VNIVERSITAT DE VALÈNCIA

THE MIXED-METHOD ASSESSMENT OF PATIENTS' EXPERIENCE TO IMPROVE HEALTH CARE SERVICES: THE CASE OF PATIENTS WITH CHRONIC KIDNEY DISEASE

DOCTORATE IN THE PSYCHOLOGY OF HUMAN RESOURCES

DOCTORAL THESIS

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Valencia, 2024

ACKNOWLEDGEMENT

I would like to express my deepest gratitude to my doctoral advisors Vicente Gonzalez-Roma and Ana Hernandez, for their unwavering guidance, invaluable insights, and continuous support throughout the entire research process. I am grateful to Vicente GonzalezRoma for having believed in my project from the beginning to the right end. His conviction for the potential of our research played a big role in me starting this PhD journey to begin with and motivated me during difficult and uncertain times. I am also deeply thankful for Ana Hernandez, as her invaluable input helped me to expand my methodological capabilities and learn from her expertise and depth of knowledge. I am also thankful for her hard work and dedication during this last difficult stretch. I would like to thank them both for their support in helping me achieve this milestone.

I would also like to thank the IDOCAL community for their valuable feedback and constructive criticism that significantly enhanced the quality of this research. I would like to express my appreciation to my colleagues and peers who have been a source of inspiration and intellectual stimulation. Their collaborative spirit has enriched my academic experience.

I am indebted to the Hospital Universitario General de Valencia for providing me the opportunity to run the first patient experience program as part of the efforts of making healthcare services more humanizing. This initiative laid the foundation for what later became the central focus of my research project.

I extend my heartfelt appreciation to my mother for her unwavering encouragement and understanding throughout this demanding journey. She has consistently been a source of inspiration, and her tenacity and perseverance have served as my anchor, empowering me to overcome challenges and difficult times.

I want to thank all the individuals who may not be explicitly mentioned here but have played a crucial role in shaping my academic and personal growth. Your encouragement and support have not gone unnoticed.

Lastly, this thesis is a testament of my strong conviction and relentless pursuit of knowledge, underscoring my unwavering commitment to contributing meaningfully to the field and advancing the boundaries of understanding in this area of study.


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INDEX

CHAPTER I: GENERAL INTRODUCTION

In the intricate landscape of healthcare, the concept of service quality stands as a cornerstone, shaping the experiences of patients within healthcare organizations (Abbasi-Moghaddam et al., 2019). Although clinical effectiveness is essential, quality of service in healthcare organizations goes beyond this clinical proficiency, embracing a holistic approach that prioritizes patient satisfaction, positive health outcomes, and overall well-being (World Health Organization, 2018). This diverse perspective is crucial in defining and understanding healthcare quality, a term that signifies the degree to which health services contribute to desired health outcomes for individuals and populations (Chassin & Galvin, 1998). But in this definition, health outcomes do not exclusively mean physical health. The quality of healthcare services requires focusing on treatment effectiveness, but also patient well-being and the overall success of healthcare systems (Brach & Borsky, 2020). Within the realm of healthcare quality, three key variables emerge as pivotal factors: patient safety, healthcare effectiveness, and patient experience (Institute of Medicine, 2001). Patient safety focuses on minimizing the risk of harm during healthcare provision, ensuring a secure environment for patients (World Health Organization, 2004). Effectiveness evaluates the extent to which healthcare services achieve their intended outcomes, emphasizing positive and impactful results (Burches & Burches, 2020). Patient experience, a critical dimension, delves into the unique needs, preferences, and perspectives of individuals as they navigate the healthcare system (Oben, 2020). To these three pillars, some authors add a fourth relevant one: patient's satisfaction (e.g., Oyvind et al., 2011). Together, all these variables create a comprehensive framework for evaluating and enhancing the quality of healthcare services, acknowledging the multifaceted nature of patient care. For our research work, we will focus mostly on patient experience and, to a lesser extent, on the related construct of patient satisfaction.

Focusing on patient experience, this diverse concept encompassing various dimensions of healthcare interactions, holds profound implications for the well-being of individuals and the overall quality of healthcare delivery. Beyond the conventional metrics of clinical outcomes, patient experience contributes significantly to treatment adherence, patient engagement, and overall satisfaction with healthcare services (Doyle et al., 2013). Positive patient experiences have been linked to improved health outcomes, fostering a

sense of trust and collaboration between patients and healthcare providers (Price et al., 2014). This emphasis on patient experience is not merely a contemporary trend but a strategic imperative to elevate the quality-of-care delivery (Browne et al., 2010). Therefore, it becomes imperative to count on standardized methods that show adequate psychometric properties (reliability and validity) for assessing patient experience, which may be combined with other more qualitative assessment methods. The assessment of patient experience, in fact, can be critical to enhance care delivery, tailor patients' interventions, and address individual patient needs effectively, all contributing to improving the quality of the service provided in health-related organizations.

In the context of chronic kidney disease (CKD), understanding patient experience becomes particularly crucial, given the chronic and evolving nature of the condition. CKD is characterized by different stages (Levey et al., 2003) and as such, necessitates a nuanced understanding of patient experience across the trajectory of the disease. The different stages of CKDs are linked to different interactions with the healthcare system that represent distinct touchpoints in the patient's journey. As such, it is important to understand the dynamic nature of patient experience as the disease evolves and progresses. In the early stages, patients may grapple with the shock of diagnosis and the need for comprehensive information about their condition, treatment options, and lifestyle modifications. Interventions may just focus on disease management and lifestyle adjustments (i.e., diet, physical exercise, etc.). As CKD progresses, the challenges evolve, encompassing issues related to treatment modalities, treatment adherence, and the necessity for personalized care plans that align with the specific needs and lifestyles of each patient (Levey et al., 2003). In the advanced stages interventions require more intensive, intrusive, and risky treatments, such as dialysis or transplantation, that lead to additional challenges and preoccupations for CKD patients. Thus, understanding CKD in its various stages is paramount because each stage brings forth unique interactions and considerations for patient experience, demanding tailored approaches to care delivery.

Recognizing the importance of assessing patient experience throughout the trajectory of CKD is pivotal for delivering patient-centered care. This approach goes

beyond traditional metrics, allowing healthcare providers to tailor interventions based on the unique challenges and needs of patients in each stage. In the evaluation of care delivery, the literature consistently highlights the significance of patient experience and patient satisfaction as key indicators (Oyvind et al., 2011). These two constructs provide valuable insights into the quality of healthcare services and the overall impact on patients' lives ("Measuring What Matters: The Patient-Reported Indicator Surveys," 2019). Patient experience serves as a holistic measure, encompassing the broader spectrum of interactions and touchpoints, while patient satisfaction captures the subjective evaluation of care received (Larson et al., 2019).

The relationship between patient satisfaction and patient experience is a nuanced aspect, and the thesis acknowledges the mixed findings in the existing literature. While some studies suggest a correlation between satisfaction and experience (Kahn et al., 2015), others propose a more complex and dynamic interplay (Berkowitz, 2016). In this thesis, we consider that patient satisfaction is an integral component of patient experience, as the analysis of key aspects of the analysis of the definitions of patient experience suggest (Wolf et al. 2014). This perspective acknowledges the multifaceted nature of patient interactions and the subjective nature of satisfaction assessments, ensuring a comprehensive evaluation of care quality in the context of CKD.

As this thesis will show, the current landscape of literature reveals a significant gap in the comprehensive assessment of patient experience from the perspective of CKD patients (Tuttle et al., 2019). Despite the growing prevalence of CKD and its impact on patients' lives, there is a paucity of research that delves into the intricacies of their experiences at various stages of the disease trajectory. This gap poses significant implications for healthcare providers, policymakers, and researchers, as a nuanced understanding of CKD patients' experiences is vital for delivering tailored and patient-centered care. Moreover, the predominant reliance on surveys as the primary method for assessing patient experience (Bernardo, et al., 2022) introduces limitations to the depth and richness of data collected. Surveys, while valuable for quantifiable metrics, may lack the specificity needed to capture the multifaceted aspects of CKD patients' experiences. The

implications of this methodological limitation extend to the potential oversight of critical touchpoints, subtle variations in individual experiences, and the contextual nuances that shape the patient journey. As CKD is a chronic and evolving condition, relying solely on survey-based assessments may undermine the depth of insight needed to inform interventions and enhance care quality. Additionally, the existing measurements, whether generic or disease-specific, often fall short in focusing on the diverse stages of the CKD illness trajectory. The implications of this gap are profound, as patients traverse different stages of the disease with distinct challenges, needs, and priorities. Without specific attention to these stages, the current measurements may not capture the evolving nature of patient experiences, hindering the ability to tailor interventions based on the unique requirements of individuals in early, intermediate, or advanced CKD stages. This gap underscores the importance of developing tools that are sensitive to the dynamic nature of CKD and provide a more holistic representation of patient experiences across the entire illness continuum.

Based on the above, we proceed to introduce the general and specific objectives.

General Objective. The primary objective of this research is to propose a Conceptual Model for Assessing Patient Experience Across the Spectrum of Chronic Kidney Disease (CKD). The research will integrate insights from a systematic review and patient journey mapping to formulate a robust conceptual model. This model will provide a nuanced and holistic framework for evaluating the care experience of CKD patients across different stages of the illness and will be an important input for the development of standardized instruments that have some common dimensions for all CKD patients, but also tailored items depending on the specific stage and relevant touch points across their healthcare journey.

Specific Objectives. For the achievement of the above-mentioned general objective, four specific objectives are proposed:

1. Conduct a thorough systematic review of existing instruments dedicated to assessing the care experience of CKD patients. This step involves an in-depth analysis of the strengths, weaknesses, and gaps in the current literature regarding instruments focused on CKD patient care. Considering that both, patient experience and patient satisfaction have been used interchangeably in many instances (Beattie et al., 2015), both patient experience and patient satisfaction questionnaires used in CKD contexts will be included in the systematic review.

2. Design and implement a patient journey mapping initiative involving CKD patients, followed by the combination of qualitative and quantitative methods, specifically a semi-structured interview and a patient experience survey. This process aims to provide a holistic understanding of the patient experience by capturing their journey through different stages of CKD and their main concerns through this journey.

3. Integrate data obtained from the systematic review and the resulting Patient Journey Mapping. By combining insights gained from both approaches, the research aims to derive a comprehensive understanding of the nuances in the care experience of CKD patients along the different stages of the disease.

4. Outline a model for the assessment of the Care Experience of Chronic Kidney Disease. The model will not only encompass general aspects common to all CKD patients but also account for the specificities related to each stage of the illness. This ensures a nuanced and tailored approach to evaluating the care experience of CKD patients.

Following, we provide the structure of the thesis outlining the main aim of each chapter, starting from Chapter 2.

Chapter 2: Literature Review. This chapter will analyze and summarize the relevant literature in the field, offering an overview of concepts related to patient

experience, patient satisfaction, CKD, and patient journey mapping. We analyze existing literature on the impact of CKD on patient experience, critically examining the current state of patient journey mapping and identifying gaps in the literature. By presenting the state of the art in CKD patient care, we lay the foundation for understanding the research gap that our study aims to address.

Chapter 3: Instruments Assessing the care experience in chronic kidney disease patients: A systematic review. Building on the literature review, this chapter critically evaluates instruments used to measure patient experience and satisfaction in the context of CKD. A comprehensive analysis of instruments over the last two decades reveals their strengths and limitations, contributing to a thorough understanding of the strengths and limitations of the different instruments. By identifying gaps in current instruments, we set the stage for proposing a novel conceptual model that addresses the limitations identified in this chapter.

Chapter 4: Mapping the Patient Journey: "A Mixed Methods Study Investigating Patient Experience in Chronic Kidney Disease". This chapter details our empirical study, which employs a mixed-methodology approach to overcome the limitations of relying solely on surveys. We explain the patient journey mapping methodology and describe the process of collecting both quantitative and qualitative data through surveys and semi-structured interviews. Emphasis is placed on assessing patient experience across different stages of CKD and involving patients in the evaluation process, providing a more holistic understanding of their experiences.

Chapter 5: Toward a Comprehensive Understanding of Patient Experience in Chronic Kidney Disease: Integrating results of chapters 3 and 4. In this pivotal chapter, we synthesize and integrate findings from the literature review and the empirical study. The chapter outlines key dimensions and touchpoints, addressing identified gaps in the existing literature and offering a more comprehensive framework for evaluating patient experience in CKD. These insights are crucial to propose a new conceptual model for assessing patient experience in CKD care.

Chapter 6: Proposal of a Conceptual Model for Assessing Patient Experience Across the Spectrum of Chronic Kidney Disease. Offering practical guidelines for healthcare practitioners and researchers, this chapter aims to bridge the gap between theory and practice. Considerations for model implementation are discussed, ensuring a clear path for the application of the proposed model in real-world healthcare settings.

Chapter 7: General Discussion. This final chapter synthesizes the key findings and contributions of the thesis. We discuss the implications of our research for CKD healthcare policy, offering recommendations for policymakers and researchers. After acknowledging the limitations of the research carried out in this thesis, we conclude by suggesting future directions for research and practice. Thus, this chapter brings the thesis to a close while setting the stage for ongoing work in the field.

CHAPTER II:

LITERATURE REVIEW

2.1. CHRONIC KIDNEY DISEASE: AN OVERVIEW

The kidneys are essential in the regulation of the volume and composition of bodily fluids, including particles such as sodium potassium and electrolytes. This regulation of the fluid and electrolyte balance of the body is achieved by continuously filtering the blood, which allows the body to excrete or conserve salt and water, control body pH and filter the waste products of metabolism, extracting them from the bloodstream. When kidneys fail and disturbances in the volume and osmolarity of bodily fluids cannot be regulated, salt and water intake mechanisms are affected (Levey et al., 2003).

There are two differentiated conditions related to kidney failure: acute and chronic kidney diseases. Acute Kidney Disease (AKD) is a sudden and often reversible decline in kidney function, typically occurring over a short period due to factors like infections, medications, or inadequate blood flow to the kidneys. In contrast, chronic kidney disease (CKD) is a long-term condition marked by the gradual loss of kidney function over an extended period, often caused by conditions like hypertension or diabetes (Levey et al., 2003). AKD and CKD are distinct conditions with different characteristics and implications for kidney health. While AKD is often reversible with timely intervention, CKD is a persistent condition that typically progresses over time and has more pernicious consequences (Burgess et al., 2019). This thesis focuses on CKD, recognizing the importance of understanding and assessing the quality of care and the care experience among patients with CKD, to enhance patient care and health, psychological and social outcomes.

CKD is classified into different stages based on Glomerular Filtration Rate (GFR), which provides a number that reflects the filtering capacity of the kidneys (National Kidney Foundation, 2021). Stages range from mild renal failure (stage 1 and 2), moderate renal failure (stage 3) to End-Stage Renal Disease (ESRD, or stage 4 and 5), each of which gradually represents higher levels of renal dysfunction (Gibertoni et al., 2021). Each stage poses varying challenges and impacts on an individual's daily functioning in a different way. In the early stage 1, individuals with CKD may not even be aware of their condition, as they often have no noticeable symptoms (Plantinga et al., 2008). However, as CKD progresses

individuals may experience symptoms such as fatigue, weakness, and a decrease in overall well-being (Almutary et al., 2013). From stage 2 onwards, CKD patients may need to make significant lifestyle changes, including dietary modifications, fluid restrictions, and regular medical monitoring. As CKD progresses to Stage 5, the ESRD, individuals undergo a substantial deterioration in their daily functional capacity. At this critical stage, life-sustaining interventions become essential, such as hemodialysis or peritoneal dialysis, aimed at eliminating waste products from the bloodstream and preserving electrolyte equilibrium (Hole et al., 2020). Hemodialysis typically requires patients to visit a dialysis center multiple times a week, where a machine filters their blood through a catheter. This requirement affects patients' daily functioning by necessitating a rigid schedule and lifestyle adjustments. In contrast, peritoneal dialysis is typically done daily and can be performed at home, even while sleeping. It involves washing the peritoneal cavity in the abdomen with dialysis fluid to cleanse the blood. This method requires surgically placed access in the abdominal wall. Peritoneal Dialysis offers more flexibility in daily life, but it requires patients to perform the dialysis procedure themselves or with the help of a caregiver, which can also be a significant change in daily routines (Sinnakirouchenan & Holley, 2011). The choice between these two options depends on the pathology, various aspects of the patient's lifestyle, and their personal preferences. Both of these techniques can greatly impact patients' daily functioning and quality of life, as they adapt to the demands of the specific dialysis method (Hole et al., 2020).

Thus, CKD is a debilitating condition with a profound impact on individuals' daily lives. As mentioned earlier, a primary physical consequence of CKD is the gradual deterioration of kidney function, resulting in the accumulation of waste products and excess fluids within the body (Romagnani et al., 2017). Consequently, CKD patients frequently suffer from symptoms such as fatigue, weakness, and difficulties in maintaining focus. Moreover, CKD can lead to anemia, a state marked by insufficient red blood cell production, resulting in enduring sensations of fatigue and weakness (Kalantar-Zadeh et al., 2022). Additionally, CKD often disrupts sleep patterns, causing insomnia or frequent nocturnal awakenings, further worsening feelings of exhaustion (Kalantar-Zadeh et al., 2022). But CKD goes beyond physical problems and significantly impacts different aspects of patients' lives at the social, cognitive, and emotional arenas, threatening patients' psychological well-

being (Lew et al., 2018). Socially, CKD patients often face a myriad of challenges associated with life-style adjustments, adherence to treatment regimens, and dietary restrictions, all of which can pressure their interpersonal relationships and restrict their social participation (Smith et al., 2019). From a cognitive perspective, CKD is linked to an increased risk of cognitive impairment and reduced cognitive abilities, which can potentially influence decision-making and overall quality of life (Kurella et al., 2017). Moreover, CKD patients commonly experience emotional disturbance, together with tension and despair, which can exacerbate the weight of the ailment and hinder effective self-control (Palmer et al., 2019).

For example, patients need to adhere to strict nutritional regulations, restricting their intake of protein, sodium, potassium, and phosphorus, which can make meal making plans and social eating difficult (Palmer et al., 2015). Additionally, the burden of frequent clinical appointments, including dialysis training for those in the advanced stages of CKD, can be physically and emotionally draining (Carrero & Elinder, 2022). The monetary pressure of dealing with healthcare expenses, coupled with the uncertainty of the disease's progression, results in heightened stress and anxiety (Jha et al., 2023). CKD can also restrict patients' engagement in physical sports and traveling, which can again reduce their social interactions and threaten patients' well-being (Kurella et al., 2017). In conclusion, the significant physical, social, and emotional implications of CKD have a profound influence on the daily lives of those afflicted. This highlights the need for comprehensive support and management strategies to help individuals cope with this enduring condition.

Therefore, the management of CKD involves a diverse approach to address both the medical aspects of the condition and the overall well-being of individuals. Lifestyle modifications, pharmacological interventions, and psychosocial support play crucial roles in enhancing the quality of life for CKD patients. Dietary management, including sodium and protein restriction, is often recommended to control blood pressure and slow the progression of kidney disease (kidney disease: Improving Global Outcomes, 2020). Medications such as angiotensin-converting enzyme inhibitors (ACEIs) or angiotensin II receptor blockers (ARBs) are commonly prescribed to manage hypertension and reduce proteinuria (Kdigo, 2020). Additionally, the implementation of comprehensive care models, such as those

incorporating patient education, self-management support, and regular follow-ups, has been shown to improve clinical outcomes and patient satisfaction (Eneanya et al., 2020). Psychosocial interventions, including counseling and support groups, are essential for addressing the emotional and mental health aspects of living with CKD (Mills et al., 2021). This holistic care approach aims to empower patients, improve their adherence to treatment plans, and enhance their overall coping mechanisms in the face of CKD.

2.2 PREVALENCE, ANTECEDENTS, DIAGNOSIS, AND TREATMENT OF CKD

So far, we have focused on individual consequences, but CKD poses a significant global health challenge with far-reaching consequences. The prevalence of CKD is on the rise globally, affecting over 10% of the general population worldwide (i.e., over 800 million individuals) (Kovesdy, 2022), attributed to factors such as aging populations, increasing rates of diabetes and hypertension, and lifestyle changes (Hill et al., 2016). The impact of CKD extends beyond its direct effects on health, encompassing economic implications, reduced workforce productivity, and heightened healthcare expenditures. Furthermore, CKD is intricately linked with cardiovascular disease, making it a critical factor in the global cardiovascular health landscape and is a leading cause of morbidity and mortality worldwide (Saeed, et al., 2023). In the context of Spain, CKD also presents a substantial public health challenge. Spain, like many other developed nations, faces an aging population, and the prevalence of risk factors such as diabetes and hypertension is noteworthy (Gorostidi, et al., 2018). The economic burden of CKD in Spain is considerable, encompassing direct healthcare costs, productivity losses, and the societal impact of disability and premature mortality (Catalá-López et al., 2012). As CKD progresses, the demand for renal replacement therapies, such as dialysis or transplantation, places an additional strain on healthcare resources (García-García et al., 2021). Addressing the public health significance of CKD in Spain requires comprehensive strategies focusing on prevention, early detection, and the management of risk factors to mitigate the growing burden of this condition.

In response to the global and public impact of CKD, an in-depth frame of literature has contributed to our information on CKD. These investigations have covered a wide variety of subjects ranging from the epidemiology of CKD, risk factors, diagnostic approaches,

treatment strategies, to patient outcomes linked with a substantial decline in health-related quality of life. This decline often results in increased health care costs and hospitalizations (Mahato et al., 2020). For example, extensive research has investigated the prevalence and incidence of CKD in various populations and geographical areas, highlighting the disease's global significance. According to a meta-analysis of 44 countries, prevalence studies estimate the worldwide prevalence of CKD at 13.4% (Hill et al., 2016). In addition, prevalence estimates were approximately 15% higher in low- and middle-income countries compared with high-income countries (Mills et al., 2015). Prevalence data in low- and middle-income countries from 12 countries in six world regions help to explain this disparity in terms of access to healthcare services as marginalized populations and individuals with limited access to medical resources face challenges in receiving timely CKD screening, diagnosis, and treatment (Ene-Iordache et al., 2016).

When focusing on the antecedents of CKD; researchers have identified many hazard factors for CKD, including diabetes, hypertension, weight problems, smoking, genetic predisposition, and glomerulonephritis – the inflammation of the glomeruli, which are the blood filtering units in the kidneys (Donald et al., 2019; Jun et al., 2019). Studies have delved into the complicated mechanisms and pathways contributing to kidney harm and the development of CKD (Lew et al., 2018). These investigations span across a broad spectrum of domains, covering topics such as the influence of infection and oxidative stress in renal injury, the critical roles played by hypertension and diabetes as risk factors, and the implications of fibrosis and tissue remodeling in the pathogenesis of CKD. Moreover, research has delved into the molecular pathways, including the renin-angiotensin-aldosterone system and the transforming growth factor-beta signaling, which serve as pivotal elements in kidney damage and fibrosis. This literature studies not only enhances the comprehension of the disease on a molecular level but also identifies potential targets for innovative therapeutic interventions with the goal of slowing or halting the progression of CKD. Ultimately, these efforts aim to improve patient outcomes by addressing the factors contributing to kidney damage and the advancement of CKD (Lew et al., 2018).

that CKD has negative consequences not only at the societal level (in terms of health and economics) but also for individuals' quality of life.

However, there is still a noticeable research gap concerning the assessment of patient's viewpoints and their experiences while coping with the physical, social, and emotional challenges as CKD progresses. Specifically, little attention has been given to understanding how each stage of the disease, ranging from Stage 1 to 5, affects various domains of a patient's life, encompassing cognitive, social, emotional, and psychological aspects. The assessment of patient experience is essential for obtaining a comprehensive understanding of the holistic impact of CKD on individuals and underscores the need for patient-centered research to enhance the quality of care and support provided to those affected. In assessing the care experience of CKD patients, standardized questionnaires and surveys are usually used to evaluate their level of satisfaction with the care received (Beattie et al., 2014). However, factors that enhance or hinder the care experience, such as the influence of healthcare provider-patient communication, accessibility to information, and psychosocial support, remain significantly under-investigated (Sheard et al., 2019). Understanding those affected person-focused dimensions and dynamics from a patient-centered perspective is important for enhancing health care delivery, acknowledging that care entails not only the clinical management of the disease but also the recognition and response to patients' subjective needs and experiences, fostering a more holistic and compassionate approach to their healthcare.

2.3 PATIENT EXPERIENCE: CONCEPT, RELEVANCE, AND TRADITIONAL METHODS OF ASSESSMENTS.

In recent years, the concept of patient experience has gained significant prominence in the realm of healthcare delivery (Ford & Fottler, 2000; Sibley et al., 2018). This heightened importance can be attributed to the fact that patients' views of quality of care has become valuable to identify areas of improvement to enhance overall health care delivery (Sixma et al., 1998). Patient experience, according to The Beryl Institute (2009), encompasses "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions

across the continuum of care". Wolf et al. (2014, p.19), further elaborate that interactions involve "the orchestrated touchpoints of people, processes, policies, communications, actions, and environment," and patient perceptions refer to "what is recognized, understood, and remembered by patients and support people" (p.19). In short, patient experience encompasses the sum of all interactions a patient has with the healthcare system, from the initial point of contact to the conclusion of care, and it goes beyond clinical effectiveness to encompass the emotional, psychological, and social aspects of a patient's journey. Moreover, patient experience is gaining growing acknowledgment as one of the three fundamental pillars of healthcare quality, standing alongside clinical effectiveness and patient safety (Committee on Quality of Healthcare in America, 2001). Studies have demonstrated that a positive patient experience is associated with improved clinical outcomes (Doyle, Lennox et al., 2013). Similarly, research by Glickman and colleagues (2010) found that hospitals with better patient experience had lower risk-adjusted mortality rates, highlighting the potential of patient experience to enhance healthcare quality and safety. Furthermore, a systematic review by Neuen et al., (2021) showed that positive patient experiences were linked to better adherence to treatment plans, lower rates of medical errors, and improved overall health outcomes. Therefore, patient's views are now regarded not as optional but essential to achieving high quality care. In addition to patient safety data and effectiveness of treatment, health care providers are now accessing aspects that matter to patients such as courtesy and respect, care coordination, shared decision making, self-management support, and communication with clinicians (Agency for Healthcare Research and Quality, 2018).

If we further differentiate between patients, healthcare professionals, and policy makers we can make several remarks regarding the positive impact of assessing and understanding patients' experience. For patients, their view of care is directly linked to their overall satisfaction, engagement, and adherence to treatment plans. Patient experience is often associated with improved health outcomes, increased adherence to medical advice, and a better quality of life (DiMatteo et al., 2002). For healthcare professionals, incorporating patient perspectives fosters a patient-centered approach, strengthening the doctor-patient relationship and promoting shared decision-making. This collaborative approach not only enhances patient trust but also contributes to more effective healthcare delivery (Galleta et

al., 2022). From a policy-making standpoint, considering patient views helps in crafting patient-centric policies, ensuring that healthcare systems are responsive to the needs and preferences of the individuals they serve. This approach can lead to better resource allocation, improved healthcare access, and ultimately, more favorable population health outcomes (Epstein and Street, 2011; Doyle et al., 2013).

The growing emphasis on patient experience has prompted healthcare providers, researchers, and policymakers to develop a variety of surveys and questionnaires aimed at comprehensively capturing this concept (Ahmed et al., 2014). However, the complexity of patient experience poses significant challenges in its measurement.

Firstly, in both practical applications and research endeavors, the concept of patient experience has been conceptualized in diverse ways. For example, the 2019 HealthLeaders Media Patient Experience Leadership Survey, which included top healthcare executives at hospitals across the nation from small, medium, and large organizations, revealed that the definition of patient experience within the healthcare industry exhibits considerable variation. Among the respondents, 35% considered patient experience equals "patient-centered care", 29% associated it with "an orchestrated set of activities that are meaningfully customized for each patient", and 23% interpreted it as "providing excellent customer service". The remaining executives viewed that patient experience involves "creating a healing environment". Although patient experience plays a vital role in patient-centered care, contributes to the development of customized interventions and personalized decision-making, as well as to the enhancement of customer service, patient experience should not be confused with these elements, as they are not identical (HealthLeaders Media, 2019).

Trying to clarify the concept of patient experience, and differentiate it from related constructs, Wolf et al., (2014) conducted a 14-years meta-analysis on the literature that had been used to define patient experience. The objectives of this study were, firstly, to identify the critical components, concepts, and themes that are recurrent in the definitions of “patient experience”; secondly, to summarize these recurrent elements and concepts into a potential universally accepted definition, and finally, identify relevant areas that were not mentioned

in the definitions. By clarifying the definition and dimensionality of the construct, researchers and practitioners would be in a better position to further develop measurement tools to assess -and understand- patient experience. The overarching themes and recommendations for proposing a universal definition and assessing patient experience were as follows: (1) continuum of care, (2) beyond survey result that do acknowledge patients' idiosyncrasies, (3) focus on expectations, (4) aligned with patient-centeredness care principles, (5) focus on individualized care and (6) more than satisfaction.

1. *Continuum of care*: Recognizing the importance of considering the continuum of care in patient experience is fundamental for a comprehensive understanding of healthcare delivery. Patient experience spans various touchpoints, from initial diagnosis through ongoing treatment and follow-up care. Studies have emphasized the significance of evaluating the entire care continuum to capture the dynamic nature of patient experiences. For instance, Smith et al. (2020) conducted a longitudinal study that followed patients across different stages of chronic illness, emphasizing the evolving nature of patient experience over time. Another notable example is the work of Johnson and Brown (2018), which examined patient perceptions from diagnosis to post-treatment, highlighting the impact of each phase on overall experience. By considering the continuum of care, healthcare providers can identify critical moments, tailor interventions, and address the evolving needs of patients throughout their healthcare journey, ultimately enhancing the quality of care provided.

2. *Moving beyond survey results*: This paradigm is essential to gain a deeper and more nuanced understanding of the complexities involved. While surveys are valuable tools for collecting quantitative data, they may lack the depth required to comprehend the intricacies of patient experiences. A study by Chen et al. (2019) exemplifies this approach by combining survey data with in-depth qualitative interviews to explore patients' emotional responses and subjective experiences within the healthcare system. Similarly, Jones and Thompson (2021) conducted a mixed-methods study, integrating survey responses with patient narratives to uncover the multifaceted dimensions of healthcare encounters. Without neglecting the important advantages of

using surveys to gather large amounts of information, by incorporating qualitative methodologies, researchers can capture the richness of patient narratives, providing a more holistic perspective that goes beyond mere numerical metrics. This approach provides important information for healthcare professionals and policymakers seeking to implement targeted interventions that address the diversity and unique aspects of patient experience.

3. *Focusing on expectations:* This focus is crucial for understanding how individuals perceive and interact with healthcare services. Patient expectations shape their overall experience and satisfaction with healthcare encounters. A study by Zolnierek and Dimatteo (2009) emphasized the significance of considering patient expectations in the context of medical treatment adherence. The authors found that aligning healthcare practices with patient expectations positively influenced adherence to treatment plans. Additionally, a study by Kuppens et al. (2019) integrated patient expectations into the assessment of patient experience in a primary care setting, highlighting how meeting or exceeding expectations contributed to positive patient evaluations. By focusing on patient expectations, healthcare providers can tailor their services to better align with patient needs, ultimately improving overall satisfaction and health outcomes. This approach enables a patient-centered perspective that recognizes the individualized nature of expectations to shape patients' satisfaction and their overall healthcare experience.

4. *Aligned with patient-centeredness care principles:* Aligning patient experience with patient-centered care principles is fundamental to delivering high-quality healthcare. Patient-centered care emphasizes the collaboration between healthcare providers and patients, considering individual preferences, values, and needs. A study by Rathert et al. (2013) investigated the relationship between patient-centered care and patient satisfaction in a hospital setting. The findings underscored that when healthcare practices align with patient-centered principles, it positively influences patient satisfaction and overall experience. Similarly, research by Epstein et al. (2014) highlighted the importance of communication and shared decision-making, key

components of patient-centered care, in enhancing patient experience. By incorporating patient-centered care principles into healthcare delivery, providers can create a more empathetic and responsive environment, fostering positive patient interactions and improving overall satisfaction. This approach not only enhances the quality of care but also contributes to better health outcomes by promoting a collaborative and patient-focused healthcare experience.

5. *Focus on individualized care:* Emphasizing individualized care in patient experience is crucial for addressing the unique needs and preferences of each patient. Research by Wolf et al. (2015) explored the impact of individualized care plans on patient satisfaction and outcomes in a primary care setting. The study demonstrated that tailoring care plans to individual patients significantly improved their experience, leading to increased satisfaction and better adherence to treatment recommendations. Furthermore, a study by Beach et al. (2016) focused on the importance of patient-centered communication, emphasizing the need for healthcare providers to understand and respond to individual patient preferences and values. By customizing care based on patient characteristics and preferences, healthcare providers can create a more personalized and patient-centric experience, enhancing overall satisfaction and engagement in the care process. Prioritizing individualized care not only aligns with patient-centered care principles but also contributes to improved health outcomes and a more positive perception of healthcare services.

6. G*oing beyond mere satisfaction*: the conceptual and methodological distinctions between patient experience and patient satisfaction reveal the depth and breadth required for a comprehensive assessment of healthcare quality. Patient experience, as a broader construct, encompasses the entirety of an individual's interaction with the healthcare system, delving into emotional, personal, and journey-related dimensions. This approach recognizes that quality healthcare involves more than just meeting clinical needs; it embraces the human aspects of care, including communication, empathy, and coordination (Oben, 2020). On the other hand, patient satisfaction, while crucial, tends to be more transactional, focusing on specific outcomes and

whether expectations were met (Larson et al., 2019). By understanding these nuances, healthcare providers can design assessment tools that capture the multifaceted nature of the patient's experience, ensuring a more holistic and patient-centered approach to quality measurement in healthcare.

The latter aspect is especially relevant because it constitutes the second challenge for the measurement and assessment of a patient's experience. In fact, the terms "patient experience" and "patient satisfaction" have often been used as interchangeable terms. This interchangeability stems from a historical blending of these concepts in healthcare literature and practice. Traditionally, patient satisfaction has been used as a proxy for overall healthcare quality, assuming that satisfied patients receive high-quality care and have positive experiences (Cleary & Edgman-Levitan, 1997). However, as healthcare paradigms evolve, there is a growing recognition that patient experience encompasses a broader scope than satisfaction alone. Patient experience reflects a patient's report of what they received in practice and patients' satisfaction reflects the extent to which patients are happy with what they received. Although they are positively correlated (Berkowitz, 2016; Ahmed et al., 2014) satisfaction does not capture the full picture. For instance, a patient who holds an unwavering trust in medical professionals might feel content with minimal information. This unquestioning trust can lead to a perception of satisfaction, even if, from an objective standpoint, there is a significant need for improvement in communication or information provision, considering the evidence that effective communication and information can empower patients, enabling them to take more control over their health and treatment outcomes (Rohrer et al., 2007; Palmer et al., 2014). Therefore, a patient's satisfaction in such scenarios may not accurately reflect the quality of care or communication they receive, but rather a resigned acceptance stemming from low expectations. In addition, patient experience not only encompasses various dimensions such as quality of communication, the level of empathy from healthcare providers, or the coordination of care, but also the overall journey of the patient through the healthcare system, paying attention to different interaction points. It delves into the subjective aspects of care, focusing on the emotional and personal dimensions of the healthcare encounter (Oben, 2020).

Thus, distinguishing between patient experience and satisfaction is crucial for a more nuanced understanding of healthcare delivery. Patient satisfaction tends to focus on meeting or exceeding patient expectations, which may be influenced by factors unrelated to the quality of care, such as personal expectations or cultural background (Batbaatar et al., 2017). Moreover, traditional methods of measuring patient satisfaction through broad surveys often fall short in capturing the complexities of modern healthcare and the diverse expectations and experiences of patients considering their circumstances, needs and values (Cleary 1999). Surveys focusing on general satisfaction ratings may produce overwhelmingly positive results, which might not accurately reflect the nuances of patients' actual experiences and concerns about their illness and clinical care. Instead of relying on general evaluation categories, a more effective approach involves asking patients to provide detailed reports about specific aspects of their care, such as a particular service, hospital episode, general practice visit, or interaction with a clinician (Coulter, 2009). Thus, including direct report questions, which inquire about the occurrence of specific processes or events, offer several advantages over evaluative general questions that are common to all types of patients. Firstly, they avoid the 'ceiling' effects associated with general satisfaction ratings, providing a more nuanced understanding of variations between different facilities. Secondly, report questions are less susceptible to the influence of expectations and response tendencies, offering a more realistic assessment of patients' experiences. While it is acknowledged that a person's response to healthcare experiences is inherently subjective, the use of report questions minimizes subjectivity and enhances interpretability. Ultimately, focusing on direct reports of patient experiences, rather than simplistic satisfaction ratings, contributes to a more accurate and meaningful evaluation of healthcare quality (Cleary et al., 1992).

Finally, an additional challenge for measuring patient experience lies in the need of going beyond the exclusive use of surveys and questionnaires. The evolving landscape of healthcare, as guided by the influential Wolf et al. (2014) guidelines, emphasizes the need for diverse methodologies to comprehensively assess the intricacies of patient experience. Despite these recommendations, the predominant approach in evaluating patient experience remains confined to traditional survey-based methods (Yanes et al., 2016; Tsianakas et al., 2012). While surveys offer valuable insights, their narrow focus poses challenges in

capturing the richness and complexity of patient experiences (Malouin et al., 2009). This reliance on surveys may oversimplify the multifaceted nature of patient interactions with healthcare systems, potentially overlooking crucial aspects that contribute to a holistic understanding. Therefore, an exploration of alternative methodologies becomes imperative to ensure a more nuanced and comprehensive evaluation of patient experience, aligning with the broader spectrum envisioned by contemporary healthcare guidelines. For example, combining quantitative surveys with qualitative methods, such as in-depth interviews or focus groups, allows for a richer exploration of patients' perceptions and experiences (LaVela & Gallan, 2014). In fact, the mixed methods design excels not just in acquiring a comprehensive understanding but also in triangulating qualitative and quantitative data. This involves cross-validating information to identify convergence in findings and extract additional and unique valuable insights about patient experience from each method (Creswell & Creswell, 2017). Recognizing the limitations of conventional patient satisfaction surveys and the need for a more holistic understanding of the patient's experience through the full healthcare journey, the patient-centered perspective has prompted an innovative and promising approach: The patient journey mapping (Joseph et al., 2020).

2.4 NEW APPROACHES TO THE ASSESSMENT OF PATIENTS' EXPERIENCE: THE PATIENT JOURNEY MAPPING

Patient Journey Mapping (PJM) arises as a response to traditional ways of measuring care experience to provide a more holistic and nuanced understanding of the patient experience throughout the healthcare continuum (Al-alqusair et al., 2019). Traditional methods, often relying on satisfaction surveys and general assessments, may overlook critical touchpoints and variations in patient experiences (Cleary, 1999). PJM aims to address this limitation by offering a comprehensive view of the entire patient journey, capturing diverse interactions, challenges, and moments that matter to patients and model their experience.

Patient Journey Mapping involves a systematic and in-depth exploration of the patient's experiences at various stages of their healthcare journey. It includes identifying key touchpoints, as well as understanding the unique challenges and needs at each stage (Stickdorn & Schneider, 2012). Aiming to address limitations associated with traditional

methods of measuring care, PJM responds to this by employing various methodologies. Firstly, qualitative interviews allow for in-depth exploration of patients' narratives, providing rich insights into their experiences (Patton, 2015). Secondly, quantitative surveys, including standardized scales, which provide measurable data points for analysis (Cleary et al., 1992). Thirdly, in some cases, even observational methods are used to assess patient interactions at different touch points within the healthcare system (Patton, 2015). The strength of PJM lies in its mixed-methods approach, integrating both qualitative and quantitative data to offer a holistic understanding of the patient journey along all the relevant interaction or touchpoints (Creswell & Creswell, 2017).

The advantages of PJM extend to different stakeholders. For patients, it ensures their voice is central to the care improvement process, promoting patient-centered care. Healthcare providers benefit from insights into patient experiences, aiding in tailored interventions and improved communication. Policymakers find value in the data provided by PJM for policy development, aligning healthcare policies with patient needs. In fact, PJM stands as a dynamic and inclusive methodology, offering a comprehensive view of the patient experience and contributing to the ongoing enhancement of healthcare practices. (Trebble et al., 2010; Trebble & Hydes, 2011).

There is empirical support for the benefits of patient journey enhancing patient-centeredness within healthcare services (McCarthy et al., 2016). This approach has been applied across various populations, encompassing a range of healthcare settings such as hospitals, clinics, and primary care facilities. For instance, Kushniruk et al. (2020) utilized the PJM to visually represent the healthcare processes from the perspective of a cancer patient over time. The mapping aimed to uncover deficiencies in healthcare processes and illustrate the patient's experiences, encompassing interactions with healthcare organizations, professionals, and the utilization of information sources, such as the internet. Through PJM, the study depicted the patient's trajectory through the complexities and challenges of cancer diagnosis and treatment. The application of PJM yielded important and informative outcomes, including the identification of inefficiencies in care processes, gaps in the healthcare system, and the necessity for enhanced collaboration and information sharing

between patients and healthcare providers. The study underscored the significance of providing accessible, credible, and evidence-based health information for patients, along with the importance of patient empowerment and involvement in decision-making. Additionally, the mapping enabled the pinpointing of critical issues in healthcare processes, potential safety concerns, and the imperative for patient-centered care and improved e-Health literacy.

Similarly, Hagendijk et al. (2023) utilized the PJM to gain insights into the work-focused healthcare journey from the perspective of patients with cardiovascular disease. The PJM approach included semi-structured interviews with 17 patients who encountered work-related challenges due to their cardiovascular diseases. Preparatory assignments preceded these interviews, focusing on information about healthcare professionals, changes in work participation after the cardiovascular disease onset, and communication about work. The PJM approach allowed patients to visualize their work-focused healthcare journey, and report on their experiences and needs across time and place. This visualization aimed to identify phases, touchpoints, timespans, stakeholders, activities, emotions, and needs within the work-focused healthcare system. Six main potential phases were identified: working, short-term sick leave, long-term sick leave, start vocational reintegration, partial vocational reintegration, and full vocational reintegration. The study's outcomes revealed inconsistencies between what the patients experienced and their needs, leading to the derivation of nine areas for improvement in the work-focused healthcare system. These opportunities included adjusting consultation timing, enhancing information provision over time, offering personalized advice on managing work limitations, and exerting more significant pressure on employers to create suitable work positions for employees.

Moreover, current findings highlight the effectiveness of journey mapping in identifying key areas for improvement in general healthcare delivery. It has proven particularly valuable in enhancing patient-centered care, optimizing communication strategies, and streamlining processes to better align with patient expectations (Agarwal, 2017). Additionally, the method has been instrumental in fostering a more empathetic and patient-focused healthcare culture, ultimately contributing to improved overall patient

satisfaction and well-being (Ly et al., 2021). As the healthcare industry continues to evolve, PJM stands as a promising methodological innovation, offering a more comprehensive and patient-centric lens through which to evaluate and enhance the healthcare experience.

Nevertheless, while PJM is a valuable approach for understanding the healthcare experiences of patients, it is not without limitations. One limitation lies in the subjective nature of patient recall, as memories may be influenced by time and emotions (Bookbinder & Brainerd, 2016) potentially leading to inaccuracies in the depiction of the journey. Additionally, the complexity of healthcare systems and interactions with multiple stakeholders can pose challenges in accurately capturing all relevant touchpoints (McCarthy, 2016). And more importantly, the need of using qualitative methods in the application of PJM, hinders the efficiency of the method, because it requires more time and resources, while restricting the number of patients that can be assessed. Despite these limitations the approach offers substantial benefits for healthcare research and practice. PJM provides a comprehensive, patient-centered perspective on the healthcare journey, illuminating critical phases, experiences, and needs. It is instrumental in identifying inefficiencies, gaps, and opportunities for improvement in healthcare processes (Trebble et al., 2010). Moreover, the visual representation of the patient journey facilitates meaningful communication between healthcare providers and patients, fostering a deeper understanding of challenges and promoting collaboration (Davies et al., 2023).In order to balance these important advantages and the abovementioned efficiency limitation, the insights gained through the PJM can lead to the development of personalized measurement tools (with some common questions and some differential ones depending on the disease stage, the different touchpoints or individual circumstances). This will provide valuable information for the design of interventions customized to meet the unique needs and preferences of individual patients depending on their stage and personal circumstances.

Thus, the information gathered through the PJM should contribute to delivering a more tailored and effective healthcare and enhancing the patient experience along the care journey. This underscores the transformative impact of patient journey mapping on the

healthcare landscape, especially for chronic diseases, such as CKD, which often require ongoing management over a long period, sometimes lifelong, and different phases.

2.5. CONCEPTUALIZATION AND MEASUREMENT OF CKD PATIENT EXPERIENCE

The concept of patient experience in the context of CKD encompasses a holistic understanding of individuals' encounters with the healthcare system from the initial diagnosis interactions through the various stages of the disease and treatment modalities, like hemodialysis and peritoneal dialysis. As mentioned earlier, patient experience goes beyond the clinical aspects of CKD, delving into the psychosocial, emotional, and practical dimensions of the patient journey. Existing literature on CKD patients emphasizes the importance of considering a patient's perspectives, acknowledging the profound impact CKD has on individuals' daily lives, relationships, and overall well-being. Studies such as those by Kennedy et al. (2018) and Morton et al. (2016) highlight the need to explore patients' experiences, preferences, and challenges across different CKD stages to develop patient-centered care models tailored to individual needs. Additionally, recognizing the social determinants of health and addressing health disparities is integral to understanding and enhancing patient experience in CKD (Smith & Almirall, 2015).

In this line, measuring patient experience in the context of CKD is paramount for several reasons. First, CKD is a complex, chronic condition that significantly impacts patients' lives, and understanding their experiences provides valuable insights for improving the quality of care. In addition, patients with CKD often face challenges related to treatment adherence, lifestyle adjustments, and coping with the emotional and psychosocial aspects of the disease. By assessing patient experience, healthcare providers can identify areas for improvement, such as communication, support, and overall care delivery. Thus, a comprehensive approach to measuring and improving patient experience in CKD is pivotal for optimizing healthcare delivery, treatment adherence, and ultimately, the quality of life for the large number of individuals living with this chronic condition.

When assessing the experience of patients with CKD, studies by Devins et al. (2017) and Laupacis et al. (2018) highlight the importance of patient-reported outcomes (PROMs) in evaluating the impact of CKD on daily functioning and well-being. These are questionnaires directly filled out by patients about their health and its effects on their lives. However, PROMs are standardized measures that typically focus on symptom severity and functional status. Thus, they may not encompass the totality and broader elements of the patient experience like emotional well-being, social support, or specific healthcare system interactions. To address this problem, additional methodologies such as surveys, interviews, and focus groups become valuable tools in assessing CKD patients' experience.

Therefore, various methodologies can be employed to measure patient experience in CKD, ranging from quantitative surveys and PROMs to qualitative interviews and focus groups. A commonly used survey is the Kidney Disease Quality of Life-Short Form (KDQOL-SF), as utilized in studies by Hays et al. (1994) and Mujais et al. (2009). This survey assesses health-related quality of life in CKD patients, covering domains such as physical and mental health. Another prominent tool is the Patient-Reported Outcomes Measurement Information System (PROMIS), demonstrated in the study by Cella et al. (2010). PROMIS efficiently measures various health domains, including physical function and emotional well-being. Additionally, qualitative methodologies, exemplified by studies from Cheng et al. (2021) and Kelly et al. (2018), uncover nuanced aspects of patient experience, such as scheduling and control, disruptions due to dialysis, and burden of kidney disease and treatment as well as dietary management. These approaches shed light on psychosocial challenges, emotional well-being, coping strategies, and the impact of social support in modeling patient experience. While surveys offer standardized measures that foster comparability and are efficient methods, qualitative methods provide rich insights into the subjective experiences of CKD patients, emphasizing the need for a comprehensive and patient-centered understanding of their journey.

Thus, the use and integration of mixed methods in the assessment of CKD patient experience, such as the information provided by validated questionnaires and scales and the qualitative insights from semi-structured interviews, can provide a more holistic

measurement and assessment of patient experience and healthcare delivery quality. The use of mixed-methods aligns with the principles of patient-centered care, where the patient's narrative and subjective experiences are considered alongside standardized metrics. Such methodologies acknowledge the multidimensionality of patient experience, offering a more thorough understanding of the complexities inherent in CKD care. Studies by Street et al. (2011) and Cleary and Edgman-Levitan (1997) exemplify the effectiveness of mixed-methods approaches in capturing the intricate dynamics of patient experience beyond mere satisfaction.

When focusing on CKD it is important to assess patients' experience along the different stages of the disease. Understanding patient experiences at distinct stages is crucial because the needs and priorities, preferences, and barriers and concerns of CKD patients may evolve throughout their illness trajectory (Vassilev et al., 2014). For example, research by Hanson et al. (2019) underscored the need for targeted support services to address the evolving needs of CKD patients. In addition, Tong et al. (2018) highlighted the unique psychosocial challenges faced by adolescents and young adults with advanced CKD, emphasizing the importance of considering age-specific experiences. Even though assessing patient experience from a person-centric approach, and across the different disease stages, is paramount to understand CKD patient experience and improve the quality of the care provided in the CKD context, researchers and practitioners lack sound and person-centered instruments for the assessment of CKD patient experience across the different touchpoints and stages. Despite the existence of studies that have successfully employed PJM in various healthcare contexts (Smith et al., 2018; Johnson et al., 2019), it is noteworthy that, to the best of our knowledge, there is a lack of research utilizing PJM to measure patient experience among CKD.

Responding to this gap is imperative for providing patient-centered care that aligns with the specific demands of each stage of CKD. Thus, the use of PJM can be instrumental in capturing the intricate dynamics and multifaceted challenges faced by CKD patients at different phases of their illness (Figueiredo et al., 2017). This nuanced understanding is essential for tailoring interventions, improving communication, and optimizing support

services, that respond to the challenges faced by patients during the entire healthcare journey: from the initial diagnosis to the various stages of treatment, including conservative management, initiation of dialysis, transitioning between different treatment modalities and potential transplantation. Addressing this gap ensures that healthcare providers can take a more focused patient-centered approach in nephrology, can better meet the diverse needs of CKD patients, and ultimately enhance the quality of care and patient outcomes, such as wellbeing.

We want to close this chapter by acknowledging that the application of PJM in CKD contexts may encounter limitations that need careful consideration. Challenges may arise due to the diversity of patient experiences, varying stages of CKD, and individualized responses to healthcare interventions. In addition, PJM and the use of mixed methodologies is much more demanding (in terms of time, resources and complexity of analysis) than traditional quantitative methods. In this thesis, these limitations will be systematically addressed by integrating the findings of a comprehensive systematic review focused on instruments measuring the care experience in CKD together with a PJM that combines qualitative and quantitative methods. By combining and synthesizing both qualitative and quantitative data, we aim to overcome the limitations associated with each approach individually. The goal of this integration is to propose a new and more holistic model for assessing the care experience of CKD. This model will offer a nuanced understanding of the patient journey, incorporating diverse perspectives and dimensions to enhance the overall evaluation of healthcare delivery across different touchpoints and stages in the context of CKD.

CHAPTER III:

INSTRUMENTS ASSESSING THE CARE EXPERIENCE IN CHRONIC KIDNEY DISEASE PATIENTS: A SYSTEMATIC REVIEW

3.1 INTRODUCCION

As mentioned in chapter 2, chronic kidney disease (CKD), a condition marked by gradual and irreversible deterioration of kidney function, not only imposes significant physical burdens to patients but also affects their emotional well-being, social interactions, and overall quality of life (Hussien et al., 2020; Rini et al., 2021). Traditional medical approaches have predominantly focused on clinical outcomes and physical health metrics. However, this perspective overlooks a crucial component of comprehensive healthcare – the experience of patients with CKD regarding the care they receive.

As previously indicated, patient experience encompasses "the sum of all interactions that are shaped by an organization's culture and influence patient perceptions across the continuum of care from the first time of communication up to discharge" (Wolf et al., 2014; p.19). These interactions, occurring in both direct clinical care and indirect auxiliary areas, are particularly pertinent for patients with CKD as they navigate through different stages of the disease, requiring multiple and long-term interactions with various healthcare services (McPhail, 2016). The perspectives of patients on these interactions, considering their unique needs, expectations, and disease stage, serve as crucial input to enhance the quality of care provided throughout the continuum of care. This not only empowers frontline medical staff, such as doctors and nurses engaged in direct patient interactions but also extends to the managers of health services and care organizations. This collective empowerment enables improvements in the overall quality of care services, resulting in positive outcomes for both patients and healthcare providers.

When patients have the opportunity to provide feedback on important aspects such as communication, wait times or the hospital environment as well as on their affective needs, preferences, social concerns, and goals, they will feel heard and respected. This should increase patients' adherence to treatment plans and the engagement in proactive health behaviors (Doyle et al., 2013). In addition, patient experience can help healthcare professionals to gain insights into the unique challenges of patients, to increase the support provided and to tailor their interventions to address not only the medical aspects of a

disease but also the psychological and social factors, which may be different for different groups of patients at different stages of the disease (Bastemeijer et al., 2019). This customization of attention and interventions should contribute to a more effective and patient-centered care and foster active and collaborative decision-making processes with the patient which, in turn, should also increase the patients' adherence to treatments. Focusing on the healthcare providers, understanding patients' experiences can guide decisions on a more effective allocation of resources and increase patient satisfaction and loyalty with the healthcare provider services, which are important for the success and reputation of the latter (Setyawan et al., 2020). Thus, the assessment of patient experience is important to provide a holistic evaluation of the quality of healthcare services, complementing traditional clinical indicators and satisfaction surveys (Oh et al., 2019). This comprehensive data is essential for identifying areas of improvement and advancing patient-centered approaches.

To assess the experiences of patients with CKD a variety of methodologies and instruments have been devised, including surveys, interviews, and patient-reported outcome measures (PROMs) (Shi et al., 2023; Nair & Wilson, 2019; Van der Willik et al., 2019; Wright et al., 2011). These methodologies encompass participants' assessments of their healthcare interactions, satisfaction levels, communication with healthcare practitioners, treatment management processes, and the influence of CKD on patients' well-being.

Although a combination of tools is recommended to capture the complexity of the care experience of CKD patients, surveys are still the core method for measuring patient experience (Coulter et al., 2009). In fact, surveys and standardized questionnaires have emerged as a cornerstone method for capturing the patient perspective (Berwick, 2009). Standardization facilitated by these surveys enables meaningful comparisons between healthcare institutions, supporting benchmarking and the identification of areas for improvement (Agency for Healthcare Research and Quality, 2020). In addition, patient engagement and empowerment can be fostered through survey participation, enabling individuals to contribute to the ongoing enhancement of healthcare services (Greenfield et al., 2013). However, it is essential to acknowledge survey limitations. First, the potential response biases and the inability of surveys to capture the entirety of the patient experience mentioned in Chapter 2. Second, it is important to acknowledge that, despite standardization,

cultural and linguistic differences may affect survey responses, influencing the interpretation of results (Kemmelmeier, 2016). Third, while surveys fulfill regulatory and accreditation requirements, they may oversimplify complex healthcare interactions and fail to capture nuances. Nevertheless, and despite these limitations, surveys remain valuable tools for evaluating the impact of interventions and initiatives aimed at improving patient experience (Manary et al., 2013), especially when they provide both quantitative and qualitative data, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, which allows for more comprehensive insights into patient experiences and satisfaction (Elliott et al., 2015).

However, despite the existence of different questionnaires to assess patients' experience or some related components, such as satisfaction, there is not a consistently accepted and validated method for measuring CKD's patient experience (Dovgan et al., 2020; Talbot, Athavale, Jha, & Gallagher, 2021). One that incorporates patients' needs, preferences, expectations, and challenges, considering the stage of the disease. Current assessment tools may not adequately capture the various aspects of the patient experience, including the physical, emotional, social, and professional dimensions as the disease progresses. While certain questionnaires might effectively capture certain elements of a patient's experience that are consistent across various stages of CKD, they might overlook essential aspects of the experience specific to these types of patients or for particular stages of the disease. As a result, healthcare providers and researchers encounter difficulties in systematically and comprehensively evaluating the patient experience in CKD, hindering the adequate assessment of healthcare services and the identification of specific areas for improvement in CKD care (Cukor et al., 2007).

Given the above-mentioned state of the art, the aim of the study presented in this chapter is to carry out a systematic review of the questionnaires and surveys that have been used to assess CKD patients' experience. Specifically, the scope, characteristics, and psychometric quality of existing instruments will be analyzed to shed light on the strengths, limitations and applicability of the instruments in the realm of healthcare delivery, research, and patient-centered care in CKD contexts. The review of the different relevant areas that

shape the care experience of CKD patients according to different instruments will provide an important input for the holistic assessment of all relevant areas.

The assessment of CKD patients' experience by means of surveys and questionnaires.

In the context of chronic kidney disease (CKD) care, the assessment of patient satisfaction and experience is crucial for understanding the nuanced aspects of healthcare delivery. Various instruments, both specific and generic, have been developed to capture the intricate dimensions of CKD patients' experiences. Tailored instruments, such as the Patient Satisfaction Questionnaire for Hemodialysis Care (PSQ-HD), are explicitly designed to address the unique needs and challenges faced by CKD patients undergoing hemodialysis. Conversely, generic instruments, like the Chronic Patient Experience Evaluation Instrument, have been adapted to evaluate the broader experiences of patients with chronic conditions, including those with CKD. These instruments can be useful in providing insights into the quality of care, identifying areas for improvement, and ultimately enhancing patient-centered healthcare delivery.

However, it should be mentioned that generic instruments that lack disease specificity often fall short in effectively assessing care delivery, primarily due to their generalized nature and inability to account for the nuances of specific medical conditions (Kirkley & Griffin, 2003). For example, different diseases and medical conditions involve distinct sets of symptoms, treatments, and patient needs, which are crucial in evaluating the quality of care (Wacker et al., 2016). In addition, the use of non-disease-specific instruments can lead to a lack of sensitivity to the specific challenges and priorities of patients dealing with a particular condition. In the context of CKD, which encompasses various stages and interaction points in the healthcare process, the utilization of non-disease-specific instruments for assessing care delivery often fails in comprehensively capturing the complexities of this condition (Mendu et al., 2020). As mentioned earlier CKD is characterized by a spectrum of physical, psychological, social, and emotional challenges that evolve as the disease progresses (Chen et al., 2019). In fact, patients at different stages of CKD exhibit distinct needs, challenges, and experiences, which may not be fully addressed by generic surveys designed to evaluate patient experience in a generalized manner. However, generic surveys may also be useful to

capture some of the needs and expectations regarding healthcare that are common to all sorts of patients, and especially patients with chronic diseases. Thus, by including both types of questionnaires in the systematic review we will be in a better position for identifying gaps and strengths of the different instruments. This information will be an essential input for the design of sounder and context-specific measures of CKD's patient experience.

In the current systematic review, patient satisfaction measurements are included. This is due to the inherent connection between patient experience and satisfaction. Although patient experience goes beyond rating of patient satisfaction, the latter is a crucial component of the broader concept of patient experience (Cleary et al., 1992). In fact, both terms have been used interchangeably in many cases, even if they are not synonyms. Patient experience reflects a patient's report of what they received in practice (communication with professionals, respect, responsiveness of hospital staff, support in pain management, cleanliness of the hospital environment, wait times or amount of information provided) (Kumah, 2017). In contrast, patient satisfaction refers to the discrepancy between a patient's expectation and the actual care received (Crow et al., 2002)- Although both provide relevant information for assessing healthcare quality and must be interrelated to some extent (Bjertnaes et al., 2012), patient satisfaction reflects personal expectations instead of quality itself (Annufriyeva et al., 2021; Beattie et al., 2015). Factors such as age, education, self-reported health status, and personality can influence expectations and reports even when the healthcare provided is the same (Okoebor, 2018). This also constitutes an important piece of information from a patient-centered perspective. Patients' contentment with the received care regarding aspects such as communication, accessibility, health outcomes, and the overall experience (Crow et al., 2002; Baker et al., 2021) are important to improve the care provided. Thus, patient satisfaction is, together with the broader concept of patient experience, a pivotal concept within healthcare. In fact, the inclusion of patient satisfaction questionnaires into our systematic review aligns with one of axes that according to Wolf et al. (2014) shape patient experience: the consideration of patient expectations when assessing patient experience.

According to Wolf et al. (2014) focusing on patient expectations is pivotal, as these expectations significantly shape the overall experience and satisfaction in healthcare encounters. Thus, even if the exclusive use of satisfaction reports as valid and unique measure

of health quality can be questioned (Staniszewska & Ahmed, 1999), incorporating patient satisfaction measures together with measures of patient experience in the systematic review allows for a more comprehensive understanding and nuanced evaluation of the multifaceted nature of patient experience in CKD contexts. This inclusion enhances the review's capacity to offer a holistic perspective on instruments measuring patient experience.

Finally, when concentrating on chronic disease patients, particularly those with CKD, satisfaction becomes a crucial aspect. These patients often navigate complex and long-term treatment regimens, making them especially attuned to non-clinical dimensions of care, such as communication, accessibility, coordination, information provision, and empathy. Understanding and addressing these dimensions are essential for promoting patient engagement, treatment adherence, and overall well-being. Studies by Hall and Dornan (1990) and Jenkinson et al. (2002) emphasize the relevance of patient satisfaction in chronic disease management, underscoring its utility in capturing the nuanced and complex nature of the care experience for this specific population. Thus, while patient satisfaction is just one part of the larger picture of patient experience, both concepts are mutually reinforcing within the chronic disease care framework. In conclusion, "patient satisfaction" and the broader "care experience" assessments are crucial for establishing a holistic understanding of the patient perspective in chronic disease care. The integration of patient satisfaction as a comprehensive instrument aligns with the broader shift toward patient-centered care and facilitates a nuanced evaluation of healthcare quality in the management of chronic disease management, and particularly CKD.

In conclusion, the systematic review undertaken in this thesis aims to comprehensively evaluate instruments used for assessing the patient experience and satisfaction in the context of CKD, encompassing both disease-specific and generic tools. Through this review, we will systematically achieve the following objectives: (1) identify and compile the instruments proposed and utilized for assessing CKD patient experience; (2) examine the diverse domains and dimensions captured by these instruments, analyzing overlaps and uniqueness; (3) assess the psychometric quality of the varied measures employed; (4) synthesize key findings from the literature, shedding light on the utility and effectiveness of these instruments; and (5) identify existing gaps in the instruments and offer

recommendations to enhance the assessment of CKD patients' experience. This comprehensive evaluation will provide valuable insights into the strengths and limitations of current assessment tools, facilitating the design of tailored assessments and interventions that consider the diverse stages of CKD and individual patient characteristics. Ultimately, this endeavor contributes to the enhancement of healthcare services and the overall quality of life for CKD patients.

3.2. METHOD

The systematic review carried out is aimed to comprehensively synthesize existing instruments that have been used to assess patient experience (and patient satisfaction as a key proxy indicator of care experience), in the context of CKD. This systematic review follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines. These guidelines are widely recognized for their robustness in guiding the synthesis research in healthcare contexts. The use of these guidelines underscores our commitment to methodological rigor and transparency, ensuring that review process and findings are reproducible and reliable.

3.2.1. Search Strategy:

The search was performed in relevant databases, including PubMed, Embase, CINAHL, PsycINFO, Web of Science, and Google Scholar. We also manually searched the reference lists of included studies and relevant review articles to identify additional studies that might have been missed in the database search. Gray literature sources, such as websites of health organizations, were also searched to ensure a comprehensive coverage of the topic. The search strategy employed a combination of keywords as follow: ("chronic kidney disease" OR CKD OR "renal disease") AND ("patient experience" OR "patient satisfaction" OR "patient perception" OR "satisfaction survey") AND ("questionnaire" OR "instrument") AND ("generic" OR "disease-specific"). The time frame for the search included the last twenty years. Specifically, from January 1998 to June 2023 to include the latest developments in the field.

3.2.2. Inclusion and Exclusion Criteria:

Initially, studies were included if they met the following criteria: 1. The studies should involve instruments that had been proposed and validated specifically in the context of CKD, or instruments that, despite having been proposed for general or chronic patients, had been used and validated in CKD samples. 2. To be included, studies should report the psychometric properties of the questionnaire and the specific dimensions of the questionnaire (if applicable), and 3. Regarding languages, the studies should have been published in either English or Spanish. Thus, studies referred to scales designed to assess constructs other than patient satisfaction or patient experience, that were not carried out in the context of CKD, that did not report psychometric properties of the measures or were published in a language different from Spanish or English were excluded. In addition, instruments that were part of theses or were in the initial stages of development were also excluded.

3.2.3. Study Selection:

The study selection process to decide whether the studies met the inclusion criteria or not involved multiple stages, including screening of titles and abstracts, followed by a full-text assessment. Two independent reviewers conducted the screening process, with any disagreements resolved through discussion. Initially, titles and abstracts retrieved from the literature search were screened against the inclusion and exclusion criteria. Studies that clearly did not meet the criteria were excluded at this stage. The remaining studies underwent a full-text assessment to determine their eligibility for inclusion in the systematic review. Reviewers independently assessed the full texts of potentially relevant studies.

Following the initial screening (i.e., removal of duplicates and titles and abstracts screening), the studies identified for evaluation were assessed based on their relevance to measuring generic or disease specific patient experience and satisfaction in the context of CKD.

Lastly, only studies retained at this stage were evaluated against the COSMIN (Consensus-based Standards for the selection of health Measurement Instruments) and the

Quality Criteria for Measurement Properties devised by Terwee et al. (2007). Whereas the former was used to evaluate the methodological rigor of the studies, the latter was used to critique the results of the studies.

The COSMIN checklists, created and validated for the assessment of psychometric studies of healthcare instruments, offer separate checklists (referred to as boxes) for each type of measurement property. For instance, box A pertains to internal consistency, while B addresses other indicators of reliability, such as test-retest reliability or inter-rater reliability. Boxes A–H correspond to various psychometric study types, each equipped with its set of quality questions. A detailed explanation of the COSMIN checklist can be found in Mokkink et al. (2010).

3.2.4. Assessment of Study Quality:

The assessment of the quality of the retained studies and instruments involved a series of steps. Initially, as mentioned earlier we utilized the COSMIN checklist to evaluate the methodological quality of the analysis carried out to assess the different psychometric properties of the measurement instrument in each study. For example, some of the questions to evaluate the internal consistency are: was the sample size adequate for the statistical analysis performed? was the internal consistency assessed by factor analysis? was Cronbach's alpha reported? and were missing items and the reasons for missing items described? Specifically, the COSMIN four-point checklist scoring system was applied. This scoring system categorizes items as 'excellent' when there is evidence of sufficient methodological quality, 'good' when relevant information is not fully reported but adequate quality can be assumed, 'fair' if the methodological quality is uncertain, and 'poor' when there is evidence that the methodological quality is inadequate. In instances where answers to the checklist questions received variable ratings (e.g., some excellent, some just fair), Terwee's (2012) recommendation was followed and the overall score was determined by taking the lowest rating of any item, with the worst score prevailing.

Secondly, we rated the quality of the results of the psychometric studies by using the Quality Criteria for Measurement Properties devised by Terwee et al. (2007). The evaluation

resulted in assigning ratings of positive (+), indeterminate (?), or negative (−) based on the quality criteria specific to each measurement property. For instance, positive ratings for internal consistency were applied, following Terwee et al.'s criteria, if Cronbach's alpha was equal to or exceeded 0.70. Studies reporting Cronbach's alpha results below 0.70 were classified as negative, while cases where Cronbach's alpha was not determined resulted in an indeterminate categorization.

3.2.5. *Data extraction:*

In conducting this systematic review, a comprehensive data extraction process was implemented to gather key information from the selected studies. The extraction focused on various aspects, including study characteristics, instrument details, psychometric properties, domains and dimensions covered, language, results, limitations, and other relevant information. For study characteristics, details such as author(s), publication year, study design, setting, and sample demographics were recorded. Instrument characteristics encompassed the name, type, and purpose of each instrument. The psychometric properties of each instrument were a focal point in the extraction process, including reliability indicators (e.g., Cronbach's alpha), evidence of validity (e.g., based on content, criterion, or construct validity evidence), and any responsiveness indicators (i.e., the degree to which an instrument is able to measure change in the construct to be measured) where applicable. The domains and dimensions covered by each instrument were systematically recorded to elucidate the breadth and depth of their scope within the CKD context. Language and cultural adaptation details, including translations and validation processes, were also documented. Limitations and challenges identified by each study were noted to provide insights into potential shortcomings. Throughout this process, efforts were made to maintain consistency and transparency. The data extraction utilized standardized forms, ensuring a systematic and reliable approach to information retrieval from each included study.

3.2.6. Reporting:

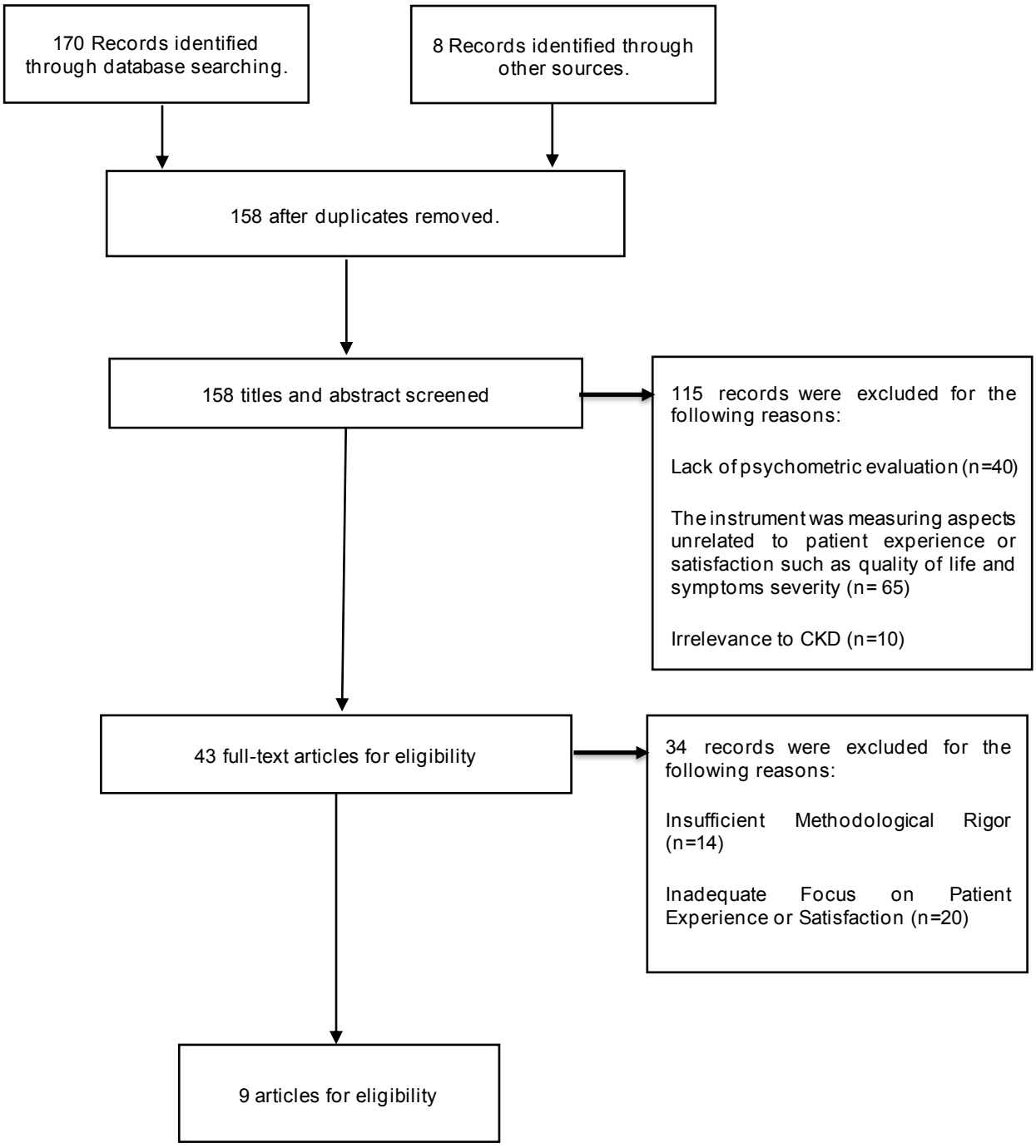
As mentioned earlier the results of the review will be presented following the PRISMA Guidelines. Apart from summarizing the study selection process by means of a

flowchart, the quality of the studies and the validity of findings will be assessed, followed by a comprehensive synthesis of the data.

3.3. RESULTS

Results of the search strategy and the selection process are documented through the PRISMA flow diagram (see Figure 1). We obtained 170 records from our searches and 8 additional records through other sources related to CKD such as websites of health organizations (e.g., National Kidney Foundation and the European Kidney Patients' Federation). Following removal of duplicates, 158 records were screened for inclusion criteria. Application of the inclusion criteria to titles and abstracts resulted in the exclusion of 115. We retrieved 43 full-text articles. Following application of inclusion criteria to full-text articles, we rejected 34 and retained 9 papers.

Figure 1. PRISMA flow chart for CKD articles on patient experience and patient satisfaction.



Note: PRISMA modified and adapted from Moher et al. (2009)

3.3.1. General overview of the scales.

The current systematic review conducted in the context of CKD encompassed a comprehensive analysis of various scales, generic or disease specific, employed to measure CKD patient satisfaction and experience. A total of nine instruments were included in our analysis. Among these, five were tailored to measure patient satisfaction, focusing on aspects related to treatment, care, and services. Notably, the Renal Treatment Satisfaction Questionnaire (RTSQ), The customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD), Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD) are specific to CKD and particularly concentrated on end-stage renal disease, hemodialysis, and peritoneal dialysis, respectively. Additionally, two instruments were identified as generic, The Sequs® which was applied to patients on hemodialysis and peritoneal dialysis, and the SERVQHOS applicable across various stages of CKD. The results are summarized in Tables 1 and 2.

The number of instruments available to assess patient experience that have been validated in the context of CKD is more limited. Only three instruments have been found: the Kidney Patient-Reported Experience Measure (PREM*), Instrumento de Evaluación de la Experiencia del Paciente Crónico* (IEXPAC) and the Consumer Quality Index. The former two are applicable to general chronic disease and the latter is tailored to CKD patients in hemodialysis and peritoneal dialysis. The results are summarized in Tables 1 and 2.

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) questionnaire for in-center hemodialysis stands out as the only instrument that measures both patient experience and patient satisfaction. This is a generic instrument adapted to measure the experience of hemodialysis patients.

Overall, the instruments encompass a wide range of domains of patient satisfaction and experience in CKD care. These domains include convenience, flexibility, freedom, and satisfaction with the current treatment approach. Additionally, aspects such as handling requests, delivery service, and customer service are addressed. For hemodialysis patients,

domains focus on dialysis center characteristics, patient information, and overall patient care. For peritoneal dialysis, training is marked as a key issue. Communication and care coordination are always emphasized covering different relevant care sources such as nephrologists' care, nurses' care, social worker's care, and dietician's care. Furthermore, organizational aspects such as the environment during dialysis sessions, medical tests, and information provision are evaluated. The assessment extends to themes like access to the renal team, support, shared decision-making, privacy, and the overall healthcare experience.

In short, the most common domains among the different scales include aspects such as dialysis center characteristics, patient information, patient care, nephrologist and healthcare provider communication, and overall experience. These domains are present in multiple instruments, indicating their significance in measuring patient satisfaction and experience in the context of chronic kidney disease and dialysis treatment. In terms of percentage, approximately 60-70% of the domains are repeated across the different scales. This indicates a significant overlap in the focus areas of the instruments, suggesting a consensus on the key domains that contribute to patient satisfaction and experience in the context of CKD and dialysis treatment. The identified instruments also explore to a lesser extent productive interactions, new relational models, and patient self-management. Interestingly, both subjective and objective dimensions of quality are assessed through the different questionnaires, including courtesy, empathy, responsiveness, professional competence, and the condition of facilities. Together, these domains provide a comprehensive understanding of patient perspectives, contributing valuable insights for enhancing CKD care quality and patient satisfaction.

Regarding the psychometric properties, overall, the instruments typically exhibit adequate levels of reliability and validity, although there were some exceptions (see Table 2). Overall, Cronbach's alpha values, which assess internal consistency demonstrated adequate to excellent reliability for the studies that reported alpha for the total scale, with values ranging from 0.70 to 0.96 across different instruments. More modest were the internal consistency coefficients for some specific dimensions of the instruments, particularly the IEXPAC (α = .56) and the Consumer Quality Index (α =.61) Additionally, test-retest

reliability, assessed in specific cases (i.e., CSQPD, ESUR-HD, PREM), is satisfactory, with coefficients ranging from 0.72 to 0.80. Factor analysis results confirm the expected structures, supporting the instruments' construct validity. Notably, all items load appropriately on their respective factors, accounting for a substantial percentage of variance. This provides initial evidence to support that the instruments effectively measure the intended dimensions. The psychometric evaluation provides confidence in the instruments' ability to deliver reliable and valid assessments of patient satisfaction and experience in CKD care across diverse domains.

In the following paragraphs, after the overview presented, we provide a more detailed description of the scales, the instruments' design, their intended use, and their dimensionality and psychometric properties.

3.3.2. Dimensionality and psychometric properties.

Disease Specific Instruments. This set of instruments is specifically designed to evaluate the patient experience or satisfaction of individuals with CKD, in general or at specific stages of the disease.

Instruments for Hemodialysis and Peritoneal Dialysis.

(1) The Renal Treatment Satisfaction Questionnaire (RTSQ) is an 11-item scale designed to measure patient satisfaction with treatment for chronic kidney failure. It measures satisfaction with different aspects of treatment, such as convenience, flexibility, freedom, understanding of the condition, time taken by treatment, discomfort or pain involved with treatment, and how well treatment fits in with patients' lifestyle. The scale demonstrated high reliability and robustness across different treatment subgroups, with excellent internal consistency ($\alpha = 0.93$) in the full sample and coefficient (α) values ranging between 0.89 and 0.95 in separate treatment subgroups. The unforced principal component analysis resulted in a single factor accounting for 59% of the variance, and all items loaded greater than 0.58 on this single factor. Thus, there is no need to differentiate distinct dimensions.

(2) The customer Satisfaction Questionnaire (CSQ) in peritoneal dialysis is a 31-item scale designed to measure patient satisfaction with various aspects of peritoneal dialysis care, including customer service, delivery service, peritoneal dialysis training, and handling requests. The CSQ shows high internal consistency ($\alpha = 0.93$), test-retest reliability estimated using a time interval of approximately 205.6 ± 78.4 days was also satisfactory($r=0.41$), In addition exploratory factor analysis confirmed an interpretable four-factor structure and identified distinct factors associated with patient satisfaction in peritoneal dialysis care: satisfaction with customer service, with service delivery, training and with the way patients' requests are handled. The internal consistency of the CSQ dimensions was also adequate for all subscales: customer service ($\alpha = 0.76$), delivery service ($\alpha = 0.71$), peritoneal dialysis training ($\alpha = 0.72$) and handling requests ($\alpha = 0.72$).

(3) The Scale for Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a CKD Unit (ESUR-HD). This 44-item scale measures nine domains related to patient satisfaction with hemodialysis services. These domains are as follows: facilities and organization of the service, care provided by attending nurses and/or assistants, attention to psychological and administrative issues, contact and social work personnel, medical attention and care, nutrition attention and care, medications supply and quality, features of the admissions process, attention and care provided by head nurses. The alpha coefficient for the entire scale was 0.96, indicating high internal consistency. Alpha coefficient values for each domain ranged from 0.83 to 0.93, also demonstrating good internal consistency within each domain. The scale demonstrated good test-retest reliability with a mean time lag of two days and a correlation coefficient of 0.85.

(4) The Consumer Quality Index (CQ index) includes a total of 71 questions for hemodialysis (HD) patients and 56 questions for peritoneal dialysis (PD) patients. It measures nine domains related to patient experience with hemodialysis and peritoneal dialysis services. These domains are as follows: nephrologist's care and communication, nurses' care and communication, social worker's care and communication, dietician's care and communication, communication and cooperation between care providers, organization of care delivery, medical tests, information in general and environment during dialysis

sessions. The study conducted an exploratory factor analysis to identify the underlying factors within the core experience items. Each domain was expected to yield one scale or factor with an eigenvalue of at least 1.0. Items were assigned to a scale if they had a loading exceeding 0.30. The factor analysis resulted in the identification of scales for each experienced domain, with the study identifying one scale for each domain based on the factor loadings and internal consistency reliability. Although the internal consistency (Cronbach's α) was considered acceptable (α= 0.70), the reliability of some of the dimensions was more limited with values ranging from .61 to 0.66 for social worker's care and communication, organization of care delivery and environment during dialysis sessions domains, respectively.

General CKD Assessment Tools

(5) The Kidney Patient-Reported Experience Measure (PREM) measures patient experience with regards to different aspects such as communication, information provision, scheduling, tests, diet, fluid, patient information, environment, overall experience, and others. It consists of 38 items grouped into 13 themes, and it is designed to capture the broadest possible range of experiences of all patients using renal services, regardless of disease stage and treatment modality. It also includes one item for assessing the overall patient experience. The psychometric properties of the Kidney PREM are robust, as evidenced by the rigorous development and validation process. The overall scale demonstrates high internal consistency, with a Cronbach's α coefficient of 0.94. Test-retest reliability analysis also showed high reliability, with correlation coefficients (r) of 0.79 for the average total scale scores and 0.72 for the overall experience item, indicating the stability of the scale over time. Despite initially differentiating different themes, exploratory factor analysis yielded a single underlying dimension reflecting the construct of "patient experience" that accounted for 78% of the observed variance.

Generic Instruments. This second group involves instruments that have been adapted or are generally used to measure either patient satisfaction or experience in the context of CKD but that were not developed specifically for CKD contexts. However, some

of these generic instruments were adapted to be used with CKD patients, in general or at specific stages.

Adapted to hemodialysis and/or peritoneal dialysis.

(6) The Sequs® includes a total of 39 questions for hemodialysis (HD) patients and 26 questions for peritoneal dialysis (PD) patients. It measures patient satisfaction with CKD care across three dimensions: patient satisfaction with dialysis center characteristics, with dialysis sessions course, and with the information received. It is not explicitly stated whether confirmatory or exploratory factor analyses were carried out to assess the dimensionality of the scale. Nevertheless, the study did report 3 factors. The reported Cronbach's alpha values for each dimension, ranging from 0.72 to 0.94 for peritoneal dialysis patients and from 0.77 to 0.89 for hemodialysis patients indicate a high level of internal consistency within each domain. Internal consistency for the overall scales was not reported.

(7) The Consumer Assessment of Healthcare Providers and Systems (CAHPS) questionnaire for in-center hemodialysis (HD) is a 40-item scale. It measures various aspects of care, including communication with healthcare providers, staff professionalism, patient involvement, patient education, patient safety, and patient rights. The survey also includes global ratings of the nephrologist, staff, and dialysis center, allowing patients to rate their satisfaction with the care received. The study conducted an exploratory factor analysis identifying 3 scales: nephrologists' communication and caring, dialysis center care and operations, and providing information to patients. Internal consistency reliability of the dimensions was estimated using Cronbach's alpha, with values ranging from 0.75 to 0.93 for the three scales, indicating strong reliability. The reliability of the overall scale was not reported.

General CKD Assessment Tools.

(8) *Instrumento de Evaluación de la Experiencia del Paciente Crónico* (IEXPAC). The IEXPAC is a 15-item scale that measures the patient experience of chronic illness. In the

study, an exploratory factor analysis resulted in a three-factor solution, explaining 57.5% of the common variance. These factors were named productive interactions, new relational models, and patient self-management. The Cronbach's alpha values for the domains of the IEXPAC scale range from 0.56 to 0.79.

(9) The SERVQHOS scale is a 19-item scale that measures two domains of perceived quality in hospital care: subjective quality (e.g., courtesy, empathy, responsiveness of the treatment team) and objective quality (e.g., condition of the rooms, reliability in scheduling). It has been administered to CKD patients regardless of the stage of the illness. The exploratory factor analysis supported the two proposed factors, explaining 65.3% of the variance. The Cronbach's Alpha values for the two subscales were reported as 0.95 for subjective quality and 0.89 for objective quality. These values indicate high internal consistency for both domains, demonstrating the reliability of the scale in measuring these specific dimensions of perceived quality in hospital care.

Table 1. Instrument overview

Instrument/Abbreviation	Associated Paper	Country of Origin	Patient - Experience Vs. Patient Satisfaction	Content	Instrument Design	Generic vs. CKD Specific	General CKD vs. Specific CKD Stage
The Renal Treatment Satisfaction Questionnaire (RTSQ)	Barendse et al. 2005	United Kingdom	Patient satisfaction	Convenience, flexibility, freedom, and satisfaction to continue with the present form of treatment.	The development of the Renal Treatment Satisfaction Questionnaire (RTSQ) involved qualitative work, including in-depth interviews with patients on various forms of dialysis therapy and those with current or failed transplants.	CKD Specific	Specific CKD stage: end-stage renal disease
The customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD)	Kirchgessner et al. 2006	Hungary	Patient satisfaction	Handling requests, PD training, delivery service, and customer service.	The CSQPD was developed by a multidisciplinary group consisting of a nephrologist, a nurse, a psychologist, marketing, customer service and sales representatives, and a statistician.	CKD Specific	Specific CKD stage: DP
Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD)	Sanabria-Arenas et al. 2017	Colombia	Patient satisfaction	Facilities and organization of the service. Care provided by attending nurses and/or assistants. Attention to psychological and administrative issues Contact and social work personnel. Medical attention and care. Nutrition attention and care. Medications supply and quality. Features of the admissions process Attention and care provided by head nurses.	The scale development involved a literature review and four focus groups comprising nurses, a nephrologist, and administrative personnel from different regions. The focus groups aimed to identify aspects influencing chronic kidney patients' satisfaction.	CKD Specific	Specific CKD stage: HD

The Sequs®	Wasserfallen et al. 2006	Switzerland	Patient satisfaction	Dialysis center characteristics. Patient information. Patient care.	The study's scale development involved two steps: first, identifying satisfaction dimensions through a focus group with patients and nurses, and second, selecting relevant questions from the Sequence® data bank for assessing patient satisfaction in outpatient care.	Generic	Adapted to CKD specific stage: HD and PD (2 scales)
The Consumer Quality Index (CQ index) instrument	Sabine et al. 2012	Canada and USA	Patient experience	Nephrologist's care and communication. Nurses' care and communication. Social worker's care and communication. Dietician's care and communication Communication and cooperation between care providers. Organization of care delivery. Medical tests. Information in general. Environment during dialysis sessions.	The development of the CQ index involved a comprehensive process of item selection, factor analysis, reliability testing, and validation to ensure that the scale effectively measured the experience and priority of chronic dialysis patients.	CKD Specific	Specific CKD stage: HD and PD
The Kidney Patient-Reported Experience Measure (PREM)	Hawkins et al. 2022	UK	Patient experience	Access to the renal team, Support, Communication, Patient information, Fluid, Diet, Needling, Tests, Sharing decisions about your care, Privacy and dignity, Scheduling and planning, Transport, Environment, Overall experience	It involved a rigorous and comprehensive process, including exploratory and confirmatory factor analyses, sensitivity analyses, cognitive interviews, and expert group input, resulting in a final version and a shorter form of the instrument to assess patient experiences with renal services.	CKD Specific	General CKD
The Consumer Assessment of Healthcare Providers and Systems (CAHPS) questionnaire for in-center hemodialysis (HD)	Weidmer et al. 2014	US	Patient experience and Patient satisfaction	Nephrologists' Communication and Caring. Quality of Dialysis Center Care and Operations. Providing Information to patients.	Formative research, stakeholder input, field testing, and psychometric analysis.	Generic	Adapted to CKD specific stage: HD
Instrumento de Evaluación de la Experiencia del Paciente Crónico (IEXPAC)	Mira et al. 2016	Spain	Patient experience	Productive Interactions. New relational model. Patient self-management.	The scale was developed through a rigorous process, including a literature review, expert panel evaluation, pilot studies, and field studies with 350 chronic primary care patients.	Generic	General CKD

SERVQHOS: un cuestionario para evaluar la calidad percibida de la atención hospitalaria	Mira et al. 1998	Spain	Patient satisfaction	Subjective Quality (courtesy, empathy, responsiveness, and professional competence). Objective Quality (condition of the rooms, reliability in scheduling, and the information provided by the healthcare staff).	The development process involved the selection of 19 items with the best metric behavior from previous versions of the scale. The response format combined patient expectations and perceptions to obtain an estimation of the score difference between expectations and perceptions. The scale was then validated through various statistical analyses, including internal consistency, factorial analysis, discriminant validity, and reliability.	Generic	General CKD

Note: CKD: Chronic Kidney Disease; HD: Hemodialysis; PD: Dialysis Peritoneal.

Table 2. Quality of methods and results of psychometric studies.

Instrument/Abbreviation	Measurement Property	Results (reliability and dimensionality)	Quality rating of results	Quality rating of methods
The Renal Treatment Satisfaction Questionnaire	Internal consistency Construct Validity	Cronbach's alpha 0.93 for overall scale An exploratory factor analysis resulted in 1 factor.	Positive	Good
The customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD)	Internal consistency Test Retest-Reliability	Cronbach's alpha 0.91 for overall scale Cronbach's alpha ranges from 0.71 to 0.76 of the 4 domains. Test-retest reliability: The mean time between the two interviews was 205.67 ± 8.4 days. (r =0.41, P =0.0016) An exploratory factor analysis resulted in 4 factors.	Positive	Excellent
Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD)	Internal consistency Test-Retest Reliability Construct validity	Cronbach's alpha 0.96 for overall scale. Cronbach's alpha ranges from 0.83 to 0.93 of the 9 domains. The test-retest reliability = 0.80 (Time lag: 2 days) An exploratory factor analysis resulted in 9 factors.	Positive	Good
The Sequs®	Internal consistency	Cronbach's alpha values for HD in the 3 dimensions: 0.89, 0.77 and 0.72. Cronbach's alpha values for PD in the 3 dimensions: 0.72, 0.77 and 0.94. An exploratory factor analysis resulted in 3 factors.	Positive	Good
The Consumer Quality Index (CQI).	Internal Consistency	Cronbach's alpha of ≥ 0.70 for the overall scale. Cronbach's alpha ranges from 0.61 to 0.72 of the 10 domains. An exploratory factor analysis resulted in 10 factors.	Positive	Good More questionable at the dimension level
The Kidney Patient-Reported Experience Measure (PREM)	Internal Consistency Test Retest-Reliability	Cronbach's alpha of 0.94 Test-retest reliability 0.72 (Time lag: 3 weeks) An exploratory factor analysis resulted in 1 factor.	Positive	Excellent
The Consumer Assessment of Healthcare Providers and Systems (CAHPS) questionnaire for in-center hemodialysis (HD)	Internal Consistency	Cronbach's alpha ranges from 0.75 to 0.93 of the 3 domains. An exploratory factor analysis resulted in 3 factors.	Positive	Good

Instrumento de Evaluación de la Experiencia del Paciente Crónico (IEXPAC)	Internal Consistency	Cronbach's alpha of the overall scale: 0.76 Cronbach's alpha ranges from 0.56 to 0.79 of the 3 domains. An exploratory factor analysis resulted in 3 factors.	Positive	Good More questionable at the dimension level
SERVQHOS: *un cuestionario para evaluar la calidad percibida de la atención hospitalaria*	Internal Consistency	Cronbach's alpha values: 0.95 for subjective quality and 0.89 for objective quality. An exploratory factor analysis resulted in 2 factors.	Positive	Good

Note: CKD: Chronic Kidney Disease; HD: Hemodialysis; PD: Dialysis Peritoneal.

3.3.3. Patient Involvement in Instrument Design.

In the development of diverse scales aimed at assessing patient satisfaction and experiences in the context of CKD treatment, patient input emerged as a cornerstone. However, patient involvement took place after the initial proposal of the items.

In the case of the Customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD), the Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD), the Consumer Quality Index (CQI), the Kidney Patient-Reported Experience Measure (PREM), CAHPS In-Center Hemodialysis Survey and the IEXPAC scale, patient input was incorporated after the initial version of the questionnaires had been proposed, allowing patients to modify items for enhanced relevance. Patient involvement in these stages is important for the refinement of items, ensuring they align closely with the dynamic and evolving needs of CKD patients.

Across various scales, such as the RTSQ, PREM, CQI, CSQPD and the ESUR-HD, patient input was sought through qualitative interviews, focus groups, and direct participation in the refinement and modification of questionnaire items. In addition, the ESUR-HD engaged not only patients, but also healthcare professionals and administrators in focus groups, underscoring the multidimensional nature of patient satisfaction and the multiple stakeholders involved in patient experience.

Some other scales used patients to assess content validity. In the CAHPS In-Center Hemodialysis Survey, patients played a vital role in confirming essential domains and refining survey items through focus groups, cognitive interviews, and a technical expert panel. The IEXPAC scale showcased a comprehensive patient-centric approach, involving expert panels and pilot studies for content and face validity, demonstrating the importance of patient input in shaping instruments.

The SERVQHOS scale, specifically tailored for assessing perceived quality in hospital care, emphasized patient input in overcoming methodological challenges, refining

response formats, and enhancing applicability in healthcare settings. Patient perceptions and expectations were considered from the early phases of the design to foster the reliability and validity of the scale.

Finally, unique, and particularly effective methods were evident in the Sequs® scale, where patient and nurse focus groups identified satisfaction dimensions, offering a nuanced perspective to the assessment of patient experience. This is the only scale where patient input was included in the design from the initial stages of its development.

Collectively, the results of this review reaffirm the significance of continuous patient involvement in refining and shaping instruments, enriching their relevance to the diverse experiences of CKD patients. However, more efforts to involve patients in the design of the measurement instruments should be made.

3.3.4. Summary of results and trends.

The results of the systematic review provide a comprehensive overview of scales designed to measure patient satisfaction and experiences in the context of CKD. Nine instruments were analyzed, with six specifically tailored to CKD, focusing on end-stage renal disease, hemodialysis, and peritoneal dialysis, and three being generic tools applicable to general chronic disease and CKD without stage specificity.

The identified scales cover a wide range of domains, including convenience, flexibility, freedom, satisfaction with treatment, care, and services. Common themes across scales include patient care, communication, dialysis center characteristics, patient information, and overall experience, emphasizing their significance in measuring patient satisfaction and experience in CKD care. Despite some overlap in focus areas, the diversity of domains captured by the scales, when combined, ensures a comprehensive understanding of patient perspectives.

In terms of psychometric properties, instruments generally demonstrated adequate reliability and evidence of validity. Cronbach's alpha values consistently indicated high internal consistency, test-retest reliability was satisfactory, and factor analysis confirmed the expected structures (when a specific dimensionality was hypothesized), supporting the instruments' construct validity. This comprehensive evaluation instills confidence in the ability of these scales to provide reliable and valid assessments of patient satisfaction and experience in CKD care for the specific dimensions assessed.

Among the disease-specific instruments, the RTSQ, CSQPD, ESUR-HD, and CQ index exhibited strong internal consistency and reliability, confirming their effectiveness in measuring patient satisfaction in the specific contexts of hemodialysis, peritoneal dialysis, and CKD units. The generic instruments, Sequs® and CAHPS, adapted to HD, demonstrated high reliability in measuring satisfaction with chronic dialysis care and in-center hemodialysis, respectively. The general CKD assessment tool, IEXPAC, showcased more questionable reliability coefficients for some of the dimensions, although factor analyses supported the hypothesized dimensionality.

Notably, patient input played a crucial role in refining and modifying these instruments. While most scales incorporated patient feedback after the initial development item questionnaires, the Sequs® scale stood out as the only tool where patient input was integrated from the initial stages of development. Patient involvement, through qualitative interviews, focus groups, and direct participation, facilitated the refinement of items, aligning them closely with the dynamic needs of CKD patients. The multidimensional nature of patient satisfaction was emphasized in the ESUR-HD, where patients, healthcare professionals, and administrators participated in focus groups.

Despite the strengths identified in the assessment instruments predominantly focused on patient satisfaction in the context of CKD, certain limitations warrant consideration. Notably, a recurrent pattern was observed where patient input was incorporated post-initial item questionnaires across various scales, potentially missing out on crucial perspectives in the early stages of instrument development. Additionally, the scales exhibit a limited

representation of certain domains, such as shared decision-making, privacy, and new relational models, suggesting a potential gap in comprehensiveness. Moreover, the predominant design of these instruments to measure end-stage renal disease raises concerns about their applicability to patients in the initial stages of CKD. The exclusion of individuals in early CKD stages neglects a significant portion of the patient population and hinders a comprehensive understanding of their experiences. To address these limitations and contribute to the refinement of these instruments, an empirical study specifically responding to these gaps is essential. Such a study would ensure a more inclusive representation of patient experiences, spanning different CKD stages and capturing a broader array of relevant domains, ultimately enhancing the effectiveness and relevance of the assessment tools.

3.4. DISCUSSION

This systematic review has undertaken a comprehensive analysis of scales employed in the measurement of patient satisfaction and experience within the context of chronic kidney disease (CKD). The evaluated scales have exhibited robust psychometric properties, including adequate to strong reliability coefficients based on internal consistency, with Cronbach's alpha coefficients ranging from 0.70 to 0.93 across different instruments. Cronbach's alpha coefficients are also generally adequate for the different dimensions when tests are multidimensional; however, in some instances, such as the Consumer quality Index and the IEXPAC, the reliability of the proposed subscales/dimensions is not high enough with values ranging from .56 to .66, respectively. The inclusion of test-retest reliability evaluations for some of the instruments, further strengthened the scales' credibility in 3 of the scales, demonstrating stability over time with correlation coefficients ranging from 0.72 to 0.82. With the exceptions, together the results suggest that the scales are reliable tools within each domain, providing a solid foundation for their application in assessing various dimensions of patient satisfaction and experience. Regarding the validity evidence, this is much more limited, although the results are in general satisfactory. The studies mostly focus on two types of validity: based on content and based on the dimensionality of the test. Evidence based on content validity provided by patients and other relevant stakeholders yield support for the validity of tests such as the Renal Treatment Satisfaction Questionnaire, the Customer

Satisfaction Questionnaire (CSQ), Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD), the Consumer Quality (CQ) index, the Kidney Patient-Reported Experience Measure (PREM), he CAHPS In-Center Hemodialysis Survey, the IEXPAC and the SERVQHOS scale.

Regarding the dimensionality, although the studies find interpretable factors or dimensions that explain a relevant amount of variance, the number of dimensions and their meaning change from study to study. Satisfaction questionnaires, for example, such as the RTSQ identified 1 dimension, CSQPD identified 4 dimensions (i.e., satisfaction with customer service, PD training, delivery service, and handling requests), ESUR-HD identified 9 dimensions (i.e., facilities and organization of the service, care provided by attending nurses and/or assistants, attention to psychological and administrative issues, contact and social work personnel, medical attention and care, nutrition attention and care, medications supply and quality, features of the admissions, process attention and care provided by head nurses) The Sequs® identified 3 dimensions (i.e., dialysis center characteristics, patient information and patient care) and the SERVQHOS identified 2 dimensions (i.e., objective quality and subjective quality). Similarly, patient experience questionnaires such as the CQ index identified 10 domains (i.e., nephrologist's care and communication, nurses' care and communication, social worker's care and communication, dietician's care and communication, communication and cooperation between care providers, organization of care delivery, medical tests, information in general and environment during dialysis sessions), the PREM identified 1 dimension (i.e., patient experience), the CAHPS -HD identified 3 domains (i.e., nephrologists' communication and caring, dialysis center care and operations, and providing information to patients) and IEXPAC identified 3 dimensions (i.e., self-management, productive interactions and new relational model). This diversity of domains covered by the identified scales in assessing patient satisfaction and experience in the context of CKD, makes it difficult to compare results across scales. However, the information that they deem as relevant across the different scales is an important input to determine which are the most relevant common aspects, and which additional ones, despite of being less common may be important to understand CKD patient experience.

Most importantly, the current review sheds light on the difference between the domains covered by patient satisfaction questionnaires and those assessing patient experience. Patient satisfaction questionnaires predominantly focus on subjective evaluations of healthcare services. Patients indicate how satisfied they are with several aspects of the care and the treatments, and this satisfaction may depend on personal characteristics and their expectations. This has been reported in Rahmqvist's et al. (2010) work. Older patients, particularly those reporting very good or excellent health or undergoing day surgery, tended to be more satisfied than younger patients. Additionally, individuals with better self-reported health or shorter education demonstrated higher Patient Satisfaction Index (PSI) scores. In contrast, patient experience questionnaires have a broader scope, encompassing not only satisfaction-related domains but also organizational aspects, even if they share some common aspects, such as communication. It is important to note that, in contrast to Patient-Reported Outcome Measures (PROMs), patient experience surveys do not have the focus on outcomes of care but on the process of care. In addition, although patients' views may not be fully objective, patient experience surveys are less subjective than patient satisfaction questionnaires because the types of judgments required in the former are about what happened in the care process, not about how much patients are satisfied with what happened. For example, patients need to report on the degree to which the nephrologist listens to them attentively or whether they were informed about the complaint's procedure.

Therefore, while patient satisfaction questionnaires are important, the review suggests that tools like IEXPAC, CQ index and the PREM which focus more on patient experience, seem to give us a richer understanding of the various parts of care in CKD. Nevertheless, both experience and satisfaction ratings provide complementary information that can be useful input for improving the quality of care and patients' wellbeing.

Despite the content richness and psychometric quality of the instruments according to this review, certain limitations are apparent in the existing instruments:

First, the predominant focus on the assessment of the care experience and satisfaction during the final stages of the disease, particularly in the context of hemodialysis suggests a

potential gap to assess patient experience at other stages of CKD. This is a significant limitation, as the needs and experiences of individuals with CKD evolve throughout the progression of the disease, and those in the earlier stages may have distinct needs, concerns and expectations. Consequently, the overrepresentation of instruments tailored for the final stages of CKD hinders a comprehensive understanding of the diverse experiences and challenges encountered by patients at different points in their disease trajectory. Future research should strive to address this limitation by developing and validating instruments that are inclusive of the entire CKD spectrum, ensuring a more holistic assessment of patient satisfaction and experiences throughout the continuum of care.

Second, the variation in the degree of patient involvement in scale development raises considerations about the comprehensiveness of the measures. Most of the identified scales in this review actively integrate patient input post item questionnaire generation. This results in potentially limiting the breadth of perspectives considered during the initial stage of development of the instrument and including patients at different stages of the CKD. Surveys that do not take into consideration the patient's perspective during the initial phase, specifically in determining what aspects of care should be measured, are at risk of falling short in their ability to comprehensively assess care delivery. As mentioned earlier, patient-centered care is the foundational principle of modern healthcare, emphasizing the importance of involving patients in decision-making and tailoring care to their unique needs and preferences (Greene et al., 2012). Patients can provide valuable insights about their care experience that extend beyond clinical outcomes (Doyle et al., 2013). They can provide valuable information on their interactions with healthcare professionals, their emotional well-being, and the impact of healthcare processes on their daily lives. Ignoring these perspectives when developing the questionnaires can lead to an incomplete and potentially biased evaluation which ultimately undermines the validity and relevance of the measurement instruments. Despite the supported dimensionality, the representation of the patient experience may be partial since some relevant areas across the different stages of CKD may be missing.

Unlike the other scales, the Sequs® scale stood out as the only tool where patient input was integrated from the initial stages of development. However, it's important to note that this scale primarily concentrates on assessing patient satisfaction rather than delving into the broader realm of patient experience. While it is commendable for including patients in the early stages, the limitation lies in its narrow focus on satisfaction, potentially overlooking important and informative aspects of the patient journey. This focus limits the scale from thoroughly capturing the diverse dimensions of patient experience, missing out on elements beyond mere satisfaction that contribute to a more nuanced understanding of CKD care.

The implications for both practice and research are manifold. The identified scales have the potential to significantly contribute to the advancement of patient-centered care by providing healthcare professionals with reliable and valid tools to assess various aspects of care delivery and collect useful information to improve care quality in CKD patients. The focus should now shift towards the development of culturally sensitive instruments applicable to different stages of CKD. Furthermore, the review suggests that a shift towards prioritizing patient experience over satisfaction (without totally excluding the later) aligns with the evolving understanding of healthcare assessment, ensuring a more thorough and patient-centric evaluation of the complex and multifaceted nature of CKD care. Patient involvement remains a cornerstone in the development and refinement of assessment tools. Incorporating ongoing patient input from the initial stages of instrument development ensures the relevance, acceptability, and effectiveness of measures in capturing the diverse experiences of individuals with chronic kidney disease along all the stages of the disease. This collaborative approach is particularly crucial for maintaining the validity and applicability of these measures in the complex landscape of healthcare settings.

As any other study this systematic review has certain limitations that warrant consideration. Firstly, regarding gray literature, the exploration was limited to only two sources, namely the European Kidney Patients' Federation and the National Kidney Foundation websites. Consequently, potentially relevant studies or scales present in other gray literature sources may not have been captured, introducing a possible source of bias. Additionally, the inclusion criteria for scales focused exclusively on those that have

undergone both development and validation processes. While this stringent criterion ensures the inclusion of robust and well-established instruments, it may result in the exclusion of emerging scales or tools that, although not yet fully validated, could provide valuable insights. These limitations should be acknowledged when interpreting the findings and may impact the comprehensiveness of the review's scope.

However, despite these limitations, this systematic review not only highlights the strengths and weaknesses of various scales but also identifies key gaps in knowledge, paving the way for future research directions. For example, multidimensional questionnaires referring to areas that are common to all types of patients but that also contain tailored sections aimed at assessing patients' experience at different stages of the disease will be very valuable and informative for improving health care in CKD patients. For the design of such a questionnaire it is crucial to previously gather information from CKD patients at different stages of the disease to determine which are the most crucial interaction points across the patient journey and which areas of experience are relevant at each interaction point.

Building up on this idea, Chapter 4 of this doctoral thesis embarks on an empirical study that involves a patient journey map and the combination of quantitative and qualitative methods. The aim is to address the limitations of the reviewed questionnaires (the overrepresentation of instruments tailored for the final stages of CKD setting aside initial stages of the disease, and the lack of patient input involvement at initial stages of the instrument design.

CHAPTER IV: EMPIRICAL STUDY

"MAPPING THE PATIENT JOURNEY: A MIXED METHODS STUDY INVESTIGATING PATIENT EXPERIENCE IN CHRONIC KIDNEY DISEASE"

4.1. INTRODUCTION

As it has been previously stated, chronic kidney disease (CKD) is a major global health concern, affecting over 10% of the general population worldwide (i.e., over 800 million individuals) (Kovesdy, 2022). Patients with CKD experience a high burden of symptoms associated with the progression of the disease, such as physical disability, cognitive impairment, and social isolation (Zoccali et al., 2010). As CKD progresses through five different medical stages, quality of life deteriorates, which prompts patients with renal failure to be in ongoing contact with the healthcare system and to interact with multiple healthcare service providers (Mcphail, 2016).

Both clinical practice and research have seen increasing efforts to further understand the factors enhancing healthcare experiences from patients' perspectives. This is partially a result of shifts in public policy and an emergence of a consumer mindset regarding healthcare (Wolf et al., 2021); thus, increased attention has been placed on person-centred measures (Godovykh & Pizzam, 2022; Kuppelwieser & Klaus, 2021) such as patient experience and patient satisfaction as indicators of healthcare quality. The results of the systematic review presented in chapter 3 showed that there are different questionnaires with good psychometric properties that can be useful in this regard. However, new metrics and methodologies for measuring patient experience are demanded (Godovykh et al., 2022), as traditional approaches are typically influenced by self-reported biases (Godovykh & Tasci, 2022). Likewise, existing approaches do not reflect the dynamic nature of patients' journey (Becker & Jaakkola, 2020; Roggeveen et al., 2020), and there is no standardized methodological approach to measure the healthcare experience of CKD patients through the disease stages and the care journey. This is an important gap because patients may have specific social, physical, and emotional related needs depending on the disease stage (Duenas et al., 2016). As we previously showed, even if there are several patient-reported scales that have been designed or adapted assess healthcare quality in CKD contexts -such as the Consumer Assessment of Healthcare Providers and Systems (CAPHS) (Crofton et al., 1999), the Instrument of the Experience of Chronic Patients (IEXPAC) (Mira et al., 2016), or the Kidney Patient-Reported Experience Measure (PREM), for patient experience, or the Renal

Treatment Satisfaction Questionnaire (RTSQ) (Barendse et al. 2005), or the customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD) (Kirchgessner et al. 2006), for patient satisfaction- the reviewed questionnaires have a predominant focus on the final stages of the disease, do not conceptualize patient experience through the same dimensions, and did not involve CKD patients from all stages in the questionnaire design.

The study carried out in this chapter sheds light on patients' intrinsic needs, expectations, and concerns that are common to all patients and those that differ as they go through the different stages of the disease while in ongoing contact with the healthcare system. To do this, we collaborate with CKD patients to develop a patient journey mapping to define the most relevant interaction "touchpoints" with the healthcare. By taking a person-centred perspective and a mixed-method approach combining qualitative and quantitative data, we will be in a better position to understand patients' experiences across different stages and interaction points. This is crucial to improve the healthcare experience and respond to the call made by policymakers seeking to gather patient experience feedback data to monitor the performance of healthcare providers to promote quality improvement and the quality of life of CKD patients (Ahmed et al., 2014).

4.1.1. Experience Beyond Satisfaction

Although patient experience and patient satisfaction have been used as interchangeable terms (Beattie et al., 2014; Sofaer & Firminger, 2005), the concept of patient experience is broader (Cleary et al., 1992). Patient experience is the account of what a patient encounters in their interactions with the health system, including interactions with medical staff, respect, communication, pain management support, and the cleanliness of the hospital (Kumah, 2017), while patient satisfaction is the gap between what a patient expects and the care they receive (Crow et al., 2002). Although there are patient experience questionnaires - both for general and CKD contexts- that can be used, currently most healthcare organizations assess care delivery by using questionnaires referring to patient satisfaction, which are more subjective as they depend on expectations (e.g., 'How satisfied you are with the length of time you waited to speak to a care provider?'). In contrast, patient experience reflects upon

what they experienced in their interactions with providers and the healthcare system by posing more objective and unbiased questions (e.g., 'How long did you wait to speak to a care provider?'). Data provided by these questions are more easily attainable for quality improvement initiatives (Browne et al., 2010). Thus, although patient experience and satisfaction can provide useful information for assessing healthcare quality, in this chapter we focus on the assessment of patient experience.

When focusing on patient experience, several scales are available. Although most of them are general surveys that do not refer to a particular disease or a specific population, some have been adapted to CKD contexts as it was shown in chapter 3. However, despite the efficiency of assessing patient-experience by means of surveys (Dalati & Gomez, 2018; Wisniewski, 2003) they also have several limitations. Setting aside the limitations already mentioned -existing questionnaires focused mostly on the final stages of the disease and did not involve CKD patients from all stages in the questionnaire design, these surveys are subject to poor return rates and high levels of missing data, particularly in elderly subjects (Palonen et al., 2016). Likewise, they might lead to inaccuracies and bias from patients who are typically asked to recall healthcare interactions and report their experience several hours or days after those interactions took place (Seymour et al., 2001). In fact, effective measurement of CKD patients' experience should start by relying on more immediate patient reports.

Thus, taking into account these limitations and considering that healthcare needs vary depending on the specific CKD stage (Schell et al., 2012), as each call for different tests and treatments (American Kidney Fund, 202) we propose to assess CKD patients' experience through patient journey mapping (PJM), which allows us to identify the most important interaction points across stages of the disease.

4.1.2. Patient Journey Mapping

PJM is an exercise that healthcare managers employ for a better understanding of how patients engage with a healthcare system over the course of their care pathway (Gualandi et

al., 2019); therefore, exploring and understanding PJM can lead to improving healthcare delivery (Ben-Tovim et al., 2008). It facilitates the identification, from the patients' perspective, of consecutive series of touchpoints or interactions between the patient and the healthcare system where care experience occurs (Trebble & Hydes, 2011; Trebble et al., 2010; Zomerdijk, 2009). By identifying those touchpoints, PJM can help gather quantitative and qualitative information about the studied phenomenon and gain insights into users' interests, feelings, and motivations throughout, as well as identify problems to be addressed with future interventions in specific interaction points (Madathil et al., 2020). Ciria-Suarez et al. (2021) provides an example of PJM, exploring the experiences of women going through the different stages of breast cancer. Through PJM, they were able to identify seven stages corresponding to the different medical processes from the patients' perspective, uncovering positive and negative aspects associated with the care experience that matter most to patients across the patient journey.

Our approach to measuring the CKD patient experience will follow PJM guidelines. We will identify specific "touchpoints" between patients and the healthcare system by employing a focus group and, through in-depth semi-structured interviews coupled with a self-reported questionnaire, we will delve into the care experience across the CKD trajectory. Specifically for the self-reported questionnaire we will use the IEXPAC which provides information on key aspects of healthcare from the patient's perspective, such as respect for the patient's values, preferences, and expressed needs; provision of information and education; access to care; involvement of family and friends; and coordination of care (Mira et al., 2016). The utilization of the IEXPAC questionnaire in this study is justified by its unique standing as the only patient experience instrument developed and validated in Spain. Its adaptability to the context of chronic kidney disease (CKD) and prior application within this population underscore its relevance for assessing patient experience in the local setting. However, the decision to reevaluate its psychometric properties is prompted by identified limitations, particularly concerning low internal consistency values below the acceptable Cronbach's alpha threshold of 0.70 in its domains. This reevaluation aims to enhance the instrument's reliability and ensure the robustness of its psychometric properties within the

specific CKD context, contributing to the refinement of measurement tools in this critical area.

Combining qualitative and quantitative information sources we will be in a better position to identify areas of concern, as well as positive and negative aspects associated with CKD patients' experience across the different stages.

4.2. METHOD

4.2.1. Participants

The population of interest for this study is adults over 18 with a diagnosis of CKD. The sample was made of patients attending the nephrology services at a hospital in Valencia (Spain), In total 110 adults aged 33–85 participated in the study; more than half were male (67%) and the rest were female. 24 participated in Phase 1 and 86 in Phases 2 and 3 (see description in the *Procedure* section)

4.2.2. Procedure

Phase 1. Focus groups. A convenience sample of 24 participants was recruited from the hospital during routine appointments. It included 17 men and 7 women aged 37–78. Through three focus groups, patients were invited to participate in the identification of ¨touchpoints¨ between them and the hospital over the last six months. Each focus group was held in the hospital setting and lasted 20–30 minutes. With this information, a CKD-PJM was proposed.

Phase 2. IEXPAC. A convenience sample of 86 patients was recruited from the hospital during routine appointments. It included 59 men (68.6%) and 27 women aged 32–85, who were at different medical stages of the disease. For consistency and considering age and limitations (such as visual problems and/or small cognitive limitations), a researcher who

had had no contact with the participants before the study read items of the IEXPAC to all patients; explanations of the items were provided if needed.

Phase 3. Semi-structured Interviews. Upon completing the IEXPAC, all 86 patients participated voluntarily in in-depth semi-structured interviews to facilitate exploration of the healthcare experience on each of the "touchpoints" identified in phase 1. Interviews were held in the hospital and lasted 30–40 minutes each. They were carried out by a member of the research team.

Participation was voluntary in all phases. Participants were given a full explanation of the study and a written consent form was obtained throughout all phases. The Hospital's Clinical Investigation Ethics Committee reviewed and approved the study.

4.2.3. Instruments

Patient Journey Mapping. There is not a single standard form to design PJM, since its design and development depend on the objectives of the inquiry (Joseph et al, 2020). However, there are a few guidelines common to all journey maps. For the scope of our work, we follow the three main steps of Grau's guidelines (2017) to create and effectively use PJM: 1) defining the audience, 2) running qualitative focus groups and identifying "touchpoints", and 3) gathering relevant information in each touchpoint. After audience identification (patients with CKD at different stages), a focus group guide was designed to identify main touchpoints along the care process. Figure 2 shows examples of questions and probes used.

Figure 2. Focus Group Guide

Example of Focus Group Questions and Probes
1. Have you received healthcare services at the Consortium Hospital of Valencia, over the last six months? 2. Can you walk us through your experience from the initial diagnosis of CKD? What were the key touchpoints in the early stages? 3. Moving into the later stages of CKD, such as when dialysis became necessary, can you describe the touchpoints during this transition? 4. In the context of CKD, did you encounter touchpoints related to community services or external support?

Instrument of Evaluation of the Experience of Chronic Patients (IEXPAC). This instrument was proposed by Mira et al. (2016) and consists of 11 items referring to the experience of the patients during the previous six months, plus an additional item for patients hospitalized during the last three years. Our study excluded this additional item, since none of the participants was hospitalized due to a direct complication related to CKD. Items were answered using a graded scale of the frequency of the behaviours and beliefs reflected: always (10) -best experience-, almost always (7.5), sometimes (5), rarely (2.5) and never (0) -worst experience. Items are grouped into: 1) Productive interactions (items 1, 2, 5 and 9), referring to the characteristics and content of interactions between patients and professionals aimed at improving health outcomes; 2) New relational model (items 3, 7 and 11), referring to the new forms of patient interaction with the healthcare system, through the internet or with peers; and 3) Patient self-management (items 4, 6, 8, 10), referring to individuals' ability to cope with their diseases, manage their care and improve their well-being, based on interventions mediated by healthcare professionals. Although the IEXPAC proposed these three dimensions, the reliability of two of them was modest at best. While Mira et al. (2016) reported a Cronbach's Alpha of 0.79 for factor 1, 0.56 for factor 2, and 0.63 for factor 3 (0.76 for the total scale); in our sample, Cronbach's alpha was 0.35 for factor 1; 0.40 for factor 2; and 0.28 for factor 3 (.65 for the total scale). Considering the low internal consistency of the dimensions, we decided to run an analysis at the individual item level to obtain crucial information about specific issues that need improvement.

Semi-Structured Interview. An interview guide was designed based on Schell et al. work's (2012) to gather information and assess the healthcare experience of CKD patients at each touchpoint. Probing questions were asked depending on the responses given to the initial questions (Figure 3). Interviews were audio-recorded and transcribed; field notes were also immediately taken following each interview.

Figure 3. Semi-structured Interview Guide

Example of Interview Questions and Probes
1. Tell me about your experience in regard to your kidney disease and the interaction with the health care system in "a specific touch point is mentioned" (this question was repeated for each of the touchpoints) ● Who is in the treatment team? ● Is your family involved in your follow-up? ● How is the relationship between you, the health care professionals, and the caregivers regarding your treatment? ● Is there anyone more involved in your follow up at this stage? 2. What aspects are relevant to discuss regarding this "touchpoint"? ● Which factors do you think are contributing to having a good experience, if any? ● Which factors do you think are hampering your experience, if any? ● What other factors do you consider important to discuss at this stage?

4.2.4. *Analysis*

Focus Groups

We recorded all participants' responses and grouped them into categories, which were referred to as "touchpoints" named and sequenced by discussion among participants. One of the researchers acted as a moderator during the group discussion and presented to the patients a preliminary list of touchpoints mentioned. Participants decided unanimously which were considered most important during their care experience. Disagreements or inconsistencies were resolved through discussion and consensus.

IEXPAC

We computed means and Standard Deviations (SD) for the 11 IEXPAC items and the total IEXPAC score. Due to their low reliability, we did not differentiate the initially proposed three dimensions of the IEXPAC. To understand the differential experience across touchpoints, we run a set of one-way ANOVAs to compare item means as well as IEXPAC mean scores.

Interviews

We used Atlas.ti (Version 7) (Soratto et al., 2020) to assist with storage, text coding and data search of the interviews' transcripts. Transcripts were analyzed line-by-line. I searched for concepts, themes, and ideas to develop a preliminary coding scheme. Initial themes were labelled and grouped into higher-order themes following an inductive process. The coding scheme was revised by two additional researchers and any disagreement about individual coding choices was resolved by discussion.

4.3. RESULTS

4.3.1. Phase 1: Using Patient Journey Map to Identify "Touchpoints"

Four interaction points directly related to the trajectory of the kidney disease were identified: Outpatient Clinic (OC) Kidney Disease, Patient Renal Education Program (PREP), Hemodialysis (HD), and Peritoneal Dialysis (PD). Among the patients that participated in the focus groups, 20.83% were in OC, 29.16% in PREP, 20.83% in PD, and 29.16% in HD.

Outpatient Clinic Kidney Disease (i.e., stages 1 and 2): Patients at this stage typically represent individuals in the early phases of their kidney disease journey. At this stage, patients do not report severe complications and their main focus is on monitoring and managing the progression of CKD. This touchpoint involves regular visits to a nephrologist and a healthcare professional specializing in kidney health. Patients have periodic outpatient

appointments to assess kidney function, review lab results, and discuss lifestyle modifications. Health care professionals provide education about CKD, including information about dietary changes, the importance of blood pressure control, and the potential trajectory of the disease. Patients undergo routine diagnostic tests to assess kidney function, such as blood tests and urine tests, as part of the ongoing monitoring process. At this stage, family members may offer support and encouragement to help patients understand and adapt to the lifestyle changes necessary for managing early-stage CKD effectively.

Patient Renal Education Program (i.e., stage 3): It involves structured educational programs, group sessions, and comprehensive support to enhance patients' knowledge and skills in managing their moderate-stage CKD effectively. At this stage, patients participate in structured educational programs specifically designed for individuals with moderate-stage CKD. These programs may cover various aspects of the disease, including its progression, management strategies, and lifestyle modifications. The format of the touchpoint involves group sessions where patients can interact with healthcare professionals, educators, and other individuals facing similar challenges. Group dynamics can facilitate shared learning and support. Given the increasing importance of dietary management in stage 3 CKD, patients receive detailed nutritional guidance to address specific dietary needs and restrictions associated with kidney health.

Hemodialysis (i.e., stages 4 and 5): Patients have reached an advanced stage of kidney disease necessitating renal replacement therapy. Hemodialysis is a critical intervention aimed at managing the compromised kidney function. This therapy becomes a crucial aspect of their routine to perform the functions their kidneys can no longer effectively carry out. Patients in this touchpoint undergo regular hemodialysis sessions, typically 3 to 4 times a week. They receive close clinical monitoring which involves assessing vital signs, fluid status, and addressing any potential complications arising during the hemodialysis. This touchpoint may include aspects related to the physical environment during dialysis, ensuring patients are comfortable and feel supported. Patients require psychosocial support from the treatment team and family members.

Dialysis peritoneal (i.e., stages 4 and 5): Patients have reached an advanced stage of kidney disease requiring renal replacement therapy. Peritoneal dialysis offers an alternative to hemodialysis. Unlike hemodialysis, peritoneal dialysis is often conducted at home, allowing patients more flexibility in managing their treatment. This touchpoint involves patients who have chosen or are suitable for peritoneal dialysis, reflecting their preference for home-based care. Given the home-based nature of peritoneal dialysis, patients in this touchpoint receive extensive training and education. This involves teaching patients how to perform dialysis exchanges, maintain a sterile environment, and recognize signs of complications. Clear information, step-by-step guidance, and adequate teaching tools contribute to a positive learning experience. Establishing good rapport between patients and healthcare providers, particularly PD nurses, is emphasized in this touchpoint.

Before presenting the results regarding phases 2 and 3, it is important to provide information regarding the participants distribution across the above-mentioned touchpoints: 8.6% were in OC, 26.74% in PREP, 37.20% in HD and 24.41% in PD (see more detailed information in Table 3).

Table 3. Patient Characteristics and distribution across touchpoints for phases 2 and 3

	Outpatient Clinic CKD		Renal Educational Program		Renal Replacement Therapy Hemodialysis		Peritoneal Dialysis	
	n	%	n	%	n	%	n	%
Gender								
Female	2	20	6	26	12	38	7	34
Male	8	80	17	74	20	62	14	66
Total	10	8.6	23	26.74	32	37.20	21	24.41
Age, M & SD	*M=69. 40*	*SD=10.2 1*	*M=62.3 9*	*SD=6.15*	*M=65.9 1*	*SD=11.5 3*	*M=58.0 4*	*SD=10.2 9*

Note: n=86. The mean age of all respondents was 63.45 and the standard deviation of 10.40.

4.3.2. Phase 2: IEXPAC Results

IEXPAC Global Score and Touchpoints Mean Differences

The global score of the IEXPAC scale was 5.57 ± 1.07. Before comparing differences in the total scores of IEXPAC across the different touchpoints, we tested whether the data were normally distributed and homoscedastic. Although scores were normally distributed according to the Shapiro-Wilks test ($p > 05$), the assumption of variance homogeneity did not hold and thus, we applied the Welch-Satterthwaite's robust test. Results showed a significant effect across touchpoints (Welch's $F(3, 30.10) = 47.87$, $p < .05$).

A post-hoc Games Howell test showed that patients in the PD touchpoint scored on average higher on the IEXPAC scale (M=6.53, SD=.60) than patients in PREP (M=5.93, SD=.53), (Dif= .60; p<.05; 95% C.I.= [.14, 1.06]) and patients in HD (M=4.57, SD=.61), (Dif= 1.96; p<.05, 95% C.I.= [1.50, 2.41]). Patients in the PREP touchpoint also scored significantly higher on the IEXPAC than patients in HD (Dif= 1.36; p<.05; 95%, C.I.= [.94, 1.77]). There were no statistical differences between OC (M=5.90, SD=1.42) and other touchpoints. These results support the importance of differentiating patients' experiences across touchpoints.

IEXPAC Item Scores and Touchpoints Mean Differences

Regarding differences in item scores (Table 4), the Robust Welch - Satterthwaite test showed significant differences for all items except item 7, which referred to Internet and telephone use to consult medical records. Interestingly, the pattern of differences across touchpoints varied for different items.

The Games-Howell post-hoc test showed that PD patients scored significantly higher than HD patients on three (items 1, 2 and 5) out of the four items (the former plus item 9) related to productive interactions. Patients in the Peritoneal Dialysis (PD) touchpoint exhibited higher scores compared to those in the Hemodialysis (HD) touchpoint on specific items of the IEXPAC scale, signifying distinctive aspects of their healthcare experiences.

Particularly noteworthy was the significantly higher score on Item 1, indicating that healthcare providers in the peritoneal dialysis setting demonstrated a greater respect for the patient's lifestyle compared to their counterparts in hemodialysis. This underscores the importance of recognizing and accommodating individual preferences and routines in the peritoneal dialysis context. Additionally, on Item 2, which assesses the coordination of healthcare services, PD patients reported higher levels of coordination for the provision of quality healthcare. This suggests a more streamlined and integrated approach to care delivery in the peritoneal dialysis setting. Furthermore, on Item 5, focusing on assistance in following treatment plans, PD patients indicated a higher degree of support compared to those in hemodialysis. These findings emphasize the nuanced differences in patient experiences between the Peritoneal Dialysis and Hemodialysis touchpoints, shedding light on the unique qualities that contribute to the positive assessment of care in the peritoneal dialysis context.

In addition, patients in the Peritoneal Dialysis (PD) touchpoint also exhibited higher scores compared to those in the Hemodialysis (HD) touchpoint on two (items 3 and 11) out of three items (the former plus item 7) referred to a new relational model. Notably, on Item 3, which assesses assistance in obtaining information from the internet, PD patients reported higher levels of support. This finding suggests that healthcare providers in the peritoneal dialysis setting are more actively involved in facilitating patients' access to online health information, contributing to a more informed patient experience. Furthermore, on Item 11, related to encouragement to communicate with other patients, PD patients expressed a greater degree of encouragement compared to their counterparts in hemodialysis. This underscores the emphasis on peer support within the peritoneal dialysis context, highlighting its positive impact on the overall patient experience.

The PD group also scored significantly higher than the HD group on item 6, referring to whether goals for a healthy life and a better control of the illness were set. This suggests that within the peritoneal dialysis setting, there is a more proactive approach to collaboratively setting health-related goals and strategies with patients.

Results also showed that PD patients scored significantly higher than PREP patients on three out of the four items referred to productive interactions; however, the pattern of significant differences was not the same as before. Patients in the Peritoneal Dialysis (PD) touchpoint demonstrated higher scores compared to those in the Patient Renal Education Program (PREP) on specific items of the IEXPAC scale, highlighting distinctive aspects of their healthcare experience. Notably, PD patients scored significantly higher on Item 1, indicating that healthcare providers in the peritoneal dialysis setting show a greater respect for the patient's lifestyle. Additionally, on Item 5, which assesses the extent to which healthcare providers assist patients in following their treatment plans, PD patients reported higher levels of support. This underscores the importance of tailored assistance in adherence to treatment regimens for those engaged in peritoneal dialysis. On Item 9, focusing on the healthcare team's concern for the patient's welfare, PD patients indicated a higher degree of attention to their overall well-being.

Furthermore, PD patients scored significantly higher than patients in the PREP touch point on two items (items 4 and 8) out of the four items (the former plus items 6 and 10) related to patient self-management. On Item 4 ("Now I can take care of myself better") and Item 8 ("They make sure that I take medication correctly"), PD patients expressed a higher level of confidence and proficiency in managing their own health compared to those in the PREP touchpoint. These findings emphasize the distinctive aspects of patient self-management in the peritoneal dialysis context, highlighting the effectiveness of PD-related educational and support initiatives in fostering patients' abilities to care for themselves and adhere to medication regimens.

In addition, there were significant differences between the PREP and HD groups in three out of the four items of the patient self-management dimensions (items 6, 8 and 10). Notably, in item 6 ("We set goals for a healthy life and better control my illness"), PREP patients exhibited a higher inclination toward goal setting for a healthier life and improved illness control compared to their counterparts in the HD group. Additionally, in item 10 ("I have been informed about health and social resources that can help me"), PREP participants reported greater awareness and information regarding health and social resources, indicating

a more comprehensive support structure within the patient education context. In contrast, patients in the Patient Renal Education Program exhibited lower scores than those in the Hemodialysis touchpoint, specifically in item 8. This item pertains to the extent to which care professionals ensure that patients take their medication correctly. This disparity highlights a potential area for improvement in medication management within the Patient Renal Education Program, emphasizing the importance of refining strategies to enhance medication adherence among this group of CKD patients.

Lastly, patients in the Outpatient Clinic surpassed those in Hemodialysis on item 5 of the IEXPAC scale, indicating a higher perception of healthcare providers actively inquiring about and aiding in adherence to the treatment plan. Conversely, these individuals scored notably lower than those in PREP on item 11, specifically evaluating the encouragement provided by healthcare providers to engage in discussions with fellow patients.

Table 4. Overall IEXPAC Item scores across Interactions Points

		Global score		OPT (N=10)		PREP (N=23)		HD (N=32)		PD (N=21)		P-Value
		M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	
1.	**They respect my lifestyle. * (PD-PREP) - (PD-HD)**	8.58	1.74	9.25	1.20	8.37	1.43	7.89	2.11	9.52	1.01	P<.05
2.	**They are coordinated to offer good healthcare to me. * (PD-HD) (PREP-HD)**	4.74	2.73	6.00	4.12	5.43	2.08	2.81	2.08	6.31	1.69	P<.05
3.	**They help me to get information from the internet. * (PD-PREP)-(PD-HD)- (PREP-HD)**	2.38	2.51	2.50	4.08	2.83	1.74	.63	1.09	4.52	2.03	P<.05
4.	**Now I can take care of myself better. (PD-PREP) ***	8.08	1.98	7.25	2.99	7.50	1.85	8.05	1.76	9.16	1.44	P<.05
5.	**They ask me and help me to follow my treatment plan. * (PD-HD) - (PD-PREP) (OPT-HD) (PREP-HD)**	7.70	2.34	9.00	1.75	7.83	1.56	6.25	2.69	9.17	1.20	P<.05
6.	**We set goals for a healthy life and better control my illness. * (PD-HD) (PREP-HD)**	7.76	2.17	7.75	2.75	8.48	1.46	6.84	2.28	8.93	1.27	P<.05
7.	**I can use the internet and my mobile phone to consult my medical records.**	.03	.18	.0	.0	.04	.21	.0	.0	.09	.30	P<.05
8.	**They make sure that I take medication correctly. * (PD-PREP) (HD-PREP)**	8.11	2.16	8.00	2.58	6.63	2.21	8.44	1.98	9.29	1.16	P<.05
9.	**They worry about my welfare. * (PD-PREP)**	8.14	1.81	7.75	1.84	7.39	1.59	8.20	2.03	9.05	1.24	P<.05
10.	**I have been informed about health and social resources that can help me. * (PREP-HD)**	2.13	2.55	4.25	4.72	3.04	2.12	.97	1.51	1.90	1.92	P<.05
11.	**They encourage me to talk to other patients. * (PD-HD)- (PREP-PD)- (PREP-HD)- (PREP-OPT)**	3.63	3.42	3.25	4.25	7.72	1.67	.63	1.09	3.93	1.69	P<.05

SD: standard deviation
Note. The asterisk indicates that the differences in means between the touchpoints are statistically significant ($p < 0.05$). The letter pairs in parentheses indicate between which specific touchpoints there are significant differences: Outpatient Clinic Advanced Kidney Disease (OPT), Patient Renal Education Program (PREP), Hemodialysis (HD) and Peritoneal Dialysis (PD).

4.3.3. Phase 3: Semi-structured interviews

After qualitative analysis via Atlas.ti 7, a total of seven themes and 16 sub themes related to the healthcare experience of patients along the different touchpoints emerged. Main themes were (1) information and education about CKD (i.e., information about the illness and progression of it), (2) care coordination (i.e., organization of patient care activities and linkage to community resources) (3) family involvement (i.e., emotional support, accompaniment in routine medical visit, assistance for daily activities) (4) practitioners' empathy and patient orientation (i.e., disease-oriented approach and warmth/supportive attitude) (5) peer support (i.e., sense of belonging and peer mentoring) (6) high-quality dialysis (i.e., safety/comfort and careful care during dialysis) and (7) patient training (i.e., good rapport and personalized teaching). Interestingly, the first four themes emerged consistently across all touchpoints (see Table 5), whereas the last three emerged only in specific touchpoints (see Table 6). HD patients described the importance of high-quality therapy during the care experience (category 6), while PD patients noted patient training as a critical aspect of their care experience (category 7). Lastly, patients in PREP emphasized the importance of peer support (category 5)

Table 5. Common Themes found across the different touchpoints (i.e., *Outpatient Clinic "Advanced Kidney Disease", Patient Renal Education Program, Hemodialysis and Peritoneal dialysis).*

Theme	Subtheme	Quotes
Illness education	Information about the illness	❖ "The family doctor did not explain to me what the illness was and how it would evolve… he just gave me the diagnosis and didn't have time for my questions… After seeing the doctor, I was in shock and nervous'… 'I didn't feel prepared for what was coming". - Outpatient Clinic Participant. ❖ "The nephrologist explains to us, me and my wife, in a detailed manner about my illness and makes clear recommendations regarding my diet, the importance of physical activity and provides full information about the medication". - Outpatient Clinic Participant. ❖ "The doctors informed me about the different options I have to choose prior to this treatment, and I am happy with my choice, I feel that they provide me with the necessary information to make a decision that better fits my lifestyle" – Peritoneal Dialysis Patient. ❖ "I feel that I waste four hours of my life here, and we do nothing here, we just sit for many hours, I was not prepared for this, and I did not attend any education program like the others, I was just told this therapy was the best for me, and I went with it". – Hemodialysis patient ❖ "I see a lot of professionals every other week who come and teach information to get ready for what is coming to us later in time (i.e., dialysis), so I am less uncertain about the future… The medical staff provides us with a lot of information about the different alternatives of therapy so that we can choose better". -Renal Education Program.
	Information about the progression of the illness	❖ "I see a lot of professionals every other week who come and teach information to get ready for what is coming to us later in time (i.e., dialysis), so I am less uncertain about the future… The medical staff provides us with a lot of information about the different alternatives of therapy so that we can choose better". -Renal Education Program ❖ "I am grateful to participate in this group, but the psychology sessions focus too much on dealing with the illness and they forget that we are people with other needs, they should do something more fun, we want to forget that we are sick…

		❖ The psychologist for example teaches how to manage our emotions in difficult times of our illness, but they don't say anything about how to deal when problems arise at home with our families because of our disease". - Renal Education Program Participant. ❖ "I feel very happy to partake in this program, it has helped to understand that my illness is not reversible, and it goes by stages, so I have to maintain a healthy lifestyle… I learned that I must avoid processed meats like ham, bacon and to reduce salt consumption". - Outpatient Clinic Participant. ❖ "It was not that clear to me at the beginning to differentiate what kind of things to expect about choosing one therapy or the other, and the doctor focuses too much on which one can led to better prognosis, but doesn't tell in detail what it involves'… I feel lost and confused". -Outpatient Clinic Participant. ❖ "I was not ready for this, I was told about the dialysis process, but my life is not the same and I depend more on others, I ask for more help at home I feel very weak after dialysis…I was told by the doctors the benefits of the therapy, but they didn't tell me really what kind of things to expect" – Hemodialysis patient.
Care Coordination	Organization of patient care activities	❖ "I have to always wait at the ward for the transportation to come'… 'after dialysis I am exhausted, I just want to go home. I am sick of them always showing up late, I think there should be better coordination with the hospital". – Hemodialysis Patient ❖ "I agree with the treatment team on specific objectives regarding diet, physical exercise, and medication to control my health problems better" – Outpatient Clinic Participant. ❖ I review the adherence and follow up on the test and care plan with the treatment team, and if I have questions, they answer them. - Peritoneal Dialysis Patient.
	Linkage to community resources	❖ "Health care professionals did not tell me about the different community resources available to me to cope with my illness". – Hemodialysis patient.
		❖ 'My family doctor never had time for me, after he told me the diagnosis, he didn't even ask how I felt, I was very sad'… 'He was cold and didn't even look at my eyes'… 'he treats me like a number not like a person". – Outpatient Clinic Participant.

Empathy from Professionals	Disease-oriented approach	❖ "The doctors are very cold, they come for 2 or 3 minutes to tell you about test results when we are sometimes drowsy or sleepy because of the dialysis… for the doctors we are an illness to treat, we are not humans". – Hemodialysis Patient. ❖ "The doctor sometimes focuses too much on test results and medication, she never asks about how I am emotional'… 'the doctor is very professional but sometimes I just do not talk in the clinical appointment because I feel down but she just doesn't care about asking why I am silent" - Peritoneal Dialysis Patient.
	Warmth/supportive attitude	❖ "The nurses at the hospital are very warm and gentle, they treat you like family and it makes me feel valuable and understood' 'they care about me, and they show empathy and listen to my questions and give supporting calls every other week, I feel grateful for that". – Hemodialysis patient. ❖ "The nurses are so loving and caring, they are attentive all the time attentive, and they are always checking on you and they respect when you sleep'… 'they call you by your name, tease you, they treat like a normal person not like a sick person, this makes me feel valued". – Hemodialysis patient.
Family Involvement	Emotional Support	❖ "Since my wife has come along with me to the sessions, I feel that she understands me better about what I am going through". ❖ "My partner is patient with me and helps me to eat better." ❖ "I talked with my family at home about the pros and cons of the different alternatives discussed at the PREP program'… 'before making any decision, my wife helps me to consider what could be the best option for me but also for all of us in my family" ❖ "I am grateful that I can rely on my wife on this, she has helped me so much throughout this process, she is very tolerant and helps me with the treatment'…. She helped to make the decision of DP. ❖ "My family doesn't understand that I cannot always be happy, this illness is like dying inside, sometimes I just get too down but they pretend that I have to be active and positive all the time'…. 'They always nag me why I am always sleeping and why I am mad, they just don't understand the suffering."

	Assistance for daily activities	❖ "At home, my wife cooks and prepares food without salt, and that helps me to do the diet". ❖ "My son understands that I am not the same anymore. I can do a lot at home, so he helps me around the house".
	Accompaniment in routine medical visits	❖ "It is important for me to have the help of my wife, she always comes to the clinical visits along with me and helps me to understand a lot of information, I feel supported".

Common Themes Across Touchpoints

Information and education about CKD.

A total of 72.09% of CKD patients expressed the need to be informed about inherent aspects of the disease (diagnosis, monitoring health changes, recommendations on physical activity and eating habits, medication) and factors related to its progression (psycho-social changes, diet change, modality treatment and transplant possibilities). Patients reported negative experiences due to scarce and/or overwhelming information. Positive experiences were linked to adequate and manageable amounts of information. The following are two examples of adequate and too much information, respectively:

> "The nephrologist explains to me in a detailed manner what my illness is about and makes clear recommendations regarding a healthy lifestyle"; "I was given too much information about medication, and kinds of therapy, and I was not ready to accept I was sick¨

Care coordination

A total of 51.16% of CKD patients systematically mentioned the importance of information sharing among healthcare providers to guide the delivery of safe and appropriate care. Organizing care activities (e.g., medical appointments, transport coordination, health care planning activities, referrals) and tailoring them to their needs and time availability were highlighted aspects.

> "The medical staff organized medical appointments and lab tests in a way that everything is organized and well aligned with my availabilities¨; ¨there should be better organization between the hospital and the ambulance that brings us here, we always wait for too long¨

Family involvement

A total of 65.11% of CKD patients remarked that their experience is shaped by the instrumental and emotional support of their loved ones. They highlight the importance of relying on them for daily activities (e.g., cooking, hygiene, machine installation/cleaning). According to patients' reports, being accompanied by family during routine medical visits helps them understand the information and recommendations by the treatment team.

> "My wife has come along with me to the sessions, I feel that she understands better than me what I am going through… she is patient with me and helps me to eat better".

Empathy and patient orientation from professionals.

A total of 69.77% of CKD patients describe and assess their care experience in terms of a warm and supportive attitude and a disease-oriented approach from healthcare professionals, where nurses' humanized treatment was affectionate, responsive, and personalized; participants reported fewer positive experiences regarding doctors, who typically provide a service focused on treating the illness but not the patient, centred on lab results and physical considerations.

> "The nurses are so loving and caring, they are there all the time, and they are always checking on you and they respect you when you sleep…they call you by your name, tease you, they treat you like a normal person, not like a sick person, this makes me feel valued."

Table 6. Unique themes found on 3 individual touch points (i.e., *Patient Renal Education Program, Hemodialysis and Peritoneal dialysis)*

Touch Point	Theme	Subtheme	Quotes
Patient Renal Education Program	Peer support	Sense of Belonging	❖ "When I meet with the other patients, I feel like I am not alone on this and that can happen to anyone'… 'sometimes when we are on the waiting area, we talked about how we are dealing with our kidney problem, and we discover who we are beyond the illness."
		Peer Mentoring	❖ "We just listen to the doctors talking and talking, there is no interaction among us, we just sit there but there is no communication between us participants, it is quite boring'… 'to me, they should invite patients that have already started the dialysis therapy and who can share the experiences and knowledge living with this health problem."
Hemodialysis		Safety/Comfort	❖ "For me it is very important the correct functioning of the machines, we depend on them, but the nurses are always checking if there is any problem, or if the machine stops for any reason'… 'the machines always work good and the nurses make sure of that, I feel secure that nothing will go wrong." ❖ "The nurses are always clean, they manipulate everything with gloves specially the tubes in which our blood goes through, and they do not touch our skin areas without the gloves'… 'the cleanliness of this place must be improved, I always see the bins full of used plastic tubes with blood it makes me feel disgusted." ❖ "The seats are very uncomfortable, and we must be there for 4 hours. It is very tiring, after we finish here, we go home with no energy and on pain."

Hemodialysis	High quality of therapy		❖ "The nurses make this process less difficult. They offer you things to do while you are seated for four hours and sometimes there is a musician that comes to play music, we appreciate that, and we wish there could be more activities like that."
		Careful care during dialysis	❖ "When I feel pain, I ask the nurse for help, they are always receptive and help us with everything we need'… 'the nurses are constantly looking for the purification of my blood." ❖ "The doctor always asks if there is any change after given the medication or if I'm not feeling well but they don't stay for too long'… 'the doctor sometimes gives tests results or information when I am bit sleepy or drowsy because of the dialysis so I don't remember what he says."
Peritoneal Dialysis (PD)	Patient training	Good rapport	❖ "During the training, the nurse was always patient and affectionate she called me with loving names, she made you feel warm and protected'… 'the nurse was always very encouraging in the learning process, she was telling me nice words and to keep trying and she always listened to my questions, I felt that she cares about me". - Peritoneal Dialysis Patient.
		Personalized teaching	❖ "For me the most important thing was to learn how to do the peritoneal dialysis on my own and I thank the nurse for taking the time and always telling all the recommendations needed to do it properly'… 'she was professional she took the time with illustrations and with simple language, and all the time I receive feedback' 'she didn't let me go on my own until she saw I was ready" ❖ "The room where we do the training it is good, it gives us privacy and no one comes there, I feel that this is a private place and I feel respected'… 'the

			seats are comfortable, and it is bright room, so it is good to do the training there." ❖ "It was a lot of time in training before I was let go to do it on my own, but I think it was for the best, I heard that you could have peritonitis if you do it wrong or do not clean your hands and the machine before starting it'…. 'because of my age I think it was good that we took a lot of time in training, I can't learn fast as younger people, I am grateful for having a lot of time to learn".

Unique themes depending on Touchpoints.

Peer Support-Renal Education Program.

This was important for patients in PREP. A total of 60.86% of patients in this group expressed that peer support during the Renal Education Program fosters a sense of belonging and connection with other individuals facing similar challenges. Moreover, patients in the PREP groups highlight the importance of having an expert patient who can serve as a mentor to discuss coping strategies and talk about life after commencing dialysis.

> "When I meet with the other patients, I feel like I am not alone on this and that this can happen to anyone.''

High Quality of Therapy- Hemodialysis patients.

A total of 56.25% of patients in the HD group mentioned their needs and expectations to have a proper functioning of the machines and safety protocols. They also highlighted the importance of receiving care beyond physical health, involving pleasure and comfort.

> "When I feel pain, I ask the nurses for help. They are always receptive and help us with everything we need… the nurses are constantly checking that the process of purifying my blood goes well."

Patient training-Peritoneal dialysis patients.

A total of 66.67% of PD patients view training as the most important aspect of their care experience since it typically requires manual dexterity and the ability to care for oneself at home. Patients expressed that clear information in a step-by-step process along with adequate teaching tools enhance a good learning experience. Patients also mentioned that establishing good rapport between them and PD nurses fosters successful training.

> "The nurse was very professional. She took her time to teach me… with illustrations and using simple language, and all the time I received feedback' 'she didn't let me go on my own until she saw I was ready."

4.4. DISCUSSION

Like other chronic diseases, CKD has a specific idiosyncrasy that needs to be considered to understand patients' experience and design interventions aimed at improving general care services and CKD patients' experiences along the different stages of the disease. To our knowledge, this is the first study to describe the CKD trajectory in terms of touchpoints following a patient-centred approach. Although Ahlberg and Carlsson (2019) developed PJM for home dialysis patients, the resulting touchpoints described individual and specific events that were not directly related to the healthcare system. Thus, our study results provide useful feedback about issues that patients deem important across different touchpoints, and those that are specific to shape the patient experience when patients are at specific touchpoints.

Results obtained from the focus group analysis showed that, when assessing CKD patients' experience, assessment systems should differentiate among the four main touchpoints mapped by CKD patients, which can be linked to medical stages differentiated by the National Kidney Foundation (Hallan & Orth, 2010): OC advance kidney disease (medical stages 1 and 2), PREP (medical stage 3), HD, and PD (medical stages 4 and 5), respectively.

Results of the IEXPAC questionnaire also support the need for differentiation across the four touchpoints. Results of the ANOVAs carried out showed that patients in PD and in PREP reported a more positive experience compared to patients in the HD group in areas such as healthcare coordination, information adequacy and peer support promotion, a pattern further supported by interview results. For example, HD patients reported that efforts should be oriented towards transport coordination from and to the dialysis center. In further

exploration during interviews, HD patients mentioned not being invited to participate in group therapies or not being encouraged to search for available resources that are useful to cope with their health problems. HD patients mentioned that during their weekly visits to the dialysis center (typically 3), it is difficult for them to ask questions about care plans and follow-up treatment since they often feel drowsy or sleepy while connected to the dialysis machine.

When comparing the kinds of dialysis and focusing on care experience, PD patients reported a better care experience than HD patients. As similar findings are found in the literature, this difference may be based on the information they receive about each treatment modality, their autonomy to choose and carry out PD, and the impact this therapy has on their lives (Rubin, 2004). Regarding their experience with the information provided by the care services, the results of our study align with previous research. PD patients reported receiving more detailed information regarding treatment modalities (e.g., considering the pros and cons of each dialysis alternative) than HD patients. Other complaints made by HD patients had to do with the discomfort, boredom and fatigue associated with the four-hour therapy at the ward and reported that activities such as music therapy during hemodialysis were comforting and uplifting. Therefore, more efforts should be put towards creating a more bearable and home-like atmosphere for HD patients. The professionals should make sure that available treatment options are well explained to patients that need to start dialysis before starting the HD treatment and accompany them in the choice (considering their lifestyles and risks).

Regardless of the touchpoint, patients do not perceive that health and social care services act in synergy to improve their well-being and quality of life, nor are they informed about other health and social resources that can be used to better cope with their challenges. This finding is similar to that of Orozco-Beltran et al. (2021), who found that chronic patients perceive that they are not being informed about self-education and the use of social resources to improve their well-being. Similarly, all patients—except those from PREP—perceived new forms of patient interaction with the system to be lacking or nonexistent. This is in line

with previous studies that, focusing on different chronic diseases, have shown the need of improving the provision of support in getting information from the internet, the facilitation of the access to medical records (e.g., by phone) and encouragement to talk to other patients (Orozco-Beltran et al., 2018). PREP patients were more encouraged to talk to other patients and participate in groups to share their illness-related experiences, and this was highly valued during the interviews.

Moreover, individual themes corresponding uniquely to each of the three interaction points in our study (i.e., renal education program-peer support, peritoneal dialysis-patient training, and hemodialysis-high quality therapy) suggest that there are specific needs, goals and expectations from patients depending on the touchpoint that cannot be assessed with surveys. Patients in renal education programs, for example, highlight the importance of peer support during group sessions. Nevertheless, past studies demonstrated that the use of social resources and interactions between patients improve lifestyle and self-management behaviours among individuals with CKD (Nicholas et al., 2009; Muhammad et al., 2014) and thus, these interactions may be beneficial and should be promoted at all CKD stages and touchpoints (even if, initially, not all patients think this is crucial).

Limitations of the study and future research

Although our study has important strengths, it also has several limitations. First, the sample size was limited and came from only one hospital located in Spain; hence, the generalizability of the findings is limited. Future research should cross-validate our results and conclusions in larger samples and across different cultures. Second, we did not collect data regarding other measures of healthcare quality such as clinical effectiveness and patient safety since our study was aimed at understanding CKD patients' experience. Future research should integrate these three pillars of healthcare quality and analyze the relationship between identified areas of improvements, as well as other healthcare indicators, which will allow us to evaluate the effect of patient experience on other healthcare-related outcomes. Finally, the low internal consistency of the IEXPAC in our sample might represent a limitation.

However, we overcame the problem by comparing the variables at the item level instead of the dimensions, which leads us to obtain in-depth information about which aspects should be areas of improvement across the touchpoints. Because the dimensions did not show adequate reliability in the original study either, further studies should be put towards improving the IEXPAC scale to increase the reliability.

Conclusions

Our study contributes significantly to the understanding of what CKD patients value the most as their illness progresses. The four main themes of illness-related education, care coordination, empathy from professionals and family involvement are considered by all subjects in our study as valuable inputs for modeling the CKD patient experience. These findings provide valuable information for healthcare leaders to promote quality improvement by monitoring performance and designing programs aimed at improving these healthcare areas.

Health policymakers should take into consideration aspects such as family and peer support, humanized treatment, and care coordination when designing programs to enhance quality of care—by doing so, they will help to improve the quality of life of CKD patients. The results of our mixed method approach also constitute an important input to design standardized instruments measuring the care experience based on the aspects most valued by CKD patients with customized areas for specific touchpoints. This will help hospital managers and CKD health care professionals to monitor patients' experience as the disease progresses and introduce remedial actions when necessary.

CHAPTER V: INTEGRATION

TOWARD A COMPREHENSIVE UNDERSTANDING OF PATIENT EXPERIENCE IN CHRONIC KIDNEY DISEASE: INTEGRATING RESULTS OF CHAPTERS III AND IV

Up to this point, it has become apparent that chronic kidney disease (CKD) poses a significant challenge in healthcare, urging a reevaluation of patient care to include some often-overlooked dimensions of patient experience across all the stages of the disease. Understanding the unique needs of CKD patients is vital for delivering effective care that meets these needs throughout their healthcare journey. Furthermore, the assessment of patient experience is an important input not only to enhance the quality of care but also to improve communication and encourage patients to play an active role in their healthcare decisions, fostering better health outcomes.

In the current chapter, we bring together and integrate the insights gleaned from two distinct, yet interconnected research endeavors discussed in chapters three and four. The first is a systematic review of instruments designed to measure patient satisfaction and experience in CKD contexts. The second is a mixed-method exploration of CKD patient experiences, tracing their journey through the healthcare system.

As it was indicated in Chapter 3, surveys and standardized questionnaires constitute the cornerstone method for capturing the patient perspective, aligning with the principles of patient-centered care (Berwick, 2009). The primary objective of this chapter was to delve into the essence of what these existing questionnaires measure within the CKD context and to evaluate the psychometric quality of these instruments. Understanding the existing landscape of instruments is important for refining our comprehension of patient experiences, essential for improving the quality-of-care delivery and facilitating meaningful comparisons across diverse healthcare contexts. The systematic review evaluated a total of 9 scales, for which we highlighted their strengths and limitations, such as the lack of focus on the full spectrum of CKD stages and the overrepresentation of hemodialysis. In addition, although patients' expectations model patient satisfaction and the subjective experience of patients, results show that patient satisfaction instruments tend to focus on more general aspects related to care quality and fulfillment of expectations (e.g., personal feelings about the treatment and interactions with healthcare providers) whereas patient experience instruments have less subjectivity and encompass a wider array of dimensions. They ask about observable and measurable aspects, like wait times, communication, scheduling, diet, fluid management,

environment during dialysis, shared decision-making, and support. Thus, patient experience questionnaires provide a more granular, actionable feedback, identifying specific areas needing improvement like wait times or communication, whereas patient satisfaction questionnaires offer a more general overview of the patient's feelings towards their healthcare experience, which might not always provide clear directions for specific improvements. Thus, the former perspective enriches our understanding of patient needs and contributes to more holistic and patient-centered care. However, the experience and the importance of different domains that shape the experience may depend on the particular stage of the disease. To gain additional insight on this possibility, in Chapter 4 we presented our mixed-methods study carried out using a sample of Spanish CKD patients receiving care in the public health system. Specifically, this study explored CKD patient experiences across different stages, using a patient-centered approach, the patient journey mapping, to identify key touchpoints that may affect the experience. We implemented qualitative and quantitative methods to assess patient experience across the different touchpoints, spanning early kidney disease to different stages of dialysis, to uncover variations in patient experiences. Our analysis of the information gathered suggests, for example, the importance of family involvement at early stages of the illness and the concerns about coordination between health and social care services. This suggests the need for differentiated interventions to improve the care provided depending on the particular stage of the disease.

In this chapter, the aim is to synthesize and integrate the findings from these two distinct yet interconnected studies, offering a comprehensive and nuanced understanding of the patient experience in the context of CKD. We strive to identify the aspects that are crucial for assessing CKD patients' experiences, discerning those that are universally relevant and common to all patients from those that vary in importance based on the specific stage of CKD. This integration of insights from both studies allows for a more holistic perspective, shedding light on the dynamic nature of patient experiences across the spectrum of CKD stages and emphasizing the need for tailored approaches that consider the evolving needs and priorities of patients at different points in their healthcare journey. The integration of the information obtained through the two studies offer a unique vantage point.

The systematic review, inherently quantitative in nature, rigorously assesses the content areas and dimensions and psychometric properties of diverse scales employed to measure patient satisfaction and experience in CKD. In contrast, the patient journey mapping study introduces a qualitative dimension (focus groups and interviews), aiming to uncover the intricacies of the CKD patient experience through all the CKD stages. By delving into patient interactions, emotions, and perceptions at different touchpoints, this qualitative approach adds depth and context, revealing unique narratives and experiences that quantitative metrics alone may not capture.

By combining the two sources of information, we will be in a better position to define a conceptual model for assessing CKD patient experience across the different stages of the disease and for developing a standardized measurement instrument tailored to different stages. Although not free of limitations as we previously pointed out, standardized instruments are well known for their efficiency in collecting data from a large number of patients in a short amount of time and for facilitating the comparability of care service quality. This mixed-method approach used in the empirical study of this thesis acknowledges the diversity of CKD patients and provides useful information for the development of tailored assessments that bridge the gap between existing standardized instruments and the nuanced reality of CKD patients. These assessments, in turn, will facilitate the identification of areas for improvement in patient care, and the design of tailored interventions to improve the quality of the care provided through the continuum of care in CKD contexts.

As we navigate through the integrated findings of these studies, our aim is to not only shed light on the intricate dimensions of CKD patient experiences but also to inform clinical practice, policy development, and future research endeavors, which will be covered in chapter 7 more in depth.

5. 1. MAIN FINDINGS OF EACH STUDY: THE HIGHLIGHTS

5.1.1. Systematic Review of instruments used to assess CKD patient experience.

In our systematic review of instruments measuring patient experience and satisfaction in the context of chronic kidney disease (CKD), we uncovered a diverse landscape comprising two distinct categories of instruments: generic and disease specific. These instruments serve as invaluable tools in measuring the diverse dimensions of care experienced by CKD patients. Generic instruments offer a broad perspective on patient experience, while disease-specific instruments tailor their focus to the unique challenges and nuances associated with CKD. Each category provides a comprehensive understanding of the care journey, collectively covering both distinctive and shared dimensions that shape the overall healthcare experience for individuals managing CKD.

Across diverse generic scales such as IEXPAC, SERVQHOS, The Consumer Assessment of Healthcare Providers and Systems (CAHPS) questionnaire, and The Sequs®, several common dimensions emerge, contributing to a comprehensive understanding of patient experience in the context of chronic kidney disease (CKD). Productive interactions between patients and professionals, encompassing courtesy, empathy, responsiveness, and professional competence, stand out as crucial elements shaping the care journey. Furthermore, the evaluation of the quality of dialysis centers, including the conditions of the rooms, is a shared dimension that resonates across these instruments. Additionally, the provision of patient information emerges as a consistent theme, underlining the significance of transparent and informative communication in fostering a positive healthcare experience for CKD patients. These common dimensions collectively contribute to a holistic assessment of the healthcare journey, emphasizing the importance of patient-professional interactions, facility quality, and information provision in shaping patient experiences across the CKD spectrum. Similarly, among the disease-specific scales, including The Renal Treatment Satisfaction Questionnaire (RTSQ), The Customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD), Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD), The Consumer Quality Index (CQ index) instrument, and The Kidney Patient-Reported Experience Measure (PREM) common dimensions emerged that underscored key aspects of the patient experience in chronic kidney disease (CKD) care. These shared dimensions encompassed the organization of care delivery, emphasizing the importance of streamlined and efficient healthcare processes. Additionally,

the environment during dialysis sessions was a recurring theme, highlighting the significance of creating a conducive and comfortable setting for patients. The quality of care provided during dialysis, as well as the overall facilities and organizational aspects of the service, stood out as crucial dimensions that collectively contribute to a comprehensive understanding of patient satisfaction and experience in the context of CKD care.

The instruments examined in the systematic review display various limitations. While certain questionnaires maintained a generic focus, designed or adapted for all types of CKD patients, the majority concentrated on advanced renal stages and underwent validation with patients undergoing hemodialysis. This is an important drawback because it raises concerns about the broader applicability of these instruments to cover the entire CKD journey, including individuals in the early stages of the illness that may have particular needs and expectations. In addition, the limited involvement of patients at different stages of the disease in the early design and development of these measurement tools poses a notable risk, potentially overlooking crucial aspects of the patient experience directly perceived by those dealing with the challenges of CKD. Furthermore, 5 out of the 9 instruments focus on measuring satisfaction exclusively. This disparity suggests a potential gap in understanding and evaluating the nuanced aspects of patient experience in the context of chronic kidney disease (CKD). Patient satisfaction, while crucial, represents just one dimension of the broader patient experience. Finally, the static nature of the measurements, capturing a specific moment in time, raises concerns about their ability to comprehensively represent the dynamic and evolving nature of CKD, where patient experiences can undergo substantial changes over the different stages and the course of treatment. These multifaceted limitations highlight the importance of careful consideration and contextualization when interpreting outcomes derived from these instruments within the complex landscape of CKD care.

When we focus on Spanish-speaking populations, the systematic review carried out showed that there are three instruments available which were developed in Spanish or adapted to Spanish: two in Spain, the SERVQHOS (Mira et al., 1998) and the IEXPAC (Mira et al., 2016) and one in Colombia, the ESUR-HD (Sanabria-Arenas et al., 2017). The limitations with these instruments are that the ESUR-HD and the SERVQHOS focus on

patient satisfaction, and both integrate patient input after the questionnaires had been developed, potentially limiting the depth of patient perspective in shaping the instruments. Similarly, even though the IEXPAC focuses on measuring patient experience, it does not even take into consideration patient input during the instrument design, which could lead to a lack of alignment with the diverse and evolving needs of CKD patients. The repercussion of this omission is the potential exclusion of vital aspects of patient experience, limiting the instrument's comprehensiveness. Lastly, although the two questionnaires validated with Spanish samples, the SERVQHOS and the IEXPAC, have been used in CKD populations, these are not disease-specific instruments. The consequence of using non-specific instruments is the potential inadequacy in capturing the unique challenges and experiences specific to CKD, potentially compromising the instruments' sensitivity and relevance in this healthcare context.

5.1.2. CKD Patient Journey Mapping

The study's primary finding revolves around the identification, by means of focus groups with CKD patients, of four crucial touchpoints in the CKD trajectory, namely the Outpatient Clinic (OC) Kidney Disease, Patient Renal Education Program (PREP), and the modalities of Hemodialysis (HD) and Peritoneal Dialysis (PD). Notably, these touchpoints serve as pivotal interaction points in the patient's journey, each presenting unique challenges and opportunities for enhancing their experience.

The mixed method implemented to gather information across all touchpoints allows us to not only quantify the nuances of patient perspectives across touchpoints but also delve into the qualitative intricacies that shape their journey through CKD.

Regarding quantitative findings, the IEXPAC results provide valuable insights into the variations in patient experiences across the four touch points identified. Although overall results show that, on average, there is room for improving patient experience (the observed mean is 5.57 over 10), patients in the Hemodialysis (HD) touchpoint exhibited the lowest scores (significantly lower than PREP and PD patients), highlighting the need to focus on

this modality. In the other extreme, patients undergoing Peritoneal Dialysis (PD) reported the highest scores (significantly higher than HD and PREP) indicating a more positive overall experience. The significance of these findings lies in their potential to inform targeted interventions and improvements in healthcare delivery. Understanding that patients undergoing Peritoneal Dialysis, followed by PREP, have a more favorable experience suggests that aspects contributing to this positivity could be identified, analyzed, and potentially implemented in other touchpoints. Analysis at the item level suggests that healthcare coordination, information adequacy and peer support promotion, are some of the areas in which service quality should be improved to enhance the experience of HD patients.

Regarding the qualitative findings, the consistent emergence of key themes across all touchpoints underscores their universal importance. Information and education about CKD, care coordination, family involvement, and empathy and patient orientation of healthcare professionals are deemed crucial elements in enhancing the CKD patient experience regardless of the stage or touchpoints they are in. Thus, healthcare providers can prioritize these aspects across all touchpoints to improve patient experience and care quality.

The identification of unique touchpoints further emphasizes the diversity of patient needs. Patients undergoing hemodialysis prioritize high-quality therapy, emphasizing the importance of not only addressing medical aspects but also considering the overall treatment experience, including aspects such as safety, comfort, and quality of care during dialysis. In the Patient Renal Education Program (PREP), peer support emerges as a vital aspect, highlighting the potential benefits of fostering a sense of community among patients facing similar challenges. Lastly, Peritoneal Dialysis patients emphasize the significance of patient training, shedding light on the pivotal role education plays in empowering patients to actively participate in their care. In conclusion, these findings serve as a roadmap for healthcare providers and policymakers to tailor interventions and strategies that enhance the patient experience at each touchpoint. By acknowledging the variations and commonalities across modalities, healthcare systems can strive towards a more patient-centric approach, ultimately leading to improved outcomes and satisfaction for individuals navigating the complexities of CKD.

5.2. INTEGRATION OF RESULTS: COMMONALITIES AND UNIQUE CONTRIBUTIONS

The synthesis of insights from the systematic review and the CKD Patient Journey Mapping study, the empirical study, offers a comprehensive understanding of dimensions and themes crucial to the patient experience. Universally applicable across CKD stages, the most important themes refer to:

1. Receiving adequate information about the illness. Some of the main issues reported during interviews in the empirical study had to do with information about the disease itself and the treatment options, how to monitor health changes, recommendations on physical activity and eating habits, medication guidelines, and how these factors may change as the disease progresses. General and patient information were also relevant dimensions in some of the questionnaires analyzed (such as the CQ index, and CAHPS) and were included in the questions of instruments such as the SERVQHOS and the Kidney PREM. Both items referred to patient information, and the PREM also highlighted the diet advice mentioned in the interviews. These questionnaires were aimed to measure either satisfaction or experience of generic CKD patients, but also HD and PD patients, particularly. This reinforces the idea of the importance that information has for all CKD patients, regardless of the stage of the disease.

   Interestingly, the interviews suggest that, when we talk about adequacy of the information, it is important to adequately manage the amount of information provided. Insufficient information can leave patients ill-prepared to manage their health, leading to poor adherence to treatment plans, misunderstanding the seriousness of their condition, and an inability to recognize symptoms that require medical attention. However, on the other extreme, too much information can be overwhelming, especially when delivered all at once or in technical language that is difficult to understand. This can lead to confusion and anxiety, potentially reducing a patient's ability to effectively manage their condition. The pernicious effects of information overload in healthcare have been previously documented (e.g., Klerings et al., 2015; Wang & Voss, 2022).

Thus, it is important to provide information at a pace and level that the patient can comfortably absorb and healthcare providers should be able to recognize and address patients' feelings of information overload (Wang & Voss, 2022).

To conclude with the information domain, it is important to mention that some questionnaires, such as IEXPAC assume that getting information from the internet (with the help of health professionals) -an item that is included in the new relational forms- is positive in shaping patient experience. However, even if the use of the internet makes information accessible to everybody, the use of the internet could be counterproductive (information may be overwhelming and, more importantly, inaccurate, or not evidence-based) and less useful for older or less-educated patients.

2. Care coordination. In the empirical study, patients, regardless of their interaction point, identified areas for improvement in care coordination activities. Specifically, they reported low scores on certain items of the IEXPAC scale, such as item 10 (i.e., "I have been informed about health and social resources that can help me") and item 2 ("My treatment team is coordinated to offer good healthcare to me"). Interviews revealed that patients lack awareness of community services like social workers, psychologists, and nutritionists, which could enhance their ability to manage their illness effectively. The recurrent theme of linkage to community services emerged as a crucial area for reinforcement, resonating with domains assessed by The Consumer Quality Index (CQ index) and the Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD). These instruments assess patient satisfaction and care experience, emphasizing the significance of communication, cooperation between providers, and linkage to community services to assist CKD patients in navigating the challenges posed by the disease.

   Conversely, patients reported positive aspects of care coordination activities, scoring significantly high on items like 5 ("They ask me and help me to follow my treatment plan"), 6 ("We set goals for a healthy life and better control my illness"), and 8 ("They make sure that I take medication correctly"). Interviews highlighted the collaborative

efforts between patients and healthcare professionals in reviewing treatment adherence, following up on tests and care plans, and creating proactive plans tailored to patients' needs and living circumstances. These aspects are also reflected in instruments like The Kidney Patient-Reported Experience Measure (PREM), The Consumer Quality Index (CQ index) instrument, and The Renal Treatment Satisfaction Questionnaire (RTSQ), which encompassed core activities such as organizing medical tests, needling, and medical appointments. Notably, the negative experience reported by HD patients, in the empirical study, due to the lack of coordination between the dialysis center and transportation aligns with the Kidney Patient-Reported Experience Measure (PREM), highlighting the critical role of transport in patient satisfaction. Similarly, the importance of technical assistance for PD patients in case of machine failure was acknowledged, emphasizing the responsiveness of customer service in a dimension covered by the Customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD) related to patient-centered medical homes.

In conclusion, while patients universally identify areas for improvement, such as the need for better linkage to community services, the positive aspects of care coordination, such as collaborative goal setting and medication management, are also evident. The common dimensions identified across various instruments, including the IEXPAC scale, CQ index, and ESUR-HD, underscore the importance of communication, cooperation between care providers, and access to community services for a comprehensive understanding of patient experiences in CKD care. Moreover, the recognition of specific challenges, such as transport coordination for HD patients and technical assistance for PD patients, emphasizes the need for tailored approaches to address diverse patient needs at different touchpoints in the CKD journey.

3. Family involvement. According to the empirical study, family involvement emerged as a pivotal dimension in the CKD patient experience, encompassing both instrumental and emotional support that significantly shapes the trajectory of the disease. In the early stages, patients at Outpatient Clinic Kidney Disease and Patient Renal Education Program touchpoints, reported the importance of family accompaniment during routine

medical visits, acknowledging the valuable role family members play in understanding and processing technical information, particularly when the emotional toll of the diagnosis is high. Moreover, as CKD advances, patients undergoing HD and PD expressed the escalating need for assistance in various daily activities, ranging from essential tasks like cooking and personal hygiene to the intricacies of machine installation and cleaning. Furthermore, the interviews reveal that emotional support from family members becomes increasingly vital across the disease trajectory. The companionship, discussions about treatment options, empathy, and words of encouragement contribute significantly to patients' feelings of support. However, an interesting revelation is the challenge patients face in conveying post-therapy mood swings to their families, indicating a gap in understanding.

Remarkably, none of the existing instruments, whether disease-specific or generic, adequately captures the multifaceted importance of family involvement from the onset of the illness. This highlights a critical oversight in the current assessment tools, emphasizing the need for a more comprehensive and patient-centric approach.

In conclusion, the exploration of family involvement in the context of chronic kidney disease (CKD) reveals a multifaceted and evolving dynamic that significantly shapes the patient experience. From the early stages through the progression of the disease, family members play pivotal roles, offering instrumental and emotional support. The crucial aspect of accompaniment to medical visits, assistance in daily activities, and the invaluable emotional sustenance provided by family members are dimensions that significantly impact CKD patients' lives.

Interestingly, the qualitative insights garnered from patient interviews expose a noteworthy gap in existing assessment instruments. The majority of both disease-specific and generic instruments fail to explicitly capture the nuanced dimensions of family involvement since the onset of the illness. This oversight not only highlights a limitation in the current tools but also underscores the need for a more comprehensive and patient-centric approach to assessing CKD experiences.

To address this gap, future assessment instruments should integrate family involvement as a distinct and essential dimension. By doing so, healthcare providers can gain a more holistic understanding of the challenges and support networks that CKD patients navigate. Recognizing the intricate interplay between patients and their families enhances the potential for tailored and effective care strategies, ultimately improving the overall patient experience in the complex landscape of chronic kidney disease.

4. Empathy and patient orientation from professionals. In alignment with the results of the empirical study, patients shared contrasting experiences with healthcare professionals. Nurses and assistants were praised for their caring attitude, making patients feel genuinely cared for. However, patients felt that doctors, especially nephrologists, were more focused on the medical aspects of their condition, leaving little room for addressing emotions or providing psychological support. This pattern persisted across different stages of the illness.

   On the positive side, patients consistently highlighted the compassionate care provided by nurses and assistants. They valued the personalized and warm approach, especially during dialysis. The interviews revealed a clear preference for the supportive attitude of nursing staff. This finding aligns with disease-specific scales, like ESUR-HD, CQ index, and PREM, emphasizing the crucial role of nurses in shaping the patient experience.

   In a broader sense, generic scales like SERVQHOS, HCAHPS, and The Sequs® stress the universal importance of healthcare marked by courtesy, empathy, responsiveness, professional competence, and privacy. These qualities underline the need for a patient-centered approach across different health conditions.

   In conclusion, our findings from both studies highlight the intricate dynamics of patient experiences in the context of chronic kidney disease (CKD). Patients' encounters with healthcare professionals reveal a nuanced landscape where the caring and supportive attitude of nurses and assistants stands out prominently. Despite the compassionate care

received from these frontline healthcare providers, a noticeable gap exists, particularly in the more disease-oriented approach exhibited by physicians, especially nephrologists. This disparity in attitudes towards patients, captured through our interviews, emphasizes the need for a more holistic and patient-centered approach across all healthcare professionals, regardless of their specific roles. The scales identified in the systematic review, both generic and disease-specific, underscore the pivotal role of nursing staff in shaping the patient experience, particularly during the advanced stages of CKD.

Moving forward, our findings advocate for a comprehensive approach that integrates emotional and psychological support alongside medical care, recognizing the evolving needs of patients throughout their CKD journey. This holistic perspective aligns with the broader healthcare discourse, emphasizing the importance of patient-centered care, where empathy, responsiveness, and personalized attention are paramount.

Collectively, insights from both the CKD Patient Journey Mapping and the systematic review converge to shed light on specific dimensions and themes related to the last stage of the illness, particularly focusing on patients in the hemodialysis and peritoneal dialysis touchpoints. The patient journey mapping, as well as findings from the systematic review, accentuates the importance of patient training in the context of peritoneal dialysis and the significance of high-quality therapy for patients undergoing hemodialysis.

5. High Quality Therapy. Patients undergoing dialysis, as revealed in the empirical study interviews, emphasize the significance of high-quality therapy, portraying their experience as marked by meticulous care provided by healthcare professionals. This includes responsiveness to patient needs, ongoing assistance with the dialysis machine, and continuous monitoring for potential side effects. Safety and comfort emerge as pivotal aspects, encompassing the correct functioning of machines, cleanliness of the renal unit, and hygienic manipulation of dialysis equipment. These themes align with dimensions identified in scales from the systematic review, including the Evaluation of Hemodialysis Patient's Satisfaction with Service provided at a Chronic Kidney Disease Unit (ESUR-HD), The Consumer Quality Index (CQ index) instrument, The Consumer

Assessment of Healthcare Providers and Systems (CAHPS) questionnaire, and The Sequs®. Additionally, patients express a desire for a comfortable environment, highlighting the importance of factors such as seating arrangements and engaging activities during the dialysis session, facilitated by art therapy students.

It is noteworthy that the existing scales primarily focus on elements related to the quality of the dialysis center, operations, and organizational aspects. While these scales comprehensively cover critical dimensions, they do not explicitly address the potential impact of entertaining activities on patient experience and satisfaction, a facet emphasized by participants in the interviews. The absence of this specific dimension in established scales suggests an opportunity for refinement and expansion in assessing the holistic patient experience during dialysis.

In moving forward, the development of comprehensive assessment instruments should consider incorporating dimensions beyond the traditional clinical and organizational aspects. Integrating elements related to patient comfort, entertainment, and holistic well-being can enhance the accuracy and relevance of tools designed to evaluate the quality of therapy. This holistic approach aligns with the patient-centric care advocated in both studies and emphasizes the importance of refining assessment tools to be more responsive to the evolving needs and preferences of CKD patients.

6. Patient training. Patient training in the context of dialysis, as reported by participants in the empirical study, emerges as a crucial dimension shaping the overall experience of individuals undergoing peritoneal dialysis (PD). The qualitative insights highlight the personalized and comprehensive approach employed by PD nurses during the training process. Notably, the DP nurse's commitment to spending ample time teaching patients, utilizing diverse resources like visual aids, is particularly significant, especially for older individuals who may face cognitive challenges. This underscores the importance of tailoring educational strategies to the unique needs of patients, promoting better understanding and adherence to self-dialysis practices.

Moreover, the emphasis on cultivating a positive rapport between patients and their nurses is a noteworthy aspect. Patients value the attentiveness, care, and affection demonstrated by the nurse, which contributes to a supportive learning environment. The positive nurse-patient relationship is seen as a facilitator for effective communication, enabling patients to feel comfortable seeking clarification and resolving doubts. This interpersonal dynamic plays a crucial role in enhancing the learning experience and fostering a sense of confidence and security among patients.

Interestingly, the systematic review reveals a limited incorporation of PD training as a dimension within existing assessment scales. Among the identified scales, only The Customer Satisfaction Questionnaire in Peritoneal Dialysis (CSQPD) explicitly includes questions related to PD training. These questions aim to assess the comprehensiveness of training, its impact on individuals' understanding and confidence, and areas for potential improvement in training programs. This finding underscores an area for improvement in the existing scales, as patient training is a pivotal element influencing the overall patient experience during dialysis.

In conclusion, the synthesis of insights from the empirical study and the systematic review highlights the critical role of patient training in shaping the experience of individuals undergoing PD. The personalized and supportive approach adopted by nurses during training contributes significantly to patients' understanding, confidence, and overall satisfaction. The inclusion of PD training as a dimension in assessment tools is crucial for a comprehensive evaluation of the patient experience and provides valuable insights for refining existing scales to better align with the diverse needs and preferences of CKD patients.

The implementation of journey mapping in the empirical study uncovered a distinct touchpoint, namely the Patient Renal Education Program (PREP), which specifically caters to patients in stage 3 of chronic kidney disease (CKD). Patients in this touchpoint emphasize peer support.

7. Peer support (i.e., sense of belonging and peer mentoring). The patient narratives gathered during interviews reveal that, before engaging in group sessions focused on educational programs, individuals proactively share personal experiences with others who are navigating similar challenges. This pre-session interaction fosters a supportive community where patients feel a strong connection with individuals who truly comprehend their journey. Moreover, patients advocate for the inclusion of peer experts, those already in stages 4 and 5 (hemodialysis and peritoneal dialysis), in these group sessions. They believe that insights from individuals with firsthand experience in advanced stages of CKD can serve as invaluable guidance, aiding others in making informed decisions about treatment modalities. Despite the significance of peer support highlighted in patient narratives, it's noteworthy that most scales identified in the systematic review largely overlook this dimension. Notably, the IEXPAC scale touches upon the importance of patient-to-patient communication, albeit with patients reporting low scores in this aspect (Item 11: "They encourage me to talk to other patients").

The absence of a structured assessment for peer support suggests a critical gap in our understanding and measurement of the comprehensive CKD patient experience. The implications of this gap are far-reaching. Peer support has been shown to contribute significantly to patient empowerment, emotional well-being, and informed decision-making, particularly in the context of chronic conditions (Nicholas et al., 2009; Muhammad et al., 2014). By not incorporating this dimension into existing scales, we risk overlooking a fundamental aspect of the patient journey. Healthcare providers and policymakers should take note of these findings, recognizing the need to reevaluate and expand existing assessment tools to encompass the holistic dimensions of patient experience. Integrating peer support measures into standardized assessments not only acknowledges the importance of community within CKD management but also aligns with a patient-centered care approach. Ultimately, bridging this gap can contribute to more tailored, effective interventions and strategies that address the nuanced needs of individuals traversing the complex landscape of chronic kidney disease.

Ultimately, this synthesis provides valuable insights for shaping future models of assessment that prioritize a comprehensive understanding of the patient journey in the context of CKD and dialysis.

5.3. IMPLICATIONS FOR A HOLISTIC ASSESSMENT OF A PATIENT-CENTRIC CARE AND THE CONTINUOUS IMPROVEMENT OF CARE:

The synthesis of insights from both the systematic review and the CKD patient journey mapping establishes the following critical points when assessing patient experience in the context of CKD.

Developing assessment methods capable of collecting data from a large and diverse array of CKD patients in a continuous and longitudinal manner. This point leads to the proposal of questionnaires as one of the most effective ways of reaching all types of patients and collecting large amounts of data efficiently. This proposal emphasizes the importance of creating brief surveys capable of continuous, online implementation with real-time response capabilities. The chronic and dynamic nature of CKD necessitates an approach that goes beyond static snapshots, requiring ongoing data collection to capture the evolving patient journey comprehensively. In this context, the implementation of brief surveys that patients can respond to in a live-stream manner becomes pivotal. This approach allows for immediate feedback, providing healthcare providers with timely insights into patients' experiences, needs, and challenges as they progress through different stages of the disease. This imperative arises from the chronic and evolving nature of CKD, which necessitates an understanding of patient experiences throughout the entire trajectory of the disease. Continuous data collection, facilitated by robust questionnaires, will serve as a cornerstone for building a comprehensive and dynamic understanding of patient perspectives over time. One primary implication is the need for questionnaires that go beyond mere snapshots of patient experiences at specific points in time. The chronicity of CKD demands a continuous feedback loop that captures the evolving needs, challenges, and priorities of patients as they traverse different stages of the disease. This longitudinal approach enables healthcare providers to track trends, identify critical touch points, and implement timely interventions to enhance the

quality of care. Moreover, the development of questionnaires capable of continuous data collection aligns with the principles of patient-centered care. By engaging patients in an ongoing dialogue, healthcare providers can establish a more nuanced understanding of the nuances, variations, and fluctuations in their experiences. This depth of insight is invaluable for tailoring interventions, adjusting care plans, and fostering a more personalized approach to CKD management. Moreover, implementing continuous data collection through well-designed questionnaires also addresses the inherent variability in patient experiences. As it has become apparent throughout the current thesis, CKD is a heterogeneous condition with diverse manifestations and trajectories. A one-size-fits-all approach is insufficient for capturing the complexity of patient experiences. Therefore, continuous data collection allows for the identification of patterns and variations across different demographic groups, disease stages, and treatment modalities, thereby enabling a more nuanced understanding of the diverse CKD landscape. In conclusion, the synthesis of both studies underscores the pivotal role of developing questionnaires that can seamlessly collect data from a multitude of CKD patients in a continuous and adaptive manner. Such instruments serve as dynamic tools for gathering real-time insights, ensuring that healthcare practices remain responsive to the evolving needs of CKD patients.

Developing assessment tools that strike a balance between common questions applicable to all stages of CKD and specific inquiries tailored to disease stages or touchpoints. This nuanced approach recognizes the dynamic nature of CKD, and the varied experiences patients undergo throughout the trajectory of the disease. The incorporation of common questions in CKD assessment tools ensures a foundational set of inquiries that captures universal aspects of the patient experience and fosters comparability of critical common issues for different types of CKD patients. These common elements, identified across both studies, provide a baseline understanding of key dimensions such as information about the illness, care coordination, and practitioner empathy, which are pertinent across all CKD stages. This consistency in questioning facilitates meaningful comparisons, allowing healthcare providers and researchers to identify overarching trends and benchmarks in patient experiences. Simultaneously, the recognition of unique dimensions uncovered by each study introduces a layer of specificity necessary for a comprehensive evaluation. Certain themes

and issues identified in the mixed-methods study, such as peer support in the Patient Renal Education Program (PREP) touchpoint, may represent critical aspects of patient experience that are not adequately captured by generic assessments. The analysis of whether certain dimensions unique to one study should be included in an all-encompassing questionnaire requires careful consideration of their relevance and generalizability. Some themes may be inherently linked to specific touchpoints or stages, and their inclusion in a broader questionnaire may not necessarily enhance its utility. For instance, the importance of high-quality therapy during hemodialysis, highlighted in both studies, and the emphasis on patient training in peritoneal dialysis showcase the distinctive needs of patients in different modalities. In conclusion, the synthesis of both studies underscores the need for assessment tools that combine common questions applicable to all stages of CKD with specific inquiries tailored to unique dimensions identified in each study. This balanced approach ensures a truly comprehensive evaluation of patient experience, capturing both universal and context-specific aspects.

Developing tools that emphasize the importance of patient involvement in refining assessments. This is a fundamental principle for achieving a holistic assessment of patient-centric care and fostering continuous improvement. Both studies emphasize the pivotal role of patients as active contributors to the shaping of instruments used to measure their experiences with CKD. This emphasis on patient involvement carries profound implications for enhancing the relevance and sensitivity of assessment tools, ultimately leading to more patient-centered care. Patient involvement ensures that assessment tools resonate with the lived experiences, preferences, and priorities of individuals navigating the complex landscape of CKD. The systematic review highlights instances where existing instruments predominantly focused on incorporating patient's input at the last stages of the instrument design, potentially overlooking the diverse needs of patients at earlier stages, such as dimensionality and conceptualization and item generation. By actively involving patients in the development process, their insights can uncover critical dimensions that might otherwise be overlooked, contributing to a more comprehensive understanding of the CKD journey. In contrast, the mixed-methods study, through its patient journey mapping approach, further exemplifies the importance of patient involvement by providing a touchpoint not covered by

traditional instruments—the Patient Renal Education Program (PREP). The emergence of themes like peer support in PREP underscores the unique perspectives patients bring to the forefront. Patients, particularly those in the early stages of CKD, can offer invaluable insights into dimensions of care that might not be immediately apparent from a healthcare provider's standpoint. The call for patient involvement echoes the broader shift towards patient-centered care, where individuals are recognized as active participants in their healthcare journey rather than passive recipients of care. By valuing the perspectives of those with lived experiences, healthcare providers and researchers can gain a more nuanced understanding of patient needs, preferences, and challenges. This, in turn, empowers patients to be advocates for their own care, fostering a sense of ownership and partnership in the healthcare process.

5.4. CONCLUDING REMARK

Implementing holistic questionnaires with common themes but also tailored to relevant touchpoints represents a paradigm shift in assessing CKD care, providing a continuous and dynamic evaluation that is pivotal for ongoing improvement in care quality. These questionnaires offer a transformative approach, capturing nuanced dimensions of patient experience across various stages and touchpoints, ensuring that healthcare practices remain responsive and patient-centered, particularly considering the evolving needs depending on the stage of CKD. These questionnaires, crafted with patient input, enable a comprehensive exploration of the diverse aspects of CKD care at different touchpoints. The dynamic nature of these assessments is particularly valuable as CKD patients traverse various stages, each characterized by distinct needs and priorities. For instance, although information is relevant for all patients, patients in the early stages may prioritize the importance of education and information, emphasizing the need of understanding their diagnosis and lifestyle adjustments. On the other hand, those in advanced stages might underscore the quality of therapy and support from family and healthcare professionals, indicating a shift in focus. By incorporating questions specific to each stage, these questionnaires create a continuous feedback loop that mirrors the evolving needs of CKD patients. The adaptability and inclusivity of diverse dimensions in holistic questionnaires that can be answered online just after the care interactions allow healthcare providers to tailor interventions based on real-

time feedback, promoting personalized and patient-centric care that evolves in tandem with the progressing disease.

Moreover, the continuous and dynamic nature of these assessments plays a pivotal role in continuous improvement by assessing the effectiveness of the interventions designed to improve patients' experience, not only short but long term. This ongoing feedback enables healthcare providers to identify emerging challenges, refine interventions, and implement changes that directly respond to the evolving needs and preferences expressed by patients.

In essence, holistic questionnaires serve as a driving force for a patient-centric, responsive healthcare system. They acknowledge the heterogeneity of patient experiences and the fluctuating nature of CKD. By continuously learning from patient feedback, healthcare practices can implement targeted strategies to enhance care quality, promote patient satisfaction, and address specific challenges encountered across different touchpoints. This iterative process ensures that the care provided aligns with the dynamic and evolving needs of CKD patients, fostering a culture of continuous improvement and adaptability within the healthcare system.

Building upon the insights gleaned from the synthesis of both studies and the implications for a Holistic Assessment of Patient-Centric Care and Continuous Improvement, in the next chapter, we will propose a conceptual model for assessing patient experience across the spectrum of chronic kidney disease. This model seeks to integrate the key dimensions and themes identified across diverse stages and touchpoints, aligning with the evolving needs of CKD patients.

CHAPTER VI: CONCEPTUAL MODEL

PROPOSAL OF A CONCEPTUAL MODEL FOR ASSESSING PATIENT EXPERIENCE ACROSS THE SPECTRUM OF CHRONIC KIDNEY DISEASE

Healthcare quality is crucial as it not only ensures patient safety and effective care (World Health Organization, 2018; European Commission, 2010), but also facilitates sustainable cultural change and continuous improvement in care delivery (Fitzgerald, 2019). This approach emphasizes to engage not only staff but also patients in the development, application, and improvement of healthcare standards, which is essential for fostering positive patient outcomes, elevating patient satisfaction and well-being. In this context, the assessment of patient experience is an important resource to provide feedback aimed at improving the care provided, not only regarding clinical proficiency but also regarding patients' wellbeing. In fact, the paradigm shift to patient-centered care places patient experience at the core of quality healthcare delivery (Institute of Medicine, 2001). Healthcare organizations that prioritize quality service and patient experience contribute to better adherence to treatment plans, increased patient satisfaction, and ultimately enhanced overall well-being (Holt, 2018; Doyle et al., 2013).

This is particularly true for chronic patients that require continuous engagement with healthcare providers, such as CKD patients (Bear & Stockie 2014). In CKD care, a comprehensive approach is required, incorporating not only proficient clinical management, but also effective information and communication about diagnosis and treatment options, empathetic interactions, emotional support, and care coordination (Yaqoob, 2023). This holistic view acknowledges the complex and multifaceted treatment modalities of CKD, including dialysis or transplantation, and recognizes the dynamic nature of the disease and the varying needs, concerns, and expectations of patients as they go to different stages of the disease. Thus, any measurement instrument designed to assess CKD patient experience should capture the dynamics and diversity of experience, considering patients' stages and treatment modalities.

Patient experience has been typically assessed by means of standardized questionnaires and surveys (Ahmed et al., 2014). When showing satisfactory psychometric properties, standardized tools offer a reliable means to capture different dimensions of patient experience and permit the collection of large amounts of data that can be compared across individuals, settings, and time frames (Beattie et al., 2015). With this information healthcare

organizations can identify their strengths and the areas requiring improvement, in general or for some types of patients, fostering a continuous cycle of quality enhancement. The significance of standardized tools becomes particularly pronounced in the context of chronic conditions like CKD, where patients undergo long-term management and treatment (Turner et al., 2012). By assessing CKD patient experience through standardized measures large amounts of information can be collected over time to understand the trajectories of patients over different stages and monitor changes, to identify areas of improvement, monitor the effectiveness of interventions, and tailor care strategies to individual preferences. Moreover, these tools contribute to the creation of a shared language among healthcare professionals and patients, facilitating communication and collaboration in multidisciplinary care teams.

Despite the potential advantages of standardized questionnaires, the systematic review of existing instruments presented in Chapter 3 revealed that many of the instruments focused on patient satisfaction and most were aimed at patients in advanced stages of CKD, particularly in the context of hemodialysis. This concentration on the final stages of the disease poses a limitation, as it neglects the experiences of individuals in earlier stages, potentially hindering a comprehensive understanding of their distinct needs and expectations. Furthermore, the review highlighted that patient input in the development of instruments often occurred after the questionnaires were created, suggesting a potential gap in capturing the diverse perspectives of patients.

In the Spanish context, the landscape of instruments for assessing patient experience in CKD is notably limited, with only two non-disease-specific instruments identified. Notably, one of these instruments, the SERVQHOS, predominantly measures patient satisfaction rather than the broader spectrum of patient experience. The other instrument, IEXPAC scale, exhibits psychometric properties that may not be as robust as desirable when examined at the dimension level, as shown in our empirical study and in Mira et al. 's study (2016). This impacts the reliability and validity of the scale in the detailed assessment of patient experience. This scarcity emphasizes the need for the development and validation of comprehensive, disease-specific tools that capture the nuanced dimensions of patient experience across various stages of CKD in the Spanish-speaking population, involving

patients of all stages to explore which are the interaction points through their care journey that become crucial when assessing patients' experience.

One remarkable finding from the interviews conducted in the empirical study is the significant role of family involvement, encompassing instrumental and emotional support, as well as accompaniment, across the entire trajectory of chronic kidney disease (CKD), spanning from its initial stages to the advanced phases. Strikingly, none of the internationally validated and adapted instruments incorporate this dimension within their scales. An insightful interpretation of this absence could be rooted in the cultural context of Spain, characterized by strong family values within a collectivistic framework (Singelis et al., 1994). In such cultural settings, the importance of family support is deeply ingrained, serving as a fundamental value that extends across various aspects of life, including health and illness (Ania-González, 2022). This cultural nuance underscores the need for a more context-specific approach when adapting and applying instruments designed in different cultural contexts. Recognizing and integrating the cultural aspects of patient experience, particularly the influence of family dynamics, is crucial for ensuring the relevance and comprehensiveness of assessment tools in diverse healthcare settings.

This thesis, particularly in chapter 4, took an initial stride in this direction through a mixed-method study employing chronic kidney disease (CKD) patient journey mapping.

The results of the patient journey mapping and the focus groups revealed four key interaction points—Outpatient Clinic (OC) Kidney Disease (which correspond to medical stages 1 and 2), Patient Renal Education Program (PREP) (which corresponds to medical stage 3), and Hemodialysis (HD) and Peritoneal Dialysis (PD) (which, depending on the severity, correspond to Medical stages 4 and 5. Further analysis by employing the IEXPAC scale, demonstrated nuanced variations in patient experiences across touchpoints, emphasizing the importance of recognizing and addressing these distinctions. Notably, the PD touchpoint emerged with higher IEXPAC scores, indicating a more positive patient experience, particularly concerning productive interactions. This dimension refers to the quality and effectiveness of the interactions between patients and healthcare professionals

aimed at improving patient outcomes. Most importantly, the qualitative component, derived from semi-structured interviews, identified seven main themes and 16 sub-themes related to healthcare experiences, ranging from information and education about CKD to care coordination (e.g., needling and lab tests, scheduling appointments, transport) family involvement, practitioner empathy, peer support, high-quality of therapy (i.e., proper functioning of the machines and safety protocols) and patient training of self-performed dialysis. Importantly, some of these themes were consistently observed across various touchpoints, whereas others were unique for specific touchpoints. Interestingly the patient journey mapping approach suggested critical touch points, particularly the Patient Renal Education Program, not covered by traditional instruments, uncovering themes like peer support that are crucial, especially for those in the early stages of the disease. Overall, the mixed-method study not only deepened our understanding of patient experiences but also underscored the need for a holistic and dynamic approach to assess and improve the quality of care throughout the CKD continuum.

Given the limitations of existing standardized instruments but based on their strengths and the knowledge generated by the patient journey map study, the purpose of this chapter is to propose a conceptual model for the assessment of the experience of patients with CKD. The primary purpose of this conceptual model is to lay the groundwork for the development of standardized instruments that comprehensively assess the CKD patient experience throughout the continuum of care across the key touch points identified (Outpatient Clinics Kidney Disease, Patient Education Renal Program, Hemodialysis and Peritoneal Dialysis. Unlike conventional approaches that predominantly focus on patient satisfaction, this model centers on the nuanced dimensions of patient experience, incorporating insights from the literature review presented in Chapter 2, the systematic review of existing measures presented in Chapter 3, and the qualitative and quantitative input of the empirical study presented in Chapter 4, with results of both studies integrated in Chapter 5. By assimilating relevant information of validated scales from the systematic review and acknowledging the distinctive touchpoints revealed by the patient journey mapping study, as well as the areas of concern, needs, etc. that were identified for each touchpoint, this model aims to transcend the limitations of generic assessments or those that focus only on end stages.

By addressing the diverse experiences encountered at each touchpoint, the model ensures its applicability across the spectrum of CKD care, offering the possibility of a holistic understanding of the patient's trajectory and fostering tailored interventions or providing differential information, to enhance the overall care experience along the different stages of the disease. Therefore, this model is aligned with the Person-Centered Care Framework rooted in the notion that care should be respectful and responsive to individual patient preferences, needs, and values, which can evolve through the different stages of CKD.

6.1. FOUNDATIONAL CONCEPTS AND GUIDING PRINCIPLES FOR THE CONCEPTUAL MODEL

Drawing on the overarching themes and recommendations provided by Wolf et al., (2014) in their 14-years meta-analysis on patient experience, introduced in Chapter 2, and the Implications for a Holistic Assessment of a Patient-Centric Care and the Continuous Improvement of care, introduced in Chapter 5, our conceptual model follows 8 guiding principles:

(1) Diversity and Dynamics: Develop questionnaires that allow collecting data from a diverse range of CKD patients repeatedly, ensuring a comprehensive representation and assessment of experiences over time.

(2) Balanced Approach: Create assessment tools that strike a balance between common questions applicable to all stages of CKD and specific inquiries tailored to particular disease stages or touchpoints. This ensures relevance and specificity in capturing patient experiences.

(3) Patient Involvement: Emphasize the importance of patient involvement in designing and refining assessments, recognizing that patients' perspectives are invaluable in shaping tools that truly reflect their experiences.

(4) Continuum of Care: Recognize and incorporate the continuum of care in patient experience assessment, acknowledging that a comprehensive understanding of healthcare delivery requires consideration of the entire care journey.

(5) Focus on Expectations: Prioritize a focus on patient expectations to understand how individuals perceive and interact with healthcare services, providing insights into areas of improvement and patient-centered care. Potential differential expectations and needs may be reflected in different ratings of satisfaction, despite reporting similar experiences. This is why satisfaction ratings together with patient experience will be highly informative.

(6) Alignment with Patient-Centered Care: Align patient experience assessment with patient-centered care principles, ensuring that the evaluation is rooted in providing care that is centered around the individual patient's needs, preferences, and values.

(7) Individualized Care: Emphasize the importance of individualized care in patient experience assessment, recognizing and addressing the unique needs and preferences of each patient.

(8) Comprehensive Understanding: Move beyond mere satisfaction and delve into the diverse aspects of healthcare encounters, contributing to a more comprehensive understanding of the patient's journey and facilitating targeted improvements in care delivery.

6.2. DEVELOPMENT OF A CONCEPTUAL MODEL TO ASSESS CKD PATIENT EXPERIENCE

The development of the conceptual model follows the guiding principles presented above and is grounded in the synthesis of insights derived from the previous chapters of this thesis.

We will start proposing a multidimensional conceptualization of the domains that shape patient experience in CKD contexts in general, and for specific touch points. This

proposal is based on the common themes/dimensions that are commonly found across the two studies for all patients regardless of the CKD stage along with those that are unique. Following, we will propose a definition of the different domains and provide indicators and examples that capture the proposed dimensions and can be useful when proposing specific items. Then we will suggest the steps that must be followed to develop the standardized quantitative measures that are flexible enough to adapt to the specific CKD stage of patients and add the possibility of providing qualitative information to explicitly consider the individuality and personal circumstances of each patient. Finally, we will conclude with some recommendations for the implementation of a continuous assessment process.

According to the systematic review and the semi-structured interviews carried out, the common dimensions that are relevant for shaping CKD patients' experience regardless of the stage of the disease were the following: information about illness, care coordination, communication, practitioner's empathy, practitioner's competence, family involvement, shared decisions about care, privacy and dignity, and patient self-management. Thus 9 common dimensions are proposed. Regarding the unique themes and domains, 6 dimensions are proposed: peer support, for patients in PREP, high quality therapy and medication supply, for patients in hemodialysis, patient training, and delivery service for patients in peritoneal dialysis and linkage to community services for both types of dialysis.

Table 7. shows the common themes and dimensions. Table 8. shows the unique themes and dimensions of specific touchpoints - stages. The dimension definition has been taken, modified, and adapted from the 9 questionnaires identified in the systematic review of chapter 3, as well as the information derived from the qualitative data of the mixed method study of chapter 4.

Table 7. Common Themes/Dimensions

Theme/Dimension	Definition
Information about Illness	Information refers to the extent to which patients receive clear, comprehensive, and understandable information regarding various aspects of their CKD. This includes details about the diagnosis, monitoring health changes, recommendations on physical activity and dietary habits, as well as information about the psycho-social changes, potential diet modifications, modality treatment options, and transplant possibilities. A) Receiving clear and understandable information about the diagnosis and progression of my CKD. B) Receiving clear recommendations of lifestyle changes, such as physical activity, dietary habits, and fluid intake. C) Receiving information about potential treatment modalities, with their potential risks and benefits and the possibility of a kidney transplant. D) Receiving adequate amounts of information. E) Receiving recommendations about internet websites that can be trusted. F) Allowing patients' questions which are responded to in an understandable way. Although the information may be critical at the diagnosis moment, information is also relevant as the disease progresses.
Care Coordination	Care coordination refers to the effectiveness and efficiency with which healthcare professionals (nephrologists, social workers, nurses, administration staff) organize and manage various aspects of CKD care. It involves the seamless coordination of activities such as needling and lab tests, scheduling and planning appointments, transport arrangements, communication, and cooperation among different care providers. A) Coordination about medical appointments, treatment appointments, needling and lab tests. B) Arrangements and coordination regarding transportation (this indicator may be of special relevance for patients in hemodialysis, who need to visit the hospital several days a week). C) Communication and collaboration among the healthcare providers. D) Coordination to tailor the care activities to the specific needs and time availability of the patient.
Practitioner's (and other healthcare professionals') Empathy	Practitioner's empathy refers to the extent to which healthcare professionals, including nephrologists, social workers, and nurses, demonstrate understanding, warmth, and emotional support towards CKD patients. It encompasses elements such as courtesy, empathy, responsiveness and emphasizing a patient-oriented approach. A) Compassionate and empathetic attitudes and behaviors from healthcare professionals. B) Active listening from healthcare professionals. C) Warm interactions with the patient from healthcare professionals. D) Respectful and individualized consideration from healthcare professionals.

Theme/Dimension	Definition
Practitioner's (and other healthcare professionals') Competence	Practitioner's competence assesses the perceived skills, proficiency, and expertise of healthcare professionals involved in the care of CKD patients. It encompasses the evaluation of the technical competence, knowledge, and effectiveness of practitioners in managing and addressing the clinical aspects of CKD. This aspect is crucial to developing patients' confidence and trust. A) Patient's confidence in the technical skills and expertise of CKD healthcare professionals. B) Patient's feelings that the effectiveness of the treatment is adequately monitored. C) Healthcare professionals explain the reasons they base their decisions on. D) Patient's beliefs that healthcare professionals make the best decisions considering patient's health and personal circumstances. E) Patient's trust in the healthcare provided.
Family Involvement	Family involvement refers to the extent to which a patient's family members are engaged and participate in supporting and assisting the individual with CKD. It assesses the instrumental and emotional support provided by family members, their involvement, but not limited, in daily activities, and their participation in routine medical visits. Although family involvement does not directly depend on healthcare professional providers, this is an important aspect to consider that has been neglected in existing questionnaires. When a patient's experiences regarding family involvement are not positive, healthcare agents can work actively to increase the levels of family involvement in patients' care and provide supportive resources for family members. A) Patient's family actively supports the patient by assisting with daily activities, such as cooking and hygiene. B) Family members accompany the patient during routine medical visits. C) Family members help the patient in understanding and remembering information provided by the healthcare team. D) Family members support the patients when making illness related decisions. E) Family members help patients cope with the stress and anxiety associated with the disease. F) Family members help patients organize and/or remember to take their medications as prescribed. Some indicators of family involvement may be more or less important depending on the level of autonomy of the patients
Share Decisions about Care	Sharing decisions about care refers to the collaborative process between healthcare providers and patients in making decisions related to the management and treatment of CKD. It assesses the extent to which patients are involved in discussions about their care, treatment options, and decisions regarding their healthcare journey considering clinical recommendations and patients' lifestyles and personal circumstances. A) Professionals share with the patient all relevant information to empower patients to make informed decisions. B) Patient feels actively involved in discussions about their CKD care before making any decision. C) Both patient's input and personal circumstances such as geographical location, lifestyle, etc. as well as clinical reasons are considered when making decisions about the treatment plans.

Theme/Dimension	Definition
Privacy and Dignity	Privacy and dignity encompass the respect for individuals' personal space, confidentiality, and the preservation of their sense of worth and honor throughout their healthcare experience. It evaluates the extent to which healthcare providers uphold and protect the privacy and dignity of patients with CKD during various interactions and procedures. A) Patients feel that their privacy is respected during medical examinations and other interactions with healthcare professionals. B) Patient believes that information is kept confidential and only the authorized professionals have access to patient's information. C) Patient feels that personal space and boundaries are respected. D) Communications regarding a patient's condition, treatment, or prognosis are conducted in private settings, away from non-essential personnel and other patients. E) Patient feels treated with dignity, the patient's self-worth and cultural background and identity are preserved.
Patient Self-Management	Patient self-management refers to the extent to which CKD patients are actively involved in the day-to-day management of their health, including adherence to prescribed treatments, lifestyle modifications, and decision-making related to their care. It assesses the level of patient empowerment and autonomy in managing various aspects of their CKD, contributing to a collaborative and patient-centered approach. A) Patient's adherence to prescribed medications. B) Patient's adherence to dietary and physical activity recommendations. C) Patient's monitoring and recognition of changes in their health status. D) Patient's voluntary change in lifestyle to better manage the disease. E) Patient asks questions and discusses concerns with health professionals. F) Patient makes suggestions to improve the care experience. G) Patient's actively look for information and support.

Table 8. Unique Themes/Dimensions.

Theme	Definition	Touchpoint/Stage
Peer Support	Peer support in the context of CKD refers to the provision of assistance, guidance, and emotional support by individuals who share similar experiences with CKD. It involves the formation of connections and relationships among patients facing similar challenges, creating a supportive network that fosters understanding, empathy, and shared coping strategies. A) Patients appreciate connecting with fellow CKD patients. B) Patients regard peer support as a valuable resource. C) Patients feel the importance of creating a supportive community for those living with CKD.	Patient Renal Education Program (i.e., stage 3)
Linkage to Community Services	Linkage to community services in the context of CKD involves the facilitation of connections between patients and various community resources that contribute to comprehensive care. These services extend beyond the clinical setting and encompass support from professionals such as social workers, nutritionists, and psychologists, aiming to address the broader well-being of individuals with CKD. A) Patients feel the necessity of connecting with community services. B) Professional help patients to seek out assistance of community services. C) Patients find useful the help offered by the community services.	Hemodialysis and Peritoneal Dialysis (i.e., stage 4 and 5)
High Quality Therapy	High-quality therapy for hemodialysis patients pertains to the overall excellence in the delivery of hemodialysis treatment, ensuring a safe, comfortable, and effective experience. This dimension encompasses aspects related to the physical environment during dialysis sessions, meticulous care during the procedure, and the overall quality of care provided within the dialysis center. A) Healthcare professionals show expertise and attentiveness during dialysis. B) The dialysis center maintains excellence in its operations, enhancing the overall therapy experience.	Hemodialysis (i.e., stage 4 and 5)
Medication Supply	The dimension of medication supply involves evaluating the availability, accessibility, and quality of medications essential for managing CKD and its related conditions. It encompasses aspects such as timely access to prescribed medications, the reliability of the supply chain, and the overall effectiveness of medication management. A) Accessibility to prescribed medications for CKD management. B) The healthcare team ensures the patient understands the medication regimen. C) The healthcare team addresses patient's concerns about medication regimens.	Hemodialysis (i.e., stage 4 and 5)

Patient Training	Patient training for peritoneal dialysis involves assessing the effectiveness and comprehensiveness of educational programs designed to empower patients with the knowledge and skills required for self-administration of peritoneal dialysis. This dimension evaluates the clarity, support, and personalized nature of the training provided to patients, ensuring they feel confident and capable in managing their dialysis at home. A) PD training is comprehensive. B) PD training is tailored to patient's needs. C) The healthcare team ensures the patient understands each step of PD (including technique, hygiene, and potential complications)	Peritoneal Dialysis (i.e., stage 4 and 5)
Delivery Service	Delivery service for peritoneal dialysis assesses the patient's experience with the logistics and support services related to the delivery and availability of peritoneal dialysis supplies. This dimension assesses the reliability of peritoneal dialysis supplies delivery, responsiveness to patient needs, and overall satisfaction with customer service in logistics and support services. A) Peritoneal dialysis supplies are reliably delivered. B) Peritoneal dialysis supplies are delivered timely through well-coordinated logistics. C) Customer service promptly addresses patient's inquiries and proactively handles any issues or concerns.	Dialysis Peritoneal (i.e., stage 4 and 5)

To ensure a comprehensive evaluation, the above survey items should consider both the frequency of events and the level of satisfaction experienced by CKD patients. For instance, in the context of information about the illness, patients should assess the frequency of receiving clear and understandable information about the diagnosis and progression of their CKD. This evaluation can be framed using response options such as "never," "sometimes," "usually," and "always." This aligns with similar methodologies used in scales like HCAHPS that evaluate patient experience in terms of frequency. Additionally, patients should indicate their satisfaction level with the provided information, using response categories like "very dissatisfied," "dissatisfied," "neutral," "satisfied," and "very satisfied." It is crucial to emphasize that this dual assessment approach addresses both patient satisfaction and patient experience.

Furthermore, the survey design should allow patients to include comments, providing an avenue for more nuanced and detailed feedback. This qualitative input enhances the objectivity of the feedback and opens the door for targeted interventions to improve care delivery. Encouraging patients to share positive aspects about their healthcare interactions with various professionals at the end of the survey can have a positive impact by reinforcing the value of their work. This constructive feedback loop not only aids in identifying areas for improvement but also fosters a culture of continuous enhancement in healthcare services for CKD patients.

6.3. IMPLEMENTATION OF THE CONCEPTUAL MODEL

Having the definition phase established, we propose that the scale goes through different phases, namely (1) patient involvement in the review of the conceptual model and item generation, (2) expert review and validation, (3) pilot testing and (4) refining and finalization following the best practices for developing and validating scales for health, social, and behavioral research (Boateng et al., 2018) and adapting to our context of CKD.

Phase 1. Patient Involvement in the validation of the conceptual model proposed and their contribution in item generation is crucial for ensuring that the developed questionnaire

truly reflects the diverse experiences and perspectives of individuals (Streiner et al., 2015) with chronic kidney disease (CKD). To initiate this process, a diverse group of CKD patients representing various stages and touchpoints should be invited to participate. The inclusion of patients across different CKD stages (i.e., outpatient clinic advanced kidney disease, patient renal education program, hemodialysis, and peritoneal dialysis; from stages 1 to 5) ensures a comprehensive understanding of the entire CKD spectrum. This could be done by means of several focus groups, with an expert in the field of testing and an expert in CKD moderating the discussion. In a second stage, participants engaged in focus groups will play a pivotal role in validating the proposed indicators. These indicators, both generic and specific, tailor the evaluation to the diverse touchpoint participants find themselves in. The validation process goes beyond merely assessing the frequency of experiences; it delves into the criticality of each aspect of care from the patient's perspective. Moreover, participants will express their satisfaction levels with the overall experience, offering a comprehensive understanding of their nuanced preferences. This analysis aims to uncover the intricacies of patient experience, acknowledging that individual differences play a significant role. Take, for instance, the dimension of patient information – while some patients may require detailed information, others may find a more concise overview sufficient. Moreover, even if two individuals receive identical information, their unique expectations may lead them to rate their satisfaction levels differently. This nuanced approach allows for a more personalized understanding of patient experiences, facilitating targeted improvements in healthcare delivery.

Finally, the patients and experts should work together for the proposal of the initial items based on the indicators that are observed with different degrees of frequency but are deemed as important.

Phase 2. Expert Review and Content Validation. This starts with the identification of relevant parties. Individuals who have expertise in the field, patient experience assessment, questionnaire development, and related domains should be invited to participate (Devellis 2012; Morgado et al., 2018). This would include healthcare professionals (e.g., nephrologists, nurses) and psychometricians. The experts will rate each item based on relevance, clarity,

comprehensiveness and appropriateness of language. If redundant or ambiguous items are found, or one of the domains is not adequately represented experts should suggest modifications, leading to the second version of the questionnaire.

Stage 3. Pilot testing using another sample of CKD patients at different stages will serve to initially assess the psychometric quality of the items, and discard those that are not adequate. Qualitative information – in terms of clarity and relevance would also be gathered. The participants should be provided with the instrument and encouraged to express their feedback on the clarity of instructions, the relevance of the items, and the overall comprehensibility. Incorporating patient's feedback during the pilot testing phase is particularly valuable, as their insights contribute to refining the instrument to align with the unique needs and perspectives of individuals experiencing CKD. This iterative process of refinement through pilot testing helps enhance the validity and reliability of the instrument, ultimately contributing to its effectiveness in capturing the nuanced dimensions of patient experience in the context of CKD.

Phase 4. Refinement and Finalization. Based on the insights gained from pilot testing, necessary modifications and adjustments are made to enhance the instrument's clarity, relevance, and comprehensibility. Ambiguous or confusing items are rephrased, and items may be excluded based on their perceived importance and appropriateness. The iterative nature of this refinement process allows for continuous improvement, ensuring that the instrument aligns with the evolving needs and expectations of CKD patients. The refined instrument then undergoes a final validation process with a larger sample to assess its psychometric properties, such as reliability and validity. Ideally the number of items should be reasonable to foster response rates. As mentioned earlier, patients should be given the possibility to add qualitative feedback when they feel that some aspects not captured by the questionnaire should be considered.

The ending part of the implementation of the conceptual model involves the regular administration of the questionnaire and evaluation of the feedback provided by the questionnaire. This phase represents the transition from instrument development to practical

application, with a focus on integrating the patient experience assessment tool into routine healthcare practices. The distribution of the questionnaire should be conducted periodically. We propose a reasonable time lag: every four months throughout the year. This strategic timeline accommodates the chronic nature of CKD, capturing the dynamic changes in patient experiences over time, but tries not to overwhelm patients. Moreover, it would be ideal to conduct the survey online, covering experiences from the past four months. However, recognizing that some patients might face challenges due to limited technical skills or educational background, it is crucial to offer assistance. In such cases, a healthcare professional can guide patients through the questionnaire. Ensuring patient privacy is paramount; they should have the option of remaining anonymous. If a patient chooses to disclose their identity on the survey, explicit consent should be obtained. This approach respects individual preferences and ensures a patient-centric and confidential data collection process.

The cyclical assessment process contributes to the continuous refinement and optimization of care delivery, aligning healthcare practices with the evolving needs of CKD patients. Prior to survey administration, the following steps are taken:

- Training and Education: Healthcare professionals involved in administering the patient experience assessment instrument undergo comprehensive training. This includes guidance on the purpose of the tool, administration procedures, and the importance of maintaining a patient-centered approach. Additionally, staff members receive education on the significance of patient experience in enhancing overall care quality.

- Integration into Clinical Workflow: To facilitate seamless implementation, the instrument is integrated into the existing clinical workflow. This ensures that the assessment becomes a routine part of patient interactions and is not perceived as an isolated or burdensome activity. Efforts are made to minimize disruption to healthcare processes while maximizing the collection of valuable patient experience data.

- Patient Engagement: Patients are actively engaged in the implementation process. Information about the purpose of the assessment, its voluntary nature, and the confidentiality of responses is communicated to patients. This engagement fosters a sense of collaboration, encouraging patients to provide candid feedback on their experiences throughout the CKD care journey.

- Regular Assessments and Updates: The patient experience assessment tool is subject to regular assessments to evaluate its ongoing effectiveness. Periodic updates may be made based on emerging trends, changes in CKD care practices, or feedback received from healthcare providers and patients. This ensures that the instrument remains responsive to evolving patient needs.

- Data Analysis and Utilization: Collected patient experience data are systematically analyzed to derive meaningful insights. The results inform quality improvement initiatives, helping healthcare organizations identify areas of strength and areas that require attention. Benchmarking against established standards or comparable healthcare settings may also be employed to contextualize the findings.

This proposal of a conceptual model for assessing patient experience across the spectrum of chronic kidney disease (CKD) represents a significant stride toward patient-centered care and continuous improvement in healthcare delivery. The carefully delineated dimensions, derived from a synthesis of systematic review insights and a mixed-methods study incorporating patient journey mapping, lay the foundation for a comprehensive and contextually relevant assessment tool. By integrating both quantitative and qualitative perspectives, this proposed model seeks to encapsulate the diverse facets of patient experience, acknowledging the unique needs and challenges encountered at different stages and touchpoints of CKD care. The iterative development process, involving patient input from item generation to ongoing assessment, ensures that the instrument remains dynamic, responsive, and aligned with the evolving landscape of CKD patient experiences. This model

not only reflects a commitment to patient involvement and empowerment but also positions healthcare organizations to deliver tailored, high-quality care that goes beyond satisfaction, promoting holistic well-being for individuals navigating the complexities of CKD. Future research should materialize the conceptual model into a questionnaire that meets all the recommendations delineated above.

CHAPTER VII: GENERAL DISCUSSION

In this chapter our aim is to highlight and discuss the key insights derived from our research, elucidating how these findings expand the current comprehension of patient experience and care delivery in the realm of chronic kidney disease (CKD). Most importantly, we aim to make a meaningful impact on the continuous improvement of care practices for individuals dealing with CKD. This section is organized into four primary parts. Initially, we revisit the core objectives guiding our inquiry, summarizing the primary findings from each of the studies encompassed in this thesis. Subsequently, we delve into and outline the significant theoretical contributions emanating from our research. Following that, we present the principal practical implications that can be derived from our research findings. Lastly, we discuss the general limitations of our studies and the directions for future research considering our findings.

7.1. STUDY OBJECTIVES AND MAIN FINDINGS

7.1.1. Objectives

The main objective of this research was to propose a Conceptual Model for Assessing Patient Experience Across the Spectrum of Chronic Kidney Disease (CKD). As it has been highlighted through this thesis, the improvement of services in healthcare organizations requires understanding of patient experience that help organizations to identify the areas that need to be improved and tailor interventions aimed at enhancing service quality from a patient-centered perspective. The focus on patient experience is crucial because positive experiences contribute significantly to treatment adherence, patient engagement, and overall satisfaction with healthcare services (Doyle et al., 2013). In fact, positive patient experiences have been linked to improved health outcomes, fostering a sense of trust and collaboration between patients and healthcare providers (Price et al., 2014). However, despite the promising outcomes shown in most of the research into patient experience, there are major gaps in the comprehensive assessment of patient experience when we focus on chronic kidney disease patients. And this is a population that deserves attention, because of the prevalence, chronicity, and huge impact that this disease has on patients and their families. The evolving nature of this disease, in addition, demands a comprehensive understanding of

patients' experiences at different touchpoints in their healthcare journey, encompassing early diagnosis to advanced stages of the disease. Given that most of the studies done on assessing patient experience of CKD patients have been quantitative in nature through surveys, several challenges, particularly when considering the diverse stages of the condition and its progression, have become apparent. While surveys offer numeric data, they might provide a limited understanding of the nuanced challenges faced by CKD patients. Additionally, the emphasis on quantitative data may neglect the crucial qualitative insights necessary for understanding the psychosocial aspects, coping mechanisms, and cultural variations in the CKD experience as the disease progresses. Finally, the surveys that have been proposed (or used) in the context of CDK patient experience (or satisfaction) are mostly suitable for advanced stages of the disease, discarding the input of patients in early stages. This is an important gap if we aim to understand how each stage of the disease, ranging from Stage 1 to 5, affects various domains of a patient's life, encompassing cognitive, social, emotional, and psychological aspects.

Therefore, the current conceptualization and assessment of patient experience in CKD contexts is far too limited for this construct to be easily integrated into mainstream healthcare assessment systems and research. Thus, it has become clear that it is necessary to catch up with the handful of studies focusing on advancing the understanding of the biological mechanisms, causes, diagnosis, and epidemiology of the disease (Gibertoni et al., 2021; Hill et al., 2016; Romagnani et al., 2017) and improve the assessment of patient's viewpoints and their experiences while coping with the physical, social, and emotional challenges as CKD progresses. The final purpose is to improve not only patients' physical health but also their wellbeing.

Before proposing any assessment method, it is worth paying attention to the existing ones, their conceptual adequacy, usefulness, and psychometric quality. When focusing on CKD patient's experience, researchers and practitioners have typically relied on surveys and standardized questionnaires. Hence, the primary objective of this thesis was to systematically review instruments designed for evaluating the care experience of CKD patients, examining their strengths, weaknesses, and identifying any existing gaps.

However, surveys may not be enough to adequately assess patients' experiences. In fact, the use of alternative assessments methodologies such as patient journey mapping has been proposed as a method that ensures a more nuanced and comprehensive evaluation of patient experience, aligning with the broader spectrum envisioned by contemporary healthcare guidelines (McCarthy et al., 2016). Despite the existence of studies that have successfully employed PJM in various healthcare contexts (Smith et al., 2018; Johnson et al., 2019), it is noteworthy that, to the best of our knowledge, there is a lack of research utilizing PJM to measure patient experience among CKD. Thus, the second aim of this thesis was to design and implement a patient journey mapping involving CKD patients in all stages of the CKD disease to gain a holistic understanding of their experiences through all the stages. As we understand, the static snapshot provided by surveys at a single point in time may not capture the dynamic changes in patients' health and well-being over the course of the disease. In fact, patient experience is not static; rather understanding patient experiences at distinct stages is crucial because the needs and priorities, preferences, barriers, and concerns of CKD patients may evolve throughout their illness trajectory (Vassilev et al., 2014).

Given the advantages of standardized measures and the richness of qualitative information for the comprehensive understanding of the nuances of CKD patient experience, the third objective of this thesis was to combine both sources of information to gain insight on the areas and domains that should be considered when assessing CKD's patient experience through the different stages of the disease. Thus, we integrated data obtained from the systematic review and the resulting Patient Journey Mapping and considered the main contributions of each methodology. From here, the last specific objective of the thesis aligned with the main objective, which was to outline a conceptual model for the assessment of the Care Experience of Chronic Kidney Disease that accounts for general aspects common to all CKD patients and the specificities related to each stage of the illness.

7.1.2. Main findings

In this section we briefly summarize the main findings within each of the two studies carried out: the systematic review of questionnaires used to assess CKD patient experience (chapter 3) and the CKD Patient Journey Mapping (chapter 4).

Before deciding the inclusion criteria for analyzing the questionnaires, it was necessary to clarify the concept of patient experience as there were ambiguities around whether patient experience is distinct from patient satisfaction or not (Cleary & Edgman-Levitan, 1997). Based on Wolf et al. 's (2014) definition that considers explicitly patient expectations we decide to also include satisfaction questionnaires that have been commonly used as a proxy for patient experience. The systematic review helped us to synthesize the existing quantitative questionnaires, how to conceptualize the construct, its dimensionality, providing a comprehensive overview of the current state of knowledge in this specific domain. Second, we identified common themes, patterns, and discrepancies across the different questionnaires. Third, this review enabled the evaluation of the psychometric quality (reliability and validity) of existing survey instruments used to measure patient satisfaction and experience in CKD.

We identified nine instruments, six of which were specifically tailored to CKD, focusing on end-stage renal disease, hemodialysis, and peritoneal dialysis, while three are generic tools applicable to general chronic diseases and CKD without stage specificity. The most common domains among the different scales include aspects such as dialysis center characteristics, patient information, patient care, nephrologist and healthcare provider communication, and overall experience. These domains are present in multiple instruments, indicating their significance in measuring patient satisfaction and experience in the context of chronic kidney disease and dialysis treatment.

Overall, the questionnaires examined in the systematic review demonstrate robust psychometric properties, indicating good validity and reliability with Cronbach's alpha coefficients ranging from 0.70 to 0.96 across different instruments. However, despite this generally positive quality, a crucial consideration emerges: the richness of the construct of patient satisfaction and experience in chronic kidney disease (CKD) does not seem to be

adequately captured by these instruments. While proving to be reliable tools, they may fall short in comprehensively addressing crucial aspects of the patient experience, particularly in the early stages of CKD. This finding underscores the ongoing need for development and innovation in measuring patient satisfaction and experience, aiming to holistically capture the complexity and progression of this health condition.

Key findings from the review stress the pivotal role of patient experience questionnaires and tools, such as IEXPAC, CQ index, and the PREM, in offering a more comprehensive understanding of care in CKD contexts when we want to understand the experience of these patients. In fact, IEXPAC, CQ index, and PREM stand out as superior healthcare quality indicators because they transcend mere clinical metrics, capturing the nuanced aspects of patient experiences in chronic kidney disease (CKD) care. Unlike traditional quantitative measures, these instruments delve into the qualitative dimensions of care, providing a richer understanding of the patient's journey. For instance, IEXPAC, through its patient-reported experience assessments, not only evaluates the effectiveness of medical treatments but also delves into the communication quality with healthcare providers, accessibility of care, and the overall patient-provider interaction. Similarly, the CQ index excels by comprehensively assessing various domains such as organization of care delivery, environment during dialysis sessions, and communication, offering a holistic view beyond clinical outcomes. PREM, focusing on patient-reported experiences, goes beyond clinical efficacy to gauge aspects like the effectiveness of treatment, the patient's understanding of their condition, and satisfaction with care, thus providing a well-rounded evaluation of CKD care quality. In essence, these instruments excel as healthcare quality indicators by embracing a patient-centered approach, acknowledging that quality extends beyond clinical measures to encompass the entirety of the patient's experience and satisfaction.

Moreover, the review highlights a critical need for questionnaires that assess patient experience at various stages of CKD. Currently, there exists a strong emphasis on existing instruments in the final stages of the disease. This imbalance may limit the applicability of findings across the spectrum of CKD experiences, potentially overlooking the challenges faced by individuals in earlier stages. Advocating for questionnaires that assess across the

entire spectrum of the disease acknowledges that CKD is a dynamic condition, and patient experiences change as it progresses. Recognizing and addressing the unique aspects of each stage is crucial for tailoring interventions and support services to meet the diverse needs of CKD patients. In addition, continuous patient involvement is underscored as an essential factor in refining and shaping instruments for assessing patient satisfaction and experience in CKD. This recommendation aligns with the broader principles of patient engagement in healthcare decision-making and research. By actively involving CKD patients in the development and validation of instruments, the resulting tools are more likely to accurately capture the multifaceted nature of their experiences. This ongoing collaboration ensures that the instruments remain relevant, culturally sensitive, and responsive to the evolving needs and preferences of CKD patients.

Building upon the insights gleaned from the systematic review, the second study carried out with a Spanish sample of CKD patients, involved a differential approach regarding the different stages of CKD. Acknowledging the limitations identified in the reviewed questionnaires, notably the tendency to overrepresent instruments tailored for the final stages of CKD, while also overlooking the initial stages of the disease, the empirical study sought to address these gaps. Additionally, recognizing the lack of patient input at the initial stages of instrument design, the study employed a patient journey map where patients play a pivotal role for the design and implementation. This comprehensive approach aimed to provide a more nuanced and inclusive perspective, ensuring a thorough examination of the diverse experiences encountered by individuals across the entire spectrum of CKD.

Results obtained from the focus group analysis identified four main touchpoints mapped by CKD patients, which were linked to different medical stages of the disease: Outpatient Clinic (medical stages 1 and 2), patient renal education program or PREP (medical stage 3) and, depending on the treatment modality chosen, both hemodialysis and peritoneal dialysis (medical stages 4 and 5). The study's findings reveal four overarching themes deemed significant by all CKD patients regardless of their touchpoint: the imperative for illness-related information and education, the crucial role of care coordination, the importance of empathy from healthcare professionals, and the involvement of family in the

patient's healthcare journey. Notably, there were also unique themes that were crucial for a positive healthcare experience depending on the touchpoint patients were located, considering the stage of the disease. Specifically, hemodialysis patients highlighted the importance of high-quality therapy (safety, comfort, and staff's caring), peritoneal dialysis patients emphasized training as a critical aspect of their care experience, and patients in earlier, specifically at the renal education program, underscored the importance of peer support. The assessment of differential patient experiences at different touch points through the IEXPAC questionnaire revealed interesting differences, suggesting different global experiences across different touchpoints. The relevance of these differences should be interpreted cautiously at the dimension level, because of the low reliability coefficients obtained in our sample. However, there were also significant differences at the item level, supporting the need to differentiate the different touch points if healthcare providers want to collect feedback where the positive experiences of some groups of patients do not cancel out the negative experiences of other groups.

The integration of the two studies yielded key findings that underscore critical dimensions of patient experience in CKD (some general and some linked to specific touchpoints). Patients consistently expressed the need for adequate information across all stages of CKD, emphasizing the importance of understanding their condition, treatment options, health monitoring, lifestyle recommendations, and medication guidelines. Furthermore, effective care coordination including linkage with community resources, health coaching and individualized care plans emerged as a crucial factor influencing patient experience. Family involvement was important for all patients, but it was identified as particularly significant in the early stages of CKD, revealing a gap in existing instruments that often overlook this vital dimension. Additionally, the attitude and approach of healthcare professionals towards patients were highlighted as fundamental to enhancing the overall patient experience. This theme emerges as fundamental factors with significant implications for enhancing the overall patient experience across different stages of chronic kidney disease (CKD). In the earlier stages of CKD, where interventions such as lifestyle modifications and early disease management significantly impact disease progression, the importance of the attitude and approach of healthcare professionals cannot be overstated. Positive and

supportive interactions during these initial phases might play a crucial role in motivating patients to embrace necessary lifestyle changes, adhere to prescribed medications, and actively engage in self-care practices. In addition, the healthcare professionals' empathetic approach fosters a collaborative relationship, empowering individuals to make informed decisions about their health. By establishing trust and effective communication, professionals create a conducive environment for patients to comprehend the importance of early interventions, facilitating better adherence to treatment plans. Thus, the attitude and approach of healthcare professionals are pivotal in ensuring successful early interventions and positively influencing the trajectory of CKD in its initial stages. As the disease advances to later stages, the supportive and empathetic attitude of healthcare professionals becomes even more critical, influencing the adaptation to advanced treatment modalities, such as hemodialysis and peritoneal dialysis. In these stages, patients often face complex challenges, including the physical and emotional demands of intensive treatments. The positive attitude and compassionate approach of healthcare professionals contribute significantly to patients' acceptance of these advanced interventions, fostering a sense of security and trust in the healthcare team. Effective communication and emotional support play a pivotal role in helping patients navigate the intricacies of their treatment, understand the potential lifestyle adjustments, and cope with the psychological impact of progressing kidney disease. Furthermore, healthcare professionals, through their empathetic stance, can address patients' concerns, enhance treatment adherence, and promote overall well-being. The patient-professional partnership established through a positive attitude becomes a cornerstone in the holistic care of individuals grappling with the complexities of advanced CKD stages.

In summary, the attitude and approach of healthcare professionals represent a cornerstone in patient-centered care, profoundly shaping the CKD patient experience throughout the continuum of the illness. Recognizing the dynamic nature of CKD, the results of this thesis (pointing the gaps of the existing measures reviewed in study 1 and the idiosyncrasy of patients at different touchpoints observed in study 2) call for the development of a holistic assessment tool that can be administered with a continuous basis and is responsive to the evolving needs of patients at different stages of the disease. Given the important advantages of standardized questionnaires such as generalizability, comparability,

efficiency and quantification (Kelle, 2006; Clearly et al., 1992), we firmly advocate for their use as the optimal method to longitudinally assess the experiences of a large number of chronic kidney disease (CKD) patients as the disease progresses. These instruments, rigorously validated for consistency and replicability, offer a standardized approach that ensures reliable data collection across diverse CKD populations and stages. Their efficiency becomes particularly valuable when assessing a large number of patients over time, saving resources while maintaining data quality. By measuring care experiences based on aspects valued by CKD patients, these standardized instruments respond to the growing demand for personalized and patient-centric approaches in healthcare assessment. The insights derived from employing these instruments not only provide a comprehensive understanding of the multifaceted CKD patient experience but also contribute significantly to the ongoing dialogue on enhancing CKD patient care. Furthermore, the standardized nature of these instruments might set a robust foundation for consistent research methodologies, facilitating comparisons and enabling evidence-based improvements in healthcare delivery for this population.

In this thesis, based on the results of the studies carried out and the literature review, we have grounded and proposed a conceptual model for assessing patient experience in CKD, integrating key dimensions and themes identified across various stages and touchpoints. This conceptual model represents a patient-centered, culturally sensitive, and methodologically rigorous approach to assessing the experiences of CKD patients throughout their healthcare journey. First, the conceptual model adopts a holistic and dynamic approach, aiming to capture the diverse and evolving experiences of CKD patients, emphasizing the inclusion of those in the early stages of the disease. Eight guiding principles underpin the model, including considerations for diversity, dynamics, and the importance of capturing experiences at various touch points along the CKD care continuum. Second, the model emphasizes patient involvement as a central tenet, with CKD patients actively participating in the validation of the conceptual model and item generation, ensuring that the questionnaire is reflective of their varied experience. Third, the model recognizes the significance of cultural context, particularly family involvement and support, in collectivistic cultures such as Spain, offering a nuanced perspective often overlooked in internationally validated

instruments. The implementation of the model requires expert review and validation processes with the involvement of patients, healthcare professionals and psychometricians, ensuring the questionnaire's relevance, clarity, and comprehensiveness. Subsequent pilot testing and refinement processes, guided by feedback, aim to enhance clarity and relevance before finalization. Practical suggestions when implementing the model include regular administration of the questionnaire, approximately every four months, to capture dynamic changes in patient experiences without overwhelming them. In short, the proposed model is designed to foster a culture of continuous quality enhancement in healthcare services for CKD patients, identifying areas for improvement and tailoring care strategies to individual preferences, whose effectiveness can be monitored.

7.2 IMPLICATIONS FOR THEORETICAL DEVELOPMENT AND RESEARCH

The current research plays a crucial role in situating the evaluation of patient experience within the broader healthcare literature, offering valuable insights into the experiences of patients suffering from chronic illness. In recent years, there has been a growing recognition of patient-centered care and the need for comprehensive assessments that go beyond traditional measures like patient satisfaction (Weldring & Smith, 2013). Apart from this recognition, there have been no empirical investigations assessing the challenges faced by CKD patients during the entire healthcare journey: from the initial diagnosis to the various stages of treatment, including conservative management, initiation of dialysis, transitioning between different treatment modalities and potential transplantation.

This thesis takes a step in this direction and contributes to significantly expanding our understanding of patient experience in the CKD context. First, the conceptual model proposed is an important contribution for pushing the research on CKD patient experience forward. The model encompasses key findings and crucial components aimed at offering a comprehensive and dynamic approach to understanding the diverse experiences of CKD patients. The model advocates for a holistic assessment that considers the evolving nature of CKD experiences over time, ensuring the inclusion of individuals in the early stages of the disease. Guided by eight fundamental principles, including diversity, dynamics, and a

balanced approach, the model emphasizes the importance of capturing experiences and satisfaction at various touch points along the CKD care continuum. Notably, patient involvement is a central tenet, with CKD patients actively participating in the validation of the conceptual model and item generation, ensuring that the questionnaire aligns with their varied experiences. The fact that we include recommendations to implement the proposed conceptual model is expected to contribute to the development of sound measurement instruments.

Second, the integration of systematic reviews and mixed-methods studies provided a nuanced understanding of which are the key dimensions and areas of concern for CKD patient experiences, emphasizing the need for personalized care across different stages of the disease. This helps to back up and solidify the limited and mostly quantitative assessment of patient experience in the context of CKD by showing that patients encountered common and unique challenges at every stage of the disease that future instruments should consider. For example, existing instruments show important gaps in the assessment of important aspects such as family involvement, emotional support, and peer support in CKD care. The benefits derived from integrating information obtained through systematic reviews and patient journey maps are not confined to chronic kidney disease (CKD) alone; they are also relevant to other populations grappling with diverse chronic conditions. Much like CKD, patients navigating through cardiovascular disease (CVD) and diabetes traverse intricate journeys marked by unique stages. In the context of cardiovascular disease (CVD), where patients may encounter risk factors, experience acute events, and manage chronic conditions, the combined insights of systematic reviews and patient journey maps offer a comprehensive understanding. For example, the risk factor management, acute events, and long-term care phases in CVD can be thoroughly explored and optimized through this integrated approach. Similarly, for patients with diabetes, the multifaceted journey of this condition involves stages like risk factor management, acute complications, and ongoing chronic care. The integration of systematic reviews and patient journey maps becomes instrumental in unraveling the intricate dynamics of diabetes care. It helps identify areas of improvement in managing risk factors, addressing acute events, and optimizing long-term patient outcomes.

Third, when focusing on the use of mixed methods in empirical samples of CKD patients, we show the advantages of involving patients in every stage of the assessment process by means of a patient journey mapping (PJM). By integrating both quantitative (i.e. surveys) and qualitative (i.e. focus groups and interviews) methodologies to gather patient's concerns, needs, etc., PJM provides a holistic view of the complex and dynamic nature of the CKD patient journey. This confirmation aligns with contemporary literature on patient-centered care and healthcare quality assessment, emphasizing the need for multifaceted methodologies to capture the diverse aspects of patient experiences (Edgman-Levitan & Schoenbaum, 2021). The design and implementation of the PJM with a Spanish sample is one the biggest contributions we make to patient experience in the context of CKD. By conducting PJM within this cultural context, we not only expanded the applicability of the methodology but also gained a more profound understanding of how cultural nuances may shape patient needs, preferences, and interactions with the healthcare system. The Spanish sample offered valuable insights into the socio-cultural dynamics influencing the CKD patient journey, allowing us to identify aspects that might be unique to this population. We observed a significant role of family involvement throughout various stages of the disease, a crucial aspect that is often overlooked in established and validated international surveys, where family support is not considered as a potential dimension. In addition, the design and execution of PJM within this specific cultural context demonstrated its adaptability and effectiveness in capturing diverse experiences, contributing to the generalizability and robustness of the methodology. Additionally, our research sheds light on PJM as a dynamic and responsive tool for assessing patient experience over the trajectory of CKD. By exploring the patient journey from early stages to advanced therapies, we illustrated the versatility of PJM in accommodating the evolving needs and challenges faced by CKD patients. This adaptability positions PJM as a valuable methodology for longitudinally assessing patient experience. The successful implementation of PJM within the Spanish sample not only advances our understanding of the CKD patient experience but also underscores the potential of PJM as a cross-cultural and dynamic assessment tool. This contribution enhances the existing literature on patient experience assessment methodologies and advocates for the broader adoption of PJM in other healthcare contexts, particularly as a first stage in the development of valid and reliable standardized measures.

Fourth, through this research, we were able to clarify the difference at the conceptual and measurement level within the current literature around patient experience and patient satisfaction. Some scholars have suggested that patient experience and patient satisfaction can be used interchangeably due to overlapping components in their definitions and measurements (Beattie et al., 2015). The confusion arises as both concepts involve assessing a patient's encounter with healthcare, and the terms are sometimes used interchangeably in the literature. Additionally, measurement tools for patient experience and patient satisfaction often share similar domains and items, further contributing to the perception that they represent similar constructs (Berkowitz, 2016; Ahmed et al., 2014). However, the literature review, the evaluation of the questionnaires that focus on satisfaction compared to experience, and the analysis of the components of the definition of patient experience based on Wolf et al.'s 14-years meta-analysis (2014), contribute to clarifying the differences and commonalities. This analysis suggests that to get a full understanding on how to enhance healthcare quality both patient satisfaction and patient experience are important, and satisfaction should also be assessed when assessing patient experience, since patient expectations is a core aspect of their subjective experience.

Patient satisfaction scales primarily focus on subjective evaluations, assessing individuals' content with various aspects of healthcare services which might be influenced by personal characteristics and expectations (Batbaatar et al., 2017; Cleary 1999). In contrast, patient experience scales have a broader scope, encompassing not only satisfaction-related domains but also organizational aspects of care (Kumah, 2017). Furthermore, patient experience is often considered a process indicator, highlighting the interpersonal dimensions of the quality of care received. This includes elements such as effective communication, respect, dignity, and emotional support (Tunçalp et al., 2015; Valentine et al., 2008). In contrast, patient satisfaction serves as an outcome measure, encompassing a patient's overall experiences with care, health outcomes, and confidence in the healthcare system. It gauges whether the care provided aligns with the patient's needs and expectations (Kruk et al., 2018). Lastly, while there is some overlap in the dimensions covered by the two types of questionnaires, such as the importance of communication, patient experience questionnaires typically cover a wider range of domains, including the organization of care delivery, medical

tests, and the environment during treatment sessions. Moreover, while patient satisfaction and patient experience questionnaires share common ground in assessing the quality of healthcare, they exhibit a nuanced distinction. The questions within these instruments may overlap to some extent, but the fundamental difference lies in the nature of inquiry. Patient experience questionnaires often prompt respondents to describe their lived experiences, capturing the intricacies and nuances of their interactions with healthcare. In contrast, satisfaction questionnaires focus on gauging the degree of contentment or fulfillment derived from these experiences. In essence, one delves into the narrative of the patient's journey, while the other seeks a quantifiable measure of their overall satisfaction. Thus, patient satisfaction scales might offer a subjective, individual assessment of care, while patient experience scales provide a more objective and comprehensive view of the healthcare process, encompassing a broader range of aspects.

However, it is noteworthy that both types of scales are valuable for assessing healthcare quality, and their integration can yield a holistic understanding of patient perspectives in CKD care. In fact, while patient experience surveys focus on narratives and detailed descriptions of lived interactions, satisfaction surveys seek a more quantitative evaluation of the overall contentment or fulfillment derived from those experiences. The importance of including satisfaction measures lies in the diversity of individual expectations and values that influence how patients interpret their experience. Some may assign greater significance to certain aspects of care than others, and these variable expectations shape satisfaction differently, even when the experience itself may be similar. By capturing satisfaction, a more complete understanding emerges of how different patients value and perceive their care, allowing for the adaptation of healthcare practices to meet a variety of needs and expectations.

Finally, the study also highlights the dynamic nature of patient experiences in CKD, showcasing how different stages of the disease require varying focus areas in terms of care and support. We found that the diverse needs and care preferences of patients with CKD are distinctly shaped by the various stages of their condition, spanning from the early phases (stages 1 and 2) to the advanced stages necessitating treatment therapies (stages 4 and 5). In

the initial stages, patients focus on monitoring and managing the disease's progression, emphasizing the importance of clear information, education about CKD, and a supportive attitude from healthcare providers. Care coordination and family involvement are crucial components at this juncture. As patients advance to stage 3 and engage in the Patient Renal Education Program (PREP), the emphasis broadens to include peer support and detailed nutritional guidance, reflecting evolving needs. Upon reaching stages 4 and 5, where renal replacement therapies like Hemodialysis (HD) or Peritoneal Dialysis (PD) are necessary, the complexity of patient needs further evolves. HD patients prioritize high-quality dialysis sessions, safety, and a comfortable care environment. Their logistical needs, such as transport coordination, and desire for a more home-like atmosphere during treatment, are pronounced. Conversely, PD patients highlight the importance of personalized training, autonomy in self-management, and a positive home-based care experience. Notably, PD patients express a higher degree of attention to their overall well-being from the healthcare team. The findings of this study significantly contribute to the positioning of the assessment of patient experience within the healthcare quality literature by offering a nuanced understanding of the evolving needs and preferences of patients across various stages of CKD. This research emphasizes that patient experience is not a static concept but a dynamic one that transforms as the disease progresses. Thus, continuous, and longitudinal data collection methods are required to better understand the evolving nature of CKD and patient needs. Research focusing on other chronic patients may also benefit from this dynamic perspective.

7.3. PRACTICAL IMPLICATIONS

The findings of the research hold crucial implications for the practical enhancement of patient care in the context of CKD. As patient experience emerges as a key factor influencing treatment adherence, engagement, and overall satisfaction with healthcare services, it becomes imperative to integrate these insights into healthcare practices. The proposed conceptual model, rooted in a comprehensive understanding of CKD patients' experiences, facilitates a more patient-centered approach to care, aligning with the broader shift towards patient-centered care in healthcare literature. This model encourages healthcare providers to tailor interventions and support services to the evolving needs and preferences

of patients at different stages of CKD, fostering a more responsive and personalized healthcare experience.

When focusing on particular areas of improvement that are crucial to shape patients' experience our research puts emphasis on several factors. For example, care coordination is a critical factor, which aligns with the existing literature on the importance of coordinated and integrated healthcare delivery systems (Agency for Health Care Research and Quality, 2018). Care coordination includes integration between healthcare with community services but also logistics. For example, effective care coordination is particularly highlighted in the advanced stages of CKD, suggesting the need for healthcare systems to prioritize seamless organization of patient care activities, including coordination between various healthcare services, dialysis centers, and transportation. Thus, service providers should foster this effective coordination. In addition, emphasis on family involvement and peer support, suggests healthcare professionals should consider the broader social support system of patients in their care strategies. The family involvement is identified as a significant dimension especially in the early stages of CKD, aligning with previous research emphasizing the role of family support in chronic illness management (Whitehead et al., 2018). Peer support seems to be more important when patients are in the renal education programs. These findings emphasize the need for healthcare practitioners to recognize and actively involve the patient's family and, in some instances, peers in care planning and delivery.

Herein, we provide some suggestions of family involvement. In optimizing the care of CKD patients, healthcare practitioners can significantly enhance the patient's well-being by actively involving their family members. For example, establishing educational programs is key, providing comprehensive information about CKD, treatment options, and the crucial role of family support. Regular family meetings can facilitate open communication, ensuring that family members are informed about the patient's condition and treatment plan. Implementing caregiver training sessions can equip family members with the skills needed for daily care, such as administering medications and recognizing symptoms. Support groups tailored to families of CKD patients can offer a platform for shared experiences and mutual

support. Care plans should actively seek family input, considering their perspectives, preferences, and practical constraints when designing treatment regimens. Lastly, flexible visitation policies can accommodate family members during medical appointments or hospitalizations, allowing them to actively participate in discussions and decision-making. Through these strategies, healthcare practitioners can create a collaborative and supportive environment that actively involves the patient's family in their CKD care journey.

Implications drawn from the study findings suggest a multifaceted approach to enhance the quality of care for patients with chronic kidney disease (CKD). First and foremost, there is a pressing need for interventions aimed at improving communication within the healthcare setting. Implementing strategies that facilitate clear, comprehensible, and stage-specific information delivery can significantly contribute to patient understanding of their condition and treatment choices. This underscores the importance of developing educational materials and communication protocols tailored to the diverse stages of CKD, promoting informed decision-making and patient empowerment.

Furthermore, the study highlights the critical role of healthcare professionals in shaping the overall patient experience. To address this, comprehensive training programs and continuous education initiatives should be prioritized, with a particular focus on enhancing empathy and patient-centered care. Empowering healthcare professionals with the skills to navigate the emotional and informational aspects of CKD care can foster stronger patient-provider relationships, ultimately contributing to improved patient satisfaction. This emphasizes the need for ongoing efforts to cultivate a healthcare workforce that is not only clinically competent but also attuned to the unique needs and experiences of individuals with CKD. In summary, these implications underscore the importance of targeted interventions and educational initiatives to foster an environment that promotes effective communication, tailored information delivery, and compassionate care, thereby elevating the overall quality of care for CKD patients.

When we focus on implications for the assessment of patient experience, the successful implementation of the Patient Journey Mapping (PJM) within a Spanish sample

highlights the adaptability and effectiveness of this methodology in capturing diverse experiences, including cultural nuances. Therefore, healthcare organizations can consider incorporating PJM as a dynamic and responsive tool for assessing patient experience over the trajectory of CKD, as well as other chronic illnesses. This input is crucial for the development of tools that remain relevant, culturally sensitive, and responsive to the evolving needs and preferences of patients suffering chronic conditions.

7.4. LIMITATIONS AND FUTURE RESEARCH

Although the present research has much theoretical and practical value, it is not without its limitations. The main limitations of the two studies carried out are described below.

In the systematic review study, in our examination of gray literature, we specifically concentrated on information from two sources – the European Kidney Patients' Federation and the National Kidney Foundation websites. It is crucial to acknowledge that this limited exploration might have overlooked potential pertinent studies or scales available in other gray literature sources. This narrow focus introduces a potential bias, as valuable insights from alternative sources may not have been captured. Additionally, our inclusion criteria for scales were stringent, emphasizing instruments that have undergone both development and validation processes. While this stringent criterion ensures the incorporation of robust and well-established instruments, it also poses a limitation. This approach may result in the exclusion of emerging scales or tools that, although not yet fully validated, could offer valuable perspectives and contribute significantly to the understanding of patient experience in the context of CKD. Therefore, it is important to recognize the potential limitation in our approach, as it prioritizes the inclusion of validated instruments at the expense of potentially insightful tools still in the early stages of development. Future research may update the results if new relevant questionnaires are obtained.

Focusing on the empirical study, despite its valuable insights into the CKD patient experience gained with this study, the patient journey mapping study exhibits certain

limitations that warrant consideration, such as the relatively small sample size (N= 86), especially in the early stages of the disease (N=10) or the suboptimal internal consistency of the Instrument for Assessing Patient Experience of Chronic Illness Care (IEXPAC), especially for some of the dimensions. The results align with the ones obtained in the reviewed study (Mira et al., 2016). This aspect suggests caution in interpreting and relying on the IEXPAC as a robust measure of patient experiences in the CKD context and corroborates the need to develop new questionnaires with better psychometric properties. Moreover, the study's reliance on a predetermined number of touchpoints, with only four unanimously decided by the subjects, introduces a potential limitation in terms of the comprehensiveness of the patient journey captured. The restricted number of touchpoints may overlook crucial phases or interactions in the CKD care trajectory, limiting the depth of understanding of the nuanced patient experience. Additionally, the low representation of patients in the early stages of CKD within the sample—only 10 out of the 86 subjects—raises concerns about the study's ability to provide a holistic view of the diverse experiences and challenges faced by individuals in the initial phases of the disease. Future research should cross-validate the adequacy of the four proposed touch points.

While acknowledging these limitations, it is essential to recognize the unique contributions of each study. First, the systematic review not only outlines the strengths and weaknesses of different scales but also pinpoints significant knowledge gaps, setting the stage for future research endeavors. Second, the empirical study uncovers the qualitative intricacies of CKD patient experiences. The insights gained, despite the constraints, offer valuable qualitative data that can complement and enrich the broader understanding of the patient journey in chronic kidney disease.

Lastly, although this doctoral thesis does not introduce and validate a specific questionnaire, its significant contribution lies in the foundational work it provides for future endeavors. By thoroughly exploring the landscape of existing questionnaires, methodologies, and patient experiences in chronic kidney disease (CKD) contexts, we offer valuable insights and identify crucial gaps. Our groundwork provides researchers and healthcare professionals with a nuanced understanding of the complexities involved in assessing patient experience

and satisfaction within CKD. Consequently, it paves the way for the development of targeted, context-specific questionnaires, ensuring that future proposals are well-informed, comprehensive, and tailored to the unique needs of CKD patients. The contribution lies not just in the immediate findings but in the strategic preparation it offers for more focused and impactful research endeavors.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REFERENCES

Abbasi-Moghaddam, M. A., Zarei, E., Bagherzadeh, R., Dargahi, H., & Farrokhi, P. (2019). Evaluation of service quality from patients' viewpoint. *BMC Health Services Research, 19*(1), 1-7.

Agarwal, R., & Epstein, A. S. (2017). Palliative care and advance care planning for pancreas and other cancers. *Chinese Clinical Oncology, 6*(3), 32.

Agency for Healthcare Research and Quality. (2018). 2018 National Healthcare Quality and Disparities Report. Rockville, MD. Retrieved from https://www.ahrq.gov/research/findings/nhqrdr/nhqdr18/index.html

Ahlberg, E., & Carlsson, P. (2019). Exploring Needs and Designing an Interactive Service to Empower Home Dialysis Patients in their Everyday Life. [Master's thesis, Lund University]

Ahmed, F., Burt, J., & Roland, M. (2014). Measuring patient experience: concepts and methods. *The Patient-Patient-Centered Outcomes Research, 7*, 235-241.

Almutary, H., Bonner, A., & Douglas, C. (2013). Symptom burden in chronic kidney disease: a review of recent literature. *Journal of Renal Care, 39*(3), 140-150.

Al-Alqusair, D., Al-Turaiki, I., Al-Humaimeedy, A., & Alhudhud, G. (2019). Measuring patient experience in real time using iBeacon technology. In Real Time Using IBeacon Technology.

American Kidney Fund. (2020). AKF 2020 Annual Report. Retrieved from https://www.kidneyfund.org/sites/default/files/media/documents/akf-2020-annual-report.pdf

Ania-González, N., Martín-Martín, J., Amezqueta-Goñi, P., & Vázquez-Calatayud, M.

(2022). The needs of families who care for individuals with kidney failure on comprehensive conservative care: A qualitative systematic review. *Journal of Renal Care, 48*(4), 230-242.

Anufriyeva, V., Pavlova, M., Stepurko, T., & Groot, W. (2021). Patient satisfaction and patient experience are not interchangeable concepts-authors' reply. *International*

Brach, C., & Borsky, A. (2020). How the U.S. Agency for Healthcare Research and Quality Promotes Health Literate Health Care. Studies in health technology and informatics, 269, 313–323. https://doi.org/10.3233/SHTI200046
Journal for Quality in Health Care, 33(1), Article 024. https://doi.org/10.1093/intqhc/mzab024

Baker, M. L., Yamamoto, Y., Perazella, M. A., Dizman, N., Shirali, A. C., Hafez, N., & Moledina, D. G. (2021). Mortality after acute kidney injury and acute interstitial nephritis in patients prescribed immune checkpoint inhibitor therapy. *Journal for Immunotherapy of Cancer*, 10(3).

Barendse, S. M., Speight, J., & Bradley, C. (2005). The Renal Treatment Satisfaction # Questionnaire (RTSQ): a measure of satisfaction with treatment for chronic kidney failure. *American Journal of Kidney Diseases, 45*(3), 572-579.

Bastemeijer, C. M., Boosman, H., van Ewijk, H., Verweij, L. M., Voogt, L., & Hazelzet, J. A. (2019). Patient experiences: a systematic review of quality improvement interventions in a hospital setting. *Patient Related Outcome Measures*, 157-169.

Batbaatar, E., Dorjdagva, J., Luvsannyam, A., Savino, M. M., & Amenta, P. (2017). Determinants of patient satisfaction: a systematic review. *Perspectives in Public Health, 137*(2), 89-101.

Beach, L. B., Wild, M., Ramachandran, G., Ikizler, H. O., & Cavanaugh, K. L. (2016).

Protocol of a randomized controlled trial of an erythropoietin stimulating agent decision aid for anemia treatment in kidney disease. *BMC Nephrology, 17*(1), 1-10.

Bear, R. A., & Stockie, S. (2014). Patient engagement and patient-centred care in the management of advanced chronic kidney disease and chronic kidney failure. *Canadian Journal of Kidney Health and Disease, 1*, 24-31.

Beattie, M., Lauder, W., Atherton, I., & Murphy, D. J. (2014). Instruments to measure patient experience of health care quality in hospitals: a systematic review protocol. *Systematic Reviews, 3*(1), 1-8.

Beattie, M., Murphy, D. J., Atherton, I., & Lauder, W. (2015). Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Systematic Reviews, 4*(1), 1-21.

Becker, L., & Jaakkola, E. (2020). Customer experience: fundamental premises and implications for research. *Journal of the Academy of Marketing Science, 48*, 630-648.

Ben-Tovim, D. I., Dougherty, M. L., O'Connell, T. J., & McGrath, K. M. (2008). Patient journeys: the process of clinical redesign. *Medical Journal of Australia, 188*(6), 14-17.

Berkowitz, B. (2016). The patient experience and patient satisfaction: measurement of a complex dynamic. *Online Journal of Issues in Nursing, 21*(1).

Bernardo, J. M. S., Mendes, G. H. D. S., Lizarelli, F. L., & Roscani, M. G. (2022). Instruments to measure patient experience in hospitals: a scoping review. *Gestão & Produção, 29*, e0821.

Berwick, D. M. (2009). What 'Patient-Centered' Should Mean: Confessions Of An Extremist: A seasoned clinician and expert fears the loss of his humanity if he should

become a patient. *Health Affairs, 28*(11), 555-565.

Bjertnaes, O. A., Sjetne, I. S., & Iversen, H. H. (2011). Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. *BMJ Quality & Safety*, 39-46. https://doi.org/10.1136/bmjqs-2011-000137

Bookbinder, S. H., & Brainerd, C. J. (2016). Emotion and false memory: The context–content paradox. *Psychological Bulletin, 142*(12), 1315.

Bookbinder, S. H., & Brainerd, C. J. (2016). Emotion and false memory: The context–content paradox. *Psychological Bulletin, 142*(12), 1315.

Bolz-Johnson, M., Meek, J., & Hoogerbrugge, N. (2020). “Patient Journeys”: improving care by patient involvement. *European Journal of Human Genetics, 28*(2), 141-143.

Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). Measuring patient experience as a strategy for improving primary care. *Health Affairs, 29*(5), 921-925.

Burches, E., & Burches, M. (2020). Efficacy, effectiveness and efficiency in the health care: The need for an agreement to clarify its meaning. *International Archives of Public Health and Community Medicine, 4*(1), 1-3.

Burgess, E. R., Reddy, M. C., Davenport, A., Laboi, P., & Blandford, A. (2019, May). " Tricky to get your head around" Information Work of People Managing Chronic Kidney Disease in the UK. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (pp. 1-17).

Carrero, J. J., & Elinder, C. G. (2022). The Stockholm CREAtinine Measurements (SCREAM) project: fostering improvements in chronic kidney disease care. *Journal*

of Internal Medicine, 291(3), 254-268.

Catalá-López, F., Peiró, S., Ridao, M., Sanfélix-Gimeno, G., Gènova-Maleras, R., & Catalá, M. A. (2012). Prevalence of attention deficit hyperactivity disorder among children and adolescents in Spain: a systematic review and meta-analysis of epidemiological studies. *BMC Psychiatry, 12*, 1-13.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., Amtmann, D., Bode, R., Buysse, D., Choi, S., & Cook, K. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology, 63*(11), 1179-1194.

Chassin, M. R., & Galvin, R. W. (1998). The urgent need to improve health care quality: Institute of Medicine National Roundtable on Health Care Quality. *JAMA, 280*(11), 1000-1005.

Chen, T. K., Knicely, D. H., & Grams, M. E. (2019). Chronic kidney disease diagnosis and management: a review. *JAMA, 322(13)*, 1294-1304.

Cheng, Y., Wei, W., Zhong, Y., & Zhang, L. (2021). The empowering role of hospitable telemedicine experience in reducing isolation and anxiety: evidence from the COVID-19 pandemic. *International Journal of Contemporary Hospitality Management, 33*(3), 851-872.

Chuasuwan, A., Pooripussarakul, S., Thakkinstian, A., Ingsathit, A., & Pattanaprateep, O. (2020). Comparisons of quality of life between patients underwent peritoneal dialysis and hemodialysis: a systematic review and meta-analysis. *Health and*

Quality of Life Outcomes, 18, 1-11.

Ciria-Suarez, L., Jiménez-Fonseca, P., Palacín-Lois, M., Antoñanzas-Basa, M., Fernández-Montes, A., Manzano-Fernández, A., Castelo, B., Asensio-Martínez, E., Hernando-Polo, & Calderon, C. (2021). Breast cancer patient experiences through a journey map: A qualitative study. *PloS One, 16*(9), e0257680.

Cleary, P. D. (1999). The increasing importance of patient surveys: Now that sound methods exist, patient surveys can facilitate improvement. *BMJ, 319*(7212), 720-721.

Cleary, P. D., & Edgman-Levitan, S. (1997). Health care quality: incorporating consumer perspectives. *JAMA, 278*(19), 1608-1612.

Cleary, P. D., Edgman-Levitan, S., McMullen, W., & Delbanco, T. L. (1992). The relationship between reported problems and patient summary evaluations of hospital care. *QRB. Quality Review Bulletin, 18*(2), 53-59.

Committee on Quality of Healthcare in America. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy of Sciences.

Coulter, A. (2009). What's happening around the world. In Edwards, A., & Elwyn, G. (Eds.), *Shared decision-making in health care: Achieving evidence-based patient choice*. Oxford University Press (p. 159).

Coulter, A., Fitzpatrick, R., & Cornwell, J. (2009). *The Point of Care: Measures of patients' experience in hospital*. The King's Fund.

Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and*

mixed methods approaches. Sage Publications.

Crofton, C., Lubalin, J. S., & Darby, C. (1999). Consumer Assessment of Health Plans Study (CAHPS). Foreword. Medical care, 37(3 Suppl), MS1–MS9. https://doi.org/10.1097/00005650-199903001-00001

Crow, H., Gage, H., Hampson, S., Hart, J., Kimber, A., Storey, L., & Thomas, H. (2002). Measurement of satisfaction with health care: Implications for practice from a systematic review of the literature. *Health Technology Assessment, 6*(32).

Cukor D, Cohen SD, Peterson RA, Kimmel PL: Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. J Am Soc Nephrol 18:3042-3055, 2007

Dalati, S., & Marx Gómez, J. (2018). Surveys and questionnaires. In Gómez, J. M., & Mouselli, S. (Eds.)., *Modernizing the Academic Teaching and Research Environment: Methodologies and Cases in Business Research* (pp. 175-186). Springer.

Davies, E. L., Bulto, L. N., Walsh, A., Pollock, D., Langton, V. M., Laing, R. E., Graham, A., Arnold-Chamney, M., & Kelly, J. (2023). Reporting and conducting patient journey mapping research in healthcare: A scoping review. *Journal of Advanced Nursing, 79*(1), 83-100.

Boer, I. H., Caramori, M. L., Chan, J. C., Heerspink, H. J., Hurst, C., Khunti, K., Liew, A., Michos, E. D., Navaneethan, S. D., Olowu, W. A., & Rossing, P. (2020). KDIGO 2020 clinical practice guideline for diabetes management in chronic kidney disease. *Kidney International, 98*(4), S1-S115.

Devellis, R. (2012). *Scale Development Theory and Applications*. Sage Publications.

Devins, G. M., & Deckert, A. (2017). Illness intrusiveness and self-management of medical conditions. In E. Martz (Ed.), *Promoting self-management of chronic health conditions: Theories and practice* (pp. 80–125). Oxford University Press. https://doi.org/10.1093/med-psych/9780190606145.003.0005

DiMatteo, M. R., Giordani, P. J., Lepper, H. S., & Croghan, T. W. (2002). Patient adherence and medical treatment outcomes a meta-analysis. *Medical Care*, 794-811.

Donald, M., Beanlands, H., Straus, S., Ronksley, P., Tam-Tham, H., Finlay, J., Smekal, M., Elliott, M.J., Farragher, J., Herrington, G., & Hemmelgarn, B. R. (2019). Preferences for a self-management e-health tool for patients with chronic kidney disease: results of a patient-oriented consensus workshop. *Canadian Medical Association Open Access Journal, 7*(4), E713-E720.

Dovgan, E., Gradišek, A., Luštrek, M., Uddin, M., Nursetyo, A. A., Annavarajula, S. K., Li, Y.C., & Syed-Abdul, S. (2020). Using machine learning models to predict the initiation of renal replacement therapy among chronic kidney disease patients. *PloS One, 15*(6), e0233976.

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open, 3*(1).

Dueñas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A review of chronic pain impact on patients, their social environment and the health care system. *Journal of Pain Research*, 457-467.

Edgman-Levitan, S., & Schoenbaum, S. C. (2021). Patient-centered care: achieving higher quality by designing care through the patient's eyes. *Israel Journal of Health Policy Research, 10*, 1-5.

Elliott, M. J., Goodarzi, Z., Sale, J. E., Wilhelm, L. A., Laupacis, A., Hemmelgarn, B. R., & Straus, S. E. (2018). Perceived significance of engagement in research prioritization among chronic kidney disease patients, caregivers, and health care professionals: a qualitative study. Can*adian Journal of Kidney Health and Disease, 5*. https://doi.org/10.1177/205435811880748

Elliott, M. N., Cohea, C. W., Lehrman, W. G., Goldstein, E. H., Cleary, P. D., Giordano, L. A., Beckett, M.K., & Zaslavsky, A. M. (2015). Accelerating improvement and narrowing gaps: trends in patients' experiences with hospital care reflected in # HCAHPS public reporting. *Health Services Research, 50*(6), 1850-1867.

Eneanya, N. D., Percy, S. G., Stallings, T. L., Wang, W., Steele, D. J., Germain, M. J., Schell, J.O., Paasche-Orlow, M.K., & Volandes, A. E. (2020). Use of a supportive kidney care video decision aid in older patients: a randomized controlled trial. *American Journal of Nephrology, 51*(9), 736-744.

Ene-Iordache, B., Perico, N., Bikbov, B., Carminati, S., Remuzzi, A., Perna, A., Islam, N., Bravo, R.F., Aleckovic-Halilovic, M., Zou, H., & Remuzzi, G. (2016). Chronic kidney disease and cardiovascular risk in six regions of the world (ISN-KDDC): a cross-sectional study. *The Lancet Global Health, 4*(5), e307-e319.

Epstein, R. M., & Street, R. L. (2011). The values and value of patient-centered care. *The Annals of Family Medicine, 9*(2), 100-103. https://doi.org/10.1370/afm.1239

Epstein, R. M., Jha, A. K., Orav, E. J., Liebman, D. L., Audet, A. M. J., Zezza, M. A., & Guterman, S. (2014). Analysis of early accountable care organizations defines patient, structural, cost, and quality-of-care characteristics. *Health Affairs, 33*(1), 95-102.

European Commission. (2010). *Patient Safety and quality of healthcare*. Eurobarometer.
Figueiredo, M. C., & Chen, Y. (2020). Patient-generated health data: dimensions, challenges, and open questions. *Foundations and Trends® in Human–Computer Interaction, 13*(3), 165-297.

European Kidney Patients' Federation. (n.d.). Home. Retrieved June 10, 2023, from https://ekpf.eu/

Ford, R. C., & Fottler, M. D. (2000). Creating customer-focused health care organizations. *Health Care Management Review*, 18-33.

Galletta, M., Piazza, M. F., Meloni, S. L., Chessa, E., Piras, I., Arnetz, J. E., & D'Aloja, E. (2022). Patient Involvement in Shared Decision-Making: Do Patients Rate Physicians and Nurses Differently?. *International Journal of Environmental Research and Public Health, 19*(21), 14229.

Garcia-Garcia, G., Tonelli, M., Ibarra-Hernandez, M., Chavez-Iñiguez, J. S., & Oseguera-Vizcaino, M. C. (2021). Access to kidney transplantation in Mexico, 2007–2019: a call to end disparities in transplant care. *BMC Nephrology, 22*, 1-12.

Gibertoni, D., Reno, C., Rucci, P., Fantini, M. P., Buscaroli, A., Mosconi, G., Giudicissi, A., Mambelli, E., Righini, M., & Altini, M. (2021). COVID-19 incidence and mortality in non-dialysis chronic kidney disease patients. *PloS One, 16*(7), e0254525.

Glickman, S. W., Boulding, W., Manary, M., Staelin, R., Roe, M. T., Wolosin, R. J., Ohman, E. M., Peterson, E. D., & Schulman, K. A. (2010). Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. *Circulation: Cardiovascular Quality and Outcomes, 3*(2), 188-195.

Godovykh, M., & Pizam, A. (2022). Measuring patient experience in healthcare. *International Journal of Hospitality Management, 112*, 103405.

Godovykh, M., & Tasci, A. D. (2022). Emotions, feelings, and moods in tourism and hospitality research: Conceptual and methodological differences. *Tourism and Hospitality Research, 22*(2), 247-253.

Godovykh, M., Fyall, A., Pizam, A., Hancer, M., & Cassisi, J. (2022). Virtual versus face-to-face events: The effects of event type on attendees' attitudes and behavioral intentions. *Event Management, 26*(8), 1689-1706.

Gorostidi, M., Sánchez-Martínez, M., Ruilope, L. M., Graciani, A., de la Cruz, J. J., Santamaría, R., ... & Banegas, J. R. (2018). Prevalencia de enfermedad renal crónica en España: impacto de la acumulación de factores de riesgo cardiovascular. Nefrología, 38(6), 606-615.

Grau, C. (2017, June 15). Tecnologia Sanitaria: Apostando por el Paciente. New Medical Economics, 54, 22-24. Retrieved from https://issuu.com/raizpublicidad/docs/nme_num54

Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of*

General Internal Medicine, 27, 520-526.

Greenfield, G., Ignatowicz, A. M., Belsi, A., Pappas, Y., Car, J., Majeed, A., & Harris, M. (2014). Wake up, wake up! It's me! It's my life! patient narratives on person-centeredness in the integrated care context: a qualitative study. *BMC Health Services Research, 14*, 1-11.

Gualandi, R., Masella, C., Viglione, D., & Tartaglini, D. (2019). Exploring the hospital patient journey: What does the patient experience?. *PloS One, 14*(12), e0224899.

Hagendijk, M. E., Zipfel, N., Oomen, F. J., Hoving, J. L., van der Wees, P. J., Hulshof, C. T., Çölkesen, E. B., Melles, M., & van der Burg-Vermeulen, S. J. (2023). Work-focused healthcare from the perspective of employees living with cardiovascular disease: a patient experience journey mapping study. *BMC Public Health, 23*(1), 1765.

Halawa, F., Madathil, S. C., Gittler, A., & Khasawneh, M. T. (2020). Advancing evidence-based healthcare facility design: a systematic literature review. *Health Care Management Science, 23*, 453-480.

Hall, J. A., & Dornan, M. C. (1990). Patient sociodemographic characteristics as predictors of satisfaction with medical care: a meta-analysis. *Social Science & Medicine, 30*(7), 811-818.

Hallan, S. I., & Orth, S. R. (2010). The KDOQI 2002 classification of chronic kidney disease: for whom the bell tolls. *Nephrology Dialysis Transplantation, 25*(9), 2832-2836.

Hannawa, A. F., Wu, A. W., Kolyada, A., Potemkina, A., & Donaldson, L. J. (2022). The aspects of healthcare quality that are important to health professionals and patients: A qualitative study. Patient education and counseling, 105(6), 1561-1570.

Hanson, C. S., Sautenet, B., Craig, J. C., Chapman, J. R., Knoll, G., Reese, P. P., & Tong, A. (2019). Informative for decision making? the spectrum and consistency of outcomes after living kidney donation reported in trials and observational studies. *Transplantation, 103*(2), 284-290.

Hawkins, J., Wellsted, D., Corps, C., Fluck, R., Gair, R., Hall, N., Busby, A., Rider, B., Farrington, K., Sharma, S., & van der Veer, S. N. (2022). Measuring patients' experience with renal services in the UK: development and validation of the Kidney PREM. *Nephrology Dialysis Transplantation, 37*(8), 1507-1519.

Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., & Carter, W. B. (1994). Development of the kidney disease quality of life (KDQOL TM) instrument. *Quality of Life Research, 3*, 329-338.

HealthLeaders Media. (2019). *The High-Impact Revenue Cycle*. HealthLeaders.

Hill, N. R., Fatoba, S. T., Oke, J. L., Hirst, J. A., O'Callaghan, C. A., Lasserson, D. S., & Hobbs, F. R. (2016). Global prevalence of chronic kidney disease–a systematic review and meta-analysis. *PloS One, 11*(7), e0158765.

Hole, B., Hemmelgarn, B., Brown, E., Brown, M., McCulloch, M. I., Zuniga, C., Andreoli, S. P., Blake, P. G., Couchoud, C., Cueto-Manzano, A. M., & Caskey, F. J. (2020). Supportive care for end-stage kidney disease: an integral part of kidney services across a range of income settings around the world. *Kidney International*

Supplements, 10(1), e86-e94.

Holt, J. M. (2018). An evolutionary view of patient experience in primary care: A concept analysis. In Nursing Forum (Vol. 53, No. 4, pp. 555-566).

Hussien, H., Apetrii, M., & Covic, A. (2020). Health-related quality of life in patients with chronic kidney disease. *Expert Review of Pharmacoeconomics & Outcomes Research, 21*(1), 43-54.

Jenkinson, C., Coulter, A., Bruster, S., Richards, N., & Chandola, T. (2002). Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Quality & Safety in Health Care, 11*(4), 335.

Jha, V., Al-Ghamdi, S. M., Li, G., Wu, M. S., Stafylas, P., Retat, L., Card-Gowers, J., Barone, S., Cabrera, C., & Garcia Sanchez, J. J. (2023). Global economic burden associated with chronic kidney disease: a pragmatic review of medical costs for the inside CKD research programme. *Advances in Therapy, 40*(10), 4405-4420.

Jones, K., & Thompson, R. (2021). To use or not to use a COVID-19 contact tracing app: Mixed methods survey in Wales. JMIR mHealth and uHealth, 9(11), e29181.

Joseph, A. L., Kushniruk, A. W., & Borycki, E. M. (2020). Patient journey mapping: current practices, challenges, and future opportunities in healthcare. *Knowledge Management & e-Learning, 12*(4), 387.

Jun, J., Ojemeni, M. M., Kalamani, R., Tong, J., & Crecelius, M. L. (2021). Relationship between nurse burnout, patient, and organizational outcomes: Systematic review. *International Journal of Nursing Studies, 119*, 103933.

Kahn, S. A., Iannuzzi, J. C., Stassen, N. A., Bankey, P. E., & Gestring, M. (2015). Measuring satisfaction: factors that drive hospital consumer assessment of healthcare providers and systems survey responses in a trauma and acute care surgery population. *The American Surgeon, 81*(5), 537-543.

Kalantar-Zadeh, K., Lockwood, M. B., Rhee, C. M., Tantisattamo, E., Andreoli, S., Balducci, A., Laffin, P., Harris, T., Knight, R., Kumaraswami, L., & Li, P. K. T. (2022). Patient-centred approaches for the management of unpleasant symptoms in kidney disease. *Nature Reviews Nephrology, 18*(3), 185-198.

Kemmelmeier, M. (2016). Cultural differences in survey responding: Issues and insights in the study of response biases. International Journal of Psychology, 51(6), 439-444.

Kennedy, D. M., Anastos, C. T., & Genau Jr, M. C. (2018). Improving healthcare service quality through performance management. *Leadership in Health Services, 32*(3), 477-492.

Kidney Disease: Improving Global Outcomes (2020). KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation. *Transplantation, 1*(103).

Kidney Disease: Improving Global Outcomes. (2013). KDIGO 2012 Clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney International Supplements, 3*(1), 1-150.

Kirchgessner, J., Perera-Chang, M., Klinkner, G., Soley, I., Marcelli, D., Arkossy, O., Stopper, A., & Kimmel, P. L. (2006). *Satisfaction with care in peritoneal dialysis*

patients. Kidney International, 70(7), 1325-1331.

Kirkley, A., & Griffin, S. (2003). Development of disease-specific quality of life measurement tools. *Arthroscopy: The Journal of Arthroscopic & Related Surgery, 19*(10), 1121-1128.

Klerings, I., Weinhandl, A. S., & Thaler, K. J. (2015). Information overload in healthcare: too much of a good thing?. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 109*(4-5), 285-290.

Kovesdy, C. P. (2022). Epidemiology of chronic kidney disease: an update 2022. *Kidney International Supplements, 12*(1), 7-11.

Kumah, E. (2017). Patient experience and satisfaction with a healthcare system: connecting the dots. *International Journal of Healthcare Management*, 173-179.

Kuppelwieser, V. G., & Klaus, P. (2021). Measuring customer experience quality: the EXQ scale revisited. *Journal of Business Research, 126*, 624-633.

Kuppens, K., Feijen, S., Roussel, N., Nijs, J., Cras, P., van Wilgen, P., & Struyf, F. (2019). Training volume is associated with pain sensitivity, but not with endogenous pain modulation, in competitive swimmers. *Physical Therapy in Sport, 37*, 150-156.

Kushniruk, A. W., Borycki, E. M., & Parush, A. (2020). A case study of patient journey mapping to identify gaps in healthcare: Learning from experience with cancer diagnosis and treatment. *Knowledge Management & E-Learning, 12*(4), 405.

Kruk, M. E., Gage, A. D., Arsenault, C., Jordan, K., Leslie, H. H., Roder-DeWan, S., Adeyi,

O., Barker, P., Daelmans, B., Doubova, S. V., English, M., García-Elorrio, E., Guanais, F., Gureje, O., Hirschhorn, L. R., Jiang, L., Kelley, E., Lemango, E. T., Liljestrand, J., Malata, A., … Pate, M. (2018). High-quality health systems in the Sustainable Development Goals era: time for a revolution. The Lancet. Global health, 6(11), e1196–e1252. https://doi.org/10.1016/S2214-109X(18)30386-3

Larson, E., Sharma, J., Bohren, M. A., & Tunçalp, Ö. (2019). When the patient is the expert: measuring patient experience and satisfaction with care. *Bulletin of the World Health Organization, 97*(8), 563.

LaVela, S. L., & Gallan, A. (2014). Evaluation and measurement of patient experience. *Patient Experience Journal, 1*(1), 28-36.

Levey, A. S., Coresh, J., Balk, E., Kausz, A. T., Levin, A., Steffes, M. W., Hogg, R. J., Perrone, R. D., Lau, J., Eknoyan, G., & National Kidney Foundation (2003). National Kidney Foundation practice guidelines for chronic kidney disease: evaluation, classification, and stratification. Annals of internal medicine, 139(2), 137–147. https://doi.org/10.7326/0003-4819-139-2-200307150-00013

Lew, Q. L. J., Allen, J. C., Nguyen, F., Tan, N. C., & Jafar, T. H. (2018). Factors associated with chronic kidney disease and their clinical utility in primary care clinics in a multi-ethnic Southeast Asian population. *Nephron, 138*(3), 202-213.

Ly, H., Ortiz-Soriano, V., Liu, L. J., Liu, Y., Chen, J., Chang, A. R., Gutierrez, O. M., Siew, E. D., Wald, R., Silver, S. A., & Neyra, J. A. (2021). Characteristics and outcomes of survivors of critical illness and acute kidney injury followed in a pilot acute kidney injury clinic. *Kidney International Reports, 6*(12), 3070-3073.

Mahato, S. K. S., Apidechkul, T., Sriwongpan, P., Hada, R., Sharma, G. N., Nayak, S. K., & Mahato, R. K. (2020). Factors associated with quality of life among chronic kidney disease patients in Nepal: a cross-sectional study. *Health and Quality of Life Outcomes, 18*(1), 1-14.

Malouin, R. A., Starfield, B., & Sepulveda, M. J. (2009). Evaluating the tools used to assess the medical home. *Managed Care, 18*(6), 44-8.

Manary, M. P., Boulding, W., Staelin, R., & Glickman, S. W. (2013). The patient experience and health outcomes. *The New England Journal of Medicine, 368*(3), 201–203. https://doi.org/10.1056/NEJMp1211775

McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y. L., Kenny, L. C., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems, 25*(1), 354-368.

McPhail, S. M. (2016). Multimorbidity in chronic disease: impact on health care resources and costs. *Risk Management and Healthcare Policy, 9*, 143-156.

Mendu, M. L., Tummalapalli, S. L., Lentine, K. L., Erickson, K. F., Lew, S. Q., Liu, F., Gould, E., Somers, M., Garimella, P.S., O'Neil, T., & Weiner, D. E. (2020). Measuring quality in kidney care: an evaluation of existing quality metrics and approach to facilitating improvements in care delivery. *Journal of the American Society of Nephrology, 31*(3), 602.

Mills, K. T. , Peacock, E. , Chen, J. , Zimmerman, A. , He, H. , Cyprian, A. , Davis, G. , Fuqua, S. R. , Gilliam, D. S. , Greer, A. , Gray-Winfrey, L. , Williams, S. , Wiltz, G. M. , Winfrey, K. L. , Whelton, P. K. , Krousel-Wood, M. , & He, J. (2021).

Experiences and beliefs of low-income patients with hypertension in Louisiana and Mississippi during the COVID-19 pandemic. *Journal of the American Heart Association, 10*(3), e018510. https://doi.org/10.1161/jaha.120.018510

Mills, K. T., Xu, Y., Zhang, W., Bundy, J. D., Chen, C. S., Kelly, T. N., Chen, J., & He, J. (2015). A systematic analysis of worldwide population-based data on the global burden of chronic kidney disease in 2010. *Kidney International, 88*(5), 950-957. https://doi.org/10.1038/ki.2015.230

Mira, J. J., Nuno-Solinis, R., Guilabert-Mora, M., Solas-Gaspar, O., Fernandez-Cano, P., González-Mestre, M. A., Contel, J.C., & del Rio-Camara, M. (2016). Development and validation of an instrument for assessing patient experience of chronic illness care. *International Journal of Integrated Care, 16*(3).

Mira, J.J., Aranaz, J., Rodríguez-Marín, J., Buil, J. A., Castell, M., & Vitaller, J. (1998). SERVQHOS: un cuestionario para evaluar la calidad percibida de la asistencia hospitalaria. *Medicina Preventiva, 4*, 12-18.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Journal of Clinical Epidemiology, 62*, 1006-1012.

Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., Bouter, L.M., & De Vet, H. C. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of Life Research, 19*, 539-549.

Morgado, L., Silva, F. J. G., & Fonseca, L. M. (2019). Mapping occupational health and safety management systems in Portugal: outlook for ISO 45001: 2018 adoption. *Procedia Manufacturing, 38*, 755-764.

Morton, D., Rankin, P., Kent, L., & Dysinger, W. (2016). The Complete Health Improvement Program (CHIP) history, evaluation, and outcomes. *American Journal of Lifestyle Medicine, 10*(1), 64-73.

Muhammad, S., Allan, M., Ali, F., Bonacina, M., & Adams, M. (2014). The renal patient support group: supporting patients with chronic kidney disease through social media. *Journal of Renal Care, 40*(3), 216-218.

Mujais, S. K., Story, K., Brouillette, J., Takano, T., Soroka, S., Franek, C., Mendelssohn, D., & Finkelstein, F. O. (2009). Health-related quality of life in CKD patients: correlates and evolution over time. *Clinical Journal of the American Society of Nephrology, 4*(8), 1293.

Nair, D., & Wilson, F. P. (2019). Patient-reported outcome measures for adults with kidney disease: current measures, ongoing initiatives, and future opportunities for incorporation into patient-centered kidney care. *American Journal of Kidney Diseases, 74*(6), 791-802.

Neuen, B. L., Ohkuma, T., Neal, B., Matthews, D. R., de Zeeuw, D., Mahaffey, K. W., Fulcher, G., Blais, J., Li, Q., Jardine, M.J., & Wheeler, D. C. (2021). Relative and absolute risk reductions in cardiovascular and kidney outcomes with canagliflozin across KDIGO risk categories: findings from the CANVAS program. *American Journal of Kidney Diseases, 77*(1), 23-34.

Nicholas, D. B., Picone, G., Vigneux, A., McCormick, K., Mantulak, A., McClure, M., &

MacCulloch, R. (2009). Evaluation of an online peer support network for adolescents with chronic kidney disease. *Journal of Technology in Human Services, 27*(1), 23-33.

Oben, P. (2020). Understanding the patient experience: a conceptual framework. *Journal of Patient Experience, 7*(6), 906-910.

Oh, T. R., Choi, H. S., Kim, C. S., Bae, E. H., Oh, Y. K., Kim, Y. S., Choi, K.H., Kim, S.W., & Ma, S. K. (2019). Association between health-related quality of life and progression of chronic kidney disease. *Scientific Reports, 9*(1), 19595.

O'Hare, A. M., Song, M. K., Kurella Tamura, M., & Moss, A. H. (2017). Research priorities for palliative care for older adults with advanced chronic kidney disease. *Journal of Palliative Medicine, 20*(5), 453-460.

Okoebor, R. (2022). The Challenges of the Healthcare System in Nigeria and the Fight against Coronavirus. *Journal of Medical Library and Information Science, 3*, 1–11. https://doi.org/10.22037/jmlis.v3i.38897

Orozco-Beltrán, D., Arriero-Marin, J. M., Carratalá-Munuera, C., Soler-Cataluña, J. J., Lopez-Pineda, A., Gil-Guillén, V. F., & Quesada, J. A. (2021). Trends in hospital admissions for chronic obstructive pulmonary disease in men and women in Spain, 1998 to 2018. *Journal of Clinical Medicine, 10*(7), 1529.

Orozco-Beltrán, D., Artola, S., Jansà, M., Lopez de la Torre-Casares, M., & Fuster, E. (2018). Impact of hypoglycemic episodes on health-related quality of life of type-2 diabetes mellitus patients: development and validation of a specific QoLHYPO©

questionnaire. *Health and Quality of Life Outcomes, 16*(1), 1-13.

Palmer, R., Dimairo, M., Cooper, C., Enderby, P., Brady, M., Bowen, A., Latimer, N., Julious, S., Cross, E., Alshreef, A., & Chater, T. (2019). Self-managed, computerised speech and language therapy for patients with chronic aphasia post-stroke compared with usual care or attention control (Big CACTUS): a multicentre, single-blinded, randomised controlled trial. *The Lancet Neurology, 18*(9), 821-833.

Palmer, S. C., Stricker, C. T., Panzer, S. L., Arvey, S. A., Baker, K. S., Casillas, J., Ganz, P.A., McCabe, M.S., Nekhlyudov, L., Overholser, L., & Jacobs, L. A. (2015). Outcomes and satisfaction after delivery of a breast cancer survivorship care plan: results of a multicenter trial. *Journal of Oncology Practice, 11*(2), 222-229.

Palonen, M., Kaunonen, M., & Åstedt-Kurki, P. (2016). Family involvement in emergency department discharge education for older people. *Journal of Clinical Nursing, 25*(21-22), 3333-3344.

Patton, M. Q. (2015). Qualitative research & evaluation methods: Integrating theory and practice. Sage Publications.

Plantinga, L. C., Boulware, L. E., Coresh, J., Stevens, L. A., Miller, E. R., Saran, R., Messer, K.L., Levey, A.S., & Powe, N. R. (2008). Patient awareness of chronic kidney disease: trends and predictors. *Archives of Internal Medicine, 168*(20), 2268-2275.

Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., Edgman-Levitan, S., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review, 71*(5), 522-554.

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: a systematic review of the literature. *Medical Care Research and Review, 70*(4), 351-379.

Renaud, M. (2019). *Measuring what matters: the Patient Reported Indicator Surveys*. Organisation for Economic Co-operation and Development.

Rini, I. S., Rahmayani, T., Sari, E. K., & Lestari, R. (2021). Differences in the quality of life of chronic kidney disease patients undergoing hemodialysis and continuous ambulatory peritoneal dialysis. *Journal of Public Health Research, 10*(2), 2209.

Roggeveen, L. F., Guo, T., Driessen, R. H., Fleuren, L. M., Thoral, P., van der Voort, P. H., Girbes, A.R., Bosman, R.J., & Elbers, P. (2020). Right dose, right now: development of autokinetics for real time model informed precision antibiotic dosing decision support at the bedside of critically ill patients. *Frontiers in Pharmacology, 11*, 646.

Romagnani, P., Remuzzi, G., Glassock, R., Levin, A., Jager, K. J., Tonelli, M., Massy, Z., Wanner, C., & Anders, H. J. (2017). Chronic kidney disease. *Nature Reviews Disease Primers, 3*(1), 1-24.

Rubin, H. R., Fink, N. E., Plantinga, L. C., Sadler, J. H., Kliger, A. S., & Powe, N. R. (2004). Patient ratings of dialysis care with peritoneal dialysis vs hemodialysis. *JAMA, 291*(6), 697-703.

Saeed, D., Reza, T., Shahzad, M. W., Mandokhail, A. K., Bakht, D., Qizilbash, F. H., ... & Bokhari, S. F. H. (2023). Navigating the Crossroads: Understanding the Link Between Chronic Kidney Disease and Cardiovascular Health. Cureus, 15(12).

Sanabria-Arenas, M., Marín, J. T., Certuche-Quintana, M. C., & Sánchez-Pedraza, R. (2017). Validation of an instrument for measuring satisfaction of patients undergoing hemodialysis. *BMC Health Services Research, 17*, 1-13.

Schell, J. O., Patel, U. D., Steinhauser, K. E., Ammarell, N., & Tulsky, J. A. (2012). Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *American Journal of Kidney Diseases, 59*(4), 495-503.

Setiawan, H., Suhanda, S., Roslianti, E., & Firmansyah, A. (2020). Theory Development of Genetic Counseling among Patients with Genetic Diseases. *International Journal of Nursing and Health Services (IJNHS), 3*(6), 709-715.

Seymour, D. G., Ball, A. E., Russell, E. M., Primrose, W. R., Garratt, A. M., & Crawford, J. R. (2001). Problems in using health survey questionnaires in older patients with physical disabilities. The reliability and validity of the SF-36 and the effect of cognitive impairment. *Journal of Evaluation in Clinical Prractice, 7*(4), 411-418.

Sheard, L., Peacock, R., Marsh, C., & Lawton, R. (2019). What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a

three-site UK qualitative study. *Health Expectations, 22*(1), 46-53.

Shi, X., Wang, S., Hu, J., Chen, F., Zhang, H., Yang, Y., Li, X., & Ma, Q. (2023). Relationship of frailty with kidney function in adults more than 60-years-old: effect of using different formulas to estimate glomerular filtration rate. *Clinical Interventions in Aging*, 999-1007.

Sibley, M. H., Rohde, L. A., Swanson, J. M., Hechtman, L. T., Molina, B. S., Mitchell, J. T., Arnold, L.E., Caye, A., Kennedy, T.M., Roy, A., & Stehli, A. (2018). Late-onset ADHD reconsidered with comprehensive repeated assessments between ages 10 and 25. *American Journal of Psychiatry, 175*(2), 140-149.

Singelis, T. M. (1994). The measurement of independent and interdependent self-construals. *Personality and Social Psychology Bulletin*, 20(5), 580-591.

Sinnakirouchenan, R., & Holley, J. L. (2011). Peritoneal dialysis versus hemodialysis: risks, benefits, and access issues. *Advances in Chronic Kidney Disease, 18*(6), 428-432.

Sixma, H. J., Kerssens, J. J., Campen, C. V., & Peters, L. (1998). Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. *Health Expectations, 1*(2), 82-95.

Smith, S. N., Lai, Z., Almirall, D., Goodrich, D. E., Abraham, K. M., Nord, K. M., & Kilbourne, A. M. (2018). Implementing effective policy in a national mental health re-engagement program for Veterans. *The Journal of Nervous and Mental Disease, 205*(2), 161.

Smith, S., Almirall D., Prenovost, K., Goodrich, D.E., Abraham, K.M., Liebrecht, C., & Kilbourne, A.M. (2018) Organizational culture and climate as moderators of enhanced outreach for persons with serious mental illness: Results from a cluster-randomized trial of adaptive implementation strategies. *Implementation Science, 13*(1), 93.

Smith, S., Almirall, D., Bauer, M., Liebrecht, C., & Kilbourne, A. (2020). (When) Is More Better? Comparative Effectiveness of External Vs External+ Internal Facilitation on Site-Level Uptake of a Collaborative Care Model in Community-Based Practices That Are Slow to Adopt. *Health Services Research, 55*, 61-62.

Sofaer, S., & Firminger, K. (2005). Patient perceptions of the quality of health services. *Annual Rev. Public Health, 26*, 513-559.

Soratto, J., Pires, D. E. P. D., & Friese, S. (2020). Thematic content analysis using ATLAS. ti software: Potentialities for research in health. *Revista brasileira de enfermagem*, 73.

Staniszewska, S., & Ahmed, L. (1999). The concepts of expectation and satisfaction: do they capture the way patients evaluate their care?. *Journal of Advanced Nursing, 29*(2), 364-372.

Stickdorn, M., & Schneider, J. (2012). *This is service design thinking: Basics, tools, cases*. John Wiley & Sons.

Street, M., Eustace, P., Livingston, P. M., Craike, M. J., Kent, B., & Patterson, D. (2011).

Communication at the bedside to enhance patient care: A survey of nurses' experience and perspective of handover. *International Journal of Nursing Practice, 17*(2), 133-140.

Streiner, D. L., Norman, G. R., & Cairney, J. (2015). Health measurement scales: a practical guide to their development and use. Oxford University Press.

Talbot, B., Athavale, A., Jha, V., & Gallagher, M. (2021). Data challenges in addressing chronic kidney disease in low-and lower-middle-income countries. *Kidney International Reports, 6*(6), 1503-1512.

Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., Bouter, L.M., & de Vet, H. C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology, 60*(1), 34-42.

Terwee, C. B., Mokkink, L. B., Knol, D. L., Ostelo, R. W., Bouter, L. M., & de Vet, H. C. (2012). Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of Life Research, 21*, 651-657.

The Beryl Institute. (2024). Defining Patient and Human Experience. https://theberylinstitute.org/defining-patient-experience/

Tong, A., Manns, B., Wang, A. Y. M., Hemmelgarn, B., Wheeler, D. C., Gill, J., Tugwell, P., Pecoits-Filho, R., Crowe, S., Harris, T., & Van Biesen, W. (2018). Implementing core outcomes in kidney disease: report of the Standardized Outcomes in

Nephrology (SONG) implementation workshop. *Kidney International, 94*(6), 1053-1068.

Trebble, T. M., & Hydes, T. (2011). Redesigning services around patients and their doctors: the continuing relevance of lean thinking transformation. *Clinical Medicine, 11*(4), 308.

Trebble, T. M., Hansi, N., Hydes, T., Smith, M. A., & Baker, M. (2010). Process mapping the patient journey: an introduction. *BMJ*, 341.

Trudel-Fitzgerald, C., Millstein, R. A., Von Hippel, C., Howe, C. J., Tomasso, L. P., Wagner, G. R., & VanderWeele, T. J. (2019). Psychological well-being as part of the public health debate? Insight into dimensions, interventions, and policy. *BMC Public Health, 19*(1), 1-11.

Tsianakas, V., Maben, J., Wiseman, T., Robert, G., Richardson, A., Madden, P., Griffin, M., & Davies, E. A. (2012). Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both?. BMC Health Services Research, 12, 1-11.

Tunçalp, Ö., Were, W. M., MacLennan, C., Oladapo, O. T., Gülmezoglu, A. M., Bahl, R., Daelmans, B., Mathai, M., Say, L., Kristensen, F., Temmerman, M., & Bustreo, F. (2015). Quality of care for pregnant women and newborns-the WHO vision. BJOG : an international journal of obstetrics and gynaecology, 122(8), 1045–1049. https://doi.org/10.1111/1471-0528.13451

Turner, J. M., Bauer, C., Abramowitz, M. K., Melamed, M. L., & Hostetter, T. H. (2012).

Treatment of chronic kidney disease. *Kidney International, 81*(4), 351-362.

Tuttle, K. R., Alicic, R. Z., Duru, O. K., Jones, C. R., Daratha, K. B., Nicholas, S. B., McPherson, S.M., Neumiller, J.J., Bell, D.S., Mangione, C.M., & Norris, K. C. (2019). Clinical characteristics of and risk factors for chronic kidney disease among adults and children: an analysis of the CURE-CKD registry. *JAMA Network Open, 2*(12), e1918169.

Valentine, N., Darby, C., & Bonsel, G. J. (2008). Which aspects of non-clinical quality of care are most important? Results from WHO's general population surveys of "health systems responsiveness" in 41 countries. Social science & medicine (1982), 66(9), 1939–1950. https://doi.org/10.1016/j.socscimed.2007.12.002

Vander Veer, S. N., Jager, K. J., Visserman, E., Beekman, R. J., Boeschoten, E. W., de Keizer, N. F., Heuveling, L., Stronks, K., & Arah, O. A. (2012). Development and validation of the Consumer Quality index instrument to measure the experience and priority of chronic dialysis patients. *Nephrology Dialysis Transplantation, 27*(8), 3284-3291.

Van der Willik, E. M., Meuleman, Y., Prantl, K., van Rijn, G., Bos, W. J. W., van Ittersum, F. J., Bart, H.A., Hemmelder, M.H., & Dekker, F. W. (2019). Patient-reported outcome measures: selection of a valid questionnaire for routine symptom assessment in patients with advanced chronic kidney disease–a four-phase mixed methods study. *BMC Nephrology, 20*, 1-11.

Vassilev, I., Rogers, A., Kennedy, A., & Koetsenruijter, J. (2014). The influence of social

networks on self-management support: a metasynthesis. *BMC Public Health, 14*(1), 1-12.

Wacker, M. E., Jörres, R. A., Karch, A., Wilke, S., Heinrich, J., Karrasch, S., Koch, A., Schulz, H., Watz, H., Leidl, R., & Vogelmeier, C. (2016). Assessing health-related quality of life in COPD: comparing generic and disease-specific instruments with focus on comorbidities. *BMC Pulmonary Medicine, 16*, 1-11.

Wang, T., & Voss, J. G. (2022). Information overload in patient education: A Wilsonian concept analysis. *Nursing Science Quarterly, 35*(3), 341-349.

Wasserfallen, J. B., Moinat, M., Halabi, G., Saudan, P., Perneger, T., Feldman, H. I., Martin, P.Y., & Wauters, J. P. (2006). Satisfaction of patients on chronic haemodialysis and peritoneal dialysis. *Swiss Medical Weekly, 136*(13-14), 210-217.

Weidmer, B. A., Cleary, P. D., Keller, S., Evensen, C., Hurtado, M. P., Kosiak, B., Gallagher, P.M., Levine, R. & Hays, R. D. (2014). Development and evaluation of the CAHPS (Consumer Assessment of Healthcare Providers and Systems) survey for in-center hemodialysis patients. *American Journal of Kidney Diseases, 64*(5), 753-760.

Weldring, T., & Smith, S. M. (2013). Article commentary: patient-reported outcomes (pros) and patient-reported outcome measures (PROMs). *Health Services Insights, 6*, HSI-S11093.

Whitehead, L., Jacob, E., Towell, A., Abu-qamar, M. E., & Cole-Heath, A. (2018). The role

of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *Journal of Clinical Nursing, 27*(1-2), 22-30.

Wisniewski, S. R., Belle, S. H., Coon, D. W., Marcus, S. M., Ory, M. G., Burgio, L. D., Burns, R., & Schulz, R. (2003). The Resources for Enhancing Alzheimer's Caregiver Health (REACH): project design and baseline characteristics. *Psychology and Aging, 18*(3), 375.

Wolf, J. A. (2015). The state of patient experience. *Patient Experience Journal, 2*(2), 1-3.

Wolf, J. A., Niederhauser, V., Marshburn, D., & LaVela, S. L. (2021). Reexamining "Defining Patient Experience": the human experience in healthcare. *Patient Experience Journal, 8*(1), 16-29.

Wolf, J. A., Niederhauser, V., Marshburn, D., & LaVela, SL. (2014). Defining patient experience. *Patient Experience Journal., 1*(1), 7-19.

World Health Organization. (2018). *Technical Series On Primary Health Care*.

World Health Organization. (2004, January 28). Patient safety. Retrieved June 20, 2023, from https://www.who.int/news-room/fact-sheets/detail/patient-safety

Wright, J. A., Wallston, K. A., Elasy, T. A., Ikizler, T. A., & Cavanaugh, K. L. (2011). Development and results of a kidney disease knowledge survey given to patients with CKD. *American Journal of Kidney Diseases, 57*(3), 387-395.

Yanes, A. F., McElroy, L. M., Abecassis, Z. A., Holl, J., Woods, D., & Ladner, D. P. (2015). Observation for assessment of clinician performance: a narrative review. *BMJ Quality & Safety, 25*(1), 46-55. https://doi.org/10.1136/bmjqs-2015-004171

Yaqoob, A. (2023). Variants of Integration in Mixed Methods Research-An Evolutionary

Approach. *Biomedical Journal of Scientific & Technical Research, 51*(1), 42233-42243.

Zee, J., Hodgin, J. B., Mariani, L. H., Gaut, J. P., Palmer, M. B., Bagnasco, S. M., Rosenberg, A.Z., Hewitt, S.M., Holzman, L.B., Gillespie, B.W., & Barisoni, L. (2018). Reproducibility and feasibility of strategies for morphologic assessment of renal biopsies using the nephrotic syndrome study network digital pathology scoring system. *Archives of Pathology & Laboratory Medicine, 142*(5), 613-625.

Zoccali, C., Kramer, A., & Jager, K. J. (2010). Chronic kidney disease and end-stage renal disease—a review produced to contribute to the report 'the status of health in the European union: towards a healthier Europe'. *NDT Plus, 3*(3), 213-224.

Zolnierek, K. B. H., & DiMatteo, M. R. (2009). Physician communication and patient adherence to treatment: a meta-analysis. *Medical Care, 47*(8), 826.

Zomerdijk, L. G., & Voss, C. A. (2010). Service design for experience-centric services. *Journal of Service Research, 13*(1), 67-82.