



SUPPORTING LIFE PARTICIPATION: an ethnographic study of a nephrology center

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1. ABSTRACT(English)

Background:

Lost in the discourse of biomedical treatment of Chronic Kidney Disease (CKD) is the fact that it also threatens a patient's life strength, decreasing life participation. Treatment, including Kidney Replacement Therapy KRT, confines patients. Nephrologists focus on symptom severity and comorbidities, such as frailty and disability, to balance treatment and life participation. Integration of life participation in CKD care remains limited.

Objective:

This research aims to examine how integrating life participation into nephrology care can improve the quality of life and health outcomes for patients with Chronic Kidney Disease (CKD) through an ethnographical lens.

Method

Data was collected through four validated questionnaires (the Impact on Participation and Autonomy, the SONG-Life Participation, the SONG-HD Fatigue, and the EQ5D5L), semi-structured interviews, and observations. The semi-structured interview format was chosen for its flexibility, allowing for the exploration of predetermined questions while providing the opportunity to probe deeper into participants' responses.

Results:

Nine patients, two relevant others, and five health care workers were included. Findings from the study revealed that incorporating non-medical aspects into CKD care, such as social services and wellness programs, is essential. Results from the interviews revealed a significant gap in the availability of psychological and social support for CKD patients. Insufficient resources and a lack of specialized staff, such as psychologists, social workers, and dietitians, limit the ability to provide comprehensive care that addresses both medical and non-medical needs.

Conclusion:

The thematic analysis of the study revealed that integrating life participation into nephrology care is essential for improving health outcomes and quality of life for CKD patients.

Keywords: Chronic Kidney disease, life participation, nephrology, ethnographic study

2. ABSTRACT(Dutch)

Achtergrond:

Chronische nierziekte (CKD) vereist niet alleen biomedische behandeling maar beïnvloedt ook de vitaliteit van patiënten, waardoor hun deelname aan het leven vermindert. Behandeling, inclusief nierfunctie vervangende therapie, beperkt patiënten. Nefrologen streven naar een evenwicht tussen de ernst van symptomen, comorbiditeiten zoals kwetsbaarheid en invaliditeit, en deelname aan het leven, maar de integratie van levensparticipatie in de CKD-zorg blijft beperkt

Doelstelling:

Dit onderzoek beoogt te onderzoeken hoe de integratie van levensparticipatie in nefrologische zorg de kwaliteit van leven en gezondheidsuitkomsten voor CKD-patiënten kan verbeteren, gebruikmakend van een etnografische benadering.

Methode:

Data werden verzameld via vier gevalideerde vragenlijsten (Impact op Participatie en Autonomie, SONG-Life participatie, SONG-HD Fatigue, en EQ5D5L), semi-gestructureerde interviews en observaties. De flexibele aard van semi-gestructureerde interviews stond toe om dieper in te gaan op de antwoorden van de deelnemers.

Resultaten:

De studie omvatte negen patiënten, twee andere belanghebbenden en vijf zorgverleners. De bevindingen benadrukken de noodzaak om niet-medische aspecten zoals sociale diensten en welzijnsprogramma's op te nemen in de zorg voor chronische nierpatiënten. Interviews onthulden aanzienlijke kooft in psychologische en sociale ondersteuning voor patiënten, met beperkte middelen en een gebrek aan gespecialiseerd personeel zoals psychologen, maatschappelijk werkers en diëtisten, wat de mogelijkheid beperkt om uitgebreide zorg te bieden die zowel medische als niet-medische behoeften aanpakt.

Conclusie:

Thematische analyse toonde aan dat het integreren van levensparticipatie in de nefrologische zorg essentieel is voor het verbeteren van gezondheidsuitkomsten en de kwaliteit van leven voor chronische nierpatiënten.

Trefwoorden: Chronische nierziekte, levensparticipatie, nefrologie, etnografische onderzoek

3. SUMMARY

This study delves into the idea of life engagement within the realm of nephrology treatment, particularly focusing on individuals dealing with Chronic Kidney Disease (CKD) in Belgium. Through the use of an ethnographic method, the research aims to gain insight into the first hand experiences of these patients and how incorporating life participation can enhance their overall well-being and medical results.

The study commences by conducting a thorough examination of previous literature surrounding life engagement, chronic kidney disease (CKD), and the application of ethnography in medical research. This establishes a theoretical foundation for comprehending the intricate relationship among these elements and lays the groundwork for the practical investigation.

The study entails conducting thorough interviews and observations at a nephrology center in Belgium, emphasizing the empirical aspect. By approaching the research from an ethnographic perspective, the study brings to light the various hurdles CKD patients encounter on a daily basis and how their illness hinders their engagement in daily activities.

The results indicate that the importance of life participation for the well-being of patients is frequently neglected in traditional nephrology treatment. By prioritizing life participation, healthcare professionals can cater to the comprehensive needs of individuals with CKD, ultimately enhancing both their quality of life and health results.

The study ends by examining the implications of these discoveries on nephrology care and suggesting ways to incorporate life participation into caregiving procedures. It also emphasizes the possibility of additional research in this field, especially in relation to other long-term illnesses.

This thesis adds to the expanding knowledge of life participation and Chronic Kidney Disease, highlighting the importance of using an ethnographic approach in healthcare studies. It promotes the idea of reorienting nephrology care towards a patient-centered approach that emphasizes life participation as a crucial aspect of patient well-being. This change could have a significant impact on the quality of life for CKD patients, allowing them to experience more fulfilling lives despite their illness.

4. INTRODUCTION

The number of people with Chronic Kidney Disease (CKD) is still rising worldwide, and appropriate care for this growing number of people is crucial. In the past, healthcare professionals often used medical outcome as a primary treatment objective, but there is growing recognition of a need to use the basis of person-centred care with life participation as a core treatment objective. (Francis et al.2024)

According to Kerklaan et al. (2020), Life participation is an individual and meaningful engagement for the person to live with self-respect and to be an inclusive part of one's community. Life participation may vary from meaning, such as education, employment, social activities, and sport. By using life participation as a core treatment objective in CKD, multidimensional support can be delivered to help patients live better with CKD from the time of diagnosis. Therefore, identifying support that helps people with CKD maintain life participation is crucial. In person-centred care, this support must be identified by the individual person with CKD, as well as the individual care provider.

Nephrology healthcare is an excellent example of healthcare in which life participation should go beyond prevention and treatment of kidney functions towards achieving a higher quality of life by also enabling nephropathy patients to better participate in their social activities (Moreels et al.2023).

Arguably, there is a growing recognition of the importance of patient engagement and taking patient priorities and patient-centric healthcare into account in the policy. There is a need to attribute more weight to patient priorities when considering the costs and benefits of health care, individuals weighing life participation and qualitative features of life. In this approach, paradoxically, less imminently life-threatening chronic conditions, for which qualitative life-participation is the most important aspect of the health impact, are most likely to be prioritised compared with more acutely life-threatening conditions, such as over-dialyzed instead of under-dialyzed chronic conditions.

In 2019, the paper "Living Well with Kidney Disease by Patient and Care-Partner Empowerment: Kidney Health for Everyone Everywhere" researched the experience of living with chronic kidney disease (CKD) which prioritized life participation and maintaining social roles (Kalantar-Zadeh et al., 2021). Their findings also proposed that life participation in the form of meaningful activities has been shown to be the most important contributor to health-

related quality of life in CKD. A study conducted by Deb et al., (2020) also included quality of life in the structure of healthcare and support the growing recognition of the need to identify and address patient priorities, values and goals. Therefore, research and policies regarding kidney health and management of a chronic condition should take into account the ability of patients to lead a life they find meaningful despite illness.

It can be argued that the current state of care in nephrology centres often overlook the importance of life participation, focusing predominantly on the physiological management of CKD. This oversight according to Tong et al.,(2019) can lead to a diminished quality of life for patients, as their identities, roles, and social engagements suffer. By employing a qualitative research method, including semi-structured interviews and observations, this study aims to delve deep into the experiences of patients, their families, and healthcare providers. The goal is to uncover the barriers that prevent effective support for life participation and identify potential pathways to integrate this crucial aspect into the care process.

The main objective of this study is to examine how integrating life participation into nephrology care can improve the quality of life and health outcomes for patients with Chronic Kidney Disease (CKD) and is driven by the hypothesis that enhancing life participation for CKD patients can lead to better overall health outcomes and quality of life. It seeks to provide a comprehensive understanding of the current practices in nephrology centers regarding life participation, highlighting the gaps and opportunities for improvement. By focusing on the perspectives of a diverse group of participants, this research aspires to offer actionable insights that could lead to a more holistic approach to CKD care: one that identifies and supports the full spectrum of patients' lives beyond their condition.

The significance of this research lies not only in its potential to influence clinical practices and policies but also in its contribution to the broader discourse on patient-centred care. It challenges the medical community to reconsider the metrics of success in treating chronic illnesses and to recognize the value of supporting patients in leading rich, fulfilling lives. This study stands as a call to action, advocating for a shift in the nephrology care paradigm towards a more inclusive, life-participation-oriented approach.

By addressing this gap, this thesis aims to pave the way for a new standard in CKD care, where life participation is not an afterthought but a fundamental component of patient well-being. This work has the potential to not only enrich the lives of those living with CKD but also to inspire a more compassionate and comprehensive approach to healthcare across chronic conditions.

5. THEORETICAL FRAMEWORK

The framework presented in this research combines the Biopsychosocial Model of health with the social constructionism theory to examine how integrating life participation into nephrology care can improve the quality of life and health outcomes for patients with Chronic Kidney Disease (CKD) through an ethnographical lens. The Model offers a comprehensive perspective on health by taking into account biological (physical), psychological (mental), and social aspects (lifestyle), while social constructionism theory underscores the interaction between individuals, and social frameworks in healthcare environments.

5.1 Ethnographic Approach

The research approach called ethnography is a highly valuable and insightful technique for comprehensively understanding the intricate and diverse nature of human behaviour in a wide array of social environments (Liu et al., 2023). By thoroughly studying and observing the day-to-day activities, interactions, and experiences of various individuals, such as CKD patients, healthcare workers, and other relevant stakeholders, can gain profound insight into their unique perspectives, specific needs, and formidable challenges that they encounter. (Frandsen et al.2022)

Ethnography offers a remarkable opportunity to delve deep into the intricacies and nuances of these social contexts, unravelling complex relationships and unveiling common patterns that may often remain concealed within conventional theoretical frameworks (Lai, 2024). Through the discerning lens of ethnographic research, we are empowered to broaden our perspectives and enrich our understanding of the multifaceted complexities of human behaviour and the tapestry of social interactions.

(Refer to Appendix 12.1 for further details)

5.2 Conceptual Model

The conceptual model for this study demonstrates the intricate relationship between patient involvement, delivering tailored care for chronic kidney disease, and the ultimate results observed in patients manoeuvring through the healthcare system.



6. LITERATURE REVIEW

Embarking on a nuanced exploration of the landscape of nephrology care reveals a complex interplay between the clinical management of Chronic Kidney Disease (CKD) and the broader implications of such care on patients' quality of life, particularly concerning their ability to participate in life's meaningful activities. This literature review delves into three pivotal areas: the current state of nephrology care, the significance of life participation in chronic illness management, and the conspicuous gap in the literature regarding the integration of life participation into nephrology care.

(Refer to Appendix 12.2 for further details)

6.1 Current State of Nephrology Care

Nephrology is the multidisciplinary medical specialty involved in the diagnosis and treatment of diseases and disorders of the kidney. Given the burden of chronic kidney disease (CKD) and the complexity of its management in advanced stages, the nephrologist plays a determinant role throughout primary or secondary prevention, assessment, eminently medical treatment, haemodialysis, peritoneal dialysis, preparation and monitoring of patients on the waiting list for kidney transplantation, management of patients after kidney and/or pancreas transplantation, as well as end of life care. (Hervé et al. 2023)

In Belgium, just as in the Netherlands and other places in Europe, healthcare is accessible and of high quality in general (Van Ballegooijen et al., 2021) which includes nephrological services. The provision of care for patients with chronic kidney disease is structured regionally, with the process commencing from the identification of high-risk groups and extending to the placement and subsequent monitoring of Renal Replacement Therapy (RRT). The Electronic Patient Record (EPR) - the unique reference number that provides an overview of all the healthcare a patient has received or is still receiving - forms an important basis for this patient-centred approach.

According to a study conducted by Garcia Sierra in 2023, technologies in nephrology centres such as the use of telemedicine and remote monitoring of patients have made the treatment of patients suffering from chronic kidney disease (CKD) both very effective and able to support an excellent quality of life, and, in some instances, allowing -to a lesser degree- recovery of kidney functionality and -a higher degree- the consequent limitations on ordinary activities in the United States. Additionally, the current RRT technologies enable patients to begin some

form of haemodialysis, which can be accompanied by 14-42 hours a week in-centre or at home.

It can be argued that in recent times, there has been a growing recognition of the importance of patient engagement and taking patient priorities and patient-centric healthcare into account in the provision of nephrological services to patients living with CKD (Vat et al.2020). There is a need to attribute more weight to patient priorities when considering the costs, goals, preferences and benefits of health care, individuals weighing life participation and qualitative features of life.

The realm of nephrology has witnessed significant advancements over the years, with a concentrated focus on mitigating the progression of CKD and managing its myriad complications. Levin et al., (2017) provide a comprehensive overview of the strides made in understanding the pathophysiology of CKD and the subsequent improvements in treatment modalities. Their research underscores a pivotal shift towards more nuanced care strategies aimed at not just prolonging life but enhancing its quality. Despite these advancements, Levin and colleagues argue that there remain substantial challenges in translating clinical progress into tangible improvements in patients' quality of life. They advocate for a more holistic approach to care that transcends traditional clinical outcomes, emphasizing the need to consider patients' life experiences and overall well-being as integral components of care.

The call for a broader approach to nephrology care resonates with the growing acknowledgement within the medical community of the limitations inherent in a purely clinical focus. The traditional metrics of success in CKD management, while crucial, fall short of addressing the comprehensive needs of patients, particularly as they navigate the complexities of life with a chronic condition. The dissonance between clinical advancements and the lived experiences of patients highlights a critical area of concern: the need for care models that prioritize and support the full spectrum of patient well-being, including emotional, social, and psychological health.

6.2 Concept of Life Participation In Chronic Illness

Chronic kidney disease (CKD) is a progressive and irreversible pathophysiological state of the kidneys which can lead to End-Stage Renal Disease (ESRD) (De Jong et al., 2021). It is characterised by a myriad of distressful symptoms (Andersen-Hollekim et al., 2021). The challenges and consequences of CKD shapes all aspects of their daily life (Lu & Chai, 2022). Therefore, the life participation approach of helping these patients becomes necessary to enable them gain and sustain a feeling of normality and control over their lives.

According to De Paula, Juehling, & Uebernickel, (2024), it is imperative for individuals to be involved in their routine life roles and common activities to their satisfactory level, irrespective of any disabilities or health conditions. Årestedt et al. (2019) explained in their study that for those experiencing life transition in terms of CKD, existence of this transition would be successful when the person can remain the sensation of belonging to a vital aspect of his life, feel successful, and attain sense of legitimacy and reputation. Supporting life participation has an existence of transitions either in the context of life course or health conditions. The involvedness of such life transitions needs broad based and sensitive support and that there exist web of support and care that can be activated to prop up life participation.

Theoretical perspectives on the concept of life participation place heavy emphasis on the societal norms and values that influence how individuals participate in the communities in which they live, and society at large (Turuwhenua et al., 2024). Capabilities, opportunities, and choices regarding life participation are significantly influenced by broader social, political, and structural factors, such as physical environment, laws, customs, beliefs, and economic conditions.

Participation means sharing in the resources of community social life and contributing accordingly to its social and economic reproduction. The aim is to enable people increasingly to participate in...belong to...their community". Authors - Michael Young and Peter Willmott (Cymorr Kirby Martinez, 2019). Participation in events that are important to the individual, such as family gatherings, athletic events, and social events with friends, contribute meaning to life, foster friendships and relationships, and provides opportunity to represent one's self to others in an effective fashion.

Beck et al. (2019) posited that, effective self-management from a life participation perspective goes beyond better health outcomes. Effective self-management can contribute not only to long-term health of an individual, better quality of life and patient satisfaction but contributes to better outcomes of population health and long-term sustainability of healthcare systems by reducing the burden on the health care system of ambulance, emergency departments and inpatient encounters. The broader understanding of the supporting life participation could be seen in the kind of interventions that can be mapped in a broader concept of ecosystem which could be anything that adds to the health and wellbeing.

The concept of life participation has emerged as a vital outcome measure in chronic illness management, reflecting a paradigm shift towards more patient-centered care models. Vellone

et al. (2020) contribute to this discourse through their investigation of the relationship between engagement in meaningful activities and health outcomes in patients with chronic diseases. Their study finds a positive correlation between active life participation and enhanced mental and physical health status, reinforcing the notion that engagement in meaningful activities extends beyond mere leisure, serving as a critical component of overall health and well-being.

When looking specifically at people with ESKD, the existing evidence shows a significant positive correlation between life participation and a multitude of outcomes. Being able to participate in meaningful activities not only increases their quality of life, but it also reduces the risk of all-cause mortality (HR=11.94; 95%CI 2.86-49.92), lowers the risk of graft loss (HR=2.29; 95%CI 1.51-3.5), improves functional capacities (HR=2.37; 95%CI 1.92-2.94), enhances treatment adherence (HR=2.02; 95%CI 1.45-2.80) and decreases the risk of hospitalization (HR=1.28; 95%CI 1.14-1.44) (Prihodova et al., 2015, Jassal et al., 2016). For older adults (65+) - of which the majority of ESKD patients are a part of - participating in social and productive activities, even when they involve little or no physical exertion, lowers the risk of all-cause mortality as much as fitness activities do (Glass et al., 1999).

This body of research illuminates the profound impact of life participation on individuals with chronic conditions generally, and ESKD specifically, suggesting that the benefits of such engagement transcend physical health improvements to include mental well-being and social integration. The findings of Vellone and colleagues underscore the importance of adopting care strategies that facilitate life participation, thereby addressing the holistic needs of patients. The emphasis on life participation signals a growing recognition of the need to consider patients as whole individuals, with needs and aspirations that extend beyond the clinical manifestations of their conditions.

Through the work of the Standardized Outcomes in Nephrology Initiative (SONG), which involved the active participation of over 9000 patients, caregivers, and clinicians, it was found that the ability to participate in meaningful activities of daily life and life roles (i.e. life participation) is a critical core outcome in the ESKD population, carrying the highest priority for patients and their caregivers (Urquhart-Secord et al., 2016, Manera et al., 2020, Kalantar-Zadeh et al., 2021). Moreover, all stakeholders, including health professionals, caregivers, and patients, consider life participation as the most fundamental goal of treatment. As noted by the patient voices: "Dialysis is a treatment which keeps us alive to live a life, not just to wait for death." (Kalantar-Zadeh et al., 2021)

6.3 Gap in Literature

Despite the increasing recognition of the importance of life participation in chronic illness management, a notable gap persists in the literature regarding the integration of this concept into nephrology care practices (Ju et al., 2019, Ju et al., 2019, Ju et al., 2020). Kimmel et al. (2019) delve into the psychosocial challenges encountered by individuals with CKD, shedding light on the significant impact of the disease on patients' social lives, mental health, and capacity to engage in meaningful activities. Their research calls attention to the inadequacies of current care models in addressing these broader aspects of patient well-being, advocating for a more integrated approach to care that encompasses the multifaceted needs of CKD patients.

The work by SONG, which was founded with the aim of identifying core outcomes to improve for patients with CKD/ESKD, found that regardless of the type of kidney disease or treatment stage, patients expressed a desire to live well, maintain their roles and social functioning, preserve some semblance of normality, and have a sense of control over their health and well-being. Yet, despite this knowledge, there is currently a lack of research on how to practically support life participation (Kalantar-Zadeh et al., 2021).

The work of Kimmel and colleagues highlights the lacuna in nephrology care practices concerning the support of life participation. This gap in the literature not only underscores the need for comprehensive care models that holistically address patient well-being but also points to the potential benefits of such models for improving patients' quality of life. The lack of research focused on integrating life participation into nephrology care suggests a critical area for future investigation, with significant implications for the development of more effective and patient-centered care strategies.

7. METHODOLOGY

This section outlines the methodology adopted in this study, including the research design, participant recruitment strategy, data collection methods, and ethical considerations. The chosen methodology is designed to explore the nuanced perspectives of patients, families, and healthcare providers regarding the integration of life participation into nephrology care.

7.1 Research Design

The research employs an ethnographic and qualitative approach, considered apt for delving into the complex and personal experiences of individuals living with Chronic Kidney Disease (CKD) and those involved in their care. Ethnography, with its roots in cultural anthropology, is suitable for investigating the cultures and practices within nephrology centers, allowing for a deep understanding of the lived experiences of patients and the operational dynamics of healthcare providers. This qualitative method facilitates the exploration of how life participation is valued, hindered, or supported within these settings, capturing the subjective realities of different stakeholders (Hammersley, & Atkinson, 2019).

7.2 Participant Recruitment

Participants were recruited using a critical case sampling approach by sampling participants across age groups, activity levels, social support, and whom would be willing to participate in an in-depth interview about life participation. Participants were recruited from three hospitals: Ghent University Hospital (UZ Gent), General Hospital St. Lucas Ghent (AZ ST. LUCAS GENT), and General City Hospital Campus AALST (A.S.Z Aalst), ensuring a diverse representation by including an academic, urban and rural center. The sampling strategy aimed to reflect the varied journeys of the participants within their illness trajectory, and more specifically within the nephrology centre, encompassing a broad spectrum of CKD patients alongside healthcare workers. Participants were recruited by their nephrologist, the head-nurse, or the researcher as their delegate.

7.3 Setting

The study was conducted in the East-Flanders region of Belgium within Ghent University Hospital (UZ Gent), General Hospital St. Lucas Ghent (AZ ST. LUCAS GENT), and General City Hospital Campus AALST (A.S.Z Aalst) all having dialysis centres. These hospitals were purposefully chosen to represent diversity in the experiences of all selected participants. The interviews were conducted during the dialysis session, in a separate room in the hospital, or in the home/social environment of the participant, as per their preference.

7.4 Data Collection

Data was collected through validated questionnaires, semi-structured interviews, and observations. The semi-structured interview format was chosen for its flexibility, allowing for the exploration of predetermined questions while providing the opportunity to probe deeper into participants' responses.

Four questionnaires were utilized: the Impact on Participation and Autonomy (IPA) (Cardol et al., 1999), a validated and widely used scale to measure impact on life participation across nine life domains: mobility, self-care, activities in and around the home, financial aspects, leisure activities, social participation and relationships, helping others, (volunteering) work, and school and education; the SONG life participation core outcome measure (Jaure et al., 2024) which asks about life participation across four domains: leisure activities, family activities, housework and employment, and social activities; the SONG-HD-fatigue instrument (Ju et al., 2020) which inquires about fatigue by asking about the level of tiredness, energy, and its impact on usual activities; and the EQ-5D-5L ("EuroQol - a New Facility for the Measurement of Health-related Quality of Life," 2009), a widely used quality of life scale. Each questionnaire was selected for their relevance in assessing aspects of life participation and quality of life among CKD patients.

The data from the questionnaires guided the following (short) interview guide to further inquire the participants about how they experienced the (potential lack of) support regarding life participation in their healthcare trajectory and which additional support they needed. Questions to inform a SWOT (strength-weaknesses-opportunities-threats) analysis about life participation support rounded out the interview. Observations at the nephrology centers focused on the interaction between patients and healthcare providers, the integration of life participation discussions into care practices, and the overall environment's supportiveness towards life participation.

Questionnaires were not conducted with the healthcare professional participants, however their experience with life participation support was collected using (short) semi-structured interviews, including questions to further inform the SWOT-analysis.

7.5 Data Analysis

Data from the questionnaires were assessed, analyzed, and reported, using descriptive statistics. Data from the interviews and observations were analyzed using the inductive thematic analysis guidelines of Braun and Clarke (2006) using the six steps of: (1) familiarization with the data, (2) generating initial codes, (3) searching for themes and gathering

data relevant to each potential theme, (4) reviewing themes and generating a thematic map of the analysis, (5) defining and naming each theme, and (6) producing the report. The consolidated criteria for reporting qualitative research guidelines were used as a guideline (Tong, Sainsbury, & Craig, 2007).

7.6 Ethical Considerations

Ethical approval for the study was sought and granted by the Ethical Committee of the University of Ghent, followed by approvals from the respective hospitals (BC-11716). The study was carried out in accordance with the principles outlined in the Declaration of Helsinki. All participants were provided with an informed consent form, detailed in the Dutch language, outlining the study's purpose, what participation involved, and confidentiality measures. Participants were assured of their right to withdraw from the study at any point without any consequence to their care. The study adhered to strict confidentiality protocols, ensuring that all participant information was anonymized and securely stored, accessible only to the research team.

This methodological approach, grounded in ethnographic and qualitative research traditions, is poised to yield insightful findings into the integration of life participation in nephrology care, addressing a significant gap in the existing literature and contributing to the development of more holistic care models for individuals with CKD.

8. RESULTS

These results present a descriptive and qualitative analysis of interviews conducted with chronic kidney disease (CKD) patients, their relations, health workers (a doctor and three nurses) and a social worker focusing on the impact of integrating life participation into nephrology care. The primary hypothesis is that such integration will lead to improved health outcomes and enhanced quality of life for CKD patients. The secondary hypotheses are that programs focused on life participation may reduce the frequency of hospitalizations and that increased patient engagement in life participation initiatives correlates with higher patient satisfaction and better self-reported health status.

In total, the study included nine patients (44% female), two relevant others (50% female), and five healthcare professionals (three nurses, one nephrologist, one social worker; 100% female). Three participants (one patient, one church member and one family member) were linked to UZ Gent, seven participants (a mix of four patients, two nurses and a social worker) to AZ St. Lucas Gent and lastly six participants (four patients, one doctor and a nurse) to A.S.Z Aalst. The average age of the patients was 56 years old (36-80). Seven patients were receiving in-center haemodialysis, one patient was receiving peritoneal dialysis, and one patient was in the pre-dialysis phase.

8.1 Demographics

Table 1 The Demographics of CKD Patients Interviewed for the Study

Participants	Sex	Age	Location (Nephrology Centre)	Treatment Type	SONG - HD FATIGUE SCORE ($\bar{X}$)	SONG LIFE PARTICIPATION SCORE ($\bar{X}$)
Participant One	Female	40	UZ GENT	Haemodialysis	2.33	3.5
Participant Two	Male	57	AZ SINT- LUCAS	Haemodialysis	3	2
Participant Three	Female	80	AZ SINT- LUCAS	Haemodialysis	2.67	4
Participant Four	Female	78	AZ SINT- LUCAS	Haemodialysis	2.67	2
Participant Five	Male	62	AZ SINT- LUCAS	Haemodialysis	1	4

Participant Six	Female	38	A.S.Z.AALST	Peritoneal dialysis	3	3.25
Participant Seven	Male	36	A.S.Z.AALST	Haemodialysis	1.67	1.25
Participant Eight	Male	62	A.S.Z.AALST	Haemodialysis	1	4.24
Participant Nine	Male	49	A.S.Z.AALST	Pre-dialysis	1.33	4

8.2 Findings

8.2.1 Descriptive Finding

Below, the descriptive results of the questionnaires are briefly explained, with an overview of the scores provided in the accompanying tables.

8.2.1.1 IPA (Impact on Participation and Autonomy)

The IPA scoring uses an ordinal scale from 0 to 4 (0=very good, 1=good, 2=fair, 3=poor, 4=very poor) for each question within a domain, and 0 to 2 (0=no problems, 1= minor problems, 2= major problems) for the problems experienced within that particular domain. In table 2 the results are presented, higher values mean worse abilities, and larger problems are experienced within that domain.

Table 2 Descriptive Statistics of IPA

	N	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
My chances of getting around in my house where I want to are	9	0	2	.89	.928	.263	.717	-2.018	1.400
My chances of getting around in my house when I want to are	9	0	4	1.22	1.394	1.276	.717	.829	1.400
My chances of visiting relatives and friends when I want to are	9	0	4	1.78	1.394	.146	.717	-1.060	1.400

My chances of going on the sort of trips and holidays I want to are	9	1	4	2.78	1.394	-.565	.717	-1.816	1.400
if your health or your disability affect your chances of getting around where and when you want, to what extent does this cause you problems?	9	0	2	.78	.667	.254	.717	-.040	1.400
My chances of getting washed and dressed the way I wish are	9	0	4	1.33	1.414	.947	.717	-.018	1.400
My chances of getting washed and dressed when I want to are	9	0	4	1.00	1.225	2.100	.717	5.429	1.400
My chances of getting up and going to bed when I want to are	9	0	4	1.22	1.394	1.276	.717	.829	1.400
My chances of going to the toilet when I wish and need to are	9	0	4	1.00	1.323	1.666	.717	2.950	1.400
My chances of eating and drinking when I want to are	9	0	4	1.89	1.269	.260	.717	-.700	1.400
If your health or your disability affect yourself care, to what extent does this cause you problems?	9	0	2	1.11	.601	.018	.717	1.126	1.400

My chances of contributing to looking after my home the way I want to are	9	1	3	2.00	.866	.000	.717	-1.714	1.400
My chances of getting light tasks done around the house (e.g. making tea or coffee), either by myself or by others, the way I want them done are	9	0	2	1.00	.500	.000	.717	4.000	1.400
My chances of getting heavy tasks done around the house (e.g. cleaning), either by myself or by others, the way I want them done are	9	0	4	2.33	1.581	-.217	.717	-1.886	1.400
My chances of getting housework done, either by myself or by others, when I want them done are	9	0	4	1.67	1.225	.816	.717	.349	1.400
My chances of getting minor repairs and maintenance work done in my house and garden, either by myself or by others, the way I want them done are	9	1	4	2.44	1.130	.176	.717	-1.171	1.400

My chances of fulfilling my role at home as I would like are	8	1	4	2.00	1.195	.669	.752	-1.204	1.481
If your health or your disability affect your activities in and around your home, to what extent does this cause you problems?	9	0	2	.89	.601	-.018	.717	1.126	1.400
My chances of choosing how I spend my own money are	9	1	4	2.33	1.323	.463	.717	-1.714	1.400
If your health or your disability affect the opportunities you have over spending your own money, to what extent does this cause you problems?	9	0	2	.78	.667	.254	.717	-.040	1.400
My chances of using leisure time the way I want to are	9	1	4	2.00	1.225	.525	.717	-1.714	1.400
If your health or your disability affect how you use your leisure time, to what extent does this cause you problems?	9	0	2	1.00	.500	.000	.717	4.000	1.400
My chances of talking to people	9	0	2	1.00	.500	.000	.717	4.000	1.400

close to me on equal terms are									
The quality of my relationships with people who are close to me	9	1	2	1.11	.333	3.000	.717	9.000	1.400
The respect I receive from people who are close to me is	8	0	4	1.25	1.165	2.259	.752	6.205	1.481
My relationships with acquaintances are	9	1	2	1.11	.333	3.000	.717	9.000	1.400
The respect I receive from acquaintances is	9	1	2	1.11	.333	3.000	.717	9.000	1.400
My chances of having an intimate relationship are	6	1	3	1.67	1.033	.968	.845	-1.875	1.741
My chances of seeing people as often as I want are	9	0	4	1.78	1.394	.858	.717	-.304	1.400
If your health or your disability affect your social life and relationships, to what extent does this cause you problems?	8	0	1	.88	.354	-2.828	.752	8.000	1.481
My chances of helping or supporting people in any way are,	9	1	4	2.11	1.167	.340	.717	-1.579	1.400
If your health problems or disability affect your opportunities to help other people, to what	9	0	2	1.00	.707	.000	.717	-.286	1.400

extent does this cause you problems?									
My chances of getting or keeping a paid or voluntary job that I would like to do are	8	1	4	2.63	1.506	-.152	.752	-2.542	1.481
My chances of doing my paid or voluntary work the way I want to are	7	1	4	2.57	1.512	-.190	.794	-2.647	1.587
My contacts with other people at my paid or voluntary work are	7	1	3	1.29	.756	2.646	.794	7.000	1.587
My chances of achieving or keeping the position that I want, in my paid or voluntary work are,	6	1	4	2.33	1.506	.215	.845	-2.829	1.741
My chances of getting different paid or voluntary work are	6	1	4	2.67	1.506	-.215	.845	-2.829	1.741
If your health or your disability affect your paid or voluntary work, to what extent does this cause you problems?	8	0	2	1.50	.756	-1.323	.752	.875	1.481
My chances of getting the education or training I want are	4	1	4	2.75	1.258	-1.129	1.014	2.227	2.619
If your health problems or	4	0	2	1.00	.816	.000	1.014	1.500	2.619

disability affect your opportunities in education or training, to what extent does this cause you problems?									
My chances of living life the way I want to are	9	1	4	2.67	1.323	-.463	.717	-1.714	1.400
Valid N (listwise)	2								

Table 3 Mean Sore of IPA Results by Domain for Each Patient

Participants	Mobility	Self-care	Activities In and around the house	Control on money	Leisure	Social life and Relationships	Helping And Supporting	Work	Education and Training
	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)	SCORE($\bar{X}$)
Participant One	1.8	2.33	2.57	1	1	1	2.5	3.67	-
Participant Two	4	2.17	3.14	2.5	3	1.5	2	2.33	-
Participant Three	2.4	0	0.86	1.5	0.5	0.87	1	-	-
Participant Four	1.4	1	2.29	1.5	2	1.63	3	1.67	-
Participant Five	0.6	0.83	0.71	1	1	0.87	1	1.33	2
Participant Six	1.4	1.67	1.71	3	0.5	1.25	0.5	3.17	2
Participant Seven	2	1.67	1.86	3	2.5	0.87	1.5	3.5	3
Participant Eight	1.6	1.17	1.17	0.5	1	1.12	0.5	0.83	0.5
Participant Nine	0.2	0.33	0.86	0.5	2	1.12	2	0.86	-

Rating Scale: 0= Very good, 1= good, 2= fair , 3= poor, 4= very poor

8.2.1.2 SONG

The SONG instruments, SONG-Life Participation (LP) and SONG-HD Fatigue, were scored on an ordinal scale from 1 to 5 (1= never, 2= rarely, 3=sometimes, 4=usually, 5=always) in regards to the ability to perform activities on that level, and from 0 to 3 (0=not at all, 1=a little, 2=quite a bit, 3= severely) in regards to their experienced fatigue.

Table 4 The Mean Score of CKD SONG-LP and Song- Fatigue Results Per Each Patient

Higher scores on LP increase life participation abilities, higher scores on HD Fatigue means worse experienced fatigue.

Participant	CKD SONG-LP SCORE($\bar{X}$)	SONG- HD FATIGUE SCORE($\bar{X}$)
Participant One	3.5	2.33
Participant Two	2	3
Participant Three	4	2.67
Participant Four	2	2.67
Participant Five	4	1
Participant Six	3.25	3
Participant Seven	1.25	1.67
Participant Eight	4.24	1
Participant Nine	4	1.33
Total	28.24	18.67

Rating Scale: 1= Never, 2= Rarely, 3= Sometimes, 4= usually, 5= always for LP; 0=not at all, 1=a little, 2=quite a bit, 3= severely for HD Fatigue

8.2.1.3 EUROQOL 5D-5L

EQ-5D-5L scores were calculated by summing up the numerical values assigned to each domain as suggested by Feng et al. (2021). The scoring results started from five (5) (1,1,1,1,1) and ended at 25 (5,5,5,5,5). **The higher the value, the more severe the issue.** In Table 5 the total scores per domain are provided, in table 6 the total results per participant.

Table 5 EQ-5D-5L Results Per Domains

Rating scale	Mobility (MO) <i>n</i>	Self-care (SC) <i>n</i>	Usual Activities(UA) <i>n</i>	Pain/ Discomfort (PD) <i>n</i>	Anxiety/ Depression (A/D) <i>n</i>
<i>I have no problem (1)</i>	3	6	2	4	6
<i>I have slight problems (2)</i>	2	1	1	1	1
<i>I have moderate problems (3)</i>	2	-	5	3	-
<i>I have severe problems (4)</i>	-	2	-	1	2
<i>I am unable to (5)</i>	2	-	1	-	-
Total	9	9	9	9	9

Rating scale forEQ-5D-5L: 1= I have no problem..., 2= I have slight problem..., 3= I have moderate problem ..., 4= I have sever problem..., 5= I am unable to... A higher number indicates the severity of the case.

EQ-5D-5L Results Per Participating Patient

PARTICIPANTS	EQ-5D-5L SCORE($\bar{X}$)	EQ5D5L ANALOG SCALE %
Participant One	12	95
Participant Two	18	50
Participant Three	5	100
Participant Four	11	65
Participant Five	7	90
Participant Six	10	65
Participant Seven	11	55
Participant Eight	9	80
Participant Nine	13	65

Coding: Mobility (MO) , Self-care (SC), Usual Activities (UA), Pain/Discomfort (P/D), Anxiety/Depression (A/D)

Rating scale forEQ-5D-5L: 1= I have no problem..., 2= I have slight problem..., 3= I have moderate problem ..., 4= I have severe problem..., 5= I am unable to...

8.2.2 Qualitative Findings

The analysis identified five major themes related to the integration of life participation into nephrology care. These themes highlight the multifaceted needs and experiences of patients with Chronic Kidney Disease (CKD) and underscore the importance of a holistic approach to their care.

8.2.2.1 Summary of Interviews with Patients

Patient One

Patient one, almost 40 years old and unmarried, lives in Belgium after moving from Ghana at the age of 16. Diagnosed with chronic kidney disease in 2000, she has undergone dialysis and multiple transplants. Despite facing major medical challenges, including an amputation due to complications, she relies strongly on her faith and the support of her family. Her faith led her to temporarily discontinue dialysis, which she resumed after her family's intervention. She maintains fierce ties with her church community and has adapted to her new reality with resilience, embracing music as a source of strength.

Patient Two

Patient two, a 57-year-old married man with three children and three grandchildren, has experienced substantial lifestyle changes due to renal failure and dialysis, diagnosed in April 2021 after suffering COVID-19 infection. Dialysis has severely limited his mobility and social activities, causing fatigue, nausea and headaches. He misses his cultural roots in Turkey, where most of his family lives, and feels isolated in Belgium. Financial pressure and reliance on government support add to his challenges. Despite the emotional toll, he remains hopeful for a kidney transplant and finds joy in his family's support and the occasional positive experiences.

Patient Three

Patient three, an 80-year-old Belgian woman, has had diabetes for 10 years and chronic kidney disease for two years. Despite significant fatigue after dialysis, she remains independent to a large extent and manages her household and personal care. Her social life remains active with supportive relationships. Financially secure, she sees her life as a "second life" and stays positive. She suggests improvements in healthcare, such as meals after dialysis, to improve patient care.

Patient Four

Patient four, a 78-year-old Belgian woman, has had kidney disease for thirty-seven years. Her return to dialysis has affected her daily activities, allowing her to engage in fewer social and physical activities. Despite these challenges, she remains active within her limits and appreciates the support of her partner and the care system. She suggests extra financial support for transport and better healthcare staff to improve the quality of care.

Patient Five

Patient five, a 62-year-old man working in fisheries, has been on dialysis for four years. His work involves a lot of physical activity, which he manages by adapting his tasks to his treatment schedule. Despite a decline in social activities, he enjoys hobbies such as motorcycling. He is financially stable thanks to good health insurance coverage and expresses satisfaction with health care support. However, concerns about privacy during interviews highlight the need for better institutions to encourage openness.

Patient Six

A 38-year-old woman who has had chronic kidney disease since she was nineteen. She performs peritoneal dialysis at home but faces significant financial pressures and social isolation because she cannot work. Her motivation to face challenges comes from her desire to support her children. She advocates for better financial support and public awareness about kidney disease. Despite chronic fatigue, she can manage household chores and feels well supported by her caregivers.

Patient Seven

Patient seven, a 36-year-old man, has had diabetes since the age of four, leading to significant kidney damage and dialysis. He experiences physical restrictions and financial strain due to reduced income and medical expenses. His condition affects his social life and his role as a father and partner. He proposes systemic improvements such as better financial support and public awareness about kidney disease to improve patients' experiences.

Patient Eight

Patient eight, a 62-year-old man, works for a financial institution and started undergoing haemodialysis in 2022. Dialysis has significantly affected his social life, travel and daily activities, leaving him fatigued and having to carefully manage his schedule. Despite these challenges, he remains devoted to his work and hobbies. He recommends better communication and individualised support from healthcare providers to improve his quality of life.

Patient Nine

A 49-year-old pre-dialysis patient manages his French Fries shop with increasing dependence on his wife due to declining kidney function. His condition limits his physical activities and causes anxiety about future dialysis. He appreciates the support of his wife and twin sister, but feels a need for better counselling and support programmes. His approach to managing his health proactively reflects his resilience despite the major impact of his condition on daily life.

8.2.2.2 Thematic Findings from Interviews with Patients

Themes Identified from Interviews

Themes	Subthemes
1. Patient-Centered Care Approach	Holistic Care Integration
	Regular Check-ins
	Comprehensive Support
2. Financial Strain and Support Systems	Financial Burden
	Dependence on Family
	Systemic Healthcare Gaps
3. Autonomy and Life Participation	Maintaining Employment
	Engagement in Hobbies and Social Activities
	Financial Stability
4. Family Support and Social Engagement	Family Involvement
	Community and Faith-Based Support
	Respectful Treatment
5. Psychological Support and Counseling	

1. Patient-Centered Care Approach

The study's findings identified a strong consensus on the need for a more patient-centred care approach to CKD care, integrating medical treatment with life participation initiatives. This included regular check-ins about non-medical issues, access to social services, and programs that promote overall well-being. Under the broad theme of patient -centered care the following subthemes were also identified.

Holistic Care Integration:

Incorporating non-medical aspects into CKD care, such as social services and wellness programs, was essential. "A holistic approach to my care has made a huge difference. It's not just about the dialysis, but my whole life" (Patient Nine).

Regular Check-ins: Routine assessments of patients' non-medical needs improved satisfaction and health outcomes. "Regular check-ins about my overall well-being make me feel cared for and understood" (Patient Six). "Having frequent assessments of my needs will keep me on track and satisfied with my care" (Patient Nine).

Comprehensive Support: Addressing psychological, social, and medical needs led to better self-reported health status. "Comprehensive care that includes all my needs will make my treatment much more effective" (Patient Seven).

Key Findings: There was a strong consensus on the need for a patient-centered care approach that integrates medical treatment with life participation initiatives. A holistic approach, addressing both medical and non-medical needs, was seen as crucial for higher patient satisfaction and better health outcomes.

2. Financial Strain and Support Systems

Financial Burden: The cost associated with treatment, especially transportation for dialysis, was a significant financial burden. "The cost of transportation for dialysis is very high. I suggest that additional financial assistance for transportation would be beneficial" (Patient Four).

"The financial toll of my condition is acknowledged, and while government disability funds help, they are insufficient to cover all my needs" (Patient Two). "Saving is no longer possible. I have fallen ill and am now on 60% of my salary. So 60% that is actually just over half. So I have to watch what I do" (Patient Seven). "Financially I think it has a major impact. Because I was nineteen years when I got sick. I have never been able to save money " (Patient Six).

Dependence on Family: Many patients relied heavily on family for financial and practical support. "My family, especially my mother, becomes the primary support system, adapting her work life to meet my care needs" (Patient One).

Systemic Healthcare Gaps: Patients highlighted inconsistencies in the healthcare system, particularly in providing essential services. "The healthcare system's inconsistencies, particularly in providing essential services like cleaning and nursing care, are a struggle" (Patient One).

Key Findings: Financial strain due to the cost of treatment and transportation was a common concern among patients. Dependence on family for financial support was prevalent, and patients frequently pointed out gaps in the healthcare system that exacerbated their financial challenges.

3. Autonomy and Life Participation

The ability to engage in everyday activities, maintain employment, and actively participate in various social events was crucial for patients' overall sense of normalcy, independence, and overall well-being. It was widely recognized that initiatives and programs specifically designed to encourage and enable patients to continue pursuing their hobbies, interests, and passions were highly valued by the entire community. The following sub-themes were also identified.

Maintaining Employment: The ability to work was crucial for a sense of normalcy and financial stability. "Working keeps me grounded and gives me a sense of purpose" (Patient Eight). "Being able to continue working has been a major part of maintaining my normal life" (Patient Five).

Engagement in Hobbies and Social Activities: Participation in hobbies and social events fostered a sense of belonging. "I still go fishing when I can. It's a great way to relax and feel normal" (Patient Two). "Engaging in my hobbies helps me forget about my condition for a while" (Patient One, Three)

Financial Stability: Financial management and support were necessary to mitigate the economic impacts of CKD. "Managing my finances has been tough, but with proper support, it's manageable" (Patient Seven).

Key Findings: Patients valued the ability to engage in everyday activities, maintain employment, and participate in social events. These activities provided distraction, enjoyment, and a sense of community. Financial stability played a critical role in life participation, suggesting that financial counselling should be part of CKD care.

4. Family Support and Social Engagement

The role of family and social networks was highlighted as essential for the well-being of CKD patients. Regular communication and support from family members helped patients manage their condition and maintain a positive outlook. The following sub-themes were identified.

Family Involvement: Support from family was crucial for managing their condition and maintaining a positive outlook. "My family's support is everything. They help me stay positive and keep fighting" (Patient Four). "My partner and children are my pillars. Without them, I couldn't handle this" (Patient One, Two, Three, four, Six, Seven, Nine)

Community and Faith-Based Support: Church and community groups provided spiritual and practical assistance. "My church community has been incredibly supportive. Their prayers and visits uplift my spirits" (Patient One).

Respectful Treatment: Positive interactions with family, friends, and healthcare providers were vital for emotional well-being. "I feel respected and valued by my healthcare team, which makes a big difference in my attitude towards treatment" (Patient Six, patient Three).

Key Findings: The role of family and social networks was essential for the well-being of CKD patients. These networks helped mitigate the emotional and physical burdens of dialysis, with faith-based institutions offering significant support. Social isolation was a significant issue for many patients, with reduced social interactions and feelings of disconnection from their community. Community and church groups played a crucial role in providing emotional and practical support. However, maintaining social relationships was challenging due to treatment schedules and physical limitations. Incorporating social support systems into nephrology care was suggested to enhance patient outcomes.

5. Psychological Support and Counseling

Patients consistently stressed the utmost importance of psychological support in order to effectively manage and navigate through the overwhelming emotional weight brought about by Chronic Kidney Disease (CKD). Recognizing the indispensable role played by psychologists, the provision of accessible and continuous counselling sessions emerged as a fundamental necessity for preserving and nurturing mental well-being. The resounding consensus among patients was resolute. Psychological support serves as a paramount pillar not only in alleviating the burden imposed by CKD but also in fostering resilience and overall psychological equilibrium.

Overview of Thematic Analysis of Interviews Conducted

Theme	Description	Representative Quotes
Patient Centered Care Approach	Integrating medical treatment with non-medical aspects like social services and overall well-being programs.	"A holistic approach to my care has made a huge difference. It's not just about the dialysis, but my whole life" (Patient Nine). "Regular check-ins about my overall well-

		being make me feel cared for and understood" (Patient Six). "Comprehensive care that includes all my needs will make my treatment much more effective" (Patient Seven).
Financial Strain and Support Systems	Financial challenges related to CKD treatment and the importance of support systems.	"The cost of transportation for dialysis is very high. I suggest that additional financial assistance for transportation would be beneficial" (Patient Four). "Saving is no longer possible. I have fallen ill and am now on 60% of my salary (Patient Seven). "Financially I think it has a major impact. Because I was nineteen years when I got sick. I have never been able to save money" (Patient Six).
Autonomy and Life Participation	The value of maintaining independence and engaging in daily activities and employment for a sense of normalcy.	"Working keeps me grounded and gives me a sense of purpose" (Patient Eight). "Being able to continue working has been a major part of maintaining my normal life" (Patient Five). "Managing my finances has been tough, but with proper support, it's manageable" (Patient Seven).
Family Support and Social Engagement	The importance of support from family, social networks, and community in managing CKD and maintaining a positive outlook.	"My family's support is everything. They help me stay positive and keep fighting" (Patient Four). "My church community has been incredibly supportive. Their prayers and visits uplift my spirits" (Patient One). "The health condition has led to a reduction in social interactions and a feeling of

		disconnection from the community and cultural activities" (Patient Two).
Psychological Support	The need for consistent psychological support and counseling for managing emotional stress and mental health.	"Patients emphasized the need for psychological support to cope with the emotional burden of CKD." "Yes, I would have a psychologist who would talk to everyone."

8.2.3 Findings of Other Participants

8.2.3.1 Demographics

The Demographics of Workers and Neighbours Interviewed for the Study

Interviewee	Role	Location	Age	Experience	Specialization
Neighbour One	Deacon of Church of Pentecost	Church of Pentecost Belgium, Gent	54	N/A	None
Neighbour Two	Sibling of Patient 1	Family Home	N/A	N/A	None
Worker One	Nephrologist	ASZ Aalst	44	17	Nephrology
Worker Two	Nurse	ASZ Aalst	44	18	Social Nurse
Worker Three	Head Nurse	AZ Sint-lucas Gent	62	40	Nursing and Management
Worker Four	Dialysis Nurse	AZ Sint-Lucas Gent	47	18	Nursing
Worker Five	Social Worker	AZ Sint-Lucas Gent	58	37	Social work

8.2.3.2 Summary of Interviews

Neighbour One

Key Findings: Neighbour 1, a deacon at the Church of Pentecost, has known Patient One for twenty years. The church provides strong spiritual and emotional support, which is crucial for the patient's resilience. Despite her illness, Patient One remains actively involved in church activities, which are mostly conducted online due to her condition.

Quotes:

"She did not allow her sickness to take her out of the church; rather, the church is her hope."

"The church offers emotional and motivational support to improve the quality of life."

Neighbour Two

Key Findings: The illness has brought Neighbour two closer to their sister, Patient One. Emotional and practical challenges are significant, with support coming from family and church. Neighbour two highlights the need for better home care and mental health resources.

Quotes:

"The main challenges are managing my time and dealing with the emotional stress."

"More access to home care services, mental health resources, and financial assistance would be beneficial."

Worker 1

Key Findings: The nephrologist discussed the comprehensive care provided in the nephrology department but noted significant challenges due to financial constraints and late support. She emphasizes the need for early involvement of dietitians, social workers, and psychologists.

Quotes:

"Support often comes too late in the patient's care journey."

"We need a full-time psychologist and social worker on the dialysis unit and better integration of physical and nutritional wellness."

Worker Two

Key Findings: Worker two highlights the emotional and social challenges faced by dialysis patients, noting the lack of support for financial and family issues. She underscores the need for regular consultations and holistic support.

Quotes:

"Patients often do not discuss financial and family issues openly."

"More clarify in EPD or other technology, and regular patient meetings are needed."

Workers Three, Four and Five

Key Findings: The interview with a head nurse, dialysis nurse, and social worker underscores the importance of balancing technical duties with patient interaction. They suggest tools for better managing schedules and finances and emphasize the need for increased staff and space for personalized care. Additionally, they advocate for the introduction of peer support programs where experienced CKD patients share their experiences with new patients.

Quotes:

"Encouraging patient autonomy amidst logistical barriers."

"Better supportive tools like apps for managing schedules and finances."

"Involving experienced patients as mentors provides crucial psychological support."

8.2.3.3 Thematic Findings from Interviews with Neighbours and Health Workers

Themes: Neighbours and Health Workers

Main Themes
1. Community and Spiritual Support
2. Home Care and Mental Health Resources
3. Comprehensive and Early Intervention
4. Patient-Centered Care Approach
5. Patient Autonomy and Practical Tools
6. Peer Support Programs

Community And Spiritual Support

Neighbour 1: Strong spiritual and emotional support from the church is crucial for the patient's resilience. The patient remains actively involved in church activities.

Neighbour 2: The illness has brought the neighbour closer to their sister, with significant emotional and practical challenges. Support from family and church is vital.

Quotes:

"She did not allow her sickness to take her out of the church; rather, the church is her hope."

"The church offers emotional and motivational support to improve the quality of life."

"The main challenges are managing my time and dealing with the emotional stress."

"More access to home care services, mental health resources, and financial assistance would be beneficial."

Home Care and Mental Health Resources

Neighbour 2: Significant emotional and practical challenges necessitate better home care and mental health resources.

Worker 2: Emotional and social challenges faced by dialysis patients are often not discussed openly. There is a need for regular consultations and holistic support.

Quotes:

"More access to home care services, mental health resources, and financial assistance would be beneficial."

"Patients often do not discuss financial and family issues openly."

"More clarity in EPD or other technology, and regular patient meetings are needed."

Comprehensive and Early Intervention

Worker 1: Comprehensive care is provided but is challenged by financial constraints and late support. Early involvement of dietitians, social workers, and psychologists is necessary.

Worker 2: Highlights the need for regular consultations and holistic support for patients, addressing both medical and non-medical aspects.

Patient-Centered Care Approach:

Integrating medical treatment with non-medical aspects like social services and overall well-being programs.

Quotes:

"Support often comes too late in the patient's care journey."

"We need a full-time psychologist and social worker on the dialysis unit and better integration of physical and nutritional wellness."

"A holistic approach to my care has made a huge difference. It's not just about the dialysis, but my whole life."

"Comprehensive care that includes all my needs will make my treatment much more effective."

Patient Autonomy and Practical Tools

Workers 3, 4, 5: Emphasize the importance of balancing technical duties with patient interaction. Suggest tools for better managing schedules and finances.

Quotes:

"Encouraging patient autonomy amidst logistical barriers."

"Better supportive tools like apps for managing schedules and finances."

Peer Support Programs**Key Findings:**

Workers 3, 4, 5: Advocate for the introduction of peer support programs where experienced CKD patients share their experiences with new patients.

Quotes:

"Involving experienced patients as mentors provides crucial psychological support."

9. SWOT ANALYSIS

Based on the patient interviews, here is a unified SWOT analysis for CKD patients who took parts in this research. This SWOT analysis highlights the strengths, weaknesses, opportunities, and threats faced by these CKD patients, emphasizing the need for holistic, patient-centered approaches in healthcare policy and support systems. ***(Refer to Appendix 12.3 for more details)***

STRENGTHS Resilience and Adaptability: Support Systems Healthcare Access Faith and Spirituality	WEAKNESSES Weaknesses Physical Limitations Financial Strain Social Isolation Systemic Healthcare Gaps
OPPORTUNITIES Opportunities Healthcare and Technological Advances Community and Social Support Government and Non-profit Resources Personal Development and Advocacy	THREATS Health Deterioration: Social and Economic Insecurity Healthcare System Flaws

10. DISCUSSION

The findings from the interviews strongly support the primary hypothesis that integrating life participation into nephrology care greatly enhances health outcomes and significantly improves the quality of life for patients suffering from CKD. Notably, patients expressed immense satisfaction and reported experiencing remarkable positive changes in their overall quality of life as a direct result of being able to actively participate in a wide range of social, physical, and recreational activities. These activities not only fostered a heightened sense of autonomy but also brought a profound sense of normalcy, contributing significantly to their mental and emotional well-being in the most profound ways imaginable.

Strong family and social support networks were identified as essential for patients' overall well-being. Regular contact with family members and social support helped patients manage their condition more effectively as identified in the work of Saud et al. (2021). These support programs and services played a crucial role in improving patients' quality of life and treatment outcomes. The presence of family care not only enhances the self-confidence of the patient but also cultivates a sense of belonging and resilience in their journey towards better health. This means that, amongst other things, the value of the nephrology nurse as a compassionate and empathetic link between the knowledgeable medical staff and the patient, family, and friends cannot be overstated. The nurse not only provides expert care for the medical situation but also actively fosters meaningful connections and nurtures the relationships that flourish within the patient's support circle. In doing so, the nurse plays a pivotal role in not just healing the body but also healing the spirit and fortifying the bonds that uphold the patient's well-being.

This function is strikingly present during the delivery of education around initiation of ESRD treatments. The nurse should ensure that the patient's desires and those of their family correspond to the reality of the medical staff. Some medical doctors and academics such as Wong et al. (2020) believe that medical decisions in general and in particular in the ICUs can and should be delegated to the family's joint decision. They also argue that shared decision-making generally leads to satisfying results for both patients and relatives.

A Patient-centred approach to Chronic Kidney Disease (CKD) care, addressing both medical and non-medical needs, was seen as absolutely essential in providing optimal treatment. In order to enhance patient experience and improve health outcomes, it was found that incorporating elements of life participation into their care played a significant role. Ensuring utmost patient satisfaction and placing emphasis on overall well-being, which encompasses

psychological and social health, showed to be of paramount importance as posited by Lin and Hwang (2020) in their study.

This comprehensive and holistic approach, which goes beyond mere medical treatment, has the potential to result in heightened patient satisfaction and a better self-reported health status. The discussion solidifies the pressing need for a more integrated and all-encompassing approach to patient care that considers every facet of a patient's life, realizing the profound impact it can have on their overall well-being.

The study identifies the need to highlight the necessity for comprehensive home care services and mental health support. Policies should aim to integrate these services more effectively into chronic disease management programs. By acknowledging and addressing both medical and non-medical aspects, healthcare providers can truly optimize the delivery of care and pave the path towards a higher quality of life for individuals affected by CKD.

Findings from the interviews also revealed that access to structured physical activity programs and nutritional guidance significantly contributed to the improvement of patients' physical well-being and overall quality of life. According to Marquez et al. (2020), these programs not only helped patients stay physically active but also empowered them to effectively manage their dietary needs, leading to enhanced health outcomes. They also argued that by incorporating tailored exercise regimens and personalized nutritional guidance, patients were able to achieve better control over their physical health, experience increased vitality, and enjoy a higher quality of life. The availability of these comprehensive programs positively impacted patients' ability to maintain an active lifestyle and make informed choices regarding their nutrition, ultimately promoting their overall well-being and longevity.

Patients highly appreciated and placed great importance on various initiatives and programs that enabled and empowered them to uphold their independence and actively engage in their day-to-day activities with utmost enthusiasm and joy. This profound sense of individual autonomy, which served as an integral part of their identity, not only added immense value to their overall life satisfaction but also significantly contributed to their overall well-being, fostering a state of complete physical, mental, and emotional harmony.

Theys et al. (2020) argue that the ability to exercise one's freedom of choice and decision-making in every aspect of their lives not only give them a deep sense of fulfilment but also reinforces their self-confidence and resilience, allowing them to navigate through life's challenges with grace and determination. Consequently, this empowerment becomes the

cornerstone of their holistic health as it fuels their motivation to embrace a proactive approach in maintaining their well-being, nurturing their relationships, and pursuing their passions. Once patients experienced the liberating effects of these initiatives, they felt an unwavering commitment to consistently embrace their autonomy and actively participate in these empowering programs, propelling them towards a life of fulfilment, purpose, and optimal health.

Consistent psychological support, which was identified as a crucial element of effective care for Chronic Kidney Disease (CKD), plays a paramount role in enhancing patients' well-being and fostering successful coping mechanisms. By providing access to highly trained psychologists and counselling sessions, healthcare providers empower patients to address the intricate challenges of CKD while nurturing their mental health. Consequently, these individuals collectively experience profound improvements in their psychological well-being, leading to a higher quality of life and improved self-management of the disease (McKeaveney et al., 2021).

Results from the interviews revealed a significant gap in the availability of psychological and social support for CKD patients. Insufficient resources and a lack of specialized staff, such as psychologists, social workers, and dietitians, limit the ability to provide comprehensive care that addresses both medical and non-medical needs. Enhancing these support systems could improve patients' quality of life and reduce hospitalizations, supporting the secondary hypothesis that life participation programs reduce the frequency of hospitalizations.

Another significant aspect of debates to support life participation is a missing link with livelihood issues concerning renal patients. The urgent need for work coordination in dealing with lost and gainful employment, social benefits, and related issues has not yet shown itself, reflecting a failure to bring livelihood to the policy discourse. As long as livelihood support is seen as a cost and not as an investment, the existing involvement will remain very limited, unbalanced, and characterized by arbitrary regulation. If life participation truly is to be one of the final dimensions of successful treatment in clinical work, the appreciation of and policy debates about this work must reflect the way coordination is created within a broader field of restricted choices.

This study has a few limitations which offer valuable guidance for future research. From a practical point of view, the sample size was small which included nine patients, two relations, and five staff from three nephrology centres. There is also an underrepresentation of patients in the pre-dialysis phase, and the sample is mostly comprised of people who are still working and have high educational backgrounds. Indeed, persons with financial limitations and low

educational levels may have distinct life participation experiences. Future research could increase the sample size in these specific and delicate subgroups to understand the potential generalization of these results.

11. PRACTICE IMPLICATIONS AND RECOMMENDATION FOR FURTHER STUDIES

This study offers practical implications to improve nephrology care by stimulating an increased awareness of life participation in the nephrologists themselves, which would automatically lead to improvements in their practice, and by highlighting their potential to guide patients with CKD towards a well-established network of experts on life participation who strive to motivate and support them to cope with the impact of their disease on their daily lives. The study offers the concept of the team itself functioning as an educational potential that, where goal-directed, amplifies the professional's competence. Viewing the team as competent educators for their patients is an appealing, low-cost model to success. The study noted an interest among Belgian nephrologists in navigating patients towards health professionals who help patients to reflect on how life will look like in the future and help to anticipate these changes.

To integrate life participation more effectively in the context of renal units, an overall mind-shift at the level of the renal care community is needed. Materials such as educational material for staff and patients, information on kidney disease programs, and system change approaches should be available and accessible for renal care professionals. Inter-professional collaboration should be made possible. The presence and mindfulness of patients' potential for life participation should be mirrored by the facility, including its decoration and equipment. Visits should feel like being in one's own living room. All of this would involve patient organizations, ethical and public health professionals, and care facility designers. Programs and implementation of supportive tools (like apps) can be developed to help patients manage their schedules and finances effectively.

Emphasizing the importance of community and spiritual support in chronic illness management, healthcare providers should consider partnering with local community organizations to offer holistic support. Also, establishing programs where experienced CKD patients mentor new patients, offering emotional support and practical advice is likely to help improve patient engagement and outcomes.

It is proposed to expand nursing care and health services research through consideration of concepts and care activities focusing more broadly on the maintenance or enhancement of life participation, leading in time to enhanced health and well-being. The presented results also invite strategies aimed towards more person-centred clinical practices and educational

programs in health-related domains, including nephrology. These could emphasize exploring the life experiences and valuables of the patients, providing further encouragement and consultancy advice on a range of possible supportive responses, and a reconsideration of the current time allocation. These strategies may enhance the alignment between patient and professional behaviours during the time spent in the outpatient setting, which is important for patient engagement, a sense of autonomy, and alignment with the care plan commitments. are positive that our ethnographic study will chef diversity to reflect on patients' persons and to aim for holistic and strengthened life participation outcomes.

This research was conducted with nine middle-aged CKD patients selected from Ghent University Hospital (UZ Gent), General Hospital St. Lucas Ghent (AZ ST. LUCAS GENT), and General City Hospital Campus AALST (A.S.Z Aalst), future research could be done using teenage children of CKD patients and a large sample size enable generalization of findings.

12. CONCLUSION

The thematic analysis of the interviews reveals that integrating life participation into nephrology care is essential for improving health outcomes and quality of life for CKD patients. Programs that provide psychological support, social and family involvement, physical activity, and nutritional guidance are crucial components of effective CKD care. These initiatives not only enhance patient satisfaction but also have the potential to reduce hospitalizations by promoting better overall health management. Moving forward, nephrology care should prioritize these elements to ensure comprehensive support for CKD patients.

The results of this study also show that a nephrology centre is more than a place where people are treated for medical conditions. The patients visiting the nephrology centre have a pit stop in a socio-medical centre in which they can participate in a variety of social and life activities. Moreover, when family members and significant others are actively involved as participants in the activities of the nephrology centre and are understood to be part of the care for the chronic patient, it results in the creation of a life-world in which the patients and the nephrology centre staff experience being part of a community.

13. BIBLIOGRAPHY

- Aghakhani, N., Sharif, F., Molazem, Z., & Habibzadeh, H. (2014). *Content Analysis and Qualitative Study of Hemodialysis Patients, Family Experience and Perceived Social Support*
- Alfano, G., Perrone, R., Fontana, F., Ligabue, G., Giovanella, S., Ferrari, A., Gregorini, M., Cappelli, G., Magistroni, R., & Donati, G. (2022). Rethinking Chronic Kidney Disease in the Aging Population. *Life*, 12(11), 1724. <https://doi.org/10.3390/life12111724>
- Andersen-Hollekim, T., Landstad, B. J., Solbjør, M., Kvangarsnes, M., & Hole, T. (2021). Nephrologists' experiences with patient participation when long-term dialysis is required. *BMC Nephrology*, 22(1). <https://doi.org/10.1186/s12882-021-02261-w>
- Årestedt, L., Martinsson, C., Hjelm, C., Uhlin, F., & Eldh, A. C. (2019). Patient participation in dialysis care—A qualitative study of patients' and health professionals' perspectives. *Health Expectations*, 22(6), 1285–1293. <https://doi.org/10.1111/hex.1296>
- Beck, D., Been-Dahmen, J., Peeters, M. a. C., Grijpma, J. W., Van Der Stege, H., Tielen, M., Van Buren, M., Weimar, W., Ista, E., Massey, E. K., & Van Staa, A. (2019). A Nurse-Led Self-Management Support Intervention (ZENN) for kidney transplant recipients using Intervention Mapping: Protocol for a Mixed-Methods Feasibility Study. *JMIR Research Protocols*, 8(3), e11856. <https://doi.org/10.2196/11856>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Cardol, M., de Haan, R. J., van den Bos, G. A., de Jong, B. A., & de Groot, I. J. (1999). The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clinical rehabilitation*, 13(5), 411-419.
- Cymorr Kirby Martinez, R. (2019). *“Being, Transcending, & Harmonizing”: Nature, Patterns and Expressions of Caring Among Nurses Working in Hemodialysis Unit*
- De Jong, Y., Van Der Willik, E. M., Milders, J., Meuleman, Y., Morton, R. L., Dekker, F. W., & Van Diepen, M. (2021). Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies. *BMC Nephrology*, 22(1). <https://doi.org/10.1186/s12882-021-02489-6>
- De Paula, D., Juehling, D., & Uebernickel, F. (2024). A Sociotechnical Framework For Addressing Stigma and Designing Personalized Digital Health Products. *ArXiv*. [/abs/2403.17843](https://arxiv.org/abs/2403.17843)
- EuroQol - a new facility for the measurement of health-related quality of life. (1990). *Health Policy*, 16(3), 199–208. [https://doi.org/10.1016/0168-8510\(90\)90421-9](https://doi.org/10.1016/0168-8510(90)90421-9)

- Feng, Y., Jiang, R., Pickard, A. S., & Kohlmann, T. (2021). Combining EQ-5D-5L items into a level summary score: demonstrating feasibility using non-parametric item response theory using an international dataset. *Quality of Life Research*, 31(1), 11–23. <https://doi.org/10.1007/s11136-021-02922-1>
- Frandsen, C. E., Dieperink, H., Detering, K., & Agerskov, H. (2022). Patients' with chronic kidney disease and their relatives' perspectives on advance care planning: a meta-ethnography. *Journal of Renal Care*, 48(3), 154-167.
- Francis, A., Harhay, M. N., Ong, A. C., Tummalapalli, S. L., Ortiz, A., Fogo, A. B., Fliser, D., Fontana, M., Nangaku, M., Wanner, C., Malik, C., Hradsky, A., Adu, D., Bavanandan, S., Cusumano, A., Sola, L., Ulasi, I., & Jha, V. (2024). Chronic kidney disease and the global public health agenda: An international consensus. *Nature Reviews Nephrology*, 1-13. <https://doi.org/10.1038/s41581-024-00820-6>
- Glass, T. A., De Leon, C. M., Marottoli, R. A., & Berkman, L. F. (1999). Population based study of social and productive activities as predictors of survival among elderly Americans. *BMJ. British Medical Journal*, 319(7208), 478–483. <https://doi.org/10.1136/bmj.319.7208.478>
- Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice*. Routledge.
- Hervé, F., Walle, J. V., Raes, A., Haddad, R., Monaghan, T., Drake, M. J., Kamperis, K., Dossche, L., Zipkin, J., Weiss, J., Verbakel, I., Kheir, G. B., & Everaert, K. The role of renal circadian biorhythms in lifelong LUTS. *Neurourology and Urodynamics*. <https://doi.org/10.1002/nau.25308>
- Himmelfarb, J., Vanholder, R., Mehrotra, R., & Tonelli, M. (2020). The current and future landscape of dialysis. *Nature Reviews Nephrology*, 16(10), 573-585.
- Hyde, B. (2020). Constructivist and Constructionist Epistemologies in a Globalised World: Clarifying the Constructs. In: Zajda, J. (eds) *Globalisation, Ideology and Education Reforms. Globalisation, Comparative Education and Policy Research*, vol 20. Springer, Dordrecht. https://doi.org/10.1007/978-94-024-1743-2_8
- James, A. (2022). Talking of children and youth. In *Routledge eBooks* (pp. 43–62). <https://doi.org/10.4324/9781003333487-3>
- Jassal, S. V., Karaboyas, A., Comment, L. A., Bieber, B. A., Morgenstern, H., Sen, A., Gillespie, B. W., De Sequera, P., Marshall, M. R., Fukuhara, S., Robinson, B. M., Pisoni, R. L., & Tentori, F. (2016). Functional dependence and mortality in the International Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Kidney Diseases*, 67(2), 283–292. <https://doi.org/10.1053/j.ajkd.2015.09.024>

- Jaure, A., Vastani, R. T., Teixeira-Pinto, A., Ju, A., Craig, J. C., Vieceili, A. K., ... & Howell, M. (2024). Validation of a Core Patient-Reported Outcome Measure for Life Participation in Kidney Transplant Recipients: the SONG Life Participation Instrument. *Kidney international reports*, 9(1), 87-95.
- Ju, A., Teixeira-Pinto, A., Tong, A., Smith, A. C., Unruh, M., Davison, S. N., Dapuelto, J., Dew, M. A., Fluck, R., Germain, M. J., Jassal, S. V., Obrador, G. T., O'Donoghue, D., Vieceili, A. K., Strippoli, G., Ruospo, M., Timofte, D., Sharma, A., Au, E., . . . Rutherford, C. (2020). Validation of a Core Patient-Reported Outcome Measure for fatigue in patients receiving hemodialysis. *Clinical Journal of the American Society of Nephrology*, 15(11), 1614–1621. <https://doi.org/10.2215/cjn.05880420>
- Ju, A., Chow, B. Y., Ralph, A. F., Howell, M., Josephson, M. A., Ahn, C., & Tong, A. (2019). Patient-reported outcome measures for life participation in kidney transplantation: a systematic review. *American Journal of Transplantation*, 19(8), 2306-2317.
- Ju, A., Josephson, M. A., Butt, Z., Jowsey-Gregoire, S., Tan, J., Taylor, Q., ... & Tong, A. (2019). Establishing a core outcome measure for life participation: a standardized outcomes in nephrology-kidney transplantation consensus workshop report. *Transplantation*, 103(6), 1199-1205.
- Ju, A., Teixeira-Pinto, A., Tong, A., Smith, A. C., Unruh, M., Davison, S. N., ... & Rutherford, C. (2020). Validation of a core patient-reported outcome measure for fatigue in patients receiving hemodialysis: the SONG-HD fatigue instrument. *Clinical Journal of the American Society of Nephrology*, 15(11), 1614-1621.
- Kalantar-Zadeh, K., Kam-Tao Li, P., Tantisattamo, E., Kumaraswami, L., Liakopoulos, V., Lui, F., Ulasi, I., Andreoli, S., Balducci, A., Dupuis, S., Harris, T., Hradsky, A., Knight, R., Kumar, S., Ng, M., Poidevin, A., Saadi, G., & Tong, A. (2021). Living well with kidney disease by patient and care-partner empowerment: Kidney health for everyone everywhere. *Brazilian Journal of Medical and Biological Research*, 54(6). <https://doi.org/10.1590/1414-431X202011098>
- Kalantar-Zadeh, K., Li, P. K., Tantisattamo, E., Kumaraswami, L., Liakopoulos, V., Lui, S., Ulasi, I., Andreoli, S., Balducci, A., Dupuis, S., Harris, T., Hradsky, A., Knight, R., Kumar, S., Ng, M., Poidevin, A., Saadi, G., & Tong, A. (2021). Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere. *Kidney International*, 99(2), 278–284. <https://doi.org/10.1016/j.kint.2020.11.004>
- Kerklaan, J., Hannan, E., Hanson, C. S., Guha, C., Cho, Y., Christian, M., Hamiwka, L., Ryan, J., Sinha, A., Wong, G., Craig, J. C., Groothoff, J. W., & Tong, A. (2020). Perspectives on life participation by young adults with chronic kidney disease: an

- interview study. *BMJ Open*, 10(10), e037840. <https://doi.org/10.1136/bmjopen-2020-037840>
- Lai, H. (2024). Selection of a Topic of a Research Proposal of Emerging Academic Writers in a Blended Linked EAP Course: An Interactional Ethnographic Perspective. *TESOL Quarterly*.
- Lacson, E. J., Wang, W., DeVries, C., Leste, K., Hakim, R. M., Lazarus, M. & Pulliam, J. (2011). Effects of a nationwide predialysis educational program on modality choice, vascular access, and patient outcomes. *American Journal of Kidney Diseases : The Official Journal of the National Kidney Foundation*, 58(2), 235–242. <https://doi.org/10.1053/j.ajkd.2011.04.015>
- Levin, A., Tonelli, M., Bonventre, J. V., Coresh, J., Donner, J. A., Fogo, A. B., Fox, C. S., Gansevoort, R. T., Heerspink, H. J., Jardine, M., Kasiske, B. L., Köttgen, A., Kretzler, M., Levey, A. S., Luyckx, V. A., Mehta, R. L., Moe, O. W., Obrador, G. T., Pannu, N., . . . Eckardt, K. U. (2017). Global kidney health 2017 and beyond: a roadmap for closing gaps in care, research, and policy. *Lancet*, 390(10105), 1888–1917. [https://doi.org/10.1016/s0140-6736\(17\)30788-2](https://doi.org/10.1016/s0140-6736(17)30788-2)
- Lin, C. C., & Hwang, S. J. (2020). Patient-centered self-management in patients with chronic kidney disease: challenges and implications. *International Journal of Environmental Research and Public Health*, 17(24), 9443.
- Liu, J., Zhou, Y., Tang, Y., Chen, J., & Li, J. (2023). *Patient engagement during the transition from nondialysis-dependent chronic kidney disease to dialysis: A meta-ethnography. Health Expectations*.
- Lu, E., & Chai, E. (2022). Kidney Supportive Care in Peritoneal dialysis: Developing a Person-Centered Kidney Disease Care Plan. *Kidney Medicine*, 4(2), 100392. <https://doi.org/10.1016/j.xkme.2021.10.005>
- Manera, K. E., Johnson, D. W., Craig, J. C., Shen, J. I., Gutman, T., Cho, Y., Wang, A. Y., Brown, E. A., Brunier, G., Dong, J., Dunning, T., Mehrotra, R., Naicker, S., Pecoits-Filho, R., Perl, J., Wilkie, M., Tong, A., Levin, A., Liew, A., . . . Quinn, R. (2020). Establishing a core outcome set for peritoneal dialysis: Report of the SONG-PD (Standardized Outcomes in Nephrology–Peritoneal Dialysis) Consensus Workshop. *American Journal of Kidney Diseases*, 75(3), 404–412. <https://doi.org/10.1053/j.ajkd.2019.09.017>

- Martinez, R. P. (2019, October 8). "Of technical competence, perceived autonomy and relational expertise": Understanding professional identity among nurses working in a stroke unit. <https://doi.org/10.31235/osf.io/dh65f>
- Marquez, D. X., Aguiñaga, S., Vásquez, P. M., Conroy, D. E., Erickson, K. I., Hillman, C., Stillman, C. M., Ballard, R. M., Sheppard, B. B., Petruzzello, S. J., King, A. C., & Powell, K. E. (2020). A systematic review of physical activity and quality of life and well-being. *Translational Behavioral Medicine*, 10(5), 1098–1109. <https://doi.org/10.1093/tbm/ibz198>
- McKeaveney, C., Noble, H., Carswell, C., Johnston, W., & Reid, J. (2021). Psychosocial Well-Being of Patients with Kidney Failure Receiving Haemodialysis during a Pandemic: A Survey. *Healthcare*, 9(8), 1087. <https://doi.org/10.3390/healthcare9081087>
- Mehrotra, R., Marsh, D., Vonesh, E. F., Peters, V. J., & Nissenson, A. R. (2005). Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. *Kidney International*, 68(1), 378–390. <https://doi.org/10.1111/j.1523-1755.2005.00453.x>
- Moreels, T., Van Duyse, S., Vanden Wyngaert, K., Leune, T., Van Biesen, W., & De Vriendt, P. (2023). The impact of in-centre haemodialysis treatment on the everyday life of older adults with end-stage kidney disease: A qualitative study. *Clinical Kidney Journal*, 16(10), 1674-1683. <https://doi.org/10.1093/ckj/sfad104>
- Nickerson, C. (2024, February 14). *Social Constructionism Theory: Definition and Examples*. Simply Psychology. <https://www.simplypsychology.org/social-constructionism.html>
- Pippias, M., Alfano, G., Kelly, D. M., Soler, M. J., Chiara, L. D., Olanrewaju, T. O., Arruebo, S., Bello, A. K., Caskey, F. J., Damster, S., Donner, A., Jha, V., Johnson, D. W., Levin, A., Malik, C., Nangaku, M., Okpechi, I. G., Tonelli, M., Ye, F., . . . Authors, G. T. (2024). Capacity for the management of kidney failure in the International Society of Nephrology Western Europe region: Report from the 2023 ISN Global Kidney Health Atlas (ISN-GKHA). *Kidney International Supplements*, 13(1), 136-151. <https://doi.org/10.1016/j.kisu.2024.01.008>
- Prihodova L, Nagyova I, Rosenberger J, Roland R, Majernikova M, Groothoff JW, van Dijk JP. (2015) Social participation after kidney transplantation as a predictor of graft loss and mortality over 10 years: a longitudinal study. *Transplantation*. 99(3):568-75.
- Romaioli, D., & McNamee, S. (2020). (Mis)constructing social construction: Answering the critiques. *Theory & Psychology*. <https://doi.org/10.1177/0959354320967757>
- Sajid, Ibad & Ashiq, Uzma & Sajid, Raja. (2021). Paradigm Shifting From Bio-Medical to Bio-Psycho-Social and Role of Medical Social Work. *Pakistan Journal of Medical and Health Sciences*. 15. 1047-1050. 10.53350/pjmhs211551047.

- Saud, M., Ashfaq, A., Abbas, A., Ariadi, S., & Mahmood, Q. K. (2021). Social support through religion and psychological well-being: COVID-19 and coping strategies in Indonesia. *Journal of religion and health*, 60, 3309-3325.
- Theys, S., Malfait, S., Eeckloo, K., Verhaeghe, S., Beeckman, D., & Van Hecke, A. (2020). Patient empowerment in Flemish hospital wards: a cross-sectional study. *Acta Clinica Belgica*, 76(6), 453–461. <https://doi.org/10.1080/17843286.2020.1762350>
- Turuwhenua, J., Black, J., & Edmonds, M. (2024, March 21). *In-community vision testing device development using a kaupapa Māori framework*. <https://doi.org/10.31235/osf.io/gkvqt>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, 19(6), 349-357.
- Urquhart-Secord, R., Craig, J. C., Hemmelgarn, B., Tam-Tham, H., Manns, B., Howell, M., Polkinghorne, K. R., Kerr, P. G., Harris, D. C., Thompson, S., Schick-Makaroff, K., Wheeler, D. C., Van Biesen, W., Winkelmayer, W. C., Johnson, D. W., Howard, K., Evangelidis, N., & Tong, A. (2016). Patient and Caregiver priorities for Outcomes in Hemodialysis: An International Nominal Group Technique study. *American Journal of Kidney Diseases*, 68(3), 444–454. <https://doi.org/10.1053/j.ajkd.2016.02.037>
- Van Ballegooijen, H., Goossens, L., Bruin, R. H., Michels, R., & Krol, M. (2021). Concerns, quality of life, access to care and productivity of the general population during the first 8 weeks of the coronavirus lockdown in Belgium and the Netherlands. *BMC Health Services Research*, 21(1). <https://doi.org/10.1186/s12913-021-06240-7>
- Vat, L. E., Finlay, T., Schuitmaker-Warnaar, T. J., Fahy, N., Robinson, P., Boudes, M., Diaz, A., Ferrer, E., Hivert, V., Purman, G., Kürzinger, L., Kroes, R. A., Hey, C., & Broerse, E. W. (2020). Evaluating the “return on patient engagement initiatives” in medicines research and development: A literature review. *Health Expectations*, 23(1), 5-18. <https://doi.org/10.1111/hex.12951>
- Wong, P., Redley, B., Digby, R., Correya, A., & Bucknall, T. (2020). Families’ perspectives of participation in patient care in an adult intensive care unit: A qualitative study. *Australian Critical Care*, 33(4), 317–325. <https://doi.org/10.1016/j.aucc.2019.06.002>
- Yarosh, L., Bakken, S., Borning, A., De Choudhury, M., Lampe, C., Mynatt, E., Schueller, S., & Veinot, T. (2020). *Computational Support for Substance Use Disorder Prevention, Detection, Treatment, and Recovery*.

14. APPENDIX

14.1 Ethnographic Approach

Ethnographic Approach in Studying Supporting Life Participation

Ethnography is an approach that offers an exceptional chance to expeditiously divulge the multifaceted nature of specific actions, happenings, and circumstances by delving into comprehensive submergence in and mastery of the cultures and contexts that are currently under scrutiny (Hockey & Forsey, 2020). It enables researchers to have a significant engagement and intimate acquaintance with the subjects being studied, facilitating a profound exploration and analysis of the intricate interplay between individuals, biological, psychological and social dynamics at play. (Andreassen et al., 2020).

Moreover, ethnography empowers investigators to not only glean insights from observations and interviews but also unravel the underlying meanings, values, and beliefs that guide and shape human actions and interactions within certain cultural domains. Through its holistic and immersive nature, ethnography provides a unique lens through which scholarly inquiry can unravel the tapestry of human experience, celebrating the diversity and complexity of our shared world. (Lydahl et al.2021)

The purpose of this study was to examine how integrating life participation into nephrology care can improve the quality of life and health outcomes for patients with Chronic Kidney Disease (CKD). To achieve this, a qualitative ethnographic approach was used allowing deep and sensitive understanding from of the healthcare from multiple perspectives (Loizeau et al., 2023).

14.2 Theoretical Foundations

Theoretical Foundations

Biopsychosocial Model

The biopsychosocial model of health, expanded upon from Engel and later incorporated more fully by Engel and Aronson, proposes that medical understanding and treatment of an illness or health condition can't be completely understood or effectively managed without considering the biological causative agents and health outcomes, psychological factors that involve the individual's thoughts, emotions, and behaviours and social drivers of the presenting distress (Aghakhani et al., 2014).

This model is a conceptual framework that assumes the combination of biology (Physical), psychology (mental), and sociology (lifestyle) are essential in understanding a patient's case, especially chronic and disabling physical health conditions. The biopsychosocial model aligns with how nephrology trainees are being taught to understand and manage patient illnesses, as a team collaboration through multidisciplinary care (Yarosh et al., 2020). It also aligns with the nephrology program's goal of supporting patients within the context of their life participation.

Social Constructivism and Life Participation

This study emanated from social constructivism, which provides ways of understanding the world by focusing on social and cultural practices. (Hyde, 2020). It can also be seen as a critique of positivism. Social constructionism includes a commitment to recognizing the social significance given to certain phenomena. This significance has been established through ongoing interaction and in non-chronological sequences and mirrors the power relations of interaction partners. (Rimaioli & McNamee, 2021). The development of comprehensive dialysis services to support the life participation of these patients in their society requires an integrative and transformative approach that considers how medicine interfaces with social reality in dialysis centres (Himmelfarb et al. 2020).

The social constructivist theoretical standpoint argues that the social world and the individuals within it represent the products of their social, economic, and historical surrounding or the result of face-to-face interactions (Nickerson, 2024). At its base lies the notion that the human world exists through and within our interactions with others. Furthermore, the construction of the social world is accomplished through exchanges, similar to the way physical objects are constructed through their physical properties and the exchanges between them. Social interactions or dialogues with the 'significant others' create and stabilize a consensual understanding of the world. (James, 2022).

As the number of patients with End-Stage Renal Disease (ESRD) rises by roughly, nephrology centres seek additional staff and facilities to care for them (Cervantes et al., 2021). Their primary goal is maintaining patient life participation and wellbeing. To achieve these goals, more in-depth understanding and wider insights are essential. It is believed that investigating the social context (people), social relationships, and social exchanges can be beneficial in understanding the complexity of lived individual experiences (Cymorr Kirby Martinez, 2019). Social constructivist theory blends well with this study purpose by providing insights on the role of the social world in forming an individual. Patient life participation is a good lens to understand how patients with ESRD navigate their sufferings and adversities in everyday life (Cymorr Kirby Martinez, 2019).

14.3 SWOT Analysis

Strengths	Weaknesses
Resilience and Adaptability: Several patients demonstrate high resilience, adjusting to new daily routines and staying optimistic in the face of serious health issues. This is evident in their ability to handle self-care on their own, exploring new interests, and adapting to the physical requirements of undergoing dialysis. Support Systems: Robust family support systems, which encompass both emotional and practical aid from partners, offspring, and other relatives, are prevalent. Additionally, community support, such as engagement with a church, also contributes significantly to the preservation of emotional health. Healthcare Access: Accessing medical care and being placed on the kidney transplant waitlist offers a prospect of better health results. Many individuals often express contentment with dialysis centres' and medical professionals' structure and assistance. Faith and Spirituality: Many patients draw strength and motivation from their firm beliefs and spiritual faith, finding comfort and hope in the face of health-related challenges.	Physical Limitations: Continued health problems and the necessity for consistent dialysis greatly limit physical capabilities, movement, and vitality, affecting the independence and life quality of individuals. Exhaustion, discomfort, and other symptoms associated with dialysis restrict everyday tasks and social engagement. Financial Strain: The financial strain caused by transportation costs for dialysis and other medical needs is notable, especially when coupled with inadequate healthcare coverage or financial assistance. This often results in patients being unable to work or experiencing a decrease in income, ultimately leading to financial hardship. Social Isolation: Health issues and prescribed treatments often result in decreased social engagement and a sense of detachment from community and cultural events. This seclusion has the potential to affect mental and emotional well-being, leading to increased feelings of solitude and discontentment. Systemic Healthcare Gaps: Discrepancies within the healthcare system, like deficiencies in post-discharge assistance and home support aid, impact patients' access to all-encompassing care.
Opportunities	Threats
Healthcare and Technological Advances: Progress in medical technology and therapies for kidney disease presents potential for enhancing health outcomes and easing can potentially. Telehealth and home-based care choices have the potential to enhance access and lessen the need for hospital trips. Community and Social Support: Improving community support initiatives and building social connections for people with long-term health conditions can offer added emotional	Health Deterioration: The unpredictable course of CKD, and its potential for advancing into more severe stages, presents an ongoing challenge to patients' well-being and overall quality of life. The possibility of additional health issues arising and impacting treatment outcomes looms as a prominent worry. Social and Economic Insecurity: Limitations on participating in social events and activities could result in heightened feelings of being alone and can negatively affect mental well-

assistance and lessen feelings of seclusion. Personalized communication and supportive tactics tailored to specific patient demographics can enhance the impact of healthcare. Government and Non-profit Resources:Exploring additional resources, subsidies, or assistance programs through government or non-profit organizations could help alleviate financial and practical challenges .Policy changes and increased financial support for transportation and home care services are potential areas for improvement Personal Development and Advocacy:Patients' ability to bounce back from difficult situations and maintain optimistic attitudes create chances for their own development and activism, allowing them to motivate and assist others dealing with comparable obstacles.	being. Continual and possibly rising medical costs, along with the inability to work, may result in financial instability and could impact the ability to obtain essential medical care. Healthcare System Flaws:Deficiencies and ineffectiveness in the healthcare system could lead to insufficient care or assistance, directly impacting the patients' capacity to handle their condition. Relying on the healthcare system for overall wellness underscores the necessity for continual and thorough care.
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14.4 Approval of Ethics Committee

Afzender : Commissie voor medische ethiek
Prof. dr. Wim Van Biesen
UZ Gent

contact	telefoon	e-mail
Commissie voor medische ethiek	+32 (0)9 332 33 36	Ethisch.comite@uzgent.be
Aanvrager	datum	pagina
Henrietta Adom	09/01/2024	1/6
Onze referentie:	EudraCT-nr:	Belg. Regnr:
BC-11716 E02		B6702024000023

Betreft:
Supporting life participation for people with end stage kidney disease: an ethnographic study
Scriptie : Henrietta Adom

Positief advies conform de wet van 7 mei 2004 betreffende experimenten op de menselijke persoon

Beste collega

De Commissie Medische Ethiek (CME) verbonden aan de Universiteit Gent (Ugent) en het Universitair Ziekenhuis Gent (UZ Gent) geeft op 09/01/2024 een gunstig advies over deze studie.

De Commissie voor Medische Ethiek beklemtoont dat een gunstig advies niet betekent dat de Commissie voor Medische Ethiek de verantwoordelijkheid voor het onderzoek op zich neemt.
De promotor en de hoofdonderzoeker dragen de verantwoordelijkheid voor het correcte ethische en wettelijke verloop van het onderzoek.

Ingediende documenten: zie bijlage 1
Ledenlijst: zie Bijlage 2
Aandachtspunten: zie Bijlage 3a

ALGEMENE DIRECTIE
Commissie voor Medische Ethiek

VOORZITTER:
Prof. dr. R. Peleman

SECRETARIS:
Dr. L. Gommers

INGANG 75
ROUTE 7522

Met vriendelijke groeten,
Prof. dr. Renaat Peleman
Voorzitter
Commissie voor Medische Ethiek U(Z) Gent



Universitair Ziekenhuis Gent
C. Heymanslaan 10 | B 9000 Gent
www.uzgent.be

Unofficial translation in English:

Positive advice in accordance with the law of 7 May 2004 on experiments on the human person

The Ethics committee (EC) of University Ghent (Ugent) and Ghent University Hospital (UZ Gent) gives on 09/01/2024 a favourable opinion on this study

EC emphasizes that a favorable opinion does not mean that the Medical Ethics Committee assumes responsibility for the investigation.

The promotor and the principal investigator are responsible for the correct ethical and legal conduct of the research

Submitted documents: see Annex 1

List of members: see appendix 2

Points of concern: see appendix 3b

14.5 Letter of Invitation

ASZ AALST in samenwerking met Universiteit Gent
Dienst Nefrologie
Merestraat 80,
9300 Aalst

Beste,

Betreft: Uitnodiging om deel te nemen aan een etnografisch onderzoek naar chronische nierziekte

Mijn naam is Henrietta en ik ben een student aan de Universiteit Gent. In samenwerking met Algemeen Stedelijk Ziekenhuis Aalst (ASZ Aalst) voeren we een studie uit met de titel "Supporting Life Participation: Een etnografische studie van een nefrologisch centrum".

Het doel van dit onderzoek is om de niet-medische impact van chronische nierziekte op het leven van patiënten en hun naasten te onderzoeken. We willen de uitdagingen, de manieren om ermee om te gaan en de ondersteunende systemen begrijpen waarmee mensen met chronische nierziekte te maken krijgen als ze door hun dagelijkse leven navigeren. Uw deelname aan dit onderzoek zal waardevolle inzichten opleveren die kunnen bijdragen aan toekomstige interventies en ondersteunende diensten voor mensen die leven met een chronische nierziekte.

Als deelnemer aan dit onderzoek wordt u uitgenodigd om uw ervaringen, perspectieven en inzichten te delen door middel van interviews en vragenlijsten. Uw deelname is vrijwillig en alle gedeelde informatie wordt vertrouwelijk behandeld. Uw identiteit wordt geanonimiseerd om uw privacy en vertrouwelijkheid te waarborgen.

Deelname aan dit onderzoek is geheel vrijwillig en u kunt zich op elk moment terugtrekken zonder dat dit gevolgen heeft. Uw beslissing om wel of niet deel te nemen heeft geen invloed op de zorg of diensten die u ontvangt in ons nefrologiecentrum.

Als u geïnteresseerd bent in deelname of meer informatie wilt over het onderzoek, neem dan gerust contact met ons onderzoeksteam via Dr. Katrien Blanckaert (katrien.blanckaert@asz.be) of via Mevrouw Mireille Vandaele (mireille.vandaele@asz.be).

Bedankt dat u overweegt deel te nemen aan ons onderzoek. Uw inbreng is van onschatbare waarde en we waarderen uw tijd en bereidheid om bij te dragen aan een beter begrip van chronische nieraandoeningen.

Met vriendelijke groet,
Henrietta Adom
Student (Master of Science in het management en het beleid van de gezondheidszorg)
Universiteit Gent



AZ Sint-Lucas Gent in samenwerking met Universiteit Gent
Dienst Nefrologie
~~Groenebriel~~ 1,
9000 Gent

Beste,

Betreft: Uitnodiging om deel te nemen aan een etnografisch onderzoek naar chronische nierziekte

Mijn naam is Henrietta en ik ben een student aan de Universiteit Gent. In samenwerking met AZ St. Lucas Gent voeren we een studie uit met de titel "~~Supporting Life Participation~~ Een etnografische studie van een ~~nefrologisch~~ centrum".

Het doel van dit onderzoek is om de niet-medische impact van chronische nierziekte op het leven van patiënten en hun naasten te onderzoeken. We willen de uitdagingen, de manieren om ermee om te gaan en de ondersteunende systemen begrijpen waarmee mensen met chronische nierziekte te maken krijgen als ze door hun dagelijkse leven navigeren. Uw deelname aan dit onderzoek zal waardevolle inzichten opleveren die kunnen bijdragen aan toekomstige interventies en ondersteunende diensten voor mensen die leven met een chronische nierziekte.

Als deelnemer aan dit onderzoek wordt u uitgenodigd om uw ervaringen, perspectieven en inzichten te delen door middel van interviews en vragenlijsten. Uw deelname is vrijwillig en alle gedeelde informatie wordt vertrouwelijk behandeld. Uw identiteit wordt geanonimiseerd om uw privacy en vertrouwelijkheid te waarborgen.

Deelname aan dit onderzoek is geheel vrijwillig en u kunt zich op elk moment terugtrekken zonder dat dit gevolgen heeft. Uw beslissing om wel of niet deel te nemen heeft geen invloed op de zorg of diensten die u ontvangt in ons nefrologiecentrum.

Als u geïnteresseerd bent in deelname of meer informatie wilt over het onderzoek, neem dan gerust contact met ons onderzoeksteam via ~~Dr. Valerie Neiryck~~ (valerie.neiryck@azstlucas.be).

Bedankt dat u overweegt deel te nemen aan ons onderzoek. Uw inbreng is van onschatbare waarde en we waarderen uw tijd en bereidheid om bij te dragen aan een beter begrip van chronische nieraandoeningen.

Met vriendelijke groet,
Henrietta Adom
Student (Master of Science in het management en het beleid van de gezondheidszorg)
Universiteit Gent



14.6 Informed Consent for Patients

Informatiebrief voor de deelnemers

Titel van de studie: Supporting Life participation: an ethnographic study of a nephrology center

Beste,

U wordt uitgenodigd om deel te nemen aan een studie. Neem, voor u beslist om deel te nemen aan deze studie, voldoende tijd om deze informatiebrief aandachtig te lezen en dit te bespreken met de onderzoeker of zijn/haar vertegenwoordiger. Neem ook de tijd om vragen te stellen indien er onduidelijkheden zijn of indien u bijkomende informatie wenst. Dit proces wordt "informed consent" of "geïnformeerde toestemming" voor deelname aan een experiment genoemd. Eens u beslist heeft om deel te nemen aan de studie zal men u vragen om het toestemmingsformulier achteraan te ondertekenen.

1. BESCHRIJVING EN DOEL VAN DE STUDIE

U zal binnenkort een vraag tot deelname aan de studie ontvangen via een onderzoeker aan de dienst Nefrologie te ASZ AALST.

De dienst Nefrologie van het ASZ AALST voert, in samenwerking met de vakgroep Management en het beleid in de gezondheidszorg van de Universiteit Gent, een etnografisch onderzoek uit naar de kwaliteit van leven van de chronische nierpatiënt. Het onderzoek heeft als doel nieuwe inzichten te verkrijgen in het verbeteren van de levenskwaliteit van chronische nierpatiënten. In het kader van dit onderzoek zal de onderzoeker van u, na uw goedkeuren, een interview afnemen omtrent de impact van het hebben van een chronische nieraandoening op u leven en uw ervaring met de huidige ondersteuning van de levenskwaliteit tijdens het behandeltraject voor u. Dit interview zal ongeveer een uur duren en vindt plaats met u alleen, of samen met uw naaste, naargelang wat uw voorkeur draagt. De interviews zullen, na uw goedkeuren, worden opgenomen en woord voor woord worden neergeschreven, de opname wordt daaropvolgend onmiddellijk vernietigd. Er kan ook relevante data m.b.t. de onderzoeksopzet uit het patiëntendossier worden verzameld (leeftijd, werk/opleiding status, gezondheidsgegevens). Alle data wordt steeds gepseudonimiseerd. Het onderzoek zal plaats vinden tijdens een moment en plaats ter uw keuze (met de mogelijkheid tot een online interview).

Deze studie werd vooraf goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het Universitair Ziekenhuis van Gent en de Universiteit Gent. De studie wordt uitgevoerd volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki opgesteld ter bescherming van mensen deelnemend aan klinische studies.

De opdrachtgever van deze studie is de dienst Nefrologie te UZ Gent, onder leiding van Prof. Dr. Wim Van Biesen. Deze verzameling van gegevens wordt uitgevoerd onder supervisie van Prof. Dr. Wim Van Biesen (UZ Gent) en Meneer Timothy

Moreels (UGent vakgroep Revalidatiewetenschappen). Zowel medewerkers van de dienst Nefrologie UZ Gent, als studenten van de vakgroep management en het beleid in de gezondheidszorg UGent zullen deel uitmaken van het onderzoeksteam.

2. TOESTEMMING EN WEIGERING

De deelname aan deze studie is volledig vrijwillig. U kunt weigeren om aan het onderzoek deel te nemen zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enige wijze een invloed zal hebben op de verdere relatie met de onderzoeker of het onderzoeksteam.

3. VOORDELEN

Deelname aan deze studie brengt voor u geen onmiddellijk voordeel met zich mee. De verkregen resultaten kunnen echter leiden tot nieuwe inzichten inzake het verbeteren van de levenskwaliteit van de chronische nierpatiënt.

4. KOSTEN

Deelname aan deze studie brengt geen extra kosten mee voor u, maar biedt ook geen financieel voordeel.

5. VERWERKING VAN PERSOONSGEGEVENS

In overeenstemming met de Algemene Verordening Gegevensbescherming (AVG of GDPR) (EU) 2016/679 van 27 april 2016 en de Belgische wet van 30 juli 2018, betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens, zal uw persoonlijke levenssfeer worden gerespecteerd en kan u toegang krijgen tot de over u verzamelde gegevens. Elk onjuist gegeven kan op uw verzoek verbeterd worden. Ook over uw andere rechten (o.a. het recht op beperking van de verwerking van uw (persoons)gegevens, het recht om uw (reeds verzamelde) gegevens te laten wissen in bepaalde omstandigheden, en het recht om een klacht in te dienen) wordt gewaakt.

Voor meer informatie over de rechten die u heeft en hoe u die kan uitoefenen, kan u terecht op de website van UZ Gent: <https://www.uzgent.be/patient/gegevensbescherming/u-neemt-deel-aan-wetenschappelijk-onderzoek>

Uw deelname aan de studie betekent dat uw gegevens verwerkt worden voor het doel van de klinische studie. Deze verwerking van gegevens is noodzakelijk voor de vervulling van een taak in het algemeen belang volgens artikel 6, paragraaf 1 (e) en is noodzakelijk met het oog op wetenschappelijk onderzoek volgens artikel 9, paragraaf 2 (j) van de Algemene Verordening Gegevensbescherming.

Alle informatie die tijdens deze studie verzameld wordt, zal gepseudonimiseerd worden (hierbij kan men uw gegevens nog terug koppelen naar uw persoonlijk dossier door middel van een code). De sleutel tot de codes zal enkel toegankelijk zijn voor de onderzoekende arts of de door hem/haar aangestelde vervanger. De verzamelde gepseudonimiseerde gegevens kunnen gedeeld worden met andere (toekomstige) onderzoekers. Dit kan leiden tot hergebruik van uw gepseudonimiseerde gegevens voor toekomstige academische onderzoeksprojecten en studies, uitsluitend in het kader van dezelfde of een vergelijkbare ziekte/pathologie of behandeling. Dergelijke nieuwe studie en hergebruik van gegevens dient steeds ingediend en goedgekeurd te worden door het ethisch comité. Indien u wenst dat uw gegevens niet gebruikt worden voor toekomstig onderzoek, kan u de DPO hiervoor contacteren (zie contactgegevens onder hoofdstuk 5). Enkel de gepseudonimiseerde gegevens zullen gebruikt worden voor analyse van de gegevens en in alle documentatie, rapporten of publicaties (in medische tijdschriften of congressen) over de studie. Vertrouwelijkheid van uw gegevens wordt dus steeds gegarandeerd.

Zowel persoonsgegevens als gegevens aangaande uw gezondheid zullen verwerkt en bewaard worden tot minstens 10 jaar na het einde van de studie en uit veiligheidsoverwegingen ten aanzien van de uitgevoerde studie en de (eventuele) opvolging daarvan.

De verwerkingsverantwoordelijke van de gegevens is de instelling van de hoofdonderzoeker van de studie, Prof. Dr. Wim Van Biesen (UZGent). Zijn/haar onderzoeksteam zal toegang krijgen tot uw persoonsgegevens. Gegevens uit het patiëntendossier worden verwerkt in het kader van de verbeteringsprocessen van de organisatie en de gezondheidszorg in het algemeen.

Wanneer uw gegevens overgemaakt worden aan een land buiten de Europese Economische Ruimte (EER), dan zal U(Z) Gent er zich van vergewissen of het land van bestemming een passend beschermingsniveau biedt. Wanneer het land waarnaar U(Z) Gent gegevens wenst over te maken geen passende waarborgen biedt, zal U(Z) Gent via modelovereenkomsten, ter beschikking gesteld door de Europese Commissie, of andere aanvaarde maatregelen zelf passende waarborgen afdwingen.

Vertegenwoordigers van de opdrachtgever, auditoren, de Commissie voor Medische Ethiek en de bevoegde overheden, allen gebonden door het beroepsgeheim, hebben rechtstreeks toegang tot uw medische dossiers om de procedures van de studie en/of de gegevens te controleren, zonder de vertrouwelijkheid te schenden. Dit kan enkel binnen de grenzen die door de betreffende wetten zijn toegestaan. Door het toestemmingsformulier, na voorafgaande uitleg, te ondertekenen, stemt u in met deze toegang.

Om meer inhoudelijke informatie te verkrijgen over de studie en om uw rechten uit te kunnen oefenen, kan u contact opnemen met het studieteam.

De Data Protection Officer kan u desgewenst meer informatie verschaffen over de bescherming van uw persoonsgegevens. Contactgegevens: Katya Van Driessche, dpo@uzgent.be.

De Belgische toezichthoudende instantie die verantwoordelijk is voor het handhaven van de wetgeving inzake gegevensbescherming is bereikbaar via onderstaande contactgegevens:

Gegevensbeschermingsautoriteit (GBA)
Drukpersstraat 35 – 1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact@apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

6. VERZEKERING

De opdrachtgever voorziet in een vergoeding en/of medische behandeling in het geval van schade en/of letsel ten gevolge van deelname aan deze klinische studie. Voor dit doeleinde is een verzekering afgesloten met foutloze aansprakelijkheid conform de wet inzake experimenten op de menselijke persoon van 7 mei 2004, de Belgische wet van 7 mei 2017 betreffende klinische proeven met geneesmiddelen voor menselijk gebruik en de Belgische Wet van 22 december 2020 betreffende medische hulpmiddelen (Allianz Global Corporate & Specialty, Uitbreidingstraat 86, 2600 Berchem; Tel: +32 33 04 16 00; polisnummer voor UZ Gent BEL001889 – polisnummer voor UGent BEL000862).

7. CONTACT

Als er een letsel optreedt ten gevolge van de studie, of als u aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt u contact opnemen met de dienst, hoofdverpleegkundige Mireille Vandaele, diensthoofd Dr. Katrien Blanckaert, of een onderzoeker of een medewerker van zijn of haar team:

Polikliniek Nefrologie A.S.Z CAMPUS AALST

Diensthofd: Dr. Katrien Blanckaert

Hoofdverpleegkundige: Mireille Vandaele

Adres: ~~Merestraat~~ 80, 9300 Aalst

Telefoonnummer: 053 76 41 11

Naam: Timothy Moreels

Adres: C. Heymanslaan 10, 9000 Gent

~~Telefoonnummer:~~ 0487 54 71 41

Naam: Henrietta Adom

~~Adres:~~ C. Heymanslaan 10, 9000 Gent

~~Telefoonnummer:~~ 0486 827630

TOESTEMMINGSFORMULIER VOOR DE DEELNEMERS

Ik heb het document "Informatiebrief voor de deelnemers" pagina 1 tot en met 6 gelezen en begrepen en ik heb er een kopij van gekregen. Ik heb uitleg gekregen over de aard, het doel en de duur van de studie en over wat men van mij verwacht.

Ik begrijp dat deelname aan de studie vrijwillig is en dat ik mij op elk ogenblik uit de studie mag terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere behandeling.
--

Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en de Universiteit Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze
--

goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.
Men heeft mij ingelicht dat zowel persoonlijke gegevens als gegevens aangaande mijn gezondheid worden verwerkt en bewaard gedurende minstens 10 jaar na het einde van de studie. Ik ben op de hoogte dat ik recht heb op toegang en op verbetering van deze gegevens. Aangezien deze gegevens verwerkt worden in het kader van medisch-wetenschappelijke doeleinden, begrijp ik dat de toegang tot mijn gegevens kan uitgesteld worden tot na beëindiging van het onderzoek. Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de arts-onderzoeker die verantwoordelijk is voor de verwerking ervan.
Ik ben ervan op de hoogte dat mijn gepersonaliseerde gegevens gebruikt worden voor huidig wetenschappelijk onderzoek .
Ik ben ervan op de hoogte dat mijn gepersonaliseerde gegevens gebruikt kunnen worden voor toekomstig academisch wetenschappelijk onderzoek in het kader van hetzelfde/een vergelijkbaar onderzoeksdomein . Dergelijke nieuwe studie dient steeds ingediend en goedgekeurd te worden door het ethisch comité. Indien ik wens dat mijn gegevens niet gebruikt worden voor toekomstig onderzoek, zal ik de DPO contacteren (zie contactgegevens onder sectie 5).

Aankruisen door de deelnemer indien akkoord

Ik stem in om deel te nemen aan deze studie bestaande uit volgende **verplichte aspecten** zoals toegelicht onder hoofdstuk 1 van de informatiebrief:

- Ik stem ermee in om volledig samen te werken met de onderzoeker.
- Ik stem ermee in dat een interview zal worden afgenomen.
- Ik stem ermee in dat dit interview kan worden opgenomen.
- Ik stem ermee in dat relevante gegevens (leeftijd, werk/opleiding status, gezondheidsgegevens) uit het elektronisch patiëntendossier kunnen opgehaald worden.

Naam en voornaam van de deelnemer	Handtekening	Datum
Naam en voornaam van de arts-onderzoeker*	Handtekening	Datum

2 kopieën dienen te worden vervolledigd. Het origineel wordt door de onderzoeker bewaard in het ziekenhuis gedurende minstens 10 jaar, de kopie wordt aan de deelnemer gegeven.

***Aankruisen door de onderzoeker indien akkoord**

Ik verklaar de benodigde informatie inzake deze studie (de aard, het doel, en de te voorziene effecten) mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.	
Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen toestemmen tot deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.	

14.7 Informed Consent for Workers

Informatiebrief voor de deelnemers

Titel van de studie: ~~Supporting Life participation: an ethnographic study of a nephrology center~~

Beste,

U wordt uitgenodigd om deel te nemen aan een studie. Neem, voor u beslist om deel te nemen aan deze studie, voldoende tijd om deze informatiebrief aandachtig te lezen en dit te bespreken met de onderzoeker of zijn/haar vertegenwoordiger. Neem ook de tijd om vragen te stellen indien er onduidelijkheden zijn of indien u bijkomende informatie wenst. Dit proces wordt "informed consent" of "geïnformeerde toestemming" voor deelname aan een experiment genoemd. Eens u beslist heeft om deel te nemen aan de studie zal men u vragen om het toestemmingsformulier achteraan te ondertekenen.

1. BESCHRIJVING EN DOEL VAN DE STUDIE

U zal binnenkort een vraag tot deelname aan de studie ontvangen via een onderzoeker aan de dienst Nefrologie te AZ SINT-LUCAS GENT.

De dienst Nefrologie van het AZ SINT-LUCAS GENT voert, in samenwerking met de vakgroep Management en het beleid in de gezondheidszorg van de Universiteit Gent, een etnografisch onderzoek uit naar de kwaliteit van leven van de chronische nierpatiënt. Het onderzoek heeft als doel nieuwe inzichten te verkrijgen in het verbeteren van de levenskwaliteit van chronische nierpatiënten. In het kader van dit onderzoek zal de onderzoeker van u, na uw goedkeuren, een interview afnemen omtrent de impact van het hebben van een chronische nieraandoening op u leven en uw ervaring met de huidige ondersteuning van de levenskwaliteit tijdens het behandeltraject voor u. Dit interview zal ongeveer een uur duren en vindt plaats met u alleen, of samen met uw naaste, naargelang wat uw voorkeur draagt. De interviews zullen, na uw goedkeuren, worden opgenomen en woord voor woord worden neergeschreven, de opname wordt daaropvolgend onmiddellijk vernietigd. Er kan ook relevante data m.b.t. de onderzoeksopzet uit het patiëntendossier worden verzameld (leeftijd, werk/opleiding status, gezondheidsgegevens). Alle data wordt steeds ~~gepseudonimiseerd~~. Het onderzoek zal plaats vinden tijdens een moment en plaats ter uw keuze (met de mogelijkheid tot een online interview).

Deze studie werd vooraf goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan AZ Sint-Lucas Gent en de Universiteit Gent. De studie wordt uitgevoerd volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki opgesteld ter bescherming van mensen deelnemend aan klinische studies.

De opdrachtgever van deze studie is de dienst Nefrologie te UZ Gent, onder leiding van Prof. Dr. Wim Van Biesen. Deze verzameling van gegevens wordt uitgevoerd onder supervisie van Prof. Dr. Wim Van Biesen (UZ Gent) en Meneer Timothy Moreels (~~UZ Gent~~, vakgroep Revalidatiewetenschappen). Zowel medewerkers van de

dienst Nefrologie UZ Gent, Dr. Valerie Neirynck (AZ Sint-Lucas Gent) als studenten van de vakgroep management en het beleid in de gezondheidszorg UGent zullen deel uitmaken van het onderzoeksteam.

2. TOESTEMMING EN WEIGERING

De deelname aan deze studie is volledig vrijwillig. U kunt weigeren om aan het onderzoek deel te nemen zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enige wijze een invloed zal hebben op de verdere relatie met de onderzoeker of het onderzoeksteam.

3. VOORDELEN

Deelname aan deze studie brengt voor u geen onmiddellijk voordeel met zich mee. De verkregen resultaten kunnen echter leiden tot nieuwe inzichten inzake het verbeteren van de levenskwaliteit van de chronische nierpatiënt.

4. KOSTEN

Deelname aan deze studie brengt geen extra kosten mee voor u, maar biedt ook geen financieel voordeel.

5. VERWERKING VAN PERSOONSGEGEVENS

In overeenstemming met de Algemene Verordening Gegevensbescherming (AVG of GDPR) (EU) 2016/679 van 27 april 2016 en de Belgische wet van 30 juli 2018, betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens, zal uw persoonlijke levenssfeer worden gerespecteerd en kan u toegang krijgen tot de over u verzamelde gegevens. Elk onjuist gegeven kan op uw verzoek verbeterd worden. Ook over uw andere rechten (o.a. het recht op beperking van de verwerking van uw (persoons)gegevens, het recht om uw (reeds verzamelde) gegevens te laten wissen in bepaalde omstandigheden, en het recht om een klacht in te dienen) wordt gewaakt. Voor meer informatie over de rechten die u heeft en hoe u die kan uitoefenen, kan u terecht op de website van UZ Gent: <https://www.uzgent.be/patient/gegevensbescherming/u-neemt-deel-aan-wetenschappelijk-onderzoek>

Uw deelname aan de studie betekent dat uw gegevens verwerkt worden voor het doel van de klinische studie. Deze verwerking van gegevens is noodzakelijk voor de vervulling van een taak in het algemeen belang volgens artikel 6, paragraaf 1 (e) en is noodzakelijk met het oog op wetenschappelijk onderzoek volgens artikel 9, paragraaf 2 (j) van de Algemene Verordening Gegevensbescherming.

Alle informatie die tijdens deze studie verzameld wordt, zal gepseudonimiseerd worden (hierbij kan men uw gegevens nog terug koppelen naar uw persoonlijk dossier

door middel van een code). De sleutel tot de codes zal enkel toegankelijk zijn voor de onderzoekende arts of de door hem/haar aangestelde vervanger. De verzamelde ~~gepseudonimiseerde~~ gegevens kunnen gedeeld worden met andere (toekomstige) onderzoekers. Dit kan leiden tot hergebruik van uw ~~gepseudonimiseerde~~ gegevens voor toekomstige academische onderzoeksprojecten en studies, uitsluitend in het kader van dezelfde of een vergelijkbare ziekte/pathologie of behandeling. Dergelijke nieuwe studie en hergebruik van gegevens dient steeds ingediend en goedgekeurd te worden door het ethisch comité. Indien u wenst dat uw gegevens niet gebruikt worden voor toekomstig onderzoek, kan u de DPO hiervoor contacteren (zie contactgegevens onder hoofdstuk 5).

Enkel de ~~gepseudonimiseerde~~ gegevens zullen gebruikt worden voor analyse van de gegevens en in alle documentatie, rapporten of publicaties (in medische tijdschriften of congressen) over de studie. Vertrouwelijkheid van uw gegevens wordt dus steeds gegarandeerd.

Zowel persoonsgegevens als gegevens aangaande uw gezondheid zullen verwerkt en bewaard worden tot minstens 10 jaar na het einde van de studie en uit veiligheidsoverwegingen ten aanzien van de uitgevoerde studie en de (eventuele) opvolging daarvan.

De verwerkingsverantwoordelijke van de gegevens is de instelling van de hoofdonderzoeker van de studie, Prof. Dr. Wim Van Biesen (UZ Gent). Zijn/haar onderzoeksteam zal toegang krijgen tot uw persoonsgegevens. Gegevens uit het patiëntendossier worden verwerkt in het kader van de verbeteringsprocessen van de organisatie en de gezondheidszorg in het algemeen.

Wanneer uw gegevens overgemaakt worden aan een land buiten de Europese Economische Ruimte (EER), dan zal U(Z) Gent er zich van vergewissen of het land van bestemming een passend beschermingsniveau biedt. Wanneer het land waarnaar U(Z) Gent gegevens wenst over te maken geen passende waarborgen biedt, zal U(Z) Gent via modelovereenkomsten, ter beschikking gesteld door de Europese Commissie, of andere aanvaarde maatregelen zelf passende waarborgen afdwingen.

Vertegenwoordigers van de opdrachtgever, auditoren, de Commissie voor Medische Ethiek en de bevoegde overheden, allen gebonden door het beroepsgeheim, hebben rechtstreeks toegang tot uw medische dossiers om de procedures van de studie en/of de gegevens te controleren, zonder de vertrouwelijkheid te schenden. Dit kan enkel binnen de grenzen die door de betreffende wetten zijn toegestaan. Door het toestemmingsformulier, na voorafgaande uitleg, te ondertekenen, stemt u in met deze toegang.

Om meer inhoudelijke informatie te verkrijgen over de studie en om uw rechten uit te kunnen oefenen, kan u contact opnemen met het studieteam.

De Data Protection Officer kan u desgewenst meer informatie verschaffen over de bescherming van uw persoonsgegevens. Contactgegevens: ~~Katya Van Driessche~~ ~~dpo@uzgent.be~~.

De Belgische toezichthoudende instantie die verantwoordelijk is voor het handhaven van de wetgeving inzake gegevensbescherming is bereikbaar via onderstaande contactgegevens:

Gegevensbeschermingsautoriteit (GBA)
Drukpersstraat 35 – 1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact@apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

6. VERZEKERING

De opdrachtgever voorziet in een vergoeding en/of medische behandeling in het geval van schade en/of letsel ten gevolge van deelname aan deze klinische studie. Voor dit doeleinde is een verzekering afgesloten met foutloze aansprakelijkheid conform de wet inzake experimenten op de menselijke persoon van 7 mei 2004, de Belgische wet van 7 mei 2017 betreffende klinische proeven met geneesmiddelen voor menselijk gebruik en de Belgische Wet van 22 december 2020 betreffende medische hulpmiddelen (Allianz Global Corporate & Specialty, Uitbreidingstraat 86, 2600 Berchem; Tel: +32 33 04 16 00; polisnummer voor UZ Gent BEL001889 – polisnummer voor UGent BEL000862).

7. CONTACT

Als er een letsel optreedt ten gevolge van de studie, of als u aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt u contact opnemen met de dienst, hoofdverpleegkundige Ingrid Varendonck, Dr. Valerie Neirynck (een nefroloog) of een andere medewerker of onderzoeker van zijn of haar team:

AZ Sint-Lucas Gent(nierziekten)
Diensthooft: Dr. Céline Seghers
Hoofdverpleegkundige: Ingrid Varendonck
Adres: ~~Groenbriel 1~~, 9000 Gent
Telefoonnummer: 09 224 69 50

Naam: Timothy Moreels
Adres: C. Heymanslaan 10, 9000 Gent
~~Telefoonnummer: 0487 54 71 41~~

Naam: Henrietta Adom
~~Adres: C. Heymanslaan 10~~, 9000 Gent
~~Telefoonnummer: 0486 827630~~

TOESTEMMINGSFORMULIER VOOR DE DEELNEMERS

Ik heb het document "Informatiebrief voor de deelnemers" pagina 1 tot en met 6 gelezen en begrepen en ik heb er een kopij van gekregen. Ik heb uitleg gekregen over de aard, het doel en de duur van de studie en over wat men van mij verwacht.

Ik begrijp dat deelname aan de studie vrijwillig is en dat ik mij op elk ogenblik uit de studie mag terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere behandeling.

Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en de Universiteit Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.

Men heeft mij ingelicht dat zowel persoonlijke gegevens als gegevens aangaande mijn gezondheid worden verwerkt en bewaard gedurende minstens 10 jaar na het einde van de studie. Ik ben op de hoogte dat ik recht heb op toegang en op verbetering van deze gegevens. Aangezien deze gegevens verwerkt worden in het kader van medisch-wetenschappelijke doeleinden, begrijp ik dat de toegang tot mijn gegevens kan uitgesteld worden tot na beëindiging van het onderzoek. Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de arts-onderzoeker die verantwoordelijk is voor de verwerking ervan.

Ik ben ervan op de hoogte dat mijn ~~gepersonaliseerde~~ gegevens gebruikt worden voor **huidig wetenschappelijk onderzoek**.

Ik ben ervan op de hoogte dat mijn ~~gepersonaliseerde~~ gegevens gebruikt kunnen worden voor toekomstig academisch wetenschappelijk onderzoek in het kader van hetzelfde/een vergelijkbaar ~~onderzoek/doel~~. Dergelijke nieuwe studie dient steeds ingediend en goedgekeurd te worden door het ethisch comité. Indien ik wens dat mijn gegevens niet gebruikt worden voor toekomstig onderzoek, zal ik de DFO contacteren (zie contactgegevens onder sectie 5).

Aankruisen door de deelnemer indien akkoord

Ik stem in om deel te nemen aan deze studie bestaande uit volgende **verplichte aspecten** zoals toegelicht onder hoofdstuk 1 van de informatiebrief:

- Ik stem ermee in om volledig samen te werken met de onderzoeker.
- Ik stem ermee in dat een interview zal worden afgenomen.
- Ik stem ermee in dat dit interview kan worden opgenomen.
- Ik stem ermee in dat relevante gegevens (leeftijd, werk/opleiding status, gezondheidsgegevens) uit het elektronisch patiëntendossier kunnen opgehaald worden.

Naam en voornaam van de deelnemer	Handtekening	Datum
Naam en voornaam van de arts-onderzoeker*	Handtekening	Datum

2 kopieën dienen te worden vervolledigd. Het origineel wordt door de onderzoeker bewaard in het ziekenhuis gedurende minstens 10 jaar, de kopie wordt aan de deelnemer gegeven.

***Aankruisen door de onderzoeker indien akkoord**

Ik verklaar de benodigde informatie inzake deze studie (de aard, het doel, en de te voorzien effecten) mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.	
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Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen toestemmen tot deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.	
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14.8 Informed Consent for Neighbours

Information letter for participants

Study title: Supporting Life participation: an ethnographic study of a nephrology center

Best,

You are invited to participate in a study. Before you decide to participate in this study, please take sufficient time to read this information letter carefully and discuss it with the investigator or his/her representative. Also, take the time to ask questions if there are ambiguities or if you would like additional information. This process is called "informed consent" to participate in an experiment. Once you have decided to participate in the study, you will be asked to sign the consent form on the back.

1. DESCRIPTION AND PURPOSE OF THE STUDY

You will soon receive a request to participate in the study through your loved one or through a researcher at the Nephrology Department at UZ Gent.

The Nephrology Department of Ghent University Hospital, in collaboration with the Department of Management and Policy in Health Care at Ghent University, is conducting an ethnographic study on the quality of life of the chronic kidney patient. The research aims to gain new insights into improving the quality of life of chronic kidney patients. As part of this study, upon your approval, the researcher will interview you regarding the impact of having chronic kidney disease on your life and your experience with current quality of life support during the treatment process for you. This interview will last approximately one hour and will take place with you alone, or with your loved one, whichever is preferred. The interviews will be recorded and written down word for word after your approval, and the recording will be destroyed immediately afterwards. Relevant data regarding the study design can also be collected from the patient's file (age, work/education status, health data). All data will always be pseudonymized. The examination will take place at a time and place of your choice (with the possibility of an online interview).

This study was pre-approved by an independent Medical Ethics Committee affiliated with Ghent University Hospital and Ghent University. The study is conducted according to the guidelines for good clinical practice (ICH/GCP) and the Declaration of Helsinki established to protect people participating in clinical studies.

The sponsor of this study is the Nephrology Department at UZ Gent, under the direction of Prof. Dr. Wim Van Biesen. This data collection is performed under the supervision of Prof. Dr. Wim Van Biesen (UZ Gent) and Mr. Timothy Moreels (UGent, Department of Rehabilitation Sciences). Both employees of the Nephrology Department UZ Gent and students of the Department of Management and Policy in Health Care UGent will be part of the research team.

2. CONSENT AND REFUSAL

Participation in this study is completely voluntary. You may refuse to participate in the study without having to provide a reason and without in any way affecting your continued relationship with the researcher or research team.

3. ADVANTAGES

Participation in this study brings no immediate benefit to you. However, the results obtained may lead to new insights on improving the quality of life of the chronic kidney patient.

4. COST

Participation in this study entails no additional cost to you, but it also offers no financial benefit.

5. PROCESSING OF PERSONAL DATA

In accordance with the General Data Protection Regulation (AVG or GDPR) (EU) 2016/679 of April 27, 2016 and the Belgian law of July 30, 2018, on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, your privacy will be respected and you may access the data collected about you. Any incorrect data can be corrected at your request. Your other rights (including the right to restrict the processing of your (personal) data, the right to have your (already collected) data erased in certain circumstances, and the right to lodge a complaint) will also be safeguarded.

For more information on the rights you have and how to exercise them, please visit the UZ Gent website: <https://www.uzgent.be/patient/gegevensbescherming/u-neemt-deel-aan-wetenschappelijk-onderzoek>

Your participation in the study means that your data will be processed for the purpose of the clinical study. This processing of data is necessary for the performance of a task in the public interest according to Article 6, paragraph 1 (e) and is necessary for the purpose of scientific research according to Article 9, paragraph 2 (j) of the General Data Protection Regulation.

All information collected during this study will be pseudonymized (in doing so, your data can still be linked back to your personal file by means of a code). The key to the codes will be accessible only to the examining physician or his/her designated substitute. The pseudonymized data collected may be shared with other (future) investigators. This may lead to reuse of your pseudonymized data for future academic research projects and studies exclusively in the context of the same or similar disease/pathology or treatment. Such new study and data reuse must always be submitted and approved by the ethics committee. If you wish your data not to be used for future research, you may contact the DPO for this purpose (see contact details under section 5).

Only the pseudonymized data will be used for data analysis and in any documentation, reports or publications (in medical journals or congresses) about the study. Confidentiality of your data is thus guaranteed at all times.

Both personal data and data concerning your health will be processed and kept for at least 10 years after the end of the study and for security reasons regarding the study conducted and its follow-up (if any).

The data controller is the institution of the study's principal investigator, Prof. Dr. Wim Van Biesen (UZGent). His/her research team will have access to your personal data. Data from the patient file will be processed in the context of the improvement processes of the organization and health care in general.

When your data is transferred to a country outside the European Economic Area (EEA), U(Z) Ghent will ensure that the destination country provides an adequate level of protection. If the country to which U(Z) Ghent wishes to transfer data does not provide adequate safeguards, U(Z) Ghent will itself enforce adequate safeguards through model agreements, made available by the European Commission, or other accepted measures.

Representatives of the sponsor, auditors, the Medical Ethics Committee and the competent authorities, all bound by professional secrecy, have direct access to your medical records to check the procedures of the study and/or the data, without violating confidentiality. This can only be done within the limits permitted by the relevant laws. By signing the consent form, after prior explanation, you consent to this access.

To obtain more substantive information about the study and to exercise your rights, please contact the study team.

The Data Protection Officer can provide you with more information about the protection of your personal data if you wish. Contact details: Katya Van Driessche, dpo@uzgent.be.

The Belgian supervisory authority responsible for enforcing data protection legislation can be reached at the contact details below:

Data Protection Authority (GBA).
Press Street 35 - 1000 Brussels
Tel. +32 2 274 48 00
email: contact@apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

6. INSURANCE

The sponsor provides compensation and/or medical treatment in the event of damage and/or injury resulting from participation in this clinical trial. For this purpose, an insurance policy with faultless liability has been taken out in accordance with the Law on Experiments on the Human Person of May 7, 2004, the Belgian Law of May 7, 2017 on clinical trials on medicinal products for human use and the Belgian Law of December 22, 2020 on medical devices (Allianz Global Corporate & Specialty;

Uitbreidingstraat 86, 2600 Berchem; Tel: +32 33 04 16 00; policy number for UZ Gent BEL001889 - policy number for UGent BEL000862).

7. CONTACT

If an injury occurs as a result of the study, or if you require additional information about the study or about your rights and obligations, please contact the department, Chief Nurse Tamara Leune, Department Head Prof. Van Biesen, or an investigator or a member of his or her team:

Outpatient Clinic Nephrology UZ Gent

Head of service: Prof. Van Biesen Wim

Head nurse: Tamara Leune

Address: C. Heymanslaan 10, 9000 Ghent, Entrance 12, route 1231

Phone number: 09 332 45 09
Center for Dialysis and Apheresis UZ Gent

Entrance 25, route 283

Phone number: 09 332 45 67

Name: Timothy Moreels

Address: C. Heymanslaan 10, 9000 Ghent

Phone number: 0487 54 71 41

Name: Henrietta Adom

Address: C. Heymanslaan 10, 9000 Ghent

Phone number: 0486 827630

CONSENT FORM FOR PARTICIPANTS

I have read and understood the document "Information Letter for Participants" pages 1 through 6 and have been given a copy of it. I have been explained the nature, purpose and duration of the study and what is expected of me. I understand that participation in the study is voluntary and that I may withdraw from the study at any time without giving a reason for this decision and without in any way affecting my continued treatment. I am aware that this study was approved by an independent Committee on Medical Ethics attached to Ghent University Hospital and the University of Ghent and that this study will be conducted according to the guidelines for good clinical practice (ICH/GCP) and the Declaration of Helsinki, established to protect people participating in experiments. This approval was in no way the impetus for deciding to participate in this study. I have been informed that both personal data and data concerning my health will be processed and kept for at least 10 years after the end of the study. I am informed that I have the right to access and correct this data. As this data is processed for medical

scientific purposes, I understand that access to my data may be delayed until after the study has ended. If I want access to my data, I will contact the physician-investigator responsible for its processing.
I am aware that my pseudonymized data will be used for current scientific research.
I am aware that my pseudonymized data may be used for future academic scientific research within the framework of the same/similar research field. Such new study should always be submitted and approved by the ethics committee. If I wish my data not to be used for future research, I will contact the DPO (see contact details under section 5).

Check box by participant if agreed

I agree to participate in this study consisting of following **mandatory aspects** as explained under section 1 of the information letter:

- I agree to cooperate fully with the researcher.
- I agree that an interview will be conducted.
- I agree that this interview can be recorded.
- I agree that relevant data (age, work/education status, health data) can be retrieved from the electronic health record.

Name and first name of participant	Signature	Date
Name and first name of physician-investigator*	Signature	Date

2 copies should be completed. The original will be kept by the researcher in the hospital for at least 10 years, the copy will be given to the participant.

***Tick the box by the researcher if approved**

I certify that I have verbally provided the necessary information regarding this study (the nature, purpose, and foreseeable effects) as well as a copy of the information document to the participant.	
I confirm that no pressure has been exerted on the participant to get him/her to agree to participate in the study and I am willing to answer any additional questions.	

14.9 Interview Guide

Intervieweids voor Verpleegkundigen en Medewerkers in een Nefrologiecentrum

Introductie

Hartelijk dank voor uw deelname aan dit onderzoek. Uw ervaringen en inzichten zijn essentieel om de ondersteuning voor patiënten met chronische nierziekte (CKD) te verbeteren. Deze vragenlijst richt zich op uw ervaringen en observaties binnen de nefrologie en hoe deze de leven participatie van patiënten beïnvloeden. Uw antwoorden blijven anoniem en vertrouwelijk.

Demografische Gegevens

1. Hoe oud bent u?
2. Hoeveel jaar ervaring hebt u in uw huidige functie?
3. Hoe lang werkt u al op deze afdeling?
4. Welke vooropleiding hebt u gevolgd?
5. Wat is uw specialisatie?
6. Wat is uw geslacht? (Optioneel)

Missed Care

7. Wat zijn voor u de belangrijkste aspecten aan uw job?
8. Wanneer gaat u met een voldaan gevoel naar huis?
9. Wat zorgt ervoor dat u zich gewaardeerd voelt in uw werk?
10. Wanneer hebt u voornamelijk het gevoel dat u uw patiënten echt hebt geholpen?

Life Participation/Betekenisvolle Activiteiten

11. Hoe worden patiënten ondersteund in het omgaan met de impact van hun aandoening en dialyse op hun dagelijkse leven? IPA
(denk aan: bezigheden en taken in en om het huis; tijdsbesteding en ontspanning; sociale contacten en relaties; betaald werk of vrijwilligerswerk; onderwijs, cursussen en opleiding... maar ook mobiliteit; zelfverzorging; ; geldbesteding; anderen kunnen helpen of steunen...)
➤ Hier kan het helpen de 9 gebieden te overlopen uit de IPA: Mobiliteit, zelfzorg, bezigheden en taken in en om het huis, geldbesteding, tijdsbesteding en ontspanning, sociale contacten en relaties, anderen helpen en steunen, betaald werk of vrijwilligerswerk, onderwijs cursussen en opleiding
12. Wanneer en hoe komt ondersteuning voor **betekenisvolle activiteiten aan bod**? Sociale leven van patiënt
13. Vindt u dat er voldoende aandacht besteed wordt aan deze aspecten?
14. Is het belangrijk dat deze aspecten binnen uw dienst aan bod komen?
15. Wat zijn de **sterke punten** van uw dienst in het ondersteunen van deze aspecten?
16. Zijn er verbeterpunten of onbenutte kansen van u dienst?
17. Wat zijn de grootste barrières voor het bieden van ondersteuning?
18. Waar ziet u kansen voor verbetering?
19. Ziet u bedreigingen voor het ondersteunen van deze aspecten?
20. Is het haalbaar voor u of uw collega's om deze ondersteuning te bieden?
21. Hoe ondersteunt u patiënten in het omgaan met **vermoeidheid** of andere symptomen?
22. Hoe helpt u patiënten hun levensdoelen te bereiken?
23. Welke middelen of tools zouden helpen om **deze ondersteuning** te verbeteren? *(Eventueel tools: meer toelichting in **egd**, andere hybride tools/technologie....)*
24. Als u de volledige vrijheid had, hoe zou u de ondersteuning voor deze levensaspecten organiseren.

Overkoepelend/Algemeen

25. Als u de organisatie van de dialyseafdeling kon veranderen, hoe zou u dit aanpakken? Waar zou u meer of minder op focussen?

Afsluiting

Bedankt voor uw waardevolle tijd en inzichten. Deze dragen bij aan een betere zorg voor onze patiënten. Als u vragen heeft of meer wilt bespreken, neem dan gerust contact op.

Interview guide for church members

Introduction

Thank you very much for participating in this interview. Your insights are very important to our research on improving life participation for people with chronic kidney disease. We appreciate your time and contributions.

Questions

1. How well do you know her and in what capacity have you worked with her?
2. Can you describe how the church community supports her?
3. Have you noticed any changes in her involvement in church activities since her diagnosis?
4. What role do you think faith plays in response to the way she handles herself?
5. Are there any specific church programmes or groups she participates in?
6. How does the church offer emotional or spiritual support to members with serious health problems?
7. In what ways have you personally supported her or her family?
8. How do you think her condition affects her spiritual life?
9. How does the church community respond to its members' health challenges?
10. Do you think there are additional ways the church could support her or improve her quality of life?
11. Have you participated in prayer groups or spiritual sessions specifically for her?
12. What lessons or insights have you gained from being part of the support network for someone with a chronic illness?
13. How does the church educate its members about supporting people with chronic illness?
14. Can you share stories or experiences where you felt the church had a significant impact on her well-being?
15. How do you balance your commitment to supporting her with your own personal responsibilities?
16. Do you have suggestions on how the church could better organise its resources to assist people with chronic illnesses?
17. What gives you hope about her future?

Conclusion

Thank you for sharing your valuable insights.

Interview guide for siblings

Introduction

Thank you very much for participating in this interview. Your perspectives and experiences are crucial to our research aimed at improving life participation for patients with chronic kidney disease. This interview will last approximately 15-20 minutes.

Questions

1. How would you describe your relationship with your sibling since being diagnosed?
2. What changes have you observed in their lifestyle or daily activities since her diagnosis?
3. In what ways do you regularly provide support to your sibling?
4. Can you tell how her illness has affected your personal life?
5. How often do you communicate with your sibling's healthcare providers?
6. What are the main challenges you face when helping your sibling cope with her condition?
7. How do you deal with the emotional impact of your sibling's health problems?
8. Are there any specific resources or supports that you find helpful or that you think could be helpful?
9. How has your sibling's condition affected family life dynamics?
10. What financial adjustments, if any, has your family had to make to manage the condition?
11. How do you help your sibling stay involved in her hobbies or interests?
12. What activities do you enjoy doing together that help keep your sibling's mood up?
13. What improvements in the healthcare or support would you suggest based on your experiences?
14. How do you balance caring for your sibling with your own personal and professional responsibilities?
15. What gives you hope or encouragement regarding your sibling's future?

Conclusion

Thank you very much for sharing your experiences and providing such valuable insights.

14.10 Pictures During Research



Sunday church service at The Pentecost Church of Belgium (Ghent)

Permission was granted by PIWC Ghent to publish this picture

14.11 Questionnaires

'IMPACT ON PARTICIPATION AND AUTONOMY'

(IPA).

QUESTIONNAIRE

M. Cardol
m.cardol@nivel.nl

Last update: August 2004

IPA

Questionnaire : 'Impact on Participation and Autonomy'

This questionnaire asks a number of questions about daily activities.

The purpose of this questionnaire is to get a picture of how your health affects your ability to live the life you want, and how you experience and rate it.

Answering the questions is solely about **your** opinion and **your** experiences.

There are no right or wrong answers; what matters is that you give the answer you think best fits your situation.

You can answer the questions by putting a cross next to your chosen answer. For example, if you can go wherever you want in your home, you will be able to answer the question as follows:

Going <i>where</i> I want to go in my own home:	☒ very good ☐ good ☐ fair ☐ moderate ☐ poor
---	---

For each question, tick one answer at a time. Even if you think a question is unimportant or you may not have an opinion about it, we still ask you to mark the answer that best fits your situation. When in doubt about the answer to a question, try to give the answer that comes closest to what you think.

If you wish, you can provide an explanation for each question.

Completing this questionnaire takes about 20 minutes.

Thank you in advance for completing this questionnaire

MOBILITY: go wherever and whenever you want

First, we want to ask you some questions about mobility: the ability to go where and when you want, indoors and outdoors. The main focus of these questions is whether you can control where you go and when you go.

- 1a) Going *wherever* I want to go in my own home:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 1b) Going and standing in my own home *whenever* I want to go:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 1c) Visiting neighbors, friends and acquaintances *when* I want to go:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 1d) Taking trips, or a (vacation) trip *as* I want to go:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 1e) If your health or disability affects your ability to go where and when you want, to what extent is this a problem for you?
- ☐ no problem
☐ somewhat of a problem
☐ a major problem

Space for comments about your mobility:

SELF-CARE

Some questions about your personal care will now follow.

The issue in these questions is whether you can decide how and when to care for yourself, even with assistance.

- | | | |
|-----|---|---|
| 2a) | Washing, dressing
and grooming <i>in the manner</i>
the way I want it to go: | ☐ very good
☐ good
☐ fair ☐
moderate
☐ poor |
| 2b) | Washing, dressing
Or take care of <i>when</i> I
want to go: | ☐ very good
☐ good
☐ fair ☐
moderate
☐ poor |
| 2c) | Going to bed or getting up
<i>whenever</i> I want to go: | ☐ very good
☐ good
☐ fair ☐
moderate
☐ poor |
| 2d) | Going to the bathroom <i>when</i>
I desire and find it necessary
goes: | ☐ very good
☐ good
☐ fair ☐
moderate
☐ poor |
| 2e) | Deciding for myself <i>when</i> I
want to eat and drink goes: | ☐ very good
☐ good
☐ fair ☐
moderate
☐ poor |
| 2f) | If your health or disability affects your personal care, to what extent is this a problem
for you? | ☐ no problem
☐ somewhat of a problem
☐ a major problem |

Space for comments about your personal care:

OCCUPATIONS AND TASKS IN AND AROUND THE HOUSE

The following questions are about the occupations and responsibilities you have at home. These include caring for and raising children, pets, housework and garden maintenance. Again, it is about the extent to which *you* can determine when and how something is done, even if you do not do it yourself, which is why the word "let" is in parentheses in some of the questions.

- | | | |
|-----|--|---|
| 3a) | My contribution to the tasks in and around the house as I that is: | ☐ very good
☐ good
☐ reasonable
☐ moderate
☐ poor |
| 3b) | Doing (or having done) light good housework (e.g. good coffee or tea) such as it wants to go: | ☐ very
☐ making reasonable
☐ moderate
☐ bad |
| 3c) | Doing (or having done) heavier housework (e.g. cleaning) as I it will go: | ☐ very good
☐ good
☐ fairly
☐ moderate
☐ bad |
| 3d) | Doing (or having done) household when I want goes: | ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor |
| 3e) | Doing (or having done) chores and maintenance of house and garden as I want it to go: | ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor |
| 3f) | The ability to perform in house the role that belonging to me is: | ☐ very well
☐ fair
☐ moderate
☐ poor |
| 3g) | As your health or disability of affects is on your pursuits and responsibilities in and around the home, to what extent is this a problem for you? | ☐ no problem
☐ somewhat of a problem
☐ a major problem |

Space for comments about your activities and responsibilities in and around the house:

MONEY EXPENDITURE

This question is about whether your health or disability affects how you spend your income or pocket money.

- 4a) The ability to get my money to spend *as* I want it is:
- ☐ very good
 - ☐ good
 - ☐ reasonable
 - ☐ moderate
 - ☐ bad
- 4b) If your health or disability affects how you spend your money, to what extent is this a problem for you?
- ☐ no problem
 - ☐ somewhat of a problem
 - ☐ a major problem

Space for comments on your spending of money:

TIME USE AND RELAXATION

Whether you can control what you want to do in your (free) time, when you want to do it and for how long, that is what the next question is about.

- 5a) The ability to use my (free) time to spend *such as* I want it to be:
- ☐ very good
 - ☐ good
 - ☐ reasonable
 - ☐ moderate
 - ☐ bad
- 5b) If your health or disability affects your use of time, to what extent is this a problem for you?
- ☐ no problem
 - ☐ somewhat of a problem
 - ☐ a major problem

Space for comments about your use of time:

SOCIAL CONTACTS AND RELATIONSHIPS

The following questions are about the quality and frequency of your social contacts. It may be that because of your health or disability, social contacts are different or less frequent. Questions 6c and 6e refer to "respect. *Respect refers to the extent to which others treat you correctly and politely.*

- | | | |
|------|--|--|
| 6a) | The ability to have a good <i>equal</i> conversation with the close to me is: | ☐ very well people
☐ reasonable
☐ moderate
☐ poor |
| 6b) | Dealing with the people who are dear to me is: | ☐ verygood
☐ good
☐ fair
☐ moderate
☐ poor |
| 6c) | The respect I receive from people dear to me His is: | ☐ verygood
☐ good
☐ reasonable
☐ moderate
☐ poor |
| 6d) | Dealing with people who know less well is: | ☐ verygood
☐ good
☐ fair
☐ moderate
☐ poor |
| 6e) | The respect I receive from people I like less well know is: | ☐ verygood
☐ good
☐ reasonable
☐ moderate
☐ poor |
| 6f) | The opportunity for intimacy, such as I want that is: | ☐ verygood
☐ good
☐ reasonable
☐ moderate
☐ poor |
| 6g) | The frequency with which I see people is: | ☐ verygood
☐ good
☐ fair
☐ moderate
☐ poor |
| 6 h) | If your health or disability affects your social contacts or relationships, to what extent | |

is this a problem for you?

☐ no problem

☐ somewhat of a problem

☐ a major problem

Space for comments about your social contacts and relationships:

HELPING OR SUPPORTING OTHERS

This question is about your ability to help or support others. This could include family, friends, neighbors or acquaintances, as well as the club or organization you may be a member of.

- 7a) The ability to help or support people well fair O moderate O poor
O verywell who help me need is:
- 7 b) If your health or disability affects your ability to help or support others, to what extent is this a problem for you?
O no problem
O somewhat of a problem
O a major problem

Space for comments about helping or supporting others:

PAID WORK OR VOLUNTEER WORK

Now for a question about work (paid or volunteer). We would like to hear your opinion about your ability to find or keep the job of your choice, even if this topic is not so relevant to you at the moment.

- 8a) The possibility of the paid work or volunteering
To do that I want is:
- ☐ very good
☐ good
☐ reasonable
☐ moderate
☐ bad

If you do not currently have a paid job and are not volunteering, please continue with question 9. If you do have a job or are temporarily not working due to illness, please do complete the following questions.

- 8b) The ability to perform my work
as I want it is:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 8c) The contact with colleagues is:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 8d) The ability to reach the or maintain that will is:
- ☐ very well
☐ good
☐ reasonable
☐ moderate
☐ bad
- 8e) Ability to change job or employer is:
- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor
- 8f) If your health or disability affects your work, to what extent is this a problem for you?
- ☐ no problem
☐ somewhat of a problem
☐ a major problem

Space for comments about your work:

EDUCATION, COURSES AND TRAINING

This question is about how your health or disability affects your ability to (continue to) take the education or course of your choice.

If you have no desire to take an education or course, please enter "not applicable" and continue with question 10. If you would like to take or are already taking a training or course, please answer the questions below.

- 9a) The opportunity to visit the training or course of my choice to (continue to) follow is:
- | | |
|---------------------------------|--|
| ☐ very good | ☐ not of application |
| ☐ good | |
| ☐ fair | |
| ☐ moderate | |
| ☐ poor | |
- 9b) If your health or disability affects attending education or a course, to what extent is this a problem for you?
- ☐ no problem
☐ somewhat of a problem
☐ a major problem

Space for comments on taking education, training or courses:

SUMMARY

In this questionnaire you have answered questions related to the impact of your health or disability on your personal, social and community life. Would you like to indicate again in general whether you feel that you can decide for yourself sufficiently what you want to do (or have done)?

10. My ability to live the way I want is:

- ☐ very good
☐ good
☐ fair
☐ moderate
☐ poor

Space for comments on the possibility of living the way you want:

11. When you think about the topic of this questionnaire (to what extent you can control what you want to do and how it is done), what are the 3 most important problems for you as a result of your health condition?

1.
2.
3.

This is the end of the questionnaire. Perhaps you have any issues related to your health that are close to your heart. If you have any comments, please write them down below.

2. SONG-HD Fatigue

Opgeslagen in deze pc



SONG
STANDARDISED OUTCOMES IN NEPHROLOGY

SONG-HD Fatigue

Please indicate your response by ticking one box for each question.

In the past week:

Questions	Not at all	A little	Quite a bit	Severely
1. Did you feel tired?	☐ 0	☐ 1	☐ 2	☐ 3
2. Did you lack energy?	☐ 0	☐ 1	☐ 2	☐ 3
3. Did fatigue limit your usual activities?	☐ 0	☐ 1	☐ 2	☐ 3

Standardized Outcomes in Nephrology © 2019

3. SONG Life Participation Care Outcome Measure



SONG Life Participation Core Outcome Measure

Please respond to each item by marking one box per row.

During the past month...

	Never	Rarely	Sometimes	Usually	Always	N/A
I could do my leisure activities e.g. exercise, hobbies, travel	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my family activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my work e.g. employment, housework, study	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my social activities with friends/others	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐

N/A, not applicable

4. EQ-5D-5L

Health Questionnaire (EQ-5D-5L)

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- ☐₁ I have no problems in walking about
☐₂ I have slight problems in walking about
☐₃ I have moderate problems in walking about
☐₄ I have severe problems in walking about
☐₅ I am unable to walk about

SELF-CARE

- ☐₁ I have no problems washing or dressing myself
☐₂ I have slight problems washing or dressing myself
☐₃ I have moderate problems washing or dressing myself
☐₄ I have severe problems washing or dressing myself
☐₅ I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- ☐₁ I have no problems doing my usual activities
☐₂ I have slight problems doing my usual activities
☐₃ I have moderate problems doing my usual activities
☐₄ I have severe problems doing my usual activities
☐₅ I am unable to do my usual activities

PAIN / DISCOMFORT

- ☐₁ I have no pain or discomfort
☐₂ I have slight pain or discomfort
☐₃ I have moderate pain or discomfort
☐₄ I have severe pain or discomfort
☐₅ I have extreme pain or discomfort

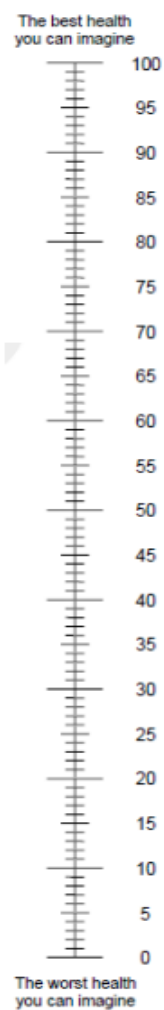
ANXIETY / DEPRESSION

- ☐₁ I am not anxious or depressed
☐₂ I am slightly anxious or depressed
☐₃ I am moderately anxious or depressed
☐₄ I am severely anxious or depressed
☐₅ I am extremely anxious or depressed

Health Questionnaire (EQ-5D-5L)

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is **TODAY**
- Now, please write the number you marked on the scale in the below.

YOUR HEALTH TODAY =



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