants understanding of their diagnosis and provider’s communication style. | Now we are going to talk a little about your provider’s communication style. Tell me what you understand about your kidney disease diagnosis. | Did the provider explain the causes of your kidney disease? Did the provider explain how your kidney disease would progress over time? Do you feel you received adequate information from your provider about your kidney disease and the causes? Did your provider give you techniques to manage your kidney disease or other comorbidities to protect your kidneys? Did your provider ever discuss dialysis or kidney transplant with you? |
| How would you describe your provider’s communication style? | Does your provider ask about your home life or social circumstances? Does your provider include you in decisions about your health? <strong>Probe:</strong> Can you provide an example? Do you think your provider puts your values and preferences first? <strong>Probe:</strong> If so, how? Are you able to communicate with your provider openly and freely? <strong>Probe:</strong> If not, why? If yes what makes this possible? Do you think your race, gender or level of education has influenced how your provider communicates with you or how you communicate with your provider? | How do you prefer to communicate or learn about your health from your provider? | Do you prefer your provider to do all the talking and make the decisions about your treatment plan? |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Do you prefer to make the decisions about your treatment plan and have a little input from your provider?</th>
<th>Do you prefer there to be an equal balance between you and your provider when developing a treatment plan?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Self-Management</strong></td>
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<tr>
<td>Participant’s self-management of chronic illness and CKD progression.</td>
<td>Now let’s discuss how you manage the progression of your kidney disease and any related chronic illnesses (hypertension/diabetes).</td>
<td>In what way have you changed your self-management practices? <strong>Probe:</strong> Do you think your provider had any influence on these changes? <strong>Probe:</strong> Are you more of a planner when it comes to your health, or do you take things as they come?</td>
</tr>
<tr>
<td>Do you think being aware of your kidney disease has changed the way you manage your health?</td>
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<tr>
<td>As you reflect on what you are experiencing now with kidney disease, is there anything you would do differently?</td>
<td>Do you believe doing things differently would change your outcome? <strong>Probe:</strong> If so, how?</td>
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</tr>
<tr>
<td>What would you advise other patients to ask their providers?</td>
<td></td>
<td>What would you tell someone in a similar situation as you who has the potential to develop kidney disease?</td>
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<tr>
<td><strong>Closure</strong></td>
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<tr>
<td>Thank participant and ask if they have any additional comments</td>
<td>Is there anything else you would like to share about your kidney disease experience or other related chronic illnesses?</td>
<td></td>
</tr>
</tbody>
</table>


Bugge, C., Entwistle, V. A., & Watt, I. S. (2006). The significance for decision-making of information that is not exchanged by patients and health professionals during consultations. *Social Science and Medicine, 63*(8), 2065–2078. https://doi.org/10.1016/j.socscimed.2006.05.010


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