Health literacy in patients with Chronic kidney disease

by

Une Elisabeth Stømer

Thesis submitted in fulfilment of the requirements for the degree of PHILOSOPHIAE DOCTOR (PhD)

University of Stavanger

The Faculty of Health science
Department of Quality and Health Technology
2020
University of Stavanger
NO-4036 Stavanger
NORWAY
www.uis.no

©2020 Une Elisabeth Stømer

ISBN: Click to enter ISBN.
ISSN: Click to enter ISSN.
PhD: Thesis UiS No. Click to enter PhD No.
Acknowledgements

The work for this PhD thesis was carried out at the Department of Nephrology, Stavanger University Hospital, and at the University of Stavanger, from 2016-2020. Acknowledgements go to the University of Stavanger, represented by the Faculty of Health Sciences, for funding my doctoral fellowship, and to Stavanger University Hospital for allowing and supporting this research.

This PhD thesis would not have been completed without invaluable help and support from many people.

Most importantly, my thanks go to the study participants who generously spent their time and shared their experiences of living with chronic kidney disease. This study relies on their contributions.

Special thanks go to my primary supervisor, Kristin Hjorthaug Urstad, and my co-supervisors, Professor Astrid Klopstad Wahl and Professor Lasse Gunnar Gøransson. They have guided me with wisdom, tireless optimism, and patience. The different positions and backgrounds of the supervisors have been challenging yet fruitful for the whole dissertation and ultimately, a successful combination: Kristin with her excellent knowledge of and experience with kidney disease patients and her optimism and patience with me as a PhD candidate, Astrid with her wisdom and expertise regarding health literacy and research, and Lasse with his vast knowledge of kidney disease and his ability to ask timely critical questions. Thank you!

Additionally, I would like to thank Professor Jan Terje Kvaløy for having a 24-hour open statistical outpatient clinic (even during holidays). His willingness to discuss statistical challenges and his suggestions for the presentation of data have been of great value for me.
The staff at the Department of Nephrology at the hospital have been patient and interested in my work, and they were flexible during the participant recruitment period. Thank you all for facilitating my work.

My dearest friend Wenche, who passed away in 2019, was my inspiration, my informal supervisor, and she had an invaluable belief in me to the very last. I am incredibly grateful that I got to be her friend and for all the support she provided. I wish you were here, Wenche!

Thanks to Joanna Haynes for the critical reading of the papers and language editing and for always being willing and ready to read at short notice. Additionally, thanks to Margot Viste for transcribing the qualitative interviews.

Further, I would like to thank my colleagues: Heidi, Britt Marit, Inger, Kine, and Foteini, for the opportunity to share the ups and downs of the process. I don’t know what I would have done without you. Kari, my dear colleague and friend in Oslo, thanks for all the useful discussions about health literacy, our Skype meetings, the trip to Washington to meet the health literacy superstars, and for cheering me on.

Friends and family, thank you for understanding the situation of writing a PhD thesis and being interested in my work, and thanks for cheering for me at “Forsker Grand Prix.”

Last but not least, dear Per and Lars, thank you for your patience. It has been a long trip, and I know you have been suffering during this period. Nevertheless, you have been generous and adapted to the situation in different phases and allowed me to be occupied and have varying attention to everyday life. Thank you!
Preface

My work experience as an intensive care nurse in a dialysis department made me aware of the numerous challenges for patients living with end-stage renal disease. It also made me aware of the considerable differences in how patients deal with chronic kidney disease. These differences triggered my curiosity. Do the patients have enough information to make informed choices about how they live their lives? Are healthcare services adapted to the patients’ need for information?

I was introduced to the concept of health literacy in 2016, and when I received the opportunity to work as a doctoral student to explore health literacy in patients with chronic kidney disease, I grasped it. This thesis provides answers to some of my questions.

It has been a pleasure and a challenge to study a concept that is continually evolving!

“If we group patients for learning according to their disease or illness, then we must also take into account the differences in individuals and provide a variety of learning experiences. To teach all patients the same thing in the same way as if their needs and experiences and perceptions are identical and to call this good education is comparable to giving all cardiac (sic) the same drug, diet, and activity schedule and calling it good medical care.”

(Kasey and Mac Mahan, 1965)
Summary

Background
Health literacy (HL) concerns an individual’s ability and motivation to gain access to, understand, and use health information. Patients suffering from chronic kidney disease (CKD) are at risk of developing severe, life-threatening complications, and experiencing progression of the disease towards end-stage renal disease (ESRD) with the need for renal replacement therapy (RRT). Day-to-day decisions about how to self-manage their disease may affect patients’ risk of complications and the progression of CKD. Adequate HL is seen as a prerequisite for sound health behaviour and desired health outcomes; however, earlier research has mostly assessed HL with one-dimensional assessment tools, evaluating individuals’ health-related reading- or numeracy skills. Over the years, the concept of HL has evolved to become a broader concept including more dimensions such as social support, interactive dimensions, and the accessibility of healthcare services. Consequently, there is a knowledge gap that needs to be filled.

Aim
The aim of this thesis was to explore HL in CKD patients.

Methods
The thesis reports three studies with equal status. In studies I and II, a descriptive, cross-sectional design with patient-reported outcome measures (PROMs) and data from medical records was used to assess and identify possible associations between HL, demographic and clinical variables, quality of life (QoL) and adherence to long-term therapy. HL was evaluated with a multidimensional tool, the Health Literacy Questionnaire (HLQ). Study III was qualitative, in which in-depth interviews were used to explore patients’ experiences of different aspects of HL for a better understanding of their needs.
Results

One hundred eighty-seven patients were included in the cross-sectional studies (I and II); the patients had a mean age (SD) of 67 years (13), and 65% were males. Of the included patients, 80 had CKD stage 3, 81 had CKD stage 4-5 and were not on dialysis, and 26 patients received haemodialysis.

Twelve patients from the cross-sectional studies (presented in papers I and II) were included in the qualitative study (presented in paper III).

**Study I:** We found that the critical appraisal of health information and the ability to find good health information were the most challenging dimensions of HL for the patients, whereas feeling understood and supported by healthcare providers and the ability to actively engage with healthcare providers were the least challenging. Female gender, lower level of education, higher pill burden, and more depressive symptoms were associated with low HL. Using cluster analysis, we identified three groups of CKD patients, characterized by low, medium, and high levels of HL.

**Study II:** We utilized the HLQ scores and the results from the cluster analysis in study I, and found that CKD patients with lower HL had lower QoL than patients with higher HL. We also found that the ability to understand health information was predictive of QoL, while the actively managing health, the ability to actively engage with healthcare providers, and the ability to find good health information were predictive of adherence to long-term therapy.

**Study III:** The thematic analysis of the interviews resulted in tree main themes that describe the patients’ HL experiences; 1. Diversity in the role as a health information seeker, 2. Fragmented healthcare system, a challenge for navigating, and, 3. The value of a good relationship with healthcare providers.
Conclusions

This thesis provides insight into HL in CKD patients. There are significant HL inequalities in patients with CKD. Based on the cross-sectional studies (papers I and II), strategies to improve HL could focus on developing guidance for finding good health information and methods for the critical appraisal of health information. Strategies to improve QoL and adherence to lifestyle recommendations could focus on providing adapted and tailored information and establishing a good relationship between healthcare providers and patients.

The qualitative study, however, revealed more nuances of the picture of HL. Patients might avoid health information as a strategy to cope with CKD and not necessarily lack the ability to gain access to, understand or use health information. Strategies for increasing HL could therefore also focus on patients’ desires and motivation to be involved. Furthermore, a fragmented healthcare system is a barrier to patients’ navigation of the system and control of their health situations that might be modified through the establishment of a competent and trusting relationship between patients and healthcare providers.
Abbreviations

ANOVA: Analyse of variance
BDI-SF: Beck Depression Inventory Short Form
BP: Blood pressure
CI: Confidence interval
CKD: Chronic kidney disease
CVD: Cardiovascular disease
DCI: Davies Comorbidity Index
DM: Diabetes mellitus
ESRD: End-stage renal disease
EGFR: Estimated glomerular filtration rate
HD: Haemodialysis
HL: Health literacy
HLR: Health literacy responsiveness
HLQ: Health Literacy Questionnaire
MARS-5: Medical Adherence Rating Scale 5
MCS-12: Mental component score Short Form-12
NRR: Norwegian Renal Registry
PCS-12: Physical component score Short Form-12
PD: Peritoneal dialysis
PRO: Patient-reported outcome
PROM: Patients-reported outcome measure
QoL: Quality of life
SF-12: Short Form-12
SD: Standard deviation
SPSS: Statistical Package for Social Sciences
SUS: Stavanger University Hospital
RRT: Renal replacement therapy
Tx: Transplantation
VAS: Visual analogue scale
WHO: World Health Organization
# Table of Contents

Acknowledgements .................................................................................................................. iii
Preface .................................................................................................................................. v
Summary ................................................................................................................................. vi
Abbreviations ........................................................................................................................ ix
PART 1 .................................................................................................................................. xvi

1 Introduction ......................................................................................................................... 1

2 Theory ............................................................................................................................... 5
   2.1 Chronic kidney disease and its treatments ................................................................. 5
   2.2 Health literacy .............................................................................................................. 8
      2.2.1 The history and development of health literacy ................................................. 8
      2.2.2 Definitions of health literacy ............................................................................ 8
      2.2.3 Assessment tools for health literacy ................................................................ 10
      2.2.4 Health literacy responsiveness ...................................................................... 12
   2.3 The theoretical framework for the thesis ................................................................. 12
   2.4 Quality of life .......................................................................................................... 15
   2.5 Adherence to long-term therapy ............................................................................. 16
   2.6 Depression and depressive symptoms .................................................................. 17
   2.7 State of the art .......................................................................................................... 18
      2.7.1 Health literacy research in various settings .................................................. 18
      2.7.2 Prevalence of limited health literacy in patients with chronic kidney disease ................................................................. 20
      2.7.3 Associations between health literacy in patients with chronic kidney disease and demographic and clinical variables ........................................ 20
      2.7.4 Associations between health literacy in patients with chronic kidney disease and adherence and quality of life ......................................... 21
      2.7.5 Qualitative health literacy research in patients with chronic kidney disease ........................................................................................................ 22
      2.7.6 Summary ........................................................................................................ 23

3 Methods ............................................................................................................................ 25
   3.1 Philosophical considerations .................................................................................... 25
   3.2 Study design for the thesis ...................................................................................... 26
3.3 Study design of the cross-sectional studies ............................................. 28
3.3.1 Sample.................................................................................................. 28
3.4 Study I instruments ................................................................................ 29
3.4.1 Health Literacy Questionnaire.............................................................. 29
3.4.2 Beck Depression Inventory-Short Form ............................................... 31
3.4.3 Davies Comorbidity Index ................................................................... 31
3.5 Study II instruments ............................................................................. 32
3.5.1 Short Form-12 ...................................................................................... 32
3.5.2 Visual Analogue Scale for global Quality of life (VAS-QoL) and adherence to general lifestyle recommendations (VAS-Adherence) ....33
3.5.3 Medication Adherence Rating Scale 5 ................................................. 34
3.6 Data analysis for the cross-sectional studies ........................................... 34
3.6.1 Regression analysis .............................................................................. 35
3.6.2 Clustering patients ................................................................................ 36
3.7 Study design of the qualitative study ...................................................... 37
3.7.1 Sample.................................................................................................. 37
3.8 Data analysis for the qualitative study .................................................... 38
3.9 Reliability, validity, and trustworthiness................................................. 39
3.10 Acquiring the patients’ perspectives in the quantitative studies .......... 42
3.11 Ethical considerations ............................................................................. 42
3.11.1 How to ensure that consent was freely given?................................. 43
3.11.2 Could participation in this study harm the patients? ......................... 43
4 Results ..................................................................................................... 45
4.1 Participants in studies I and II .............................................................. 45
4.2 A cross-sectional study of health literacy in patients with chronic kidney disease: Associations with demographic and clinical variables (Paper I) 46
4.3 Health literacy in kidney disease: Associations with quality of life and adherence (Paper II) ................................................................. 48
4.4 Participants in study III ......................................................................... 49
4.5 An exploration of health literacy in patients with chronic kidney disease, a qualitative study (Paper III) .......................................................... 50
5 Discussion ............................................................................................... 53
5.1 Discussion of the main findings ............................................................ 53
5.2 Methodological considerations ............................................................. 57
6 Conclusions .......................................................................................................................... 63
  6.1 Main findings .................................................................................................................. 63
  6.2 Implications for practice ............................................................................................... 64
  6.3 Suggestions for future research ................................................................................... 65
7 References .......................................................................................................................... 67

PART 2 .................................................................................................................................... 87
  Paper I .................................................................................................................................... 89
  Paper II ................................................................................................................................... 99
  Paper III .................................................................................................................................. 109

Appendices .......................................................................................................................... 135
  Appendix A – Questionnaires ........................................................................................... 137
  Appendix B – Interview guide ......................................................................................... 153
  Appendix C – Informed consent, quantitative studies (Paper I and II) ......................... 155
  Appendix D – Informed consent qualitative study (Paper III) ....................................... 159
  Appendix E – Regional Ethics Committee (REK) response ........................................... 161
  Appendix F – Personal Protection Officer approval of PhD project ........................... 163

Table of Figures

Figure 1 – Prevalence of renal replacement therapy in Norway ....................... 6
Figure 2 – The HLS-EU conceptual model of health literacy ......................... 13
Figure 3 – Gender differences in Health Literacy Questionnaire scores .......... 47
Figure 4 – Medication retrieval from the pharmacy in the previous three months in patients with different levels of health literacy ......... 49
Figure 5 – Main themes based on the health literacy experiences of patients with chronic kidney disease ......................................................... 51

List of Tables

Table 1 – Stages of chronic kidney disease ................................................................. 5
Table 2 – Frequently cited definitions of health literacy ........................................... 9
Table 3 – The most frequently used assessment tools for health literacy ............. 11
List of Papers

This thesis includes the following papers, which will be referred to in the text by their Roman numerals:

**Paper I**
A cross-sectional study of health literacy in patients with chronic kidney disease: Associations with demographic and clinical variables

**Paper II**
Health literacy in kidney disease: Associations with quality of life and adherence

**Paper III**
An exploration of health literacy in patients with chronic kidney disease, a qualitative study
Intentionally left blank
PART 1
Health literacy (HL) is essential for patients’ self-care abilities (Bostock & Steptoe, 2012; Green et al., 2013; Howard, Gazmararian, & Parker, 2005; Murray et al., 2009; Schillinger et al., 2002; Villaire & Mayer, 2007). According to the World Health Organization (WHO), HL means more than being able to read pamphlets and make appointments; “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (WHO, 1998). Patients with chronic illnesses make important day-to-day decisions about how to self-manage their disease.

There is a political desire, both global and nationally, for individuals to take more control of their health situation, and as a consequence, more responsibility is put on individuals (Ministry of Health and Care Services (HOD), 2011, 2015-2016, 2019b; World Health Organization, 1986a). It is, therefore, essential that individuals can obtain access to, understand, and use health information in ways that promote and maintain good health. Healthcare providers and health politicians have to develop and adapt healthcare services to meet the population’s needs.

In Norway, the government has a goal to develop “the patients’ healthcare services,” meaning that healthcare services should facilitate the inclusion of patients in decision-making concerning their health to a greater extent. To accomplish that goal, adequate HL is essential, and the Norwegian government has recently developed a strategic plan, to be implemented from 2019-2023, to increase HL in the population (Ministry of Health and Care Services (HOD), 2019b). The strategic plan is aimed at healthcare providers, decision-makers and leaders in healthcare services, patients, and patient organizations as well as the educational system. The government will increase HL in the Norwegian population by establishing the word “helsekompetanse” as the
Norwegian translation of the English term “health literacy” in the Norwegian vocabulary. The government will gather research and researchers on HL in Norway, facilitate tailored work to increase HL in the population, raise awareness about HL among healthcare professionals, and develop healthcare services that can make people health literate (Ministry of Health and Care Services (HOD), 2019b).

This thesis contributes to this strategic plan by describing and exploring HL in a population with chronic kidney disease (CKD).

Patients with CKD are at increased risk of developing severe, life-threatening complications. Untreated CKD poses an increased risk for progression towards end-stage renal disease (ESRD) with the need for renal replacement therapy (RRT) (Ministry of Health and Care Services (HOD), 2011; Tangkiatkumjai, Walker, Praditpornsilpa, & Boardman, 2016; Whaley-Connell, Nistala, & Chaudhary, 2011). Patients with CKD are also at increased risk of developing cardiovascular disease (CVD), which is the leading cause of death in this population (Gansevoort et al., 2013; Ministry of Health and Care Services (HOD), 2011; Thompson et al., 2015). At all stages of the disease, patients’ ability to follow health advice is essential. Aspects such as strict adherence to the prescribed medication, various types of food restrictions, and lifestyle behaviour are crucial for reducing comorbidity and the progression of kidney disease (K/DOQI, 2002; Whaley-Connell et al., 2011).

Earlier research has found associations between limited HL with adverse health outcomes and higher healthcare costs (Taylor, Fraser, Dudley, et al., 2017). Personal, situational, and environmental factors have been included in conceptual models of HL and described as antecedents of a person’s HL. Health behaviour, such as adherence to treatment, and health outcomes, such as QOL, have been considered results or consequences of HL (Sorensen et al., 2012). However, earlier research has mainly assessed HL with one-dimensional tools, evaluating health-related reading- or numeracy skills, not in accordance with the
Introduction

multifaceted definitions of HL. Hence, there is a knowledge gap in HL dimensions concerning social support, interactive relationships, and the accessibility of the healthcare system.

The aim of this thesis was to explore HL in patients with CKD.

The three specific objectives for the papers were as follows:

1. To describe HL strengths and challenges in a Norwegian CKD population, and to identify possible associations of demographic and clinical variables with HL on a multidimensional level (paper I);

2. To identify the associations of different dimensions of HL with QoL and adherence to long-term therapy, and to compare QoL and adherence in groups with varying levels of HL (paper II);

3. To explore patients’ experiences of HL using a qualitative approach (paper III).
Introduction

Intentionally left blank
2 Theory

This section defines and describes the fields of CKD, HL, QoL, and adherence to long-term therapy.

2.1 Chronic kidney disease and its treatments

Globally, CKD has become a significant public health burden. The mean prevalence varies from 8-18% in different geographic regions, with the highest prevalence in developed countries (Hill et al., 2016). In Norway, the prevalence of CKD is 11%, as shown in the Hunt study (Hallan et al., 2006).

The Kidney Disease Outcome Quality Initiative (K/DOQI) defines CKD as kidney damage or a reduced glomerular filtration rate (GFR) < 60 mL/min/1.73 m² with or without diagnosed kidney damage of any reason for more than three months (K/DOQI, 2002). CKD is classified into five stages, where CKD stage 5 is referred to as ESRD (Table 1).

Table 1 – Stages of chronic kidney disease

<table>
<thead>
<tr>
<th>Stages of CKD</th>
<th>Description</th>
<th>GFR (mL/min/1.73 m²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Kidney damage with normal or ↑ GFR</td>
<td>≥ 90</td>
</tr>
<tr>
<td>2</td>
<td>Kidney damage with mild ↓ GFR</td>
<td>60-89</td>
</tr>
<tr>
<td>3</td>
<td>Moderate ↓ GFR</td>
<td>30-59</td>
</tr>
<tr>
<td>4</td>
<td>Severe ↓ GFR</td>
<td>15-29</td>
</tr>
<tr>
<td>5</td>
<td>Kidney failure / ESRD</td>
<td>&lt; 15 or dialysis</td>
</tr>
</tbody>
</table>

Legend Table 1. GFR = glomerular filtration rate. Kidney damage in stages 1-2 is defined as structural damage in the kidney or haematuria and/or proteinuria (K/DOQI, 2002).

Among patients diagnosed with CKD, most (85%) are in stage 3, and only 0.1% of patients are in stage 5 (ESRD) (Hill et al., 2016). In Norway, vascular/hypertensive nephropathy is the most common
underlying renal disease for ESRD, in contrast to the rest of Europe, where DM type II is the most prevalent (Hallan et al., 2006; Norwegian Renal Registry, 2018). Due to demographic changes such as prolonged life expectancy and an increased incidence of lifestyle diseases, the incidence of CKD will likely further increase (Ministry of Health and Care Services (HOD), 2011; Wong et al., 2018). According to the Norwegian Renal Registry (NRR), the prevalence of CKD patients receiving RRT is continuously increasing (Figure 1) (Norwegian Renal Registry, 2018).

![Renal replacement therapy in Norway](image)

**Figure 1 – Prevalence of renal replacement therapy in Norway**

**Legend Figure 1.** Data from the Norwegian Renal Registry (Norwegian Renal Registry, 2018). PD = peritoneal dialysis, HD = haemodialysis, Tx = kidney transplantation.

Patients with CKD stages 3-5 (eGFR < 60mL/min/1.73 m²) are often treated with numerous medications to compensate for the failing kidney and, if possible, to reduce the disease progression. According to the
K/DOQI guidelines, attention should be paid to treating comorbidities from stages 1-2 to reduce cardiovascular disease (CVD) and slow the progression of CKD. As kidney disease progresses, treatment is focused on treating renal induced anaemia, disorders in calcium phosphate metabolism, disturbances in acid-base balance, hypertension, and hypervolemia (K/DOQI, 2002). In general, CKD patients have a higher pill burden than patients suffering from other chronic diseases (Bailie et al., 2005; Chiu et al., 2009). Poor adherence to medication is common and is associated with a higher risk of disease progression and comorbidities (Bailie et al., 2005; Tangkiatkumjai, Walker, Praditpornsilpa, & Boardman, 2017).

For patients in CKD stage 5, RRT is often required (K/DOQI, 2002). There are two main types of RRT; kidney transplantation (tx) and dialysis treatment. Dialysis is initiated when patients develop uremic symptoms such as nausea, itching, dyspnoea, and reduced well-being due to renal failure, or for the treatment of potentially life-threatening complications such as hyperkalaemia, hypervolemia or uremic pericarditis (K/DOQI, 2002). There are two kinds of dialysis modalities: haemodialysis (HD) and peritoneal dialysis (PD). HD is usually performed as an in-hospital treatment or in a dialysis clinic three days a week for 4-5 hours each session. PD is usually performed at patients’ homes.

Patients with CKD are recommended to adhere to general lifestyle advice, and as renal failure progresses, many patients also have to adhere to individual food and fluid restrictions to avoid electrolyte disturbances, hypervolemia, and malnutrition. Most of the restrictions are necessary only for patients with severe renal impairment. Furthermore, all patients are recommended to maintain a healthy lifestyle with physical activity and no smoking (Chiu et al., 2009; Efe & Kocaoz, 2015; K/DOQI, 2002; Quinan, 2007) (Tangkiatkumjai et al., 2016) (Ministry of Health and Care Services (HOD), 2011).
2.2 Health literacy

2.2.1 The history and development of health literacy

To understand the origin and evolution of the concept of HL, it is necessary to be aware of the progress in health policy over the years.

In the 18th century and beginning of the 19th century, the primary health concerns were sanitary issues and changes in societies due to the industrial revolution. In the 1970s, however, a new way of thinking about health and healthcare, initially called “A new public health,” was developing (World Health Organization, 1986). The new public health movement was less focused on individuals and disease prevention and more focused on how to create a healthy population and reduce health inequalities between nations and different subgroups. The movement was also in opposition to the top-down organization of healthcare services and worked to empower individuals. Health was raised as a political concern; at this time, health was defined holistically as physical, mental, and social well-being and not deterministically as the absence of disease and infirmity. The WHO definition from 1949 is debated but still relevant: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” (World Health Organization, 1949, 1986).

The term “health promotion” was introduced in 1974 and was later defined by the WHO as “the process of enabling people to increase control over and to improve their health” (World Health Organization, 1986, 1998). HL has been described as an essential concept in health promotion work (World Health Organization, 1986, 1998, 2009, 2013).

2.2.2 Definitions of health literacy

HL differs from other related concepts such as patient-education, patient-empowerment, and self-management. According to Batterham et al., HL
includes a range of interacting cognitive, affective, experiential, and social processes that may help or hinder an individual’s engagement with health information (R. Batterham, Beauchamp, & Osborne, 2017). According to the conceptual model, HL is a prerequisite for patient-empowerment and self-management and includes the ability to trust healthcare providers, prior experience navigating the healthcare system and the ability to discuss one’s health issues with family and friends (R. W. Batterham, Beauchamp, A. Osbourne, R.H., 2017).

Although HL is an important part of health promotion work, and the terminology is frequently used in political documents, there is still no consensus on the definition of HL. Sorensen et al. performed a systematic review of HL definitions in 2012 and identified 17 different definitions and 12 conceptual models (Sorensen et al., 2012). A more recent review of HL definitions found 250 different definitions. However, most of the definitions were modified versions of the most commonly used definitions but with different wording (Malloy-Weir, Charles, Gafni, & Entwistle, 2016). In addition, the “International handbook of health literacy” was published in 2019 with a full description of HL research and definitions, illustrating that the concept is continuously evolving (Okan, Bauer, Pinheiro, Sorensen, & Levin, 2019). Some of the most frequently cited/used definitions are presented in Table 2.

Table 2 – Frequently cited definitions of health literacy

| 1. American Medical Association (AMA) (1999) | “The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment” (“Health literacy: report of the council on scientific affairs,” 1999) |
Most of the definitions focus on the individuals’ skills and abilities, but there is an ongoing discussion and evolving of the definitions, moving the focus from the individual skills and abilities over to an interaction between individuals and the healthcare system (R.W. Batterham, Beauchamp, A. Osbourne, R.H., 2017; Okan et al., 2019; Sorensen et al., 2012).

### 2.2.3 Assessment tools for health literacy

The most commonly used tools to assess HL basically evaluate one or two aspects of HL and do not cover the full range of skills needed for HL (Altin, Finke, Kautz-Freimuth, & Stock, 2014; R. Batterham et al., 2017). The most frequently used or mentioned assessment tools for HL are listed in Table 3 in descending order (Okan et al., 2019).
Table 3 – The most frequently used assessment tools for health literacy

<table>
<thead>
<tr>
<th>Name of the assessment tool</th>
<th>Focus</th>
<th>Number of items</th>
<th>Year of origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, &amp; Nurss, 1995)</td>
<td>Reading and numeracy skills. Objective test.</td>
<td>36-67</td>
<td>1995</td>
</tr>
<tr>
<td>Brief Health Literacy Screen (BHLS) (Chew, Bradley, &amp; Boyko, 2004)</td>
<td>Questions about filling out medical forms. Reading and numeracy skills. Self-report.</td>
<td>1-3</td>
<td>2004</td>
</tr>
<tr>
<td>Newest Vital Sign (NVS) (Weiss et al., 2005)</td>
<td>Understanding of an ice-cream information label. Objective test.</td>
<td>6</td>
<td>2005</td>
</tr>
<tr>
<td>European health Literacy Survey (HLS-EU) (Sørensen et al., 2013)</td>
<td>Evaluation of four dimensions of HL. Self-report.</td>
<td>47</td>
<td>2012</td>
</tr>
<tr>
<td>Health Literacy Questionnaire (HLQ) (Osborne, Batterham, Elsworth, Hawkins, &amp; Buchbinder, 2013)</td>
<td>Evaluation of nine dimensions of HL. Self-report.</td>
<td>44</td>
<td>2013</td>
</tr>
</tbody>
</table>

The first four instruments in the table mainly assess functional HL, meaning the ability to read and understand basic information to function in an everyday setting in society. These assessment tools have been criticized for being narrow and limited as well as for appearing to lack sensitivity to change (R. Batterham et al., 2017). Subsequently, more comprehensive tools have been developed, and the first truly multidimensional tools emerged in 2012, in the form of the European Health Literacy Survey (HLS-EU) (Sørensen et al., 2013), and the HLQ (Osborne et al., 2013). As shown in the table, the earlier tools are mainly objective tests, while the more recent multidimensional tools rely on self-reports. The HLQ was used for this thesis due to the aim of the study to explore HL from a multifaceted perspective. The original article that
described the process of developing the HLQ used the WHO definition of HL as the basis (Okan et al., 2019; Osborne et al., 2013). The WHO definition of HL is therefore used as the definition of HL in this thesis.

2.2.4 **Health literacy responsiveness**

The individual HL skills required to effectively interact with health services depend on the accessibility of the services (Koh, Baur, Brach, Harris, & Rowden, 2013; Pleasant, Cabe, Martin, & Rikard, 2013). Public health service organizations have the responsibility to provide services that are accessible to individuals with varying HL skills (R. W. Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016). Health literacy responsiveness (HLR) refers to organizations' ability to make health information available and accessible to people with different HL needs (R. Batterham et al., 2017). Facilitating HLR organizations, that allow individual adaption and responsiveness to different HL needs, might be a method of increasing HL and reducing inequalities between different subgroups (Trezona, Dodson, & Osborne, 2017). Creating HLR organizations requires clear leadership with a defined goal for improving HL and available resources over time.

2.3 **The theoretical framework for the thesis**

Sørensen et al. developed a new conceptual model of HL, i.e., the HLS-EU conceptual model, which was adopted as the theoretical framework for this thesis (Figure 2). According to the HLS-EU conceptual model, HL may be assessed in different settings to address HL strengths and challenges at both the individual and population levels. The model refers to a healthcare setting, a disease prevention setting, and a health promotion setting. The current thesis focuses on HL in a healthcare setting in patients with CKD.
Figure 2 – The HLS-EU conceptual model of health literacy (Sorensen et al., 2012). With permission from Kristine Sorensen
Theory

Determinants of HL
On the left side of the model, the variables that are the determinants/antecedents of a person’s HL are presented as environmental, social, personal, and situational variables.

For this thesis, demographic variables including gender, age, level of education, level of income and living arrangement as well as clinical variables including stage of CKD, comorbidities, number of medications and depressive symptoms are used as to explain the different dimensions of HL in paper I.

Consequences of HL
On the right side of the model, the effects of HL are described as four different topics: 1. Utilization of the healthcare system, which is associated with healthcare costs; 2. Health behaviour, which is associated with health outcomes; 3. Participation, which is associated with empowerment; and 4. Equity, which is associated with sustainability. For this thesis, we chose to focus on health behaviour in the form of adherence to long-term therapy and health outcomes in terms of QoL, which is discussed in paper II. The nine dimensions of HL were used as independent variables to explain adherence and QoL.

Patient experiences of HL
The qualitative data from study III capture patients’ experiences of different dimensions of HL, which is vital to understand patients’ desires and needs relevant to HL.

The arrows between the components in the model point in both directions, illustrating that previous research has found associations between the different elements but that the causational relationship has not been clarified (Sorensen et al., 2012).
According to Batterham et al., there are several purposes of measuring HL in a healthcare setting, such as solving problems for an individual patient, training staff to respond to different HL needs and adapting healthcare services to the needs of the population (R. W. Batterham et al., 2016). A desired goal/outcome of increasing HL is the minimization of health inequalities.

Parts of this thesis aim to identify HL strengths and challenges in CKD patients, and reveal factors contributing to low HL.

2.4 Quality of life

The term “QoL” originates from the term “happiness”. The Greek philosopher and scientist Aristotle (384-322 BC) described happiness as the ultimate goal in human life, that everyone seeks (Ameriks & Clarke, 2000). The term “QoL” first appeared in medicine in the early 1960s (Elkington, 1966; Long, 1960). Before that, medicine mainly focused on the quantity of life. Elkington introduced the term “QoL” in 1966, when he pointed out that new technologies, raised further questions for clinicians: “How does a physician protect the proper QoL of an individual patient?” He also questioned where the resources of society should be allocated to achieve the most in health and QoL for the members of the society (Elkington, 1966).

There is no universal definition of QoL, but the WHO defines it as “the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals” (World Health Organization, 1998). According to this definition, QoL is a subjective experience, and individuals report their own QoL. QoL is an essential outcome in many health research projects, and the term “health-related QoL” (HRQoL) is often used to refer to the impact of health aspects on QoL (Ferrans, Zerwic, Wilbur, & Larson, 2005; Health et al., 2006). However, in the context of chronic diseases, it may be difficult to distinguish between health-related and non-health related
QoL (Ferrans et al., 2005); in this thesis, we use the term “QoL” even though both health-related QoL and global QoL were assessed. Two different assessment tools were used to evaluate QoL; one tool that contains health-related aspects such as biological, physiological, social, and spiritual functions (Short Form -12) and one visual analogue scale (VAS) that measures patients' subjective experience of their own global QoL (VAS-QoL).

A recent systematic review from 2019 investigating disease-related symptoms and HRQoL in CKD patients who did not have RRT found that QoL decreased when symptoms increased. However, the authors did not conclude which symptoms were predictive of the decrease in QoL. Over time, the mental aspects of QoL seemed to increase, while the physical aspects decreased (Yapa, Purtell, Chambers, & Bonner). The QoL of CKD patients receiving RRT in the form of dialysis, was found to be significantly lower than that of the general population as well as that of patients in earlier stages of CKD (Pagels, Soderkvist, Medin, Hylander, & Heiwe, 2012).

2.5 Adherence to long-term therapy

Previously, a patient’s therapeutic behaviour was based on the concept of compliance – meaning how closely a patient followed the treatment prescribed by a doctor. Today, a more favourable term to indicate whether a patient achieves treatment success is “adherence”. Adherence is defined as the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider (World Health Organization, 2003). In the thesis, the term “adherence” rather than “compliance” is used.

According to the WHO, more than 50% of patients with chronic diseases in developed countries are in some way non-adherent to medical treatment. Furthermore, more than 30% of medicine-related hospital
admissions occur as a result of non-adherence (World Health Organization, 2003). Non-adherence leads to poor clinical outcomes, increased morbidity, increased mortality, and unnecessary healthcare expenditures (McDonnell & Jacobs, 2002).

For this thesis, patient adherence to long-term medical therapy and adherence to general lifestyle recommendations from healthcare providers were assessed using different tools.

There is no gold standard for assessing adherence to medical therapy, and a combination of different assessment methods is recommended (Lam & Fresco, 2015). For this thesis, PROMs and data from an E-prescription module in the medical records were used to evaluate medical adherence.

To assess adherence to lifestyle recommendations, we used a single item VAS (VAS-Adherence) to assess patients’ judgments of how they followed/adhered to general lifestyle recommendations given by healthcare providers. The VAS-Adherence contains no specification of how many recommendations patients received but provides an assessment of patients’ subjective experience of lifestyle adherence. We did not set a cut-off value for non-adherence as we used the VAS-Adherence score as a continuous variable. A single-item VAS is an easy, inexpensive, and reliable tool for assessing subjective experiences (Kalichman et al., 2009).

### 2.6 Depression and depressive symptoms

Depression is a mental disorder that negatively affects a person's daily life, such as the ability to work, sleep, study, eat, and enjoy life (McQueen, 2009). Depressive symptoms can be described as negative thoughts, feelings, or behaviour that exist on a continuum of severity. In clinical studies, it is common to score depressive symptoms with the use of a screening tool with a cut-off value for clinical depression. In the
current study, the Beck Depression Inventory Short Form (BDI-SF) was used. The BDI-SF will be further described in section 3.6.2. The experience of fewer depressive symptoms than the cut-off value for clinical depression can also have clinical significance for the patient and negatively affect daily life (Lewinsohn, Solomon, Seeley, & Zeiss, 2000). Depression and depressive symptoms are well known to be underrecognized and undertreated in patients with CKD across all stages of the disease (Amira, 2011; Hedayati, Minhajuddin, Toto, Morris, & Rush, 2009a). Having depression negatively affects one’s motivation to manage health issues (Shin et al., 2017), and having depressive symptoms is associated with reduced HL (Dodson, Osicka, Huang, McMahon, & Roberts, 2016).

2.7 State of the art

2.7.1 Health literacy research in various settings

Studies have revealed that up to half of the European population, including receivers of healthcare, has limited HL (Sorensen et al., 2015). Individuals with limited HL have a higher risk of misunderstanding medical prescriptions and drug-warning labels and are less adherent to medical treatment (Davis, Wolf, Bass, Middlebrooks, et al., 2006; Davis, Wolf, Bass, Thompson, et al., 2006; Wolf et al., 2007; Wolf, Davis, Tilson, Bass, & Parker, 2006). A large population-based study from Denmark found that patients with chronic conditions had more difficulties in some aspects of HL (the ability to understand health information and the ability to engage with healthcare providers) than the general population. They also found that patients with more than one long-term condition had more difficulties engaging with healthcare providers and understanding health information than patients with one long-term condition (Friis, Lasgaard, Osborne, & Maindal, 2016). In addition, lower HL was associated with a lower level of education, and lower education was associated with more unhealthy behaviours such as
smoking, poor diet and, physical inactivity (Friis, Lasgaard, Rowlands, Osborne, & Maindal, 2016). A review article from 2011 included 96 different studies focusing on the relationship between limited HL and health outcomes. The study found that insufficient HL, in general, was associated with increased hospitalization, increased all-cause mortality, less ability to take medications correctly, and less participation in health-preventing activities such as mammography screening programmes and influenza vaccination (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

A systematic review from 2018 investigated HL from the perspective of healthcare providers and healthcare consumers (Rajah, Ahmad Hassali, Jou, & Murugiah, 2018). The review included 19 quantitative and nine qualitative studies focusing on knowledge of HL and perceived barriers to HL. Healthcare providers divided HL barriers into different categories: healthcare system-related, patient-related, and healthcare provider-related barriers to HL. The most frequently perceived barriers to HL in the healthcare system were time constraints, a lack of educational resources and a lack of leadership support. Patient-related barriers were language barriers, cultural barriers, age, and educational level. Healthcare providers-related barriers included a lack of skills, lack of knowledge, lack of interest, and lack of a physician-patient alliance. Qualitative studies that have explored perceived barriers to HL from patients’ perspectives have revealed medical jargon, time constraints, socioeconomic background, education, and family support to be the most common barriers to adequate HL (Rajah et al., 2018).

Several studies have reported that healthcare professionals overestimate patients’ HL or fail to identify patients with limited HL (Bass, Wilson, Griffith, & Barnett, 2002; Dickens, Lambert, Cromwell, & Piano, 2013; Goggins, Wallston, Mion, Cawthon, & Kripalani, 2016). Hence, characterizing patients with all around low HL may be necessary to identify vulnerable patients who need extra attention to strengthen their HL.
2.7.2 Prevalence of limited health literacy in patients with chronic kidney disease

Earlier HL research utilizing unidimensional assessment tools has indicated that limited HL is prevalent in patients with CKD across different stages of the disease. (Fraser et al., 2013; Green et al., 2013; Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Taylor et al., 2016). Fraser et al. (2013) found limited HL in more than 22% of CKD patients in a systematic review of six different studies including a total of 1405 patients (Fraser et al., 2013). A British study that included 6842 patients in various stages of CKD, found low HL in 20% of CKD patients on maintenance dialysis, in 15% of patients on a waiting list for a kidney transplant, and in 12% of kidney transplant recipients (Taylor et al., 2016). Another Australian study, utilizing a multidimensional assessment tool for HL (HeLMS), reported that kidney transplant recipients were the group of CKD patients with the most HL deficits (Lambert, Mullan, Mansfield, & Lonergan, 2015). The prevalence of inadequate or limited HL differs across studies, possible due to the various assessment tools used for HL, which makes it difficult to compare results between studies (Jordan, Osborne, & Buchbinder, 2011).

2.7.3 Associations between health literacy in patients with chronic kidney disease and demographic and clinical variables

The systematic review by Fraser et al. found associations between limited HL and less education, male gender, lower income, living alone, and older age (Fraser et al., 2013). Two other studies observed associations between reduced kidney function and limited HL (Devraj et al., 2015; Ricardo et al., 2014). One of the studies, which included 2340 patients, reported that compared with patients with adequate HL, patients with limited HL were more likely to have lower kidney function, higher
urinary protein excretion, and higher self-reported CVD and were less likely to have a blood pressure (BP) $< 130/80$ mmHg (Ricardo et al., 2014). Another study including 181 patients with CKD stages 1-4 found that patients with reduced HL were more likely to have lower kidney function (Devraj et al., 2015). An Australian study utilizing a multidimensional assessment tool for HL found that patients with moderate HL had more anxiety and depressive symptoms than patients with higher HL (Dodson, Osicka, Huang, McMahon, & Roberts, 2016c), while an American study utilizing a less sophisticated assessment tool for HL (the TOFHLA) found no such associations (Green et al., 2011).

2.7.4 Associations between health literacy in patients with chronic kidney disease and adherence and quality of life

Limited HL is associated with higher medical costs; in an American study conducted in 2013 that included 260 HD patients, patients with limited HL more often dropped out of scheduled dialysis sessions, were more likely to be referred to the emergency care unit, and were at increased risk for hospitalization (Green et al., 2013). Patients with ESRD and limited HL were less likely to be referred for kidney tx (Grubbs et al., 2009), which is considered the best RRT. Numerous studies have found that kidney tx patients have better QoL than dialysis patients (Tonelli et al., 2011; van Sandwijk et al., 2019).

A Canadian study evaluating adherence to immunosuppressants in kidney transplant patients found associations between lower HL (assessed with the HLQ) and lower adherence (Demian, Shapiro, & Thornton, 2016).

Green et al. identified no association between HL and QoL in a study of 288 HD patients, while Dodson et al. found a negative association between lower HL and lower QoL in 100 HD patients (Dodson et al., 2016).
Theory

Previous research utilizing multidimensional assessment tools for HL in CKD patients is scarce, but an Australian study from 2015 used the precursor to the HLQ, the Health Literacy Management Scale (HeLMS). The researchers observed differences between pre-dialysis, PD, HD, and kidney tx patients. Kidney tx patients had the most significant proportion of HL deficits in finding health information, indicating that this group of patients cannot easily access information. For the whole group of patients, the dimensions of understanding health information, attending to one’s health needs, social support and socioeconomic factors were the HL dimensions with the most deficits in CKD patients, and the predictors of inadequate HL were lower education and male gender (Lambert et al., 2015).

Taylor et al.’s 2017 systematic review of HL and patient outcomes in CKD concluded that there is limited evidence of the causal effects of HL on patient outcomes in CKD (Taylor, Fraser, Bradley, et al., 2017). The authors suggested that prospective studies are necessary to determine the causality of HL for patient outcomes and that intervention studies are necessary to assess whether HL is a modifiable determinant of poor outcomes in CKD.

2.7.5 Qualitative health literacy research in patients with chronic kidney disease

Qualitative research on HL and CKD patients is also scarce and characterized by different definitions of the concept. An integrative literature review from 2019 identified 21 articles reporting qualitative studies on the engagement and participation of people with CKD in their care (Almeida, Santos, Rehem, & Medeiros, 2019) and described low HL as a cultural barrier to engaging in managing CKD. Another qualitative study evaluating HL in patients with diabetes and stage 3 CKD found that the relationship between patients and healthcare providers was important. Simple language, repeated messages, and encouragement were helpful for patients, while a lack of follow-up and
a lack of coordination with other specialists were barriers to adequate HL (Sakraida & Robinson, 2009).

2.7.6 Summary

Recent studies indicate that limited HL is prevalent among CKD patients and is associated with worse health outcomes and higher medical costs. Focusing on increasing HL in CKD patients may therefore benefit this group of patients and society. Previous studies have mostly focused on the assessment of health-related numeracy- and reading skills with a quantitative approach. However, we need to know more about the cognitive, interactive, and social aspects of HL as well as patients’ perceived experiences of HL. Therefore, both quantitative and qualitative studies are needed to explore the possibilities for intervention to increase HL in patients with CKD.
3 Methods

3.1 Philosophical considerations

A paradigm or worldview is a set of philosophical assumptions shared by researchers that regulate inquiry within disciplines (Weaver & Olson, 2006). Qualitative and quantitative research have different natures, but the different approaches both aim to answer research questions to create a theory or to refute an existing theory. Quantitative research mainly deals with numbers and statistical interpretations, and objectivity is desired. In contrast, qualitative research involves non-numerical data and the interpretation of data in such way that subjectivity of both researcher and research subject is essential and valuable for the results (Polit & Beck, 2009). Traditionally, quantitative and qualitative research approaches were seen as two opposite, incompatible research paradigms or worldviews. Researchers were expected to take a stand on one paradigm/worldview and use the methodology that supported their chosen worldview in their research (Creswell & Clark, 2017). However, at the end of the last century, it was claimed that the different approaches did not have to be seen as opposite to each other but rather represented different ends of a continuum (Newman, Benz, & Ridenour, 1998). During recent decades, a pragmatic approach to research and research methodology has been developed according to which the researcher can choose the method that is best suited to answer the research question, which allows for a multi-method approach (Creswell & Clark, 2017; Jick, 1979). A multi-method approach with a pragmatic worldview constitutes the philosophical background for this thesis describing and exploring HL in a group of CKD patients, based on the utilization of both quantitative and qualitative methods.

The overall aim of this thesis was to explore HL in patients with CKD.

Through both quantitative and qualitative methods, strengths and challenges related to HL were explored in this group of patients. The
methods

associations between HL and other variables, such as demographic and clinical variables, adherence to long-term therapy, and QoL were assessed by quantitative methods, and a deeper understanding of CKD patients’ experiences with different aspects of HL was acquired using qualitative methods. The two approaches were complementary and strengthened the results by addressing the shortcomings of the other method (Malterud, 2001).

3.2 Study design for the thesis

Following the overall aim of this thesis, a multi-method research design (Jick, 1979) was used. The thesis reports two observational cross-sectional studies (quantitative approach) that were conducted to describe and identify the associations between demographic and clinical variables with multidimensional HL, as well as the associations of multidimensional HL with QoL and adherence to long-term therapy. A qualitative approach was used to obtain a more in-depth insight into patients’ experiences of different dimensions of HL to better understand their HL needs. As a whole, this thesis can be described as having a pragmatic stance, as we combined methods from different paradigms/worldviews.

An overview of the different studies in the PhD project, including the aims, design, variables, assessment tools, participants, and data analyses, is presented in Table 4.
Ⅰ To describe multidimensional health literacy in patients with CKD.
To identify the associations of dimensions of HL with demographic and clinical variables
To identify and characterize patients with low HL

### Variables
- Health literacy
- Age, gender
- Education level
- Income level
- Living arrangement
- Depressive symptoms
- Number of medications
- Presence of comorbidity
- Stage of CKD

### Assessment tools/data
- HLQ
- BDI-SF
- DCI

### Participants
- n = 187

### Data analysis
- Statistical analysis: Descriptive statistics
- Comparison of means
- Hierarchical cluster analysis
- Regression analysis

Ⅱ To identify the HL dimensions associated with adherence to long-term therapy and QOL in CKD patients.
To compare adherence to long-term therapy and QOL in patients with different levels of HL

### Variables
- Health literacy
- Global QoL
- Mental QoL
- Physical QoL
- Adherence to medications
- Adherence to lifestyle recommendations

### Assessment tools/data
- HLQ
- VAS-QOL
- SF-12 (MCS-12)
- SF-12 (PCS-12)
- MARS-5
- E-prescription module
- VAS-Adherence

### Participants
- n = 187

### Data analysis
- Statistical analysis: Descriptive statistics
- Comparison of means
- Hierarchical cluster analysis
- Regression analysis
- Chi-square analysis

Ⅲ To explore CKD patients’ experiences of different dimensions of HL.

### Assessment tools/data
- Individual interviews
- Semi-structured interview guide

### Participants
- n = 12

### Data analysis
- Qualitative analysis: Thematic analysis following Braun and Clarke

---

**Legend Table 4.** The same participants (n=187) as in study I. The participants in study III (n=12) were recruited from the participants in studies I and II. CKD: Chronic kidney disease, HL: Health literacy, HLQ: Health Literacy Questionnaire, QoL: Quality of life, VAS: Visual Analogue Scale, MCS-12: Mental Component Score-12, PCS-12: Physical Component Score-12, MARS-5: Medical Adherence Rating Scale.
Methods

3.3 Study design of the cross-sectional studies

A descriptive cross-sectional design was used to describe HL and to identify the associations of different dimensions of HL with demographic and clinical variables, QoL, and adherence to long-term therapy in CKD patients.

3.3.1 Sample

The Stavanger University Hospital (SUS) provides health care services for approximately 330,000 people in the southwestern part of Norway (Stavanger Web, 2014). The possible study population consisted of approximately 500 individuals diagnosed with CKD stages 3-5 who were treated in the outpatient clinic of the Department of Nephrology. Patients in HD were treated in the in-hospital dialysis unit. Patients with CKD stages 1 and 2 were not recruited, as they are mainly followed up in the primary healthcare system and have fewer medical implications.

Inclusion criteria: Age > 18 years, CKD stages 3-5, written informed consent, and ability to read and understand the Norwegian language.

Exclusion criteria: Active, non-cutaneous cancer; unstable CVD; cardiovascular incident (myocardial infarction, transient ischaemic attack, or cerebral vascular accident) in the last three months; or major surgery in the previous three months.

Patients were included consecutively at routine outpatient clinic visits or scheduled HD treatments over a period of six months (from February to August 2017). The approach to determining the eligibility of participants is further described in the ethical considerations section (section 3.9).

The rationale for excluding patients with severe unstable conditions, such as unstable CVD and active cancer, was to support the investigation of the impact of CKD on HL. Severe, unstable medical conditions might...
have strongly influenced the results, shifting the focus from kidney disease.

According to the research protocol, we estimated that a total of 200 patients (80 with CKD stage 3, 80 patients with stages 4 and 5 not on dialysis and 40 HD patients) would be sufficient to answer our research question. The estimation was based on the number of variables to be included in the statistical analysis. It was not possible to perform sample size calculations, as the numbers for calculation were not available.

### 3.4 Study I instruments

#### 3.4.1 Health Literacy Questionnaire

The HLQ was used to assess HL. The HLQ is a validated questionnaire that was developed using a validity-driven approach comprising in-depth grounded consultations, psychometric analysis, and cognitive interviews (Osborne et al., 2013). The questionnaire contains 44 items across nine independent scales, and it has been translated and culturally adapted for use in several European and Asian contexts, including Norway (Hawkins, 2010; Jessup, Osborne, Beauchamp, Bourne, & Buchbinder, 2017; Kolarcik et al., 2017; Maindal et al., 2016; Nolte et al., 2017). The HLQ allows for a multidimensional evaluation of HL to explore HL from a broad perspective.

Each of the nine scales provides independent information about different dimensions of HL, with each scale assessing one dimension, and the questionnaire is divided into two main parts. In the first part (HLQ scales 1-5), the respondents have four options to indicate how strongly they disagree or agree with a set of statements: “strongly disagree”, “disagree”, “agree” or “strongly agree.” In the second part (HLQ scales 6-9), the respondents have five options to indicate how difficult or easy different tasks are: “cannot do/is always difficult”, “usually difficult”, “sometimes difficult”, “usually easy” or “always easy.” Because the
HLQ includes these nine independent dimensions of HL, there is no total score. An overall summary score in HLQ would not distinguish between the varying strengths and limitations of the different aspects of HL, and consequently, the main advantage of a multidimensional approach would be lost. Furthermore, there is no cut-off to indicate adequate or limited HL, but higher scores indicate better HL (Osborne et al., 2013). The nine dimensions of the HLQ are presented in Table 5, and the whole questionnaire is presented in Appendix A.

Table 5 – The Health Literacy Questionnaire scales, with the number of items in each scale and the possible range of scores

<table>
<thead>
<tr>
<th>Health Literacy Questionnaire scales (Number of items)</th>
<th>Possible range of scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feel understood and supported by healthcare providers (4)</td>
<td>1-4</td>
</tr>
<tr>
<td>2. Have sufficient information to manage my health (4)</td>
<td>1-4</td>
</tr>
<tr>
<td>3. Actively managing health (5)</td>
<td>1-4</td>
</tr>
<tr>
<td>4. Have social support for health (5)</td>
<td>1-4</td>
</tr>
<tr>
<td>5. Appraise health information (5)</td>
<td>1-4</td>
</tr>
<tr>
<td>6. Ability to actively engage with healthcare providers (5)</td>
<td>1-5</td>
</tr>
<tr>
<td>7. Ability to navigate the healthcare system (6)</td>
<td>1-5</td>
</tr>
<tr>
<td>8. Ability to find good health information (5)</td>
<td>1-5</td>
</tr>
<tr>
<td>9. Ability to understand health information well enough to know what to do (5)</td>
<td>1-5</td>
</tr>
</tbody>
</table>

By acknowledging that HL is a multidimensional concept, we acknowledge that people can have varying HL strengths and limitations and that they are not only characterized as having inadequate or adequate HL.

The apparent advantage of a multidimensional- versus a one- or two-dimensional assessment tool for HL is that the use of a multidimensional tool can reveal which aspects of HL are most challenging for patients. The identification of the most challenging areas for patients’ HL may enable healthcare providers to create targeted interventions to increase HL.
3.4.2 Beck Depression Inventory-Short Form

The full Beck Depression Inventory (BDI) is a well-known and widely used self-assessment tool to evaluate depressive symptoms (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Richter, Werner, Heerlein, Kraus, & Sauer, 1998). The BDI is a validated tool for screening for depression in CKD patients (Hedayati, Minhajuddin, Toto, Morris, & Rush, 2009b) and is divided into two subscales: one subscale evaluating cognitive-affective symptoms (items 1-13) and one subscale evaluating somatic-symptoms (items 14-21). The Beck Depression Inventory-Short Form (BDI-SF) assesses cognitive-affective symptoms (the first 13 items) and is recommended for evaluating depressive symptoms in a medical setting. We used the short version because we were mainly interested in the cognitive-affective symptoms and not the physical symptoms. The BDI-SF scores ranges from 0 -39, and cut-off scores for clinical depression in earlier research vary between 10 and 14 (Andrade et al., 2010; Furlanetto, Mendlowicz, & Romildo Bueno, 2005; Hedayati et al., 2009b). The BDI-SF score was included as a continuous clinical variable relevant to HL in the cross-sectional studies. In the first study (paper I), the BDI-SF score was used as an independent variable to explain HL, and in the second study (paper II), it was included as a covariate in the regression analysis, as it might have been a confounder of the results (Appendix A).

3.4.3 Davies Comorbidity Index

The number of patient comorbidities was determined using the Davies Comorbidity Index (DCI). The DCI was developed to predict the risk of hospitalization and mortality in CKD patients due to seven different comorbidities: active cancer, ischaemic heart disease, peripheral vascular disease, left ventricular dysfunction, diabetes mellitus, systemic collagen vascular disease, and other significant pathologies, i.e., asthma, cirrhosis, and chronic obstructive lung disease. DCI = 0 indicates no comorbidity and is associated with a low risk for hospitalization and
Methods

mortality, DCI = 1 indicates the presence of one or two comorbidities and is associated with medium risk for hospitalization and mortality, and DCI = 2 indicates the presence of three or more comorbidities and is associated with a high risk for hospitalization and mortality (Davies, Phillips, Naish, & Russell, 2002; Davies, Russell, Bryan, Phillips, & Russell, 1995).

3.5 Study II instruments

3.5.1 Short Form-12

The Short Form-12 (SF-12) is a generic assessment tool for QoL derived from the well-known Medical Outcome Study 36-item Short-Form Health Survey (SF-36) (J. E. Ware, Jr. & Sherbourne, 1992). The questionnaire has been validated for patients with CKD in the Norwegian population (Osthus et al., 2012). SF-12 contains 12 items across eight different scales, i.e., physical functioning, role (physical), vitality, mental health, role (emotional), social functioning, general health, and physical pain, and provides component scores for physical (PCS-12) and mental (MCS-12) QoL (Farivar, Cunningham, & Hays, 2007; J. Ware, Jr., Kosinski, & Keller, 1996). The subscales of the instrument have a theoretical score range of 0-100, with higher scores indicating better QoL. The component scores are transformed to have a mean value of 50 and an SD of 10. We chose the SF-12 instead of the longer SF-36 because the two versions have been found to be comparable in predicting health outcomes (Osthus et al., 2012) and because we wanted to limit the total number of items in the survey (Appendix A).
3.5.2 Visual Analogue Scale for global Quality of life (VAS-QoL) and adherence to general lifestyle recommendations (VAS-Adherence)

A VAS is a single-item tool to evaluate subjective experiences. A VAS can have different appearances, with either a vertical or a horizontal line, with or without anchoring lines and with or without grading such as numbers or illustrating figures (Cox, 2005). For this thesis, a 100 mm line with anchoring lines at each end was used. The line represents a continuum of experience, in this case, global QoL (VAS-QoL) and adherence to general lifestyle recommendations from healthcare providers (VAS-Adherence). The respondents were asked to mark a point on the line representing the experience that was being assessed. The distance from the left anchoring line to the marked point was measured in mm and represented the score; the possible score range was 0 to 100. A VAS was used to evaluate two different experiences: global QoL (VAS-QoL) and adherence to general lifestyle recommendations (VAS-Adherence) (Appendix A).

For the VAS-QoL, the left anchoring line represents “worst imaginable QoL,” and the right anchoring line represents “the best imaginable QoL.” A higher number indicates better QoL (De Boer, 2004; Grunberg, Groshen, Steingass, Zaretsky, & Meyerowitz, 1996; Huskinsson, 1983). In earlier research, the VAS-QoL was found to be a reliable and validated tool for assessing global QoL (De Boer, 2004) and a more sensitive tool than the SF-36 to assess the subjective experience of QoL in CKD patients (Stomer, Bergrem, & Goransson, 2013).

For VAS-Adherence, the left anchoring line represents “never following lifestyle recommendations,” and the right line represents “always following lifestyle recommendations.” The VAS-Adherence provides no information about the number of recommendations given but reflects patients’ subjective judgments of their adherence. A single-item VAS is
an easy, inexpensive, and reliable tool for assessing subjective experiences (Kalichman et al., 2009) (Appendix A).

### 3.5.3 Medication Adherence Rating Scale 5

The Medication Adherence Rating Scale 5 (MARS-5) was used to evaluate medical adherence. The MARS-5 contains five items evaluating medication-taking behaviour. The respondent is provided with five different options to respond to each item, and the possible scores ranges from 5-25, with a score of 25 indicating perfect adherence. The MARS-5 includes more than yes/no answers, and allows for graded adherence and the identification of patients taking too much medication. The tool was initially developed to assess adherence to medical treatment in patients with mental illness but has also been utilized in different patient populations, such as patients with asthma and chronic obstructive pulmonary disease (Horne & Weinman, 2002; Johnson & Maddigan, 2004). The questionnaire was translated into the Norwegian language using standardized translation methods, with the back translation approved by the original author (Jonsdottir et al., 2010).

The retrieval of prescribed medications from the pharmacy was assessed using an E-prescription module in medical records. Only up to a three-month supply of prescription medications are filled by pharmacies in Norway, and patients were categorized as non-adherent to medical treatment if his or her medications had not been collected for the past three months.

### 3.6 Data analysis for the cross-sectional studies

Categorical data are presented as frequencies and percentages, and continuous data are presented as means and standard deviations (SDs) if normally distributed and as medians and ranges otherwise. Student’s t-test and ANOVA were used to test the differences between normally distributed samples, and Kruskal-Wallis tests were used for samples that
Methods

were not normally distributed. Mann-Whitney tests were performed as post hoc tests to identify where the differences were located when we tested more than two samples for data that were not normally distributed (Altman, 2018).

3.6.1 Regression analysis

Multiple linear regression analyses were used in both studies to identify the associations between HL and other variables. We used backward stepwise regression analysis, meaning that we first performed univariate analyses with all the independent variables for each dependent variable and included variables with a p-value < 0.2 in the initial regression models. Then, we systematically removed the non-contributing variables one by one; the variable with the highest p-value was removed first until all the remaining independent variables had a p-value ≤ 0.05 (Altman, 2018). Consequently, the final regression models consisted solely of variables that were statistically significant and contributed to explaining the dependent variables in both studies (I and II).

In study I, the nine HLQ scales were the dependent variables (the variables to be explained), and the demographic and clinical variables were the independent variables (the explaining variables). The regression models followed the conceptual model that was used as a theoretical framework for this thesis, in which personal, situational, and social variables were described as antecedents or determinants of HL (Sorensen et al., 2012).

In study II, we changed the HLQ scales from dependent variables to independent variables that explained QoL and adherence to long-term therapy. According to the integrated model for HL, health behaviour (adherence) and health outcomes (QoL) are effects of HL and, therefore, are variables to be explained by HL. The regression analyses were corrected for age, gender, level of education, and depressive symptoms.
due to the results of the first study (presented in paper I). A p-value ≤ 0.05 was considered statistically significant (Altman, 2018).

3.6.2 Clustering patients

The HLQ will be comprehensively described in the instruments section, but importantly, it does not provide a total summative score. Instead, it provides a comprehensive picture of a person’s HL strengths and limitations in nine different dimensions (Osborne et al., 2013). In a group of patients, there will be variation in the HLQ profiles (varying HL strengths and limitations), so an overall mean score would not provide useful information. To be able to group patients with similar HLQ profiles, we utilized cluster analysis, as recommended by the authors of the HLQ (A. D. Beauchamp, S. Batterham, R. Osborne, R., 2017). Ward’s minimum variance method was conducted with standardized scores (z-scores) of each of the nine different HLQ scales to group patients with similar HLQ profiles. Ward’s minimum variance method minimizes the total within-cluster variance. At each step, the clusters with minimum between-cluster distance are merged (Ward, 1963). The number of clusters was selected based on the minimum accepted number of cases in a cluster. By using this method, we found that our participants tended to score all-around low, medium or all-around high on all the HLQ dimensions, enabling us to characterize patients with all-around low-, medium- and high levels of HL.

Pearson’s chi-square test was used to compare the retrieval of medication from the pharmacy between the different clusters of patients (Altman, 2018). All statistical analyses were performed with the Statistical Package of the Social Sciences, SPSS 25, and Excel 2016 (pivot table in the cluster analysis).
3.7 Study design of the qualitative study

In the qualitative study, individual semi-structured in-depth interviews were conducted to understand CKD patients’ experiences with different aspects of HL.

An interview is the most common method of data collection in qualitative studies and is defined as a professional conversation in which participants talk about their personal experiences with topics that the researcher has determined (Kvale & Brinkmann, 2009; Rubin and Rubin 1995).

The rationale for the use of a semi-structured interview guide was to ensure that the HLQ dimensions were covered while still allowing the patients talk about what they considered relevant without restrictions (Polit & Beck, 2009).

The semi-structured interview guide was based on the nine different dimensions of HL in the HLQ (Table 6). The interview guide for the qualitative study is presented in paper III and the appendix (Appendix B). We performed a pilot interview during the development of the interview guide in which a colleague with diabetes was interviewed (SSL). We made several changes to the interview guide based on her feedback.

The pragmatic worldview that constitutes the philosophical background for this thesis allowed for the use of a combination of quantitative and qualitative methods to address the research questions.

3.7.1 Sample

A total of 12 patients from the cross-sectional studies were invited to participate in the qualitative study when attending the outpatient clinic or the dialysis unit for a routine session/follow-up. As the aim was to capture an in-depth yet broad understanding of HL experiences in the
Methods

A group of CKD patients in different stages of the disease, we used maximum variation sampling, which is a purposeful sampling strategy to capture diversity (Creswell & Clark, 2017; Malterud, Siersma, & Guassora, 2016; Palinkas et al., 2015). We considered twelve patients sufficient to achieve diversity across the different levels of HL, ages, genders, and stages of CKD (Malterud et al., 2016). The levels of HL were based on the participants’ HLQ scores from the quantitative studies (papers I and II). All of the invited patients agreed to participate in the study and gave written consent before the interviews were conducted. The interviews lasted between 17 to 48 minutes, with a mean time of 35 minutes. Data were collected in a private room at the outpatient clinic or the patients’ homes from October 2017-March 2018. All the interviews were audio-recorded and performed by the same researcher (UES). The interviews were transcribed verbatim by UES and a trained health secretary (MV).

3.8 Data analysis for the qualitative study

Braun and Clarke’s steps for thematic analysis were used to analyse the interviews. The analysis process consists of six phases, as shown in Table 6.

Table 6 – Braun and Clarke’s six steps of thematic analysis

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarizing yourself with your data</td>
<td>Transcribing data (if necessary), reading, and re-reading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme.</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic “map” of the analysis.</td>
</tr>
</tbody>
</table>
Methods

5. Defining and naming themes
Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.

6. Producing the report
The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

(Braun & Clarke, 2006).

Thematic analysis is a flexible method for analysing qualitative data. It provides theoretical freedom and can be used with different epistemological and theoretical frameworks depending on the aim of the study or what the researcher wants to know (Braun & Clarke, 2006); thematic analysis was well suited to the pragmatic worldview that constituted the philosophical background of this thesis. The data were interpreted with a traditional hermeneutic approach in the sense that the researcher considered the intentional meaning of the data and not the text alone in the interpretation (Polifroni & Welch, 1999). The main themes (results) were identified based on their representation of a pattern in the data, and they addressed the research questions/aim of the study (Braun & Clarke, 2006).

Table 7 – Example of the analytic process

<table>
<thead>
<tr>
<th>Raw citations</th>
<th>Initial code</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>So, when I say I have little information and stuff…It is right to tell, but I am not sure if I want more because I feel it is enough for me.</td>
<td>Has limited information, feels it is enough.</td>
<td>Passive information receiver</td>
<td>Diversity in the role as a health information seeker</td>
</tr>
</tbody>
</table>

3.9 Reliability, validity, and trustworthiness

Validity and reliability are key criteria in both quantitative and qualitative methodologies for the quality of the research. However, there
Methods

are different processes to appraise the quality of the different research approaches (Leung, 2015).

In quantitative research, “validity determines whether the research truly measures that which it was intended to measure or how truthful the research results are. In other words, does the research instrument allow you to hit ‘the bull’s eye’ of your research object?” (Joppe, 2000). For the cross-sectional studies, we used questionnaires that had been validated with CKD patients or populations with other chronic conditions, such as diabetes or chronic obstructive pulmonary disease. Each of the PROMs are further described in the study I and study II instruments sections. The statistical methods and analyses must be appropriate to answer the research question and should consider confounders, systematic errors, and the likelihood of the accuracy of the (P-values). Reliability refers to the extent the results could be replicated and stable over time. The statistical analyses are further described in the statistical section. External validity refers to the extent to which the findings can be generalized to other settings or samples (Creswell & Clark, 2017).

In qualitative research, more focus is placed on validity rather than reliability. Trustworthiness is another term for validity in qualitative research, and concerns whether the information obtained is accurate. Examining to what extent the information is credible, transferable, dependable, and confirmable (Lincoln, 2007) will determine its trustworthiness. According to Polit and Beck, qualitative studies do not specifically aim for generalizability. Instead, it seeks to generate knowledge that can be transferred to other settings, which is also referred to as transferability (Polit & Beck, 2009).

To obtain trustworthiness in the qualitative study, Braun and Clarke’s six steps of thematic analysis and the 15-point checklist of criteria for good thematic analysis were followed, as shown in Table 4 (Braun & Clarke, 2006).
In the first phase, the first author conducted all of the interviews, and a trained secretary transcribed the interviews verbatim within weeks after the interviews were conducted. Then, the first author read the transcribed interviews and replayed the audio recordings to ensure that the transcription was accurate.

In phase two, while reading and familiarizing herself with the data, the first author systematically wrote the initial codes. Initially, NVivo12 software was used.

In phase three, during the process of familiarizing herself with the data and initial coding, the first author began to identify themes and drew mind maps to organize them.

In phase four, another researcher and co-author of the qualitative paper read the interviews discussed the initial codes and initial themes with the first author. The themes were checked against the initial codes and revised several times after discussion with the co-author. The two other co-authors were included in the discussion of the initial themes until consensus was reached.

In phase five, the first author wrote the story of that the data told based on the analysis and discussed it with the co-authors until consensus was reached.

In phase six, the paper was written, and illustrative examples from the interviews were extracted to illuminate the themes. The results were related to the research question and the literature.

An important strategy to obtain trustworthiness is to let other researchers read the data, discuss the findings, and agree on the results (themes) (Creswell & Clark, 2017). All four authors of the qualitative paper contributed to the analysis process, but only the first and last authors had access to the interviews.
3.10 Acquiring the patients’ perspectives in the quantitative studies

Due to the evolving healthcare system that aims to empower individuals, research has increasingly focused on patient-centred care and patients’ perspectives and experiences of health and healthcare (Weldring & Smith, 2013).

“Patient-reported outcome (PRO) is a patient’s directly reported response about the patients’ health, QoL, or functional status associated with healthcare or treatment without interpretation by anyone else” (Higgins & Green, 2011). Patient-reported outcome measures (PROMs) are the tools or instruments used to assess PROs. PROMs can be used as primary or secondary outcomes in a study (Weldring & Smith, 2013). For this thesis, PROMs were the primary outcomes.

PROMs were used to explore CKD patients’ perspectives on how they gained access to, understood, and used health information. PROMs were also used to identify the associations of HL with demographic and clinical variables as with subjective experiences such as QoL and to determine to what extent patients adhered to recommended long-term therapy (Appendix A).

3.11 Ethical considerations

Both the Nuremberg Code and the Declaration of Helsinki are cornerstones in protecting human beings from harmful and unethical research. Voluntary, informed consent from research participants is essential (Annas & Grodin, 1992; WMA, 2013). The National Ethical Guidelines for Research in Social Sciences and Humanities (NESH) were used as guidance to ensure that the project followed current legal and ethical preferences (De nasjonale forskningsetiske komiteene, 2016). The study protocol was initially sent to the Ethical Regional Committee (REK) in Norway but was ultimately approved by the
Methods

personal protection officer at SUS, indicating that the potential risk of participating was considered acceptable and outweighed by the possible advantages of the project (Appendix E and F).

3.11.1 How to ensure that consent was freely given?

The potential participants were asked by the researcher to participate in the study in conjunction with a scheduled visit to the outpatient clinic or HD treatment. They received both oral and written information, and the patients could take the written information home before deciding whether they would participate. Two prepaid addressed envelopes, one for the questionnaires and the other for the informed consent, were provided to the participants if they completed the questionnaires at home (most participants chose to take the survey at home) so they could return the materials to the researcher. Additionally, patients who signed the informed consent and who completed and returned the questionnaire were considered cognitively capable of participating. They were informed that they could withdraw from the study at any time without explaining the reason. They were also assured of the confidentiality and anonymity of their participation (Appendix C and D, informed consent for studies I, II, and III).

3.11.2 Could participation in this study harm the patients?

Ethical research guidelines are a critical part of research, and most importantly, they have been developed to protect participants from being harmed in research projects (De nasjonale forskningsetiske komiteene, 2016; WMA, 2013).

The patients were asked to complete a survey including six questionnaires that was estimated to take 30-40 minutes to complete. The questionnaires have been described elsewhere; they were rather comprehensive, with a total of 81 items. Some patients were invited to
Methods

participate in the qualitative study, which involved an in-depth interview that was estimated to last 1 hour, to explore their HL experiences.

The participants were not exposed to any interventions. The potential harm that participants could experience was mental harm, such as through triggering of depressive symptoms and/or anxiety, while participants answered questions about their feelings and experiences related to their kidney disease. The patients had the contact information of the researchers and they were informed that they could make contact if they had additional questions or comments about the study. All participants visited the outpatient clinic or the dialysis unit regularly and were followed up by healthcare providers who were aware of the ongoing study. Completion of the questionnaires and participation in the interviews was time-consuming, and the time spent may have been a disadvantage for some of the patients.

Potential benefits of participating in the study were satisfaction due to contributing to the generation of new knowledge and the potential for a better understanding of increasing HL in the actual group of patients. Furthermore, participants had the opportunity to talk about their situations with a dedicated person, which may have been a positive experience for some of the participants.

All of the collected data were coded and de-identified to protect the participants’ anonymity. The key code to access data was stored in a dedicated area in the hospitals’ secure server for research to maintain data security. The only person with access to the key code was the head researcher. All of the data will be deleted by the 31st of December 2021 (Appendix F).

In paper III, limited information about the participant characteristics is described to protect the participants’ anonymity due to the small sample size.
4 Results

4.1 Participants in studies I and II

A total of 187 patients with CKD stages 3-5 were included: 80 patients with CKD stage 3, 81 patients with CKD stages 4 and 5 not on dialysis, and 26 HD patients. Thirty-five percent of the participants were female, and the participants had a mean (SD) age of 67 years (13).

Table 8 – Patients’ characteristics, n = 187

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, years</td>
<td>67 ± 13</td>
</tr>
<tr>
<td>Women, no (%)</td>
<td>65 (35)</td>
</tr>
<tr>
<td>Education level, no (%)</td>
<td></td>
</tr>
<tr>
<td>Lower secondary school</td>
<td>36 (19)</td>
</tr>
<tr>
<td>Higher secondary school</td>
<td>77 (41)</td>
</tr>
<tr>
<td>Higher education ≤ 3 years</td>
<td>44 (24)</td>
</tr>
<tr>
<td>Higher education &gt;3 years</td>
<td>29 (16)</td>
</tr>
<tr>
<td>Household income in NOK, no (%)</td>
<td></td>
</tr>
<tr>
<td>&lt; 300 000</td>
<td>37 (20)</td>
</tr>
<tr>
<td>≥ 300 000 &lt; 600 000</td>
<td>83 (45)</td>
</tr>
<tr>
<td>≥ 600 000 &lt; 900 000</td>
<td>39 (21)</td>
</tr>
<tr>
<td>&gt; 900 000</td>
<td>25 (14)</td>
</tr>
<tr>
<td>Living alone, no (%)</td>
<td>49 (26)</td>
</tr>
<tr>
<td>Renal diagnoses, no (%)</td>
<td></td>
</tr>
<tr>
<td>Hypertensive nephropathy</td>
<td>62 (33)</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>40 (22)</td>
</tr>
<tr>
<td>Diabetic nephropathy</td>
<td>23 (12)</td>
</tr>
<tr>
<td>Polycystic kidney disease</td>
<td>14 (7)</td>
</tr>
<tr>
<td>Other</td>
<td>30 (16)</td>
</tr>
<tr>
<td>Unknown</td>
<td>18 (10)</td>
</tr>
<tr>
<td>DCI score, no (%)</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>66 (35)</td>
</tr>
<tr>
<td>1</td>
<td>88 (47)</td>
</tr>
<tr>
<td>2</td>
<td>33 (18)</td>
</tr>
<tr>
<td>BDI-SF scores, median (range) (n = 182)</td>
<td>2 (0-29)</td>
</tr>
<tr>
<td>Number of prescribed medications, mean ± SD</td>
<td>7.5 ± 3.7</td>
</tr>
<tr>
<td>Time with known CKD in months, median (range)</td>
<td>46 (1-515)</td>
</tr>
<tr>
<td>Active employment, no (%)</td>
<td>36 (19)</td>
</tr>
</tbody>
</table>
Legend Table 8. Davies Comorbidity Index (DCI) = 0 indicates no comorbidity, DCI = 1 indicates 1-2 comorbidities and DCI = 2 indicates ≥ 3 comorbidities. BDI-SF = Beck Depression Inventory-Short Form.

4.2 A cross-sectional study of health literacy in patients with chronic kidney disease: Associations with demographic and clinical variables (Paper I)

The aims of study I were to describe HL strengths and challenges in patients with CKD stages 3-5 and to investigate the associations between different dimensions of HL and demographic and clinical variables.

The most challenging dimensions were appraise health information, in part 1 of the HLQ, and ability to find good health information, in part 2 of the HLQ.

Males scored better than females on four out of the nine HL dimensions; females scored better than males on the actively managing health dimension (Figure 3).
Results

Demographic and clinical variables including: gender, level of education, living situation, number of medications, depressive symptoms, and duration of CKD were associated with different dimensions of the HLQ.

We clustered patients with similar HLQ profiles and found three different groups characterized by low, medium, and high levels of HL.
Results

4.3 Health literacy in kidney disease: Associations with quality of life and adherence (Paper II)

The aims of study II were to compare QoL and adherence to long-term therapy in patients with different levels of HL and to identify specific dimensions of HL that are associated with QoL and adherence.

The study population was identical to the population described in paper I.

Physical and general QoL (PCS-12 and VAS-QoL) were significantly better in the high-level HL group than in the medium- and low-level HL groups. Better ability to understand health information was associated with better physical and global QoL. Adherence to general lifestyle recommendations was positively associated with actively managing health, and the ability to engage with healthcare providers and negatively associated with the ability to find good health information. We found no association between HL and adherence to medications as assessed with the MARS-5. Regarding the retrieval of medications from the pharmacy, the low-level HL group had 50% non-adherence, whereas the medium- and high-level groups had 40% and 31% non-adherence, respectively. However, by the use of a chi-square test, we found that the differences were not statistically significant (Figure 4).
Results

Figure 4 – Medication retrieval from the pharmacy in the previous three months in patients with different levels of health literacy

Legend Figure 4. HL = health literacy. Non-adherence seemed to be highest in the low-level HL group; however, the results were not statistically significant.

4.4 **Participants in study III**

Twelve patients, who were all former participants in the cross-sectional studies, were included. We used a purposeful sampling strategy to ensure diversity in age, gender, stage of CKD, and level of HL.
Table 9 – Patients’ characteristics, n = 12

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, median (range)</td>
<td>66 (41-80)</td>
</tr>
<tr>
<td>Female gender, no (%)</td>
<td>6 (50)</td>
</tr>
<tr>
<td>CKD stage, no (%)</td>
<td></td>
</tr>
<tr>
<td>- 3</td>
<td>5 (42)</td>
</tr>
<tr>
<td>- 4 and 5, not on dialysis</td>
<td>4 (33)</td>
</tr>
<tr>
<td>- 5, on haemodialysis</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Level of HL, no (%)</td>
<td></td>
</tr>
<tr>
<td>- Low</td>
<td>5 (42)</td>
</tr>
<tr>
<td>- Medium</td>
<td>3 (25)</td>
</tr>
<tr>
<td>- High</td>
<td>4 (33)</td>
</tr>
<tr>
<td>Living alone, no (%)</td>
<td>5 (42)</td>
</tr>
<tr>
<td>Duration of known CKD in months, median (range)</td>
<td>52 (3-259)</td>
</tr>
<tr>
<td>Presence of comorbidity, no (%)</td>
<td>6 (50)</td>
</tr>
</tbody>
</table>

Legend Table 9. CKD = chronic kidney disease, HL = health literacy

4.5  **An exploration of health literacy in patients with chronic kidney disease, a qualitative study (Paper III)**

The aim of study III was to provide insight into CKD patients’ HL experiences related to the dimensions of the HLQ.

The analyses revealed three main themes that described HL experiences among CKD patients (Figure 5).
Figure 5 – Main themes based on the health literacy experiences of patients with chronic kidney disease

Legend Figure 5. CKD = chronic kidney disease.

**Theme 1.** Diversity in the role as a health information seeker.

The most prominent theme concerned different strategies for handling health information. While some patients actively sought information, were interested in learning more about CKD, and tried to achieve control over their health situations, others were passive receivers of health information or actively avoided health information. Patients passively received or avoided health information not necessarily because they lacked of competence but rather as a strategy to keep the focus on the...
Results

good things in life and not worry about unpleasant information that made them feel sicker.

**Theme 2.** A fragmented healthcare system, a challenge for navigating.

For patients with comorbidities, the healthcare system appeared fragmented and made it difficult for them to maintain control of their health situations. A lack of knowledge about which doctor to see for different health concerns and the experience of inconsistency in treatment were frustrating for some patients.

**Theme 3.** The value of a good relationship with healthcare providers.

The experience of a good relationship with healthcare providers characterized by trust and continuity could compensate for fragmented care and facilitate HL, indicating that healthcare providers are important for CKD patients’ HL.

Our findings imply that CKD patients have different needs and desires for health information and that providing more information is not always the solution to increasing HL or the patient’s wish. Furthermore, our study indicates that continuity of care in healthcare providers is important to patients and can compensate for HL barriers such as a fragmented healthcare system.
Discussion

5 Discussion

The overall aim of this thesis was to explore HL in patients with CKD. The three specific objectives for the different papers were as follows:

1) To describe HL strengths and challenges in a CKD population and identify the associations of HL with demographic and clinical variables (paper I);
2) To identify associations of various aspects of HL with QoL and adherence to long-term therapy (paper II);
3) To gain more in-depth insight into CKD patients’ experiences of different aspects of HL (paper III).

In this section, the results from the different papers are discussed together.

5.1 Discussion of the main findings

The results show a complex picture of HL in this population. The HL strength of CKD patients seemed to be relationships and cooperation with healthcare providers. Both the quantitative and qualitative studies indicate that a good and trusting relationship with healthcare providers is an important dimension of HL because it is associated with better adherence to lifestyle recommendations and can compensate for a fragmented healthcare system, which seems to be a barrier to HL.

It is expected that some patients would experience a fragmented healthcare system, as CKD patients often have comorbidities. They meet healthcare providers from different health departments who often focus on different organs (Fraser & Taal, 2016; Tonelli et al., 2015). Fragmentation of the healthcare system between different departments and institutions is a well-known problem that is associated with increased hospitalization and worse health outcomes both in CKD patients and in patients with other chronic diseases (Chang, Chien, Bai, Lin, & Chiou,
Discussion

2018; Clemens et al., 2019; Ibrahim et al., 2018; Kern, Seirup, Rajan, Jawahar, & Stuard, 2018; Lin, Wu, & Huang, 2015). However, fragmentation might also occur within a department in terms of patients seeing new healthcare providers at each appointment. Several studies in different healthcare settings have reported that the patient-provider alliance is a cornerstone for successful treatment and necessary for both QoL and adherence (Chang et al., 2018; Clemens et al., 2019; Fuertes et al., 2017). To establish a patient-provider alliance in which the patient and provider get to know each other, continuity of care is necessary. At the Department of Nephrology at the study hospital, continuity of care has been a focus, which has stimulated the formation of patient-provider alliances and in turn, may have contributed to the results.

The most challenging dimensions of HL for CKD patients were to find good- and appraise health information, which is in accordance with earlier research in CKD patients (Demian et al., 2016; Dodson et al., 2016; Dahl et al., 2020) and also in other groups of patients with chronic diseases (A. Beauchamp et al., 2015). It is well-known that the rapidly growing amount of health information available on the internet and social media can have both advantages and disadvantages. The internet enables people to have timely and convenient access to health information that may contribute to a better understanding of their conditions. On the other hand, the potential problems include the varying quality of the information, lack of regulations, complicated language, and potential for misleading information (Jordan-Marsh, 2010).

The use of and access to the internet varies between individuals, which places higher demands on healthcare professionals to adapt the information to each patient (Jacobs, Amuta, & Jeon, 2017; Manierre, 2016). The massive amount of information available on the internet may be a disadvantage, especially if patients prefer to trust information found on the internet over information from a healthcare provider. An American nephrologist recently reported his concern about CKD patients who stopped taking certain medications after finding information on the
internet (Weiss, 2019). The quality of communication between the patient and provider affects patients’ health-seeking behaviour on the web. An interaction between the patient and healthcare provider in which the patient’s opinion is taken seriously and a setting in which the healthcare provider has sufficient time to discuss health concerns with the patient, has been described in a qualitative study to be important for patients’ confidence in information provided by healthcare providers (Costello, 2016; Lopez-Vargas, Tong, Phoon et al., 2014).

Based solely on the quantitative results, it seems that there is a need to develop strategies for finding and appraising health information and filtering unhealthy information to increase CKD patients' HL. However, the results from the qualitative study (study III) indicate that some patients might choose a strategy to avoid health information to not focus on their disease. In these patients, access to more health information will probably not increase their HL. The findings are in accordance with a recent Norwegian qualitative study with renal recipients, which claimed that some CKD patients avoided or tried to limit the amount of health information to be able to live a life that was not all about the disease. The qualitative study concluded that the patients needed a “trigger” or a concern about the health condition to start searching for information and ask questions (Gire Dahl, Engebretsen, Andersen, Urstad, & Wahl, 2019). However, this conclusion conflicts with another qualitative study suggesting that patients want to know as much as possible about their CKD as early as possible (Nunes, Roney, Kerr, Ojo, & Fagerlin, 2016).

For patients with limited skills or motivation to utilize the healthcare system, improving their HL is critically important for reducing health discrepancies (R. Batterham et al., 2017) (Paasche-Orlow & Wolf, 2010). Since healthcare professionals often overestimate patients’ HL (Bass et al., 2002; Dickens et al., 2013; Goggins et al., 2016), our findings on the characteristics of vulnerable CKD patients are a significant contribution to help healthcare providers identify these patients. The findings regarding characteristics related to low
Discussion

Socioeconomic status, such as lower education levels in patients with low HL, are consistent with other studies in different settings and using various assessment tools for HL (A. Beauchamp et al., 2015; Friis, Lasgaard, Osborne, et al., 2016; Sorensen et al., 2015). In our sample of CKD patients, the low-level HL patient group used more medications, were more likely to live alone, and had more depressive symptoms than the other groups of patients. These findings may help healthcare providers work with CKD patients, and identify vulnerable CKD patients.

According to other studies utilizing both one-dimensional (Green et al., 2013; Ricardo et al., 2014; Wolf et al., 2006) and multidimensional assessment tools (Demian et al., 2016; Dodson et al., 2016) the consequences of low HL include worse QoL and worse adherence to long-term therapy. This study, however, is to our knowledge, the first to determine that understanding health information and being able to engage with healthcare providers are predictive of QoL and adherence. The communicative skills of healthcare providers are therefore important for adapting health information and underline the significance of the patient-provider alliance. Our results support the Norwegian strategic plan for increasing HL in the Norwegian population in that all healthcare providers should have access to courses to enhance communication skills and to practice communication skills at work. (Ministry of Health and Care Services (HOD), 2019b). Indirectly, increased communication skills among healthcare professionals might increase QoL in CKD patients.

From a theoretical perspective, the findings from the cross-sectional studies mostly fit the conceptual framework for this thesis in that the demographic and clinical variables were found to be predictive of different aspects of HL and that HL was found to be predictive of health outcomes such as QoL and adherence. However, the qualitative study revealed that intentionally not involving with the health information
Discussion

An interesting theoretical discussion that arises from our results is whether a patient can be characterized as health literate and, at the same time, deliberately make unhealthy choices or choose not to relate to information about their diseases. According to the WHO definition, only the individuals that make decisions that promote and maintain good health are health literate (World Health Organization, 1998). Other definitions allow for individuals to be health literate if they make unhealthy priorities as long as the decisions are informed (Sorensen et al., 2012). A consensus on the definition of HL is urgently needed for further mapping of the term in future studies.

The healthcare system is working to empower patients and develop healthcare services that enable patients to take more responsibility and make better decisions about health, which is considered positive for both individuals and society and both nationally and internationally (Ministry of Health and Care Services (HOD), 2019a) (World Health Organization, 2013). From an ethical perspective, however, the evolution of the healthcare system can also result in suboptimal healthcare if patients refrain from engaging with their health situations. It is a political desire to create the patients' healthcare services, but it might be a challenge for healthcare services to respond to individuals who do not want to be health literate or make sound health decisions. The discussion includes ethical dilemmas that affect patients, healthcare workers, and politicians.

5.2 Methodological considerations

Research design

A pragmatic worldview as a philosophical background and the use of a multi-method design to answer our research questions provided no limitations to the methods (Creswell & Clark, 2017). However, the thesis
could have been characterized as a mixed-method design in that the HLQ scores from the cross-sectional studies were used to ensure diversity in levels of HL of the participants in the qualitative study. However, the levels of HL were not used in the interpretation of the interviews, and according to Teddlie and Tashakkori, both qualitative and quantitative methods should be mixed within a single study to be characterized as a mixed-method study (Teddlie & Tashakkori, 2012). We performed three separate studies, and therefore, the mixed-method criteria were not met.

The multi-method approach strengthened this thesis, as it addressed the shortcomings of both quantitative and qualitative methods (Polit & Beck, 2009). The quantitative approach with the use of questionnaires and data from the medical records was necessary to describe common HL strengths and challenges in the CKD population and identify associations with other variables, while the qualitative approach with interviews was necessary to obtain insight into what patients’ HL needs were. The combination was necessary to achieve the aim of the study.

A limitation of this work is the inclusion criterion of the ability to understand, read, and speak the Norwegian language. By not including patients with limited language skills, we excluded some of the most vulnerable patients, as it is well known that individuals who do not understand the national language have lower HL than individuals who are able to understand the national language (A. Beauchamp et al., 2015; Sorensen et al., 2015). The reason for solely including patients who could speak and understand the Norwegian language was the study design with extensive use of PROMs to assess HL and other variables. Future research should aim to include CKD patients who are not able to speak the Norwegian language, as they may have other HL challenges.

Another limitation of this work is that we did not evaluate the patients’ cognitive function. Other research have found that CKD patients with cognitive impairment have reduced self-management skills (Lambert,
Mullan, Mansfield, & Lonergan, 2017). It is likely that cognitive impairment will affect HL as well.

**Cross-sectional studies**

We were unable to include more than 26 HD patients, even though we aimed to include 40. The total number of patients receiving HD varies due to natural causes, such as death and transplantation. There were a total of 74 HD patients at the time of recruitment, forty-four of whom did not fulfil the inclusion criteria. Of the thirty HD patients eligible for our study, four declined to participate.

The cross-sectional design of the quantitative studies was useful to describe HL strengths and challenges at a specified time and to identify associations between HL and several pre-specified variables. According to medical statisticians, a cross-sectional design is well suited to form the basis for administrative and political decisions as the design is time- and cost-effective and allows the researcher to study many different variables in the same study (Laake, Lydersen, & Veierød, 2012). However, a cross-sectional study design limits the possibility of evaluating causality since both exposure and outcomes are measured only once.

**Assessing adherence**

Assessing adherence is a well-known challenge. Both adherence to medication and adherence to lifestyle recommendations bring challenges, as we know that patients tend to over-report adherence to please healthcare providers or authorities (Vik, Maxwell, & Hogan, 2004).

**Adherence to medical treatment**

There is no gold standard for assessing medication adherence, but a multi-measure approach seems to be the currently preferred method (Lam & Fresco, 2015). The most commonly used approach for assessing adherence to medication is self-reporting (Lam & Fresco, 2015). Self-
reporting is easy and inexpensive, but the main disadvantage is that patients tend to underreport non-adherence to avoid the disapproval of healthcare providers (Osterberg & Blaschke, 2005; Vik et al., 2004). The results from the PROM assessing medical adherence indicated that patients idealized their adherence to prescribed medications. The retrieval of medicines from the pharmacy was, however, non-significantly worse among patients with lower levels of HL.

**Adherence to lifestyle recommendations**

Regarding adherence to general lifestyle recommendations, we assessed subjective experience only, and no objective assessment was available. Objective data on adherence to general lifestyle recommendations are not easy to acquire, and since this was a cross-sectional study, we could not track changes in physical parameters. We still find this variable valuable and vital in this study, as it represents patients’ judgement of their adherence. However, these results are highly subjective, and the possibility of idealization of their adherence cannot be excluded.

**Missing data**

Less than 5% of the items in the questionnaires were missing. We did not compensate for missing data, except for the HLQ, for which the scoring manual allows the researcher to perform calculations and obtain scores for the different dimensions if less than half of the items in the individual dimensions are missing (A. D. Beauchamp, S. Batterham, R. Osborne, R., 2017). Two participants were excluded from some of the statistical analyses due to incomplete HLQs.

Twenty-three percent of the data from the E-prescription module were missing. We did not compensate for these missing data, as the missing data were from participants who had denied others than their primary medication prescribers to access this information.
**Discussion**

**Qualitative study**

Individual interviews were the preferred method to acquire in-depth data of the CKD patients’ experiences of different aspects of HL.

The researcher (UES) had working experience with dialysis patients, which may have affected the pre-understanding, and some of the participants’ answers. In qualitative studies, the researcher himself or herself is an instrument and might influence the interviews and the analysis (Creswell & Poth, 2016; Kvale & Brinkmann, 2009). Three of the participants were receiving HD and knew the researcher from the dialysis unit. It is possible that the patients did not explain everything since they knew the researcher was familiar with dialysis routines. The advantage of being familiar with the dialysis treatment and CKD, in general, was that the researcher had a better basis for understanding patients’ disease burden and could ask relevant questions.

Another limitation was that all of the dialysis patients (n=3), chose to be interviewed directly after a dialysis session to limit their time at the hospital. Many patients are tired and indisposed immediately after dialysis, which may have affected the interviews (Bossola & Tazza, 2016).

In general, qualitative studies are not suited for generalization (Polit & Beck, 2009). Hence, caution should be taken in extrapolating our results from this study to other contexts.
6 Conclusions

This thesis provides comprehensive knowledge about HL in adults with CKD stages 3-5 in a Norwegian healthcare setting and thereby contributes to the strategic plan to increase HL in the Norwegian population. The thesis describes HL strengths and challenges, and the associations of HL with demographic and clinical variables, QoL, and adherence to long-term therapy. Additionally, we went beyond the surface and explored the patients’ experiences of different dimensions of HL. The results show a complex picture of HL in this population. The concluding chapter presents the main findings, followed by implications for practice and suggestions for future research.

6.1 Main findings

The first study revealed that an HL strength in patients with CKD was the cooperation between patients and healthcare providers, while the abilities to find good health information and critically appraise it were the most challenging aspects of HL. Furthermore, we found that patients with CKD stages 3-5 have different levels of HL and that lower socioeconomic status, a complex health situation, female gender, and depressive symptoms were associated with more moderate HL.

The second study showed that patients with all-around low HL had worse QoL and possibly worse adherence to lifestyle recommendations than patients with all-around high levels of HL. A better ability to understand health information was associated with better QoL, whereas being active in managing health and having the ability to actively engage with healthcare providers promoted adherence to general lifestyle recommendations. A better ability to find good health information were negatively associated with adherence to general lifestyle recommendations.
Conclusions

The third study provided a deeper understanding of the patients' HL experiences and concluded that patients with CKD have different ways of relating to health information, from avoiding to actively seeking health information. We found that avoiding health information might be a strategy to cope with CKD and keep one’s focus on good things in life. Additionally, we found that a good relationship with healthcare providers seems to facilitating HL in CKD patients.

6.2 Implications for practice

The findings in this thesis are useful for all kinds of healthcare professionals working with CKD patients as well as health politicians involved in developing “the patients’ health care system.”

To address the main HL challenges, the focus could be on developing strategies to enabling patients to find relevant health information and to critically appraise and filter unhealthy information.

To increase HL in vulnerable patients, multidimensional HL could be assessed to identify individual HL challenges that are modifiable.

Healthcare providers should consider screening for depression in patients that seem vulnerable to detect treatable depression and indirectly contribute to better HL.

Due to the importance of the healthcare providers’ impact on CKD patients’ HL, we support the suggestion from the Norwegian Health Department to incorporate HL as a topic in education for all healthcare professionals to increase their awareness of HL and how to respond to different needs (Ministry of Health and Care Services (HOD), 2019b).

To help CKD patients navigate the healthcare system and keep control over their health situations, health institutions could consider providing continuity of care.
Conclusions

At an organizational level, healthcare leaders and health politicians could contribute to developing HLR organizations by prioritizing such organizations in budgets and keeping the focus on the topic of HL as well as ensuring that the workforce holds sufficient HL skills and have access to appropriate tools to assess and adapt health information to individual needs.

6.3 Suggestions for future research

This thesis contributes as a base for future research in patients with CKD and possible in other chronic illnesses, as it is highly hypothesis generating. Because of our findings, we suggest the following topics for future research.

To explore the significance of the relationship between patients and healthcare providers for CKD patients’ HL, researchers could compare the HL of patients with CKD not receiving continuity of care with that of patients receiving continuity of care.

Future research could also focus on the significance of the communicative skills of healthcare professionals for CKD patients’ HL. For example, interventional studies could evaluate the effect of improved communicative skills (i.e., motivational interview) in a group of healthcare professionals, compared with a control group of patients receiving conventional care.

In addition, future research investigate whether alternative ways of providing health information can improve HL. For example, interventional studies could evaluate the effect of developing and providing health information films instead of written or oral information.

There is a lack of robust data about causality between HL and other variables (Taylor, Fraser, Dudley, et al., 2017). Therefore, cohort studies following CKD patients’ HL over time as the disease progresses to
Conclusions

different stages could be conducted to evaluate of the impact of symptoms and treatment on the level of HL.

Another important task for future research could be the description and comparison of HL between CKD patients who do not speak the national language and patients who speak or understand the national language to identify other possible barriers to HL.
7 References


References


References


De nasjonale forskningsetiske komiteene. (2016). Forskningsetiske retningslinjer for samfunnsvitenskap, humaniora, juss og teologi (NESH). In: Oktan Oslo AS.


References


71


Hawkins, M. O., R. (2010). Questionnaire translation and cultural adaption procedure. Retrieved from Burwood:


References


References


References


doi:10.1016/j.jdiacomp.2017.01.026

Sorensen, K., Pelikan, J. M., Rothlin, F., Ganahl, K., Slonska, Z.,
doi:10.1093/eurpub/ckv043

Sorensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J.,
Health literacy and public health: a systematic review and
doi:10.1186/1471-2458-12-80

Stavanger Web. (2014). Stavanger University Hospital,. Retrieved from
https://stavanger-web.com/Stavanger-University-Hospital.php

quality of life in kidney transplant patients and non-renal

Sørensen, K., Van den Broucke, S., Pelikan, J. M., Fullam, J., Doyle,
populations: illuminating the design and development process of the
European Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC
Public Health, 13*(1), 948.

Tangkiatkumjai, M., Walker, D. M., Praditpornsilpa, K., & Boardman,
outcomes in patients with chronic kidney disease: a prospective
doi:10.1007/s10157-016-1312-6

Taylor, D. M., Bradley, J. A., Bradley, C., Draper, H., Johnson, R.,
Metcalf, W., . . . Investigators, A. (2016). Limited health literacy in
doi:10.1016/j.kint.2016.05.033

Taylor, D. M., Fraser, S., Dudley, C., Oniscu, G. C., Tomson, C.,
Ravan, R., & Roderick, P. (2017). Health literacy and patient
outcomes in chronic kidney disease: a systematic review. *Nephrol


References


Intentionally left blank
PART 2
Paper I
Chronic kidney disease (CKD) affects between 11%–13% of the population worldwide, and the incidence of CKD has increased in developed countries due to an ageing population and an increased prevalence of lifestyle-related diseases such as obesity, type 2 diabetes and hypertension (Eckardt et al., 2013; Hallan et al., 2006; Helsedirektoratet, 2011; Hill et al., 2016). CKD is divided into five stages where stage 5 also is referred to as end-stage renal disease (K/DOQI, 2002). If left untreated, CKD in earlier stages is more likely to progress to end-stage renal disease, requiring renal replacement therapy, developing comorbidities such as cardiovascular disease and posing a higher risk of mortality (Helsedirektoratet, 2011; Tangkiatkumjai, Walker, Praditpornsilpa, & Boardman, 2017). In addition to being provided with a complex medication regime, patients with CKD are often recommended a range of lifestyle changes such as a complex dietary regime, fluid control, regular exercise and weight control to reduce these risks (Levey & Coresh, 2012; Levey, Schoolwerth, et al., 2009; Whaley-Connell, Nistala, & Chaudhary, 2011). To comply with the health recommendations, it is crucial that patients are literate in the health-care environment.
the patients are able to gain access to, understand and use health information.

Health literacy (HL) is a multidimensional concept defined by the World Health Organization (WHO) as the cognitive and social skills that determine the motivation and ability to gain access to, understand and use information in ways which promote and maintain good health (WHO, 1998). Previous studies indicate that HL in patients with CKD is not optimal (Fraser et al., 2013; Taylor et al., 2017) and that lower levels of HL is associated with worse health outcomes and higher medical costs (Devraj et al., 2015; Fraser et al., 2013; Green et al., 2013; Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Ricardo et al., 2014; Taylor et al., 2016). Health literacy (HL) is therefore seen as an essential aspect of the care of patients with CKD (Berkman, Sheridan, Donahue, Halpere, & Crotty, 2011; Fraser et al., 2013; Green et al., 2011).

1.1 | Background

Over the last decades, the concept of HL has evolved from being a personal attribute solely depending on personal skills, to a broader concept also including dimensions such as trust and interaction with healthcare providers, social support and accessibility of the healthcare services (Batterham, Beauchamp, & Osbourne, 2017; Van der Heide et al., 2018; Sorensen et al., 2012). ‘The integrated model of HL’ from 2012 describes HL to be a prerequisite for use of health services, health behaviour, active participation in own health situation and equality in health (Sorensen et al., 2012). According to the model, social, environmental, personal and situational factors are determinative for a person’s HL; hence, demographic and clinical characteristics are essential when exploring HL in patients with CKD.

Furthermore, depressive symptoms are well known to be under-recognized and undertreated in patients with CKD across all stages of the disease (Amira, 2011; Hedayati, Minhajuddin, Toto, Morris, & Rush, 2009) and such symptoms are also associated with low HL (Dodson, Osicka, Huang, McMahon, & Roberts, 2016). Depressive symptoms negatively affect the motivation to manage health issues and may therefore influence a patient’s HL (Dodson et al., 2016; Shin et al., 2017).

Until recently, instruments measuring HL have mostly been one- or two-dimensional, focusing on health-related numeracy and reading skills. Frequently used instruments have been the ‘Rapid Estimate of Adult Literacy in Medicine’, focusing on word recognition (Davis et al., 1991) and the ‘Test Of Functional Health Literacy in Adults’, which tests reading and numeracy skills (Parker, Baker, Williams, & Nurss, 1995). However, having good health-related numeracy and reading skills does not mean that one can understand the consequences of the choices one makes; in addition, former instruments used for measuring HL have been reported to be sub-optimal (Jordan, Osborne, & Buchbinder, 2011). To identify HL challenges beyond reading and numeracy skills, such as a lack of social support, difficulties in engaging with healthcare providers and difficulties in navigating the healthcare system, a multidimensional assessment tool is required. Hence, the aim of this study was to describe multidimensional HL in patients with CKD and to identify possible associations between different dimensions of HL and demographic and clinical variables.

2 | THE STUDY

2.1 | Design

The present study was a descriptive, single-centre cross-sectional study. We used patient-reported outcome measures (PROMs) and data from the patients’ medical records to assess HL and the associations between HL and both demographics (gender, age, education, income, employment status and living arrangement) and clinical variables (medications, comorbidity, depressive symptoms, stage and duration of CKD).

3 | METHODS

3.1 | Participants

The study hospital provides healthcare services for approximately 330,000 people in the south-western part of Norway. According to the renal registry at the hospital, the potential study population consisted of approximately 500 individuals diagnosed with CKD stages 3–5 who were followed in the outpatient clinic and in the in-hospital dialysis unit at the Nephrology Department. Patients with CKD stages 1 and 2 were not included, as they are mainly followed in the primary healthcare system. According to the research protocol, we estimated that a total of 200 patients (80 with CKD stage 3, 80 patients with stages 4 and 5 not on haemodialysis and 40 haemodialysis patients) were sufficient to answer our research question. It was not possible to perform sample size calculations, as numbers for calculation are not available. The inclusion criteria were age 18 years and older, CKD stages 3–5, written informed consent and ability to read and understand the Norwegian language. Patients with active noncancerous cancer or unstable cardiovascular disease, patients with a history of a significant vascular incident (myocardial infarction, transient ischaemic attack or cerebral vascular accident) in the last three months and patients who had undergone major surgery in the previous three months were excluded.

3.2 | Data collection

Consecutive patients at routine outpatient appointments or who were scheduled for haemodialysis treatment during a six-month period (from February–August 2017) were included until the prespecified number of patients was reached (Figure 1). However, we were unable to include more than 26 haemodialysis patients because the total number of haemodialysis patients at the time of recruitment was 74, 44 of whom did not fulfil the inclusion criteria. Of the 30 haemodialysis patients eligible for our study, four declined to participate.
HL was assessed using the Health Literacy Questionnaire (HLQ), which is a multidimensional validated questionnaire that contains 44 items across nine independent scales. Each of the nine scales consists of 4–6 items and provides independent information about different dimensions of HL (measures using one scale per dimension). The questionnaire is divided into two main parts. In the first part (HLQ scales 1–5), the respondents have four options to indicate how strongly they disagree or agree with a set of statements (1 = strongly disagree, 2 = disagree, 3 = agree and 4 = strongly agree). In the second part (HLQ scales 6–9), the respondents have five options to indicate how difficult or easy different tasks are (1 = cannot do, 2 = usually difficult, 3 = sometimes difficult, 4 = usually easy and 5 = always easy). The questionnaire does not provide a total score.

### TABLE 1  Patient characteristics for the overall cohort and the different HL clusters

<table>
<thead>
<tr>
<th></th>
<th>Total group (N = 187)</th>
<th>Low-level (N = 27)</th>
<th>Mid-level (N = 106)</th>
<th>High-level (N = 52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, mean ± SD</td>
<td>67 ± 13</td>
<td>69 ± 11</td>
<td>67 ± 13</td>
<td>66 ± 13</td>
</tr>
<tr>
<td>Female gender, N (%)</td>
<td>65 (35)</td>
<td>16 (59)</td>
<td>33 (30)</td>
<td>15 (29)</td>
</tr>
<tr>
<td>Education level, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low = &lt;higher secondary school</td>
<td>113 (60)</td>
<td>22 (81)</td>
<td>62 (59)</td>
<td>28 (53)</td>
</tr>
<tr>
<td>High = &gt;higher secondary school</td>
<td>73 (40)</td>
<td>5 (19)</td>
<td>43 (41)</td>
<td>24 (46)</td>
</tr>
<tr>
<td>Household income in NOK, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low = ≤300,000</td>
<td>37 (20)</td>
<td>9 (33)</td>
<td>21 (20)</td>
<td>7 (13)</td>
</tr>
<tr>
<td>Average = &gt;300,000</td>
<td>147 (80)</td>
<td>18 (67)</td>
<td>83 (80)</td>
<td>44 (85)</td>
</tr>
<tr>
<td>Living alone, N (%)</td>
<td>49 (26)</td>
<td>11 (40)</td>
<td>28 (27)</td>
<td>9 (13)</td>
</tr>
<tr>
<td>DCI score, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>66 (35)</td>
<td>8 (30)</td>
<td>34 (32)</td>
<td>24 (46)</td>
</tr>
<tr>
<td>1</td>
<td>88 (47)</td>
<td>12 (48)</td>
<td>50 (47)</td>
<td>25 (48)</td>
</tr>
<tr>
<td>2</td>
<td>33 (18)</td>
<td>6 (22)</td>
<td>22 (21)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>BDI-SF, median (range)</td>
<td>2 (0–29)</td>
<td>3 (0–29)</td>
<td>2 (0–25)</td>
<td>0 (0–19)</td>
</tr>
<tr>
<td>Medications, mean (SD)</td>
<td>7.5 ± 3.7</td>
<td>9.11 ± 3.24</td>
<td>7.71 ± 3.80</td>
<td>6.12 ± 3.22</td>
</tr>
<tr>
<td>Renal diagnosis, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertensive nephropathy</td>
<td>62 (33)</td>
<td>7 (24)</td>
<td>31 (29)</td>
<td>22 (42)</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>40 (22)</td>
<td>6 (22)</td>
<td>22 (21)</td>
<td>12 (23)</td>
</tr>
<tr>
<td>Diabetic nephropathy</td>
<td>23 (12)</td>
<td>5 (19)</td>
<td>14 (13)</td>
<td>4 (7)</td>
</tr>
<tr>
<td>Polycystic kidney disease</td>
<td>14 (7)</td>
<td>3 (11)</td>
<td>6 (6)</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Other</td>
<td>30 (16)</td>
<td>4 (15)</td>
<td>18 (17)</td>
<td>8 (15)</td>
</tr>
<tr>
<td>Unknown</td>
<td>17 (10)</td>
<td>2 (7)</td>
<td>15 (14)</td>
<td>7 (2)</td>
</tr>
<tr>
<td>Time CKD in months, median (range)</td>
<td>46 (1–515)</td>
<td>81 (1–270)</td>
<td>41 (1–516)</td>
<td>50 (2–278)</td>
</tr>
<tr>
<td>Employment, N (%)</td>
<td>36 (19)</td>
<td>3 (11)</td>
<td>12 (23)</td>
<td>21 (20)</td>
</tr>
</tbody>
</table>

Abbreviations: BDI-SF, Beck Depression Inventory Short Form; CKD, chronic kidney disease; DCI, Davies Comorbidity Index; DCI = 0 means no co-morbid condition, DCI = 1 means 1–2 co-morbid conditions and DCI = 2 means ≥3 co-morbid conditions, NOK, Norwegian kroner.
Depressive symptoms were assessed by the Beck Depression Inventory Short Form (BDI-SF), which has been used to assess depressive symptoms in patients with CKD across different stages of the disease (Andrade et al., 2010). The questionnaire contains 13 items concerning guilt, pessimism, suicidal thoughts and other depressive symptoms. The maximum possible score is 39 and indicates severe depression. The cut-off score to detect clinical depression in a medical context is commonly set to 13–14 (Furlanetto, Mendlowicz, & Bueno, 2005). Renal function, renal diagnosis, number of prescribed medications, comorbidities and duration with known CKD expressed in months were extracted from the patients’ medical records.

Renal function was estimated using the CKD-EPI creatinine equation to find the estimated glomerular filtration rate (eGFR; Levey, Stevens, et al., 2009). Renal diagnoses were classified as vascular/hypertensive, diabetic nephropathy, glomerulonephritis, polycystic kidney disease, other diseases or unknown.

The number of comorbidities was expressed according to the Davies Comorbidity Index (DCI). The DCI was originally developed to predict the risk of hospitalization and mortality in patients with CKD based on the presence or absence of seven different comorbidities: active cancer, ischaemic heart disease, peripheral vascular disease, left ventricular dysfunction, diabetes mellitus, systemic collagen vascular disease and other significant pathology (e.g., asthma, cirrhosis and chronic obstructive lung disease). DCI is scored as follows: 0 = no comorbidity, 1 = one or two comorbidities and 2 = three or more comorbidities (Davies, Russell, Blyan, Phillips, & Russell, 1995). Demographic data, including gender, age, level of education, level of household income, living arrangement, employment status and clinical data, are listed in Table 1.

### 3.4 | Data analysis

SPSS package 25 and Excel 98 (pivot table in the cluster analysis) were used in the statistical analysis, and p < .05 was considered statistically significant. Categorical data are presented as frequencies, and percentages and continuous data are presented as the mean and standard deviations (SDs) if normally distributed and as the median and range otherwise. Student’s t test and ANOVA were used to test differences between normally distributed samples, and Mann–Whitney and Kruskal–Wallis tests were used to test for samples that were not distributed normally. Stepwise backward multiple linear regression analysis was performed to identify associations between HLQ scales as the dependent variables and the following independent variables: gender, age, level of education, level of household income, living situation, number of prescribed medications, presence of comorbidity, depressive symptoms, stage of CKD and duration of known CKD. We used the BDI-SF total score as a continuous variable for depressive symptoms and the DCI scores as a dichotomous variable indicating the presence or absence of comorbidity. Independent variables were included in the model if the univariate analysis resulted in p < .2, and then, the variables were stepwise excluded from the model in a backward manner if p > .05. Hierarchical cluster analysis (Ward’s minimum variance method) was used on standardized scores (z-scores) for each HLQ scale to identify patients with similar HLQ profiles (Ward, 1963). For the total data set, there were less than 5% data missing, and no correction was performed.

### 3.5 | Ethical considerations

The study was approved by the Data Protection Officer at the study hospital (ID number 2017/1). All participants signed a written, informed consent form.

### 4 | RESULTS

#### 4.1 | Patient characteristics

A total of 241 patients (150 in CKD stage 3, 101 in CKD stages 4 and 5 not in dialysis and 30 patients receiving maintenance haemodialysis) fulfilled the inclusion criteria and were consecutively invited to participate; 22% of the invited patients declined (Figure 1). In all, 187 patients were included, 35% of whom were female, with a mean (SD) age of 67 years (13) (Table 1). Patients who refused to participate were not significantly different from our sample in terms of age and gender (mean (SD) age of 65 years (14), 33% female). Of the 187 patients, 39% had higher education and 20% of the patients had a household income characterized as low in Norway (Statistics Norway, 2016). Sixty-five per cent of the patients had comorbidities, and the main renal diagnosis was hypertensive nephropathy (Table 1). The patients were mainly Caucasian with a Norwegian cultural background. Two non-Caucasians with a non-Norwegian cultural background were also included.

#### 4.2 | HLQ scores

The highest HLQ scores of the questionnaire were obtained for the scales feels understood and supported by healthcare providers (mean 3.19, 95% CI 3.12–3.27) in part one and ability to actively engage with healthcare providers (mean 3.83, 95% CI 3.74–3.93) in part two. The lowest scores were obtained for the scales appraise health information (mean 2.56, 95% CI 2.48–2.63) in part one and ability to find good health information (mean 3.42, 95% CI 3.33–3.51) in part two (Table 2). Males scored significantly higher than females for the scales ability to actively engage with healthcare providers, ability to navigate the healthcare system, ability to find good health information and ability to understand health information well enough to know what to do. Females scored significantly higher than males for the scales actively managing health.

#### 4.3 | Associations between demographic and clinical variable HLQ scales

After we performed the stepwise backward multiple linear regression analysis, gender, level of education, living situation, number of prescribed medications, depressive symptoms and duration of CKD
were the remaining independent variables that possibly explained the different HLQ scores in part 2. Furthermore, HLQ scores in part 2 indicate the following responses: 1 = cannot do, 2 = usually difficult, 3 = sometimes difficult, 4 = usually easy and 5 = always easy. 

**Note:** HLQ scores in part 1 indicate the following responses: 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree.

**Abbreviations:** CI, confidence interval; HLQ, Health Literacy Questionnaire.

### 4.4 Clustering HL in CKD patients

To characterize patients with different HL profiles, we divided the total group of patients into smaller groups using Ward’s method for hierarchical clustering. Patients with similar HLQ profiles were clustered in three different groups with low, medium and high HL. Twenty-seven (14%) patients were in the group with overall low HL scores (low-level group) and 52 (28%) patients were in the group with overall high HL scores (high-level group). The remaining 106 (57%) patients were clustered in the mid-level group (Figure 2).

### 4.5 Characteristics of the different clusters

Of the 27 patients in the low-level group, 59% were female, 70% had comorbidities, 19% had higher education levels and 40% lived alone (Table 1). The mid-level group was characterized as follows: 30% were female, 68% had comorbidities, 41% had higher education and 27% lived alone. The 52 patients in the high-level group were characterized as follows: 29% were female, 54% had comorbidities, 47% had higher education and 13% lived alone.

## 5 DISCUSSION

By using a multidimensional tool, we identified HL strengths and weaknesses in a Norwegian CKD population. Based on our results, cooperation between healthcare providers and patients seems to be the least problematic dimensions of HL, while finding and appraising health information seems most challenging for this population. Female gender, lower level of education, medication burden and depressive symptoms are variables associated with low HL. The cluster analysis confirmed the results from the regression analysis and revealed that living alone and having comorbidity also might be unfavourable for the CKD patients’ HL.

In general, few published studies have evaluated the HL of patients with CKD by using a multidimensional tool. In an Australian study including patients in haemodialysis and in a Canadian study including renal transplant patients, higher scores were found in almost all HLQ scales compared with results from our current study which included patients with CKD across different stages of the disease (Demian, Shapiro, & Thornton, 2016; Dodson et al., 2016). This difference might be explained by the fact that patients on haemodialysis and renal transplant patients usually have more frequent contact with healthcare providers than patients with CKD followed in an outpatient clinic. Frequent contact with the healthcare system might provide patients with more opportunities to discuss health challenges and obtain relevant health information, which may explain the higher HLQ scores in these patient groups. Furthermore, renal transplant patients are, as a group, highly selected and often highly motivated towards information gathering and learning in terms of caring for their new graft (Ursstad, Wahl, Andersen, Øyen, & Fagermoen, 2012). Earlier research shows that patients with low HL are less likely to receive access to renal transplantation than patients with higher HL (Grubbs et al., 2009). Despite previous studies reporting better HLQ scores in haemodialysis and renal transplant patients than in the group of unselected CKD patients in our study, the HLQ profiles were similar. That the HLQ profiles were similar indicates that the patients have the same HL challenges irrespective of the disease stage. In general, finding good health information and critical appraising health information appears to be the most challenging dimensions of HL for patients with CKD. Challenges in finding and appraising health information may reflect the overload of health information accessible by the Internet and social media, which may confuse patients (Klerings, Weinhandl, & Thaler, 2015). To reduce confusion due to information overload, strategies for filtering out irrelevant information should be developed and healthcare providers should be able to inform patients where to find and how to interpret relevant information (Klerings et al., 2015).

### Table 2: Health literacy questionnaire scale scores for overall cohort (N = 187)

<table>
<thead>
<tr>
<th>Part 1. HLQ scale scores, possible range of scores 1–4</th>
<th>Mean</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling understood and supported by healthcare providers</td>
<td>3.19</td>
<td>3.12–3.27</td>
</tr>
<tr>
<td>2. Having sufficient information to manage health</td>
<td>2.92</td>
<td>2.85–3.01</td>
</tr>
<tr>
<td>3. Actively managing health</td>
<td>2.94</td>
<td>2.87–3.02</td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>3.02</td>
<td>2.94–3.10</td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td>2.56</td>
<td>2.48–2.63</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part 2. HLQ scale scores, possible range of scores 1–5</th>
<th>Mean</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Ability to actively engage with healthcare providers</td>
<td>3.83</td>
<td>3.74–3.93</td>
</tr>
<tr>
<td>7. Ability to navigate the healthcare system</td>
<td>3.51</td>
<td>3.42–3.60</td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td>3.42</td>
<td>3.33–3.51</td>
</tr>
<tr>
<td>9. Ability to read and understand health information well enough to know what to do</td>
<td>3.71</td>
<td>3.63–3.80</td>
</tr>
</tbody>
</table>
### TABLE 3  Relationships between Health Literacy Questionnaire scales and demographic and clinical variables

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Uni</td>
<td>MA</td>
<td>MaB</td>
</tr>
<tr>
<td>Female gender</td>
<td>.78</td>
<td>.85</td>
<td>.84</td>
</tr>
<tr>
<td>Age</td>
<td>.22</td>
<td>.81</td>
<td>.30</td>
</tr>
<tr>
<td>Education</td>
<td>.25</td>
<td>.49</td>
<td>.44</td>
</tr>
<tr>
<td>Low income</td>
<td>.06</td>
<td>.18</td>
<td>.16</td>
</tr>
<tr>
<td>Living alone</td>
<td>.11</td>
<td>.15</td>
<td>.99</td>
</tr>
<tr>
<td>Medications</td>
<td>.10</td>
<td>.63</td>
<td>.04</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>.27</td>
<td>.10</td>
<td>.24</td>
</tr>
<tr>
<td>BDI-SF</td>
<td>.38</td>
<td>.20</td>
<td>.01</td>
</tr>
<tr>
<td>CKD stage</td>
<td>.52</td>
<td>.85</td>
<td>.38</td>
</tr>
<tr>
<td>CKD duration</td>
<td>.21</td>
<td>.20</td>
<td>.34</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>.03</td>
<td>.03</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Uni</td>
<td>MA</td>
<td>MaB</td>
</tr>
<tr>
<td>Female</td>
<td>.66</td>
<td>.82</td>
</tr>
<tr>
<td>Age</td>
<td>.22</td>
<td>.18</td>
</tr>
<tr>
<td>Education</td>
<td>.08</td>
<td>.41</td>
</tr>
<tr>
<td>Low income</td>
<td>.39</td>
<td>.69</td>
</tr>
<tr>
<td>Living alone</td>
<td>.01</td>
<td>.01 (.23)</td>
</tr>
<tr>
<td>Medication</td>
<td>.78</td>
<td>.28</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>.14</td>
<td>.51</td>
</tr>
<tr>
<td>BDI-SF</td>
<td>&lt;.01</td>
<td>&lt;.01 (.03)</td>
</tr>
<tr>
<td>CKD stage</td>
<td>.42</td>
<td>.55</td>
</tr>
<tr>
<td>CKD duration</td>
<td>.03</td>
<td>.05 (.001)</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>.10</td>
<td>.02</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Uni</td>
<td>MA</td>
<td>MaB</td>
</tr>
<tr>
<td>Female</td>
<td>&lt;.01</td>
<td>.04 (.23)</td>
</tr>
<tr>
<td>Age</td>
<td>.99</td>
<td>.68</td>
</tr>
<tr>
<td>Education</td>
<td>.01</td>
<td>.12</td>
</tr>
<tr>
<td>Low income</td>
<td>.08</td>
<td>.91</td>
</tr>
<tr>
<td>Living alone</td>
<td>.11</td>
<td>.45</td>
</tr>
<tr>
<td>Medications</td>
<td>&lt;.01</td>
<td>.14 (.04)</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>.08</td>
<td>.40</td>
</tr>
<tr>
<td>BDI-SF</td>
<td>&lt;.01</td>
<td>.06 (.22)</td>
</tr>
<tr>
<td>CKD stage</td>
<td>.84</td>
<td>.71</td>
</tr>
<tr>
<td>CKD duration</td>
<td>.84</td>
<td>.71</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>16</td>
<td>.12</td>
</tr>
</tbody>
</table>

Abbreviations: Adjusted R²; adjusted R squared; BDI-SF, Beck Depression Inventory Short Form; CKD stage, stage of chronic kidney disease; CKD duration, duration of chronic kidney disease in months; Comorbidity, presence of comorbidity (no/yes); Education, higher education (no/yes); MA, multiple regression analysis after stepwise backward elimination; Medications, number of prescribed medications; beta, unstandardized coefficient; Uni, univariate analysis.
Generally, patients in the low-level HL group had low scores on all HLQ scales. The low-level group is characterized by low education, the presence of comorbidities, a high medication burden and the presence of depressive symptoms. The patients in the low-level HL group may not understand their health situation or the health consequences of the choices they make. The motivation for active self-management in patients with CKD is also most likely influenced by the patients’ understanding of the risks and benefits related to the different treatments, which may be difficult for these patients. Ideally, healthcare providers should be able to identify patients with HL challenges, but earlier research indicates that they often fail at identifying these patients (Bass, Wilson, Griffith, & Barnett, 2002; Dickens, Lambert, Cromwell, & Piano, 2013; Goggins, Wallston, Mion, Cawthon, & Kripalani, 2016). Integrating HL training into the education of healthcare professionals and screening a patient’s HL are solutions suggested to increase the ability to identify vulnerable patients with low HL (Bass et al., 2002; Dickens et al., 2013; Health Literacy: Report of the Council on Scientific Affairs, 1999). When healthcare providers recognize patients with low HL, alternative methods for information dissemination, such as the teach-back method, might be useful to ensure that crucial information is understood (Ha Dinh, Bonner, Clark, Ramsbotham, & Hines, 2016). In addition, measuring multidimensional HL in patients with comorbidities and a high medication burden may help healthcare providers identify HL needs in an individual patient and respond to them. From a long-term perspective, creating HL-responsive organizations by integrating how to respond to different HL needs into the education of healthcare professionals might improve the HL for the individual patient (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016).

According to previous research, the level of education is a strong predictor of HL (Friis, Lasgaard, Osborne, & Maindal, 2016; Van der Heide et al., 2013; Maindal et al., 2016; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2015). In our study, higher education was associated with a better ability to find good health information and to understand health information. Some examples of finding and evaluating health information include the ability to compare information from different sources and to be critical of new information given. Highly educated individuals are more likely able to understand, interpret and evaluate the information given than are individuals with a lower education. Our findings indicate that the current information available to patients may be too complicated or not adapted to patients with lower education levels, which underlines the importance of individualized and facilitated information and follow-up.

Our study indicates that male patients with CKD are more confident than females in their abilities to navigate the healthcare system, engage with healthcare providers and find and understand health information. Other studies have also found gender differences in HL, but the differences are not consistent across the literature. A Slovakian HLQ study including 360 adults found that females had fewer difficulties understanding health information than males (Kolarcik et al., 2017), while an Australian study including 814 health consumers found that males had fewer difficulties engaging with healthcare providers than females (Beauchamp et al., 2015). However, in our CKD population, more males than females had higher education, which may contribute to our findings that males scored higher than women in four out of the nine HLQ scales. In contrast to other studies that have found associations between older age and lower HL (Jessup, Osborne, Beauchamp, Bourne, & Buchbinder, 2017; Sorensen et al., 2015), we found no such association in our study. An explanation for the lack of association between age and HL may be that the age spread in our study sample was narrow, with most patients aged 60–80 years. The narrow age spread limits the possibility of identifying such associations. However, our study population reflects the typical age spread for CKD and a larger study population is probably necessary to identify any potential association between age and HL.

Patients living alone experienced less social support for health in our study, which is in accordance with findings in previous works (Beauchamp et al., 2015; Sorensen et al., 2015). Living with someone...
may be favourable for discussing health issues and obtaining mental and physical support, resulting in better HL (Lee, Arozullah, & Cho, 2004). Patients who live alone or need more social support can benefit from referrals to relevant patient organizations because patient organizations often arrange social gatherings that may create an arena for receiving social support from peers. In addition, patient organizations offer classes and conferences to educate patients on disease-specific topics as well as legal rights relevant to patients living with CKD, which may be useful for most patients regardless of social support.

To the best of our knowledge, this is the first HLQ study investigating the association between HL and the number of prescribed medications in patients with CKD. We found that a higher number of prescribed medications were associated with a reduced ability to find and appraise health information, to navigate the healthcare system and to understand health information well enough to know what to do. An explanation for the negative association between pill burden and lower HL may be that a heavy pill burden causes unpleasant side effects and is a marker of comorbidity, which makes the health situation more complicated. According to previous studies that use less complex tools to evaluate HL, patients with low HL are more likely to misunderstand medical prescriptions and take drugs improperly than patients with high HL (Davis et al., 2006; Wolf, Davis, Tilson, Bass, & Parker, 2006). A heavy pill burden may not in itself lead to low HL, but it is likely that the pill burden is linked to comorbidity. Patients with comorbidities must visit more specialists, which demand more navigation in the healthcare system. Additionally, the level of medical instructions and information might be complicated, which may explain why these patients find it difficult to understand health information. The different specialties involved in patients with comorbidities should aim to cooperate regarding the medical treatment regimens so the patient does not need to be the messenger between the different departments.

Having more depressive symptoms was negatively associated with the CKD patients’ experience of having sufficient health information and social support for health, the ability to engage with healthcare providers and the ability to navigate the healthcare system. The negative association between depressive symptoms and HL in general is in accordance with the findings in an Australian HLQ study that included 100 dialysis patients. The level of HL in the Australian study was strongly associated with the level of depressive and anxiety symptoms (Dodson et al., 2016), but the specific dimensions of HL were not reported. Another study including 702 patients with type 2 diabetes showed impaired self-management and problem-solving in depressed patients compared with nondepressed patients (Shin et al., 2017), indicating that depression is an important factor in self-management. The results from the diabetes study correspond with our findings that more depressive symptoms were associated with reduced abilities to actively engage with healthcare providers and to navigate the healthcare system. We also found that depressive symptoms were more prevalent in the low-level HL group than in the middle and high-level groups, but whether depressive symptoms are the cause or a result of low HL needs to be explored. Healthcare providers should be aware of depressive symptoms in patients with low HL because they can be more vulnerable about HL and the self-management of CKD.

5.1 | Limitations

Most patients were Caucasians with a Norwegian cultural background. Perception of illness might vary by culture and might affect approaches to health care, and future research should therefore aim to include patients with CKD of other ethnicities and with different cultural backgrounds. Due to the modest participation from non-Caucasians, the regression models were not corrected for race. Furthermore, the cross-sectional design of this study limits the possibility of identifying causation.

6 | CONCLUSION

This study provides extended knowledge about HL in patients with CKD. The multidimensional perspective put us in a better position to identify vulnerable patients and to develop target interventions that may reduce health inequalities in this patient group. When designing and implementing HL interventions for patients with CKD, extra focus should be placed on providing patients with strategies to access relevant health information and enabling them to critically appraise the information they access. Furthermore, special attention should be given to vulnerable patients characterized by a complex health situation, presence of depressive symptoms, low education levels and low social support.

ACKNOWLEDGEMENTS

The authors are grateful to the patients who participated in this study and to the Nephrology Department staff at Stavanger University Hospital for their cooperation during the data collection period. We also thank biostatistician Anastasia Usukova at Stavanger University Hospital and Professor Jan Terje Kvaløy at the University of Stavanger for statistical advice.

CONFLICT OF INTEREST

There is no conflict of interest to report.

AUTHOR CONTRIBUTIONS

Une Elisabeth Stømer have made substantial contributions to conception and design, analysing and interpreting data and been involved in drafting the article. Lasse Gunnar Garansson, Astrid Klopstad Wahl and Kristin Hjorthaug Uurstad have made substantial contributions to conception and design and been involved in drafting the article and revising it critically for important intellectual content. All of the authors have given final approval for the final version to be published and are accountable for all aspects of the work in ensuring
that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ORCID

Une Elisabeth Stamer https://orcid.org/0000-0001-6867-523X
Kristin Hjorthaug Urstad https://orcid.org/0000-0002-6830-4554

REFERENCES


How to cite this article: Stømer ET AL., Geransson LG, Wahl AK, Ustad KH. Cross-sectional study of health literacy in patients with chronic kidney disease: Associations with demographic and clinical variables. Nursing Open. 2019;00: 1–10. https://doi.org/10.1002/nop2.350
Paper II
HEALTH LITERACY IN KIDNEY DISEASE: ASSOCIATIONS WITH QUALITY OF LIFE AND ADHERENCE

Une Elisabeth Stømer1,2, Astrid Klopstad Wahl2, Lasse Gunnar Garansson3,4, Kristin Hjorthaug Urstad2
1Faculty of Health Science, University of Stavanger, Stavanger, Norway
2Department of Nephrology, Stavanger University Hospital, Stavanger, Norway
3Faculty of Medicine, University of Oslo, Oslo, Norway
4Department of Clinical Medicine, Faculty of Medicine, University of Bergen, Bergen, Norway


SUMMARY
Background: Health literacy (HL) is a multidimensional concept with significance for self-management and health outcomes in patients with chronic kidney disease (CKD); however, research with a multidimensional perspective on HL is scarce.
Objectives: This study aimed to explore the relationship between multidimensional HL, quality of life (QoL) and adherence to long-term therapy in CKD patients.
Design: A descriptive single-centre cross-sectional study.
Participants: Patients with CKD in stages 3–5 were recruited from the nephrology unit in a Norwegian hospital.
Measurements: The Health Literacy Questionnaire (HLQ) was used to assess HL, QoL was measured by the Short Form-12 (SF-12) and a Visual Analogue Scale (VAS-QoL). Adherence to long-term therapy was measured by the Medical Adherence Rating Scale 5 (MARS-5), participants’ prescription withdrawals from pharmacies, and a VAS (VAS-adherence). Hierarchical cluster analysis was performed to group patients with similar HLQ scores, and multiple linear regression analysis was performed to identify the HL dimensions that were associated with QoL and adherence to long-term therapy.
Results: A total of 187 patients were included, 65% were male, and the mean (SD) age was 67 (13) years. The high-level HL group (N = 52) had significantly better QoL than patients in the mid-level (N = 106) and low-level (N = 27) HL groups. The HL dimensions “actively managing health,” “actively engage with healthcare providers,” “ability to find good health information” and “ability to understand health information” were predictive of QoL and adherence to long-term therapy.
Conclusion: HL seems to be important for both QoL and adherence to long-term therapy.

KEY WORDS Adherence to long-term therapy ♦ Chronic kidney disease ♦ Health literacy ♦ Patient-reported outcome measures ♦ Quality of life

B O I O D A T A
Une Elisabeth Stømer is a PhD candidate at the Faculty of Health Sciences at the University of Stavanger, Norway. She is an intensive care nurse (ICN) with a master’s degree in Health Sciences (MHS). Her working experience is from the intensive care unit (ICU) and the Dialysis Unit in the Department of Nephrology at Stavanger University Hospital in Norway. Her focus is currently on Health literacy in chronic kidney disease.

CORRESPONDENCE
Une Elisabeth Stømer, Faculty of Health Science, University of Stavanger, Stavanger, Norway
Email: une.stomer@uis.no

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.
INTRODUCTION
Chronic kidney disease (CKD) is globally recognised as a major public health problem, and the disease affects >10% of the Norwegian population (Kialil et al. 2006; Eckardt et al. 2013; Bruck et al. 2016). Patients living with CKD at all stages report lower quality of life (QoL) compared with the general population (Perlman et al. 2005; Osthus et al. 2010; Fruchtsoo et al. 2011; Pagels et al. 2012; Nabolis et al. 2015).

It is recommended that patients with CKD lead a healthy life-style involving physical activity and avoid smoking (K/DOQI 2016). Patients with CKD must adhere to fluid and diet restrictions as well as renal replacement therapy to optimise their health (Levey et al. 2009). It is well-known that adherence to these health recommendations can be challenging (Chiu et al. 2009; Muntner et al. 2010; Clark et al. 2014).

In general, the World Health Organisation (WHO) reports that adherence to long-term therapy in patients with chronic illnesses averages 50% in developed countries and that the consequences of non-adherence are poor health outcomes and increased healthcare costs (WHO 2003). For CKD patients, in particular, adherence to long-term therapy is crucial to avoid unnecessary progression and life-threatening complications of the disease (Levey et al. 2009; Levey & Coresh 2012). According to the conceptual model for HL described by Sørensen et al. (2012) high or adequate HL is a prerequisite for desirable health outcomes such as good QoL and sound health behaviour. Hence, knowledge about associations between HL and QoL and adherence to long-term therapy is valuable.

LITERATURE REVIEW
A concept of growing interest for health outcomes and self-management in patients with chronic diseases is health literacy (HL) (WHO 2013; Mackey et al. 2016; Taylor et al. 2017; van der Heide et al. 2018). HL is defined as a multidimensional concept, encompassing the cognitive and social skills that determine the motivation and ability to gain access to, understand and use information in ways that promote and maintain good health (WHO 1998). Earlier research utilising multidimensional assessment tools for HL showed that CKD patients have HL deficits in domains relating to attending to one’s health needs and understanding health information (Lambert et al. 2015). Recent research also shows associations between demographic and clinical variables such as sex, level of education, number of medications and depressive symptoms, and HL (Stømer et al. 2019). Further, low HL in CKD patients is associated with undesirable health behaviours, increased hospitalisation and mortality rates as well as impaired QoL (Grubbs et al. 2009; Cavanaugh et al. 2010; Magacho et al. 2011; Fraser et al. 2013; Green et al. 2013; Ricardo et al. 2014; Devraj et al. 2015; Kasby et al. 2016; Lambert et al. 2017). In general, the majority of these studies rely on HL assessed with tools that solely measure health-related reading and numeracy skills. In recent years, the concept of HL has evolved from being about individual reading and numeracy skills to a broader concept including social, critical and interactive dimensions such as support from family and friends, cooperation with healthcare providers and critical thinking (Sørensen et al. 2012; Batterham et al. 2017; van der Heide & van der Heide 2018). Consequently, new knowledge is needed about the associations between this broader definition of HL and outcomes such as QoL and adherence to long-term therapy both in general and in CKD patients in particular.

Hence, this study aimed to compare QoL and adherence to long-term therapy in patients with CKD with different levels of HL. It will also aim to identify the specific HL dimensions associated with QoL and adherence to long-term therapy in patients with CKD.

MATERIALS AND METHODS
STUDY DESIGN AND PARTICIPANTS
The current study was a single-centred descriptive cross-sectional study. The study sample is previously described (Stømer et al. 2019), but in short, patients with CKD stages 3–5 were recruited from the outpatient clinic and the haemodialysis unit at the Nephrology Department. Two hundred and forty-nine patients met the inclusion criteria and were asked to participate. One hundred and eighty-seven patients approved (response rate 78%). Patients with noncutaneous cancer, unstable cardiovascular disease, a significant vascular incident (myocardial infarction, transient ischaemic attack or cerebral vascular accident) or major surgery within the last three months, were not included because we wanted to avoid patients in acute medical crisis. An acute medical crisis is likely to be overwhelming and decisive for the results of HLQ, QoL and adherence, and would probably not reflect the situation of living with CKD. The study was approved by the Data Protection Officer at the hospital, ID number 2017/1.
MEASUREMENTS

We used patient-reported outcome measures (PROMs) to assess HL, QoL, and adherence to long-term therapy, including both medical adherence and adherence to lifestyle recommendations. Clinical data (renal function, comorbidities) and information about the collection of prescribed medications were retrieved from the medical records.

We assessed HL with the HL Questionnaire (HLQ), which is a multidimensional tool containing 44 items across nine independent scales that provides information about different dimensions of HL. The HLQ scales are described in Table 52 (Osborne et al. 2013). The HLQ is divided into two parts: In the first part (HLQ scales 1-5), the respondents have four options to indicate how strongly they disagree or agree with a set of statements (strongly disagree, disagree, agree and strongly agree), with a possible range of scores from 1 to 4. In the second part (HLQ scales 6–9), the respondents have five options to indicate how difficult or easy different HL tasks are (cannot do, usually difficult, sometimes difficult, usually easy and always easy), with a possible range of scores from 1 to 5. The HLQ has no total summative score and no cut-off for inadequate HL, however, higher scores indicate better HL (Osborne et al. 2013).

QoL was assessed with the Short Form–12 (SF–12) and a Visual Analogue Scale (VAS). The SF–12 is a non-disease-specific questionnaire containing 12 items resulting in two-component scores, the physical component score (PCS–12) and the mental component score (MCS–12). The SF–12 is derived from and comparable to the full SF–36 questionnaire, which is validated for CKD (Ware & Sherbourne 1992; Ware et al. 1996, 1998; Osthus et al. 2012). To evaluate the patients’ global QoL during the preceding four weeks, a VAS was used (VAS-QoL) (de Boer et al. 2004). The patients were asked to mark a point on the line that represented their general QoL, where the left vertical anchoring line represented “the worst imaginable QoL” and the right “the best imaginable QoL.” The distance from the left anchoring line to the marked point was measured in mm, and a higher number indicated better QoL, with a possible range of scores from 0 to 100. A single-item VAS has been validated for assessing general QoL in medical settings (de Boer et al. 2004).

Adherence to long-term therapy was measured by assessing medical adherence and adherence to lifestyle recommendations. Medical adherence was assessed by the Medical Adherence Rating Scale 5 (MARS-5) and by registering the prescription collection from the pharmacy. The MARS-5 is a non-disease-specific questionnaire containing five items concerning general statements of medication-taking habits. The MARS-5 has been used across different chronic conditions, including asthma, diabetes, hypertension and mental illness. The total score ranges from 5 to 25, where 25 is the best possible score and indicates perfect medical adherence (Jonsdottir et al. 2009; Sjolander et al. 2013). Adherence to medical treatment was also assessed by checking the participants’ collection of medical prescriptions. Prescribed medications are obtained from the pharmacy for a maximum of three months of usage. If the prescribed medications were not collected for the previous three months, we defined the patient as non-adherent to medical treatment.

Adherence to lifestyle recommendations from healthcare providers was assessed using a VAS (VAS-adherence). The left anchoring line read “never follow lifestyle recommendations from healthcare providers,” and the right anchoring line read “always follow lifestyle recommendations from healthcare providers,” with a possible range of scores from 0 to 100. There was no cut-off score for non-adherence, but a higher number indicated better adherence. A single-item VAS is validated for self-assessing medical adherence (Kalichman et al. 2009), we used it to assess adherence to lifestyle recommendations.

Beck Depression Inventory SF (BDI-SF) was used to assess depressive symptoms (Furlanetto et al. 2005). The BDI-SF has been used to assess depressive symptoms in CKD patients across different stages of the disease (Andrade et al. 2010). The questionnaire contains 13 items concerning guilt, pessimism, suicidal thoughts and other depressive symptoms. The maximum possible score is 39 and indicates severe depression. We used BDI-SF as a continuous variable to correct for depressive symptoms in the regression models.

Renal function was assessed using the CKD-EPI creatinine equation as the estimated glomerular filtration rate (eGFR) (Levey et al. 2009). The patients were thereafter classified into different CKD stages (KDIGO 2002). Renal function, renal diagnosis, time with known CKD, comorbidities as expressed by the Davies comorbidity index (DCI), and the number of prescribed medications were extracted from the patients’ medical records.
STATISTICAL ANALYSIS

IBM SPSS Statistics for Windows, Version 25.0. (IBM Corp., Armonk, NY) was used for the statistical analysis. Categorical data are presented as frequencies and percentages, and continuous data are presented as the means and standard deviations (SD) if normally distributed or as the medians and ranges if non-normally distributed. We performed Ward’s hierarchical cluster analysis to identify patients with similar HLQ profiles. Ward’s minimum variance method was run with standardised z-scores (number of SD from the mean) on each HLQ scale (Ward 1963). The number of clusters chosen was based on the minimum accepted number of cases in the smallest group. Kruskal–Wallis was used to compare QoL (PCS-12, MCS-12 and VAS-QoL) and adherence to long-term therapy scores (MARS-5, VAS-adherence) among the different clusters, and between patients with different stages of CKD. Mann–Whitney was used as post hoc tests to identify where the differences were located. We used a χ² test to compare the withdrawal of medical prescriptions from the pharmacy between the different clusters. Multiple linear regression analysis was performed in the whole group of patients to identify associations between QoL (PCS-12, MCS-12 and VAS-QoL) and adherence to long-term therapy (VAS-adherence and MARS-5) as dependent variables and the nine HLQ scales as independent variables. Independent variables were included in the model if univariate analysis resulted in a p < 0.2 and was excluded from the model in a manual backward manner if p > 0.05. p ≤ 0.05 were considered as statistically significant (Altman 2018). The dependent variables (PCS-12, MCS-12, VAS-QoL, MARS-5 and VAS-adherence) were used as continuous variables in the analysis. All regression models were corrected for age, sex, level of education and depressive symptoms (BDI-SF scores).

RESULTS

A total number of 187 patients were included in the study, 80 patients with CKD stage 3, 81 with CKD stages 4–5 not on haemodialysis and 26 haemodialysis patients. The mean age was 67 years (SD, 13), and 65% were male. Forty percent of the participants had higher education, and the mean (SD) number of prescribed medications was 7.5 (3.7). Patient characteristics are previously described (Stømer et al. 2019) and are presented in Table 1.

<table>
<thead>
<tr>
<th>Total group</th>
<th>Low-level (no = 187)</th>
<th>Mid-level (no = 106)</th>
<th>High-level (no = 52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, mean ± SD</td>
<td>67 ± 13</td>
<td>69 ± 11</td>
<td>67 ± 13</td>
</tr>
<tr>
<td>Male sex, no (%)</td>
<td>122 (65)</td>
<td>11 (40)</td>
<td>73 (70)</td>
</tr>
<tr>
<td>Education level, no (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low = ≤ higher secondary school</td>
<td>113 (60)</td>
<td>22 (81)</td>
<td>62 (59)</td>
</tr>
<tr>
<td>High = &gt; higher secondary school</td>
<td>73 (40)</td>
<td>5 (19)</td>
<td>43 (41)</td>
</tr>
<tr>
<td>Household income in NOK, no (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low = ≤ 300,000</td>
<td>37 (20)</td>
<td>9 (33)</td>
<td>21 (20)</td>
</tr>
<tr>
<td>Average = &gt; 300,000</td>
<td>147 (80)</td>
<td>18 (67)</td>
<td>83 (80)</td>
</tr>
<tr>
<td>Living alone, no (%)</td>
<td>49 (26)</td>
<td>11 (40)</td>
<td>28 (27)</td>
</tr>
<tr>
<td>DCI score, no (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>66 (35)</td>
<td>8 (30)</td>
<td>34 (32)</td>
</tr>
<tr>
<td>1</td>
<td>88 (47)</td>
<td>13 (48)</td>
<td>50 (47)</td>
</tr>
<tr>
<td>2</td>
<td>33 (18)</td>
<td>6 (22)</td>
<td>22 (21)</td>
</tr>
<tr>
<td>Stage of CKD, no (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>80 (43)</td>
<td>10 (13)</td>
<td>48 (46)</td>
</tr>
<tr>
<td>4 and 5, not on dialysis</td>
<td>81 (43)</td>
<td>11 (14)</td>
<td>44 (42)</td>
</tr>
<tr>
<td>Haemodialysis patients</td>
<td>26 (14)</td>
<td>6 (23)</td>
<td>14 (22)</td>
</tr>
<tr>
<td>BDI-SF, median (range)</td>
<td>2 (0–9)</td>
<td>5 (0–9)</td>
<td>4 (0–9)</td>
</tr>
<tr>
<td>Medications, mean (SD)</td>
<td>7.5 ± 3.7</td>
<td>9.1 ± 3.2</td>
<td>7.7 ± 3.8</td>
</tr>
<tr>
<td>Renal diagnosis, no (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertensive nephropathy</td>
<td>62 (33)</td>
<td>7 (26)</td>
<td>31 (29)</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>40 (22)</td>
<td>6 (22)</td>
<td>22 (21)</td>
</tr>
<tr>
<td>Diabetic nephropathy</td>
<td>23 (12)</td>
<td>5 (19)</td>
<td>14 (13)</td>
</tr>
<tr>
<td>Other</td>
<td>62 (33)</td>
<td>9 (33)</td>
<td>39 (37)</td>
</tr>
<tr>
<td>Time with CKD in months, median (range)</td>
<td>46 (1–515)</td>
<td>81 (1–270)</td>
<td>41 (1–516)</td>
</tr>
</tbody>
</table>

Table 1: Patient characteristics of the overall sample and patients with different levels of health literacy.

BDI-SF: Beck Depression Inventory Short Form; CKD: chronic kidney disease; DCI: Davies Comorbidity Index (DCI: 0 means no comorbid condition; DCI: 1 means 1–2 comorbid conditions and DCI: 2 means ≥ 3 comorbid conditions); NOK: Norwegian kroner.
Table 2: Nonparametric tests to compare the quality of life and adherence to long term therapy scores in patients with different levels of health literacy.

<table>
<thead>
<tr>
<th></th>
<th>Low-level HL N = 27</th>
<th>Mid-level HL N = 106</th>
<th>High-level HL N = 52</th>
<th>P-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCS-12 Median (range)</td>
<td>33.5 (16.3–55.3)</td>
<td>34.5 (13.2–60.0)</td>
<td>42.9 (18.7–59.9)</td>
<td>Low vs. high = 0.002</td>
</tr>
<tr>
<td>MCS-12 Median (range)</td>
<td>46.7 (15.4–60.7)</td>
<td>49.5 (23.8–66.1)</td>
<td>57.1 (27.4–65.0)</td>
<td>Low vs. high = 0.003</td>
</tr>
<tr>
<td>VAS-QoL Median (range)</td>
<td>50 (10–100)</td>
<td>68 (9–100)</td>
<td>82 (19–100)</td>
<td>Low vs. mid = 0.044</td>
</tr>
<tr>
<td>MARS-5 Median (range)</td>
<td>24 (14–25)</td>
<td>24 (13–25)</td>
<td>24 (18–25)</td>
<td>0.852</td>
</tr>
<tr>
<td>VAS-adherence Median (range)</td>
<td>90 (36–100)</td>
<td>85 (20–100)</td>
<td>92 (48–100)</td>
<td>Low vs. high = 0.100</td>
</tr>
</tbody>
</table>

QOL AND ADHERENCE IN PATIENTS WITH DIFFERENT HL LEVELS

By using Ward’s hierarchical cluster analysis, the patients were divided into three different groups with similar HLQ profiles. In our sample, the different groups were characterised by all-over low, medium and high levels of HL (Ward 1963). Twenty-seven patients (14%) were in the low-level group, 52 (28%) were in the mid-level group and 106 (57%) were in the mid-level group (Table 1) (Stamer et al. 2019).

Significantly better QoL, as assessed by the SF-12 (PCS-12, MCS-12) and VAS-QoL, was found in the high-level group compared with the low-level group (Table 2). The mid-level group had significantly higher MCS-12 and VAS-QoL scores than the low-level group and significantly lower MCS-12 and VAS-QoL scores than the high-level group. The PCS-12 scores were not significantly higher in the mid-level group compared with the low-level group of patients.

The VAS-adherence scores were significantly higher in the high-level group compared with the mid-level group, while the score in the low-level group was not significantly different from those in the two other groups. The MARS-5 scores did not differ among the groups with different levels of HL (Table 2).

One hundred and forty-four (77%) of the included patients gave consent for the researchers to access the E-prescription module in their medical record to evaluate the collection of prescribed medication from the pharmacy. Medical adherence, as evaluated by the collection of prescribed medication, was 50% in the low-level HL group (10/20), 60% in the mid-level group (48/82) and 69% in the high-level group (29/42). However, the collection of prescribed medication was not significantly different among the groups.

The PCS-12 scores were significantly higher in patients with CKD stage 3 versus patients with CKD stage 4 and 5 not on dialysis (<0.001) and patients on haemodialysis (<0.001). VAS-QoL was significantly lower in haemodialysis patients versus patients with CKD stage 3 (p = 0.01). There were no differences between patients with different stages of CKD in MARS-5 or VAS-adherence scores (additional table).

QOL AND ADHERENCE ASSOCIATED WITH DIFFERENT HL DIMENSIONS

The HLQ scale number 9, “ability to understand health information well enough to know what to do,” was positively associated with the PCS-12 and VAS-QoL, indicating that a greater ability to understand health information was associated with better physical and global QoL. HLQ scale number 3, “actively managing health” and scale number 6, “ability to actively engage with healthcare providers” were positively associated with the VAS-adherence, indicating that being active in managing their health and having the ability to engage with healthcare providers were associated with higher adherence to...
lifestyle recommendations. The HLQ scale number 8, “ability to find good health information,” was negatively associated with VAS-adherence, indicating that the ability to find health information was associated with lower adherence to lifestyle recommendations from healthcare providers. The MARS-5 was not associated with any of the HLQ scales (Tables 3a and 3b).

DISCUSSION

Our study shows that CKD patients with high overall levels of HL have better QoL and are more adherent to lifestyle recommendations than patients with lower HL. Understanding health information seems to be important for patients’ QoL, whereas the ability to engage with healthcare providers as well as actively managing health appears to play a role in terms of adherence.

Our findings are consistent with those of an Australian study, including 100 haemodialysis patients, in which both physical and mental aspects of QoL were better in patients with high overall HL than in patients with low overall HL (Dodson et al. 2016). The association between the ability to understand health information and better QoL might be explained by patients’ improved knowledge of how to minimise the risk of CKD progression, for example, understanding how to keep blood pressure well-regulated and how to manage diabetes mellitus (Roy et al. 2013; Chang et al. 2015). Our findings, as well as earlier research, show that lower renal function is associated with worse QoL (Fructuoso et al. 2011; Pagels et al. 2012).

Furthermore, challenges in understanding health information may cause stress and anxiety, which may also affect QoL. A
HEALTH LITERACY IN KIDNEY DISEASE: ASSOCIATIONS WITH QUALITY OF LIFE AND ADHERENCE

systematic review investigating the role of different psychological challenges associated with QoL pointed out that stress and anxiety were negatively associated with QoL in CKD patients (Garcia-Llana et al. 2014). Other studies have reported that the experience of being in control of one’s health situation is important for QoL in chronic illness (Kristofferzon et al. 2018). Understanding health information well enough to know what to do may provide CKD patients with a feeling of control and thereby reduce stress.

Our findings regarding the positive association between higher HL and better QoL is also following the conceptual model for HL (Sorensen et al. 2012) and underlines the importance of aiming to improve HL in CKD patients. However, we have previously reported that patients with low overall levels of HL have less education, more comorbidities, more prescribed medications and more depressive symptoms than patients with high overall levels of HL. These conditions may also affect QoL (Stamen et al. 2019). Whether poor QoL is a result of low overall HL or vice versa needs to be further explored.

To the best of our knowledge, this is the first study of CKD patients investigating the association between HL and adherence to long-term therapy, including both medication adherence and adherence to general lifestyle recommendations. A high level of HL is, in general, associated with more favourable health behaviours, such as greater adherence to dialysis treatment, better health resource utilisation and better medical adherence (Green et al. 2013; Lambert et al. 2015; Demian et al. 2016; Taylor et al. 2017). The mentioned associations are reflected by our results, showing stricter self-reported adherence to lifestyle recommendations among the high-level versus mid-level HL groups. However, the patients in the low-level HL group did not differ significantly in terms of adherence from the mid- and high-level groups, which could be expected. A possible explanation for the lack of difference might be the small size of the low-level HL group (27 patients); more participants are probably needed to explore this further. The use of patient-reported outcome measures does not exclude the possibility of idealisation of self-adherence (Magacho et al. 2011; Brown & Bussell 2011; Lam & Fresco 2015).

Patients’ ability to engage with healthcare providers was positively associated with patients’ adherence to lifestyle recommendations. A patient-healthcare provider partnership that is based on trust, mutual respect and room for compromise is described in previous studies as the core of all successful attempts to improve adherence behaviours (Martin et al. 2005; Fuertes et al. 2017a,b; Washington et al. 2016). Providing continuity of care is important in establishing such a sound alliance (Lin et al. 2015), and previous research reports that CKD patients receiving continuity of care are more adherent and have less disease progression (Chang et al. 2018). Together with previous research, our findings emphasise the importance of the relationship between patients and healthcare providers, which should be in focus when developing interventions to improve HL in CKD patients.

An interesting and unexpected finding was that the ability to find good health information was negatively associated with adherence to lifestyle recommendations provided by health care providers. One might assume that patients who are competent health information seekers may not seek advice from healthcare professionals to the same degree as patients with lower capacity in this area. Such an interpretation might arise due to the rapid proliferation of health information on the internet and the fact that a competent informant seeker might turn to the internet as the preferred source of health information instead of recommendations provided directly from the health care provider (Gualtieri 2009). Also, the healthcare system is currently evolving from being paternalistic to empowering patients; it would be interesting to explore further whether our result is an expression of patient empowerment or have other explanations such as lack of trust in, or difficulties in navigating the healthcare system.

We found no association between adherence to medical treatment and HL. Most patients reported very high degrees of medical adherence, which is in contrast to the results of previous research on medical adherence in CKD patients (Loghman-Adham 2003; Demian et al. 2016). However, when evaluating patients’ medical prescription collection from the pharmacy, our findings were less encouraging and were following those of previous studies, e.g. the WHO’s estimate of 50% medical adherence (WHO 2003; Brown & Bussell 2011). The inconsistency of medical adherence, as evaluated by subjective and objective assessment tools, shows that self-reported medical adherence data should be interpreted with caution and preferably in conjunction with an objective assessment tool (Lam & Fresco 2015).

**IMPLICATIONS FOR PRACTICE**

We found that HL is of importance for both QoL and adherence in CKD patients. Hence, efforts to increase HL in this
Many dimensions of HL are important for CKD patients, including QoL, and adherence to lifestyle recommendations. Healthcare services should focus on developing HLR organisations to increase QoL and adherence to long-term therapy. Additional studies with more participants and objective assessment tools are needed to investigate the relationship between CKD patients’ HL and medical adherence.

ACKNOWLEDGEMENTS

The authors would like to thank the patients who generously participated in this study. We would also like to thank the staffs of the Nephrology Department at the Stavanger University Hospital for their cooperation during the data collection period. Dr. Joanna Haynes for language editing and last but not least, we thank Professor Jan Terje Kvaløy at the University of Stavanger for contributing with statistical advice.

AUTHOR CONTRIBUTIONS

UEW: Principal Project Leader, conceived the study, collected and analyzed the data, drafted the manuscript, coordinated and approved the final manuscript. AKW: Participated in the design, helped to analyse the data, drafted the manuscript, read and approved the final manuscript. LGG: Participated in the design, helped to analyse the data, drafted the manuscript, read and approved the final manuscript. KHU: Participated in the design and coordination, helped to analyse the data and drafted the manuscript, read and approved the final manuscript.

REFERENCES

Chang P.Y., Chien L.N., Bai C.H. et al. (2018). Continuity of care with physicians and risk of subsequent hospitalization and end-stage renal disease in newly diagnosed type 2 diabetes patients group are very important. On the basis of our results, healthcare providers working with CKD patients should focus on establishing a good relationship with patients and develop strategies to encourage patients to take an active role in managing their own health. Furthermore, healthcare providers should develop strategies for individualised and adapted health information aiming to provide patients with an understanding of essential aspects needed for coping with CKD.

At an organisational level, there is a new term in the field of HL, called HL responsiveness (HLR). HLR means that healthcare organisations take responsibility for adapting the healthcare services to the HL needs and preferences of the population they serve, which requires awareness about HL as an important topic and individualised, tailored patient information adapted to the patients’ specific needs (Tezona et al., 2017, 2018). From a long-term perspective, creating HLR organisations might improve QoL and adherence to long-term therapy in CKD patients.

STRENGTHS AND LIMITATIONS

The strengths of this study are the inclusion of CKD patients with a strong response rate of 78%. The use of PROMs to assess HL, QoL, and adherence to long-term therapy, acquired the perspectives of the patients, who we consider to be the most important stakeholders. The single-centred design is a strength that ensures that the study participants received similar healthcare services. The limitations of the study are the exclusion of patients unable to read and write in Norwegian, which may have excluded the most vulnerable patients. Further, we did not assess cognitive impairment, which is found to compromise the ability for self-managing in patients with advanced kidney disease (Lambert et al. 2017). Another limitation is the cross-sectional study design that excludes the possibility of causal interpretation, although the study is highly hypothesis-generating.

CONCLUSION

Several dimensions of HL seem to be important for CKD patients’ QoL and adherence to lifestyle recommendations. Healthcare services should focus on developing HLR organisations to increase QoL and adherence to long-term therapy. Additional studies with more participants and objective assessment tools are needed to investigate the relationship between CKD patients’ HL and medical adherence.

Acknowledgements

The authors would like to thank the patients who generously participated in this study. We would also like to thank the staffs of the Nephrology Department at the Stavanger University Hospital for their cooperation during the data collection period. Dr. Joanna Haynes for language editing. In addition, we thank Professor Jan Terje Kvaløy at the University of Stavanger for contributing with statistical advice.

Author Contributions

UEW: Principal Project Leader, conceived the study, collected and analyzed the data, drafted the manuscript, coordinated and approved the final manuscript. AKW: Participated in the design, helped to analyze the data, drafted the manuscript, read and approved the final manuscript.
LGG: Participated in the design, helped to analyze the data, drafted the manuscript, read and approved the final manuscript.
KHU: Participated in the design and coordination, helped to analyze the data and drafted the manuscript, read and approved the final manuscript.

References


SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.
Paper III
Paper III

Exploring health literacy in patients with chronic kidney disease, a qualitative study

Une Elisabeth Stomer1,2*, Astrid Klopstad Wahl3, Lasse Gunnar Goransson4,4 and Kristin Hjorthaug Urstad1

1 Faculty of Health Science, University of Stavanger, Stavanger, Norway
2 Department of Nephrology, Stavanger University Hospital, Stavanger, Norway
3 Faculty of Medicine, University of Oslo, Oslo, Norway
4 University of Bergen, Faculty of Medicine, Department of Clinical Medicine, Bergen, Norway

*Corresponding author
Une Elisabeth Stomer, Email: une.stomer@uis.no

Abstract

Background:

Patients with chronic kidney disease make day-to-day decisions about how to self-manage their disease. Having chronic kidney disease (CKD) includes a risk for progression towards end-stage renal disease and for developing comorbidities, such as cardiovascular disease, which represents the leading cause of death among these patients. To reduce these risks, CKD patients are recommended to follow a healthy lifestyle with physical activity, individual food, and fluid restrictions, and adherence to complex medication regimes throughout all phases of the disease. To manage the complexity of the health situation, health literacy (HL) is considered essential. The currently prevailing understanding is that HL is a multidimensional concept and comprises a range of cognitive, affective, social, and personal skills that determine the motivation and ability to gain access to, understand, and use health information. Recently we described multiple aspects of HL in CKD patients in a quantitative cross-
sectional study utilizing the Health Literacy Questionnaire (HLQ) and found that the ability to find good health information and appraising health information were the most challenging aspects of HL. This study aimed to explore CKD patients’ lived experiences in different dimensions of HL based on the HLQ.

Methods:

This is a qualitative study utilizing in-depth semi-structured interviews. Twelve patients with different levels of HL were included. The interviews were analyzed using thematic analysis, according to Clarke and Braun.

Results:

We created three main themes that were significant for the CKD patients’ HL: 1. *Diversity in the role as a health information seeker*, 2. *Fragmented healthcare system - a challenge for navigation*, and 3. *The value of a good relationship with healthcare providers*.

Conclusion:

CKD patients take different approaches to health information. Limiting or avoiding health information can be a strategy to cope with the disease and does not necessarily mean that health information is inaccessible or difficult to understand. Comorbidity and a fragmented healthcare system can make the healthcare system challenging to navigate. A good and trusting relationship with healthcare providers seems to promote several aspects of HL and should be provided to optimize CKD patients’ HL.

Keywords: Health literacy, chronic kidney disease, patients’ experiences, qualitative study

Background
Patients with chronic kidney disease (CKD) make day-to-day decisions about how to self-manage their disease. Having CKD in early stages includes a risk for progression towards end-stage renal disease (ESRD), and for developing comorbidity, such as cardiovascular disease, which represents the leading cause of death in this population [1, 2]. Physical symptoms are often diffuse and nonspecific before the disease reaches ESRD [3], which can make CKD easy to neglect in earlier stages. Still, patients are recommended a healthy lifestyle with physical activity, individual food- and fluid restrictions, as well as adhering to complex medication regimes trough all phases of the disease, to reduce the risk for progression of the kidney disease and the development of comorbidities [3-6].

To manage the complexity of the health situation, health literacy (HL) is considered essential [7, 8]. The currently prevailing understanding is that HL is a multi-dimensional concept comprising a range of cognitive, affective, social, and personal skills that determine the motivation and ability to gain access to, understand, and use health information [9].

A mixed-method study in cardiac patients revealed that many patients threw away the information leaflets they received and found it hard to understand the healthcare professionals’ information, regardless of which level of HL they had [10]. Another qualitative study in chronic obstructive pulmonary disease, reported from both patients and professionals, that time constraint and medical jargon were the most prominent barrier for HL [11]. A systematic review article included both qualitative and quantitative studies of patients and healthcare professionals perceived barriers for HL, also found time constrain to be the most common barrier for both patients and providers across different studies [12].

HL in patients with CKD is reported to be limited and associated with lower kidney function and higher hospitalization- and mortality rates [13-16]. Low HL is also related to unsound health behavior such as skipping scheduled dialysis sessions [17], and low immunosuppressant adherence in kidney transplant patients [18]. Besides, patients with low
HL have less access to kidney transplantation [19]. A recent qualitative study in the context of kidney transplantation found that patients needed to be triggered by a symptom or a concern to start seeking health information actively (20), but more research is needed to understand barriers for HL in the CKD population.

Due to the recent focus on a multifaceted picture of HL, multidimensional assessment tools have recently been developed [20]. The Health literacy questionnaire (HLQ) is one of a few multidimensional HL assessment tools that cover a range of dimensions such as personal abilities, social support as well as accessibilities of the healthcare system [21]. The HLQ is widely used, translated, and culturally adapted into more than 30 languages, including Norwegian [22-24]. The HLQ includes nine domains and gives data for creating HL profiles, which, in turn, facilitate intervention development to improve HL and assessment of healthcare services [25]. Recent research utilizing the HLQ in the context of CKD revealed that the ability to find and to appraise health information seems to be the most challenging part of CKD patients' HL competence [18, 26, 27]. However, it is claimed to be discordance between what patients and clinicians mean by their HLQ responses [24]. Qualitative research can provide an in-depth understanding of personal experiences that quantitative surveys are unable to acquire [28]. Based on the domains from the HLQ, the current study aimed to gain insight into CKD patients' experiences of HL utilizing a qualitative approach.

Methods

Study design

This is a qualitative study utilizing individual in-depth interviews to gain insight into CKD patients' experiences in different aspects of HL.

Setting and context
The current study is part of a broader project aiming to explore HL in CKD patients utilizing both quantitative and qualitative approaches [26]. Participants in the present study had already been included in the first quantitative part of the project. The study participants suffered from CKD stages 3-5 and were receiving treatment at the outpatient clinic or the hemodialysis unit at the department of nephrology in a Norwegian hospital. The frequency of the appointments was individual, depending on the stage- and progression of the disease. The outpatient clinic was practicing continuity of care, which means that the patients saw the same nephrologist each appointment. The Data Protection Officer at the study hospital approved the study ID number 2017/1[26].

Data collection and sampling

Twelve patients were invited to participate either by phone or in connection with a scheduled appointment at the hospital. Maximum variation sampling was used, as this is a purposeful sampling strategy to capture diversity [29-31]. Twelve participants were considered sufficient to achieve diversity across the different levels of HL, age, gender, and stages of CKD [31]. The levels of HL were based on the participants’ scores on the HLQ from the quantitative parts of the project [26]. All of the invited patients approved to participate in the study and gave written consent before the interviews were conducted.

Table 1. Participants characteristics, n = 12.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, median (range)</td>
<td>66 (41-80)</td>
</tr>
<tr>
<td>Female gender, no (%)</td>
<td>6 (50)</td>
</tr>
<tr>
<td>CKD stage, no (%)</td>
<td></td>
</tr>
<tr>
<td>- 3</td>
<td>5 (42)</td>
</tr>
<tr>
<td>- 4 and 5, not on dialysis</td>
<td>4 (33)</td>
</tr>
<tr>
<td>- 5, on hemodialysis</td>
<td>3 (25)</td>
</tr>
</tbody>
</table>
Data collection/Interviews

Data were collected in a private room at the outpatient clinic or the patients’ home, during the period October 2017-March 2018. All the interviews were audio-taped and performed by the same researcher (UES). The interviews lasted from 17 to 48 minutes (median 35 minutes) and were transcribed verbatim by the first author and a trained health-secretary (MV).

The semi-structured interview guide was based on the HLQ, which again is based on the World Health Organisation’s (WHO) definition where HL is described as; “the cognitive and social skills which determine the motivation and ability of individual to gain access to, understand and use information in ways which promote and maintain good health [32].” The nine aspects of HL included in the HLQ is 1. Feel understood and supported by healthcare providers, 2. Have sufficient health information to manage my health, 3. Actively managing health, 4. Have social support for health, 5. Appraise health information, 6. Ability to actively engage with healthcare providers; 7. Ability to navigate the healthcare system, 8. Ability to find good health information, and 9. Ability to understand health information well enough to know what to do [21]. The interview-guide for the current study is presented in Table 2.
Insert Table 2 here.

Data analysis

Thematic analysis was used to organize data into a structured format systematically and to facilitate a deeper understanding of the CKD patients’ experiences of HL. We followed the 6 phases of thematic analysis described by Braun and Clarke [33]. One investigator (UES) generated initial codes from the complete text and organized the data further into meaningful groups (with similar content). After initial coding and organizing the total dataset into meaningful groups, we searched for themes relevant for HL, by the use of mind-maps, resulting in sub-themes and themes. An additional investigator (KHU) contributed in organizing the initial codes and extracting them into sub-themes and themes. During the analytic process, the four authors (UES, AKW, LGG, and KHU) discussed the themes until we reached consensus. The data reported are following Braun and Clarke’s 15-point checklist of criteria for good thematic analysis [33].

Results

The thematic analysis resulted in three main themes of patients’ experiences relevant to HL: 1. Diversity in the role as health information seeker, 2. Fragmented healthcare services - a challenge for navigation, and 3. The value of a good relationship with healthcare providers (Figure 1.) The themes revealed both individual and systemic strengths and barriers related to different dimensions of HL.

Table 3. Examples of the analytic process, including full citations, initial codes, sub-themes, and themes.

<table>
<thead>
<tr>
<th>Citations/raw-data</th>
<th>Initial codes</th>
<th>Sub-themes</th>
<th>Theme</th>
</tr>
</thead>
</table>

115
### Theme 1. Diversity in the role as health information seeker

The thematic analysis revealed a great diversity in participants’ attitudes towards health information seeking. On the one hand, a group of participants described a desire for control and a keen interest in their health conditions. On the contrary, participants expressed a need to protect themselves towards a load of health information surrounding them, either by actively limiting the information input or by being a passive receiver of health information, waiting for the healthcare provider to give them information. Some were confused about their responsibility as patients; if they were expected to ask questions or wait for the nephrologist to inform them.

Participants characterized as actively health information seekers described how they actively utilized both available written information material, internet, and consultations with...
health care providers to get an overview and understanding of their health situation. They expressed that health aspects interested them, and they wanted to learn more. A 69-year-old female participant found it interesting to read about her conditions:

“I read! I find it interesting. The more diseases you have, the more interesting it gets.” (178. Female (F), 69 years)

Further, educational sessions – held by academic staff were suggested as an excellent opportunity to get engaged in their health situation; “...It had to be invited to a lecture or something. Shouldn't have professors or anything like that, but right down to the core plan ... ..... Make it more attractive for people to get involved in their disease.” (99. F, 67 years).

Internet users seemed to be aware of the risk of junk information and information overload and were selective, of which sources of information visited. Participants described how they appraised information on the internet and how they were conscious about which website they accessed for their health information seeking. One of the participants gave an example of one of the resources he relied on:

“I read Norwegian health informatics or something like that or other articles; there is enough information out there... If you find good pages, it is okay, I think... I know my diagnosis, and I look for similar information about it online... ”(57. Male (M), 45 years.)

In contrast to the active health information seekers, some participants seemed to restrain from seeking health information for different reasons. Either a desire to focus on the “present” and on “good things in life” instead of setting focus on the illness and possible long-term problems, or trusting the healthcare providers to give sufficient information, and therefore did not see any reason for searching for or reading health information. Instead of engaging them, they expressed that too much focus on health made them feel worse, as described by this male participant:
“...I am very conscious about keeping the focus on the present. I have had enough problems associated with diabetes and defibrillator. I am happy to be alive. ... I feel that if I know too much, and if I stay in the same environment, it becomes very much like... (pause).

Interviewer: Do you feel sicker? Yes, I feel like getting sicker.” (148, M, 41 years).

Knowing everything about their health condition was not a goal for everybody. As two of the participants explained it in straightforward words when describing the amount of health information that was necessary for them:

“I would just stop and not ask anymore. Because I feel it is enough for me... (148, M, 41 years) and...I am almost 80 years old; it is not that important for me to know everything.” (23, M, 79 years).

They did not only restrain from seeking health information, but some also actively avoided the information. One female said she “moved away” (118, F, 64 years) when peers started to talk about dialysis treatment at a kidney arrangement because she did not want to hear about it. Another male described how he was selective about what he wanted to hear: “...Something I want to listen to and something I do not want to hear. Yeah, because I do not want to hear about all the bad.” (148, M, 41 years).

The passive information receivers expressed to rely on the healthcare providers to inform them about necessary aspects concerning their health condition. The female participant in the following example admits having little knowledge about her disease but explains that to avoid continually thinking and worrying, she chose to wait for- and trusted the healthcare providers to inform her when needed.

“No, but I have chosen not to familiarize myself with it because I don’t want to think about it. Yes, I know that, OK, the nephrologist has me under surveillance; therefore, I do not have to think about it. Interviewer: Do you ask any questions? Very seldom, because I know she (the
nephrologist) will tell me if there is anything I need to know... I do not read anything.” (118, F, 64 years).

Further, this group of participants showed a skeptical attitude towards seeking health information on the internet for different reasons. First, some expressed to be uncertain of their abilities to find appropriate information... “I am anti-internet or analog” (113, F, 74 years), and “No, I am absolutely not searching the internet... there are far too many people searching the internet” (222, M, 63 years). Second, the participants described how the information on the internet could cause anxiety. One participant described it like this:

“I’m not the one who reads on the web uncritically. I have quite a few diseases, so I know that starting to read everything online can make you admitted to psychiatric...” (99, F, 67 years).

These patients were conscious about protecting themselves from information that may cause anxiety or fear.

Social media, such as Facebook groups, where other patients shared their knowledge through lived experiences, was also avoided. A male patient said he had signed off disease-specific Facebook groups because he experienced to get ideas from other patients that were bad for him, for example, that some medications were better than others, and got encouraged to take medications at doses other than those prescribed by the doctor “... It put some ideas in your head, and it is almost spooky... that’s the reason why I have signed off these pages.” (148, M, 41 years).

Another reason for why some patients were not actively seeking health information or asking questions was insecurity about what was expected of them as patients regarding information seeking. A male patient described that his level of knowledge about CKD was low and that he only had short consultations with the nephrologist “...whether it is expected that the patients should ask questions to get information, that I do not know.” (148, M, 41 years).
Theme 2. Fragmented healthcare system: a challenge for navigating.

Participants’ experiences of a fragmented healthcare system seemed to make it
difficult for them to navigate in the healthcare system and to get an overview of their health
situation. Several participants described having a complex health situation in terms of having
comorbidities. When being treated in the hospital, some experienced different health
specialties and wards to have a defined responsibility for their specialty only. The fragmented
system could result in insecurity regarding which type of health issues that should be
addressed to which doctor.

“I have to say—when you have many different diseases, then it is difficult going to the doctor
because they blame it on the other disease, they forward the responsibility. I think they are
frustrated. It is difficult for me to know what the nephrologists’ area is” (227, F, 80 years).

Sometimes, the medical treatment was even contra-indicated for the other disease, and
the participants did not always experience coherent advice:

“I have psoriasis and psoriasis arthritis. Then you are told to stay away from beta-blockers.
Then I was in the heart department. They push, they give you beta-blockers. And then you get
a collision; I think it’s wrong. That there is such a poor interconnection.” (99, F, 67 years).

The same participant described how she had learned to “read between the lines,” not trusting
the healthcare providers to have control of her health situation: “...I know I have to catch/snap
what I can from the different specialists and put it together myself. That’s the way it is...” (99.
F, 67 years).

Even though the General Practitioner (GP) was coordinating the health situation for
many patients, some preferred to consult the nephrologist at the hospital. A female participant
said she was skeptical about consulting the GP after a bad experience of receiving too strong
antibiotics “...Therefore, I have not asked the GP about anything afterward. If I have any concern, I ask the nephrologist.” (118 F, 64 years).

**Theme 3.** The value of a good relationship with healthcare providers.

The participants described how a good and trusting relationship with healthcare providers was facilitating better control and understanding of the situation. By seeing the same healthcare provider each appointment, they seemed to feel safe and developed a low threshold for discussing health issues. An informal language made it easy to ask about anything. A good relationship was described in different ways: as the ability to use an everyday communication, having a low threshold for asking questions and discussing health issues, being at the same level, and previous positive experiences. One patient described how she learned more about her disease after a switch of a nephrologist. She explained that the new nephrologist had room for questions and explained more about the changes in kidney function than the previous nephrologist, resulting in a better understanding of the disease: “I feel he is teaching much more... he is more open to questions... With simple words... he shows me the development of the renal function and explains... Yes, in fact, I feel like I could be there longer if I wanted...” (178 F, 69 years).

Speaking an informal language and having the possibility to make jokes was appreciated and made it easy to share health concerns:

“...to her (the nephrologist) you can say anything... I feel I have got very good contact with her; I can ask what I want. If there is anything I am concerned about, I ask her; I get answers. If she does not know, she will find out.” (118 F, 64 years).

Certain healthcare providers were described as more natural to talk to in terms of being “on the same level,” and the quality of the relationship was decisive for how much the patients
chose to share; “...but I draw a limit. With some, I share more than with others...” (227, F, 80 years).

Positive former experiences, such as being recognized by the nephrologist when admitted to other departments, were contributing to developing trust in and a good relationship with the nephrologist. Patients described it as “a very safe feeling... he recognized me and took a grip and adjusted the medications” (148, M, 41 years), and ... “She saw me when I was admitted to the emergency room. While I was being examined and taking tests, she suddenly turned up. She was showing interest, and it felt safe...” (99, F, 67 years).

The last quotes illustrate how feeling safe in a vulnerable situation makes a significant impression and characterizes the CKD patients’ relationship with healthcare providers afterward.

Discussion

This study aimed to elicit in-depth insight in CKD patients’ experiences of HL based on the nine domains from the HLQ. Our findings reveal considerable differences in how to relate to health information and that fragmented healthcare seems to be a barrier to navigating the healthcare system. Besides, the relationship with healthcare providers appears to be essential and might compensate for HL challenges.

The diversity in handling health information related to the disease may reflect different coping strategies for patients living with CKD. Confronting and distancing strategies are two common main strategies for managing a problem, such as coping with chronic disease [34]. Confronting is referred to as a ‘problem-focused’ approach involving an active role to resolve or minimize the problem while distancing is an ‘emotional-focused’ approach aiming to regulate emotions such as anxiety and fear attached to the problem [34]. The latter approach is characterized by trying to ignore, trivialize, and not focusing on the disease to avoid
unpleasant feelings [34]. Previous studies in CKD patients report similar findings, as an Australian qualitative study characterizes CKD patients either as *receivers* (passive) or *engagers* (actively seeking) of health information [35]. Also, a recent study exploring HL in Norwegian kidney recipients found that the patients fluctuated between different phases trying to balance the amount of information, suggesting that they needed to be triggered by a symptom or concern to search for health information [36]. Based on our findings and earlier research [35, 36], we suggest that limiting the input of health information might be a strategy to cope with CKD and not necessarily a lack of the ability to gain access to, appraise or understand health information. The current study revealed that some patients deliberately choose to avoid health information. Based on this, providing more or simplifying existing information might, therefore, not always be the solution to increase HL, despite low scores on the HLQ.

Another explanation for the diversity in how they relate to health information may reflect the time we live in and the ongoing development of the patients’ healthcare services. From a paternalistic healthcare system where the patients were the passive receivers of healthcare services, we are now moving towards a system where the patients are supposed to be an equal partner with the providers and contribute in shared decision-making [37-39]. We found that some patients still see the healthcare provider as responsible for their health, leaving themselves to be passive receivers of healthcare and health information. Perhaps, emphasizing on clarifying roles and expectations in a patient-healthcare provider relationship might facilitate better HL in CKD patients.

The presence of comorbidities among CKD patients is high and associated with adverse outcomes [40, 41]. Fragmented care in terms of seeing different healthcare providers and specialties is associated with higher use of emergency department, hospitalizations,
disease progression, and higher healthcare costs compared with coherent care [42-44]. The fragmentation and inconsistency in health recommendations and the challenges in deciding which healthcare provider to contact with different health issues are also found in earlier qualitative research in patients with CKD to be a challenge [45, 46]. Patients’ suggestions to minimize the consequences of fragmentation were in a recently published study, the use of coordinated care, patient education, and self-management support [47]. However, our results show that the desire for being educated varies and that some patients prefer not to know everything about their disease.

We found that a good relationship with healthcare providers characterized by trust and good communication was important for several dimensions of HL, such as sharing health concerns, discussing health issues, and actively engaging with healthcare providers. Earlier studies in various healthcare settings have investigated the importance of the relationship between patients and healthcare providers, revealing that the healthcare provider-patient working alliance is a significant factor in CKD patients’ behavior and a direct predictor of the patients’ adherence to treatment and quality of life [48, 49]. Earlier studies have found that indifference and arrogance from healthcare professionals is a barrier for self-care in CKD patients [50]. Based on our findings and previous research, we suggest that ensuring adequate communication skills and facilitate continuity in care with healthcare professionals may promote several aspects of HL in CKD patients.

Our results show that HL in CKD patients is complex and that we need multiple approaches to understand their needs. The qualitative approach in this current study brought nuances to the recent quantitative results in the same population [26], which is important to consider when suggesting clinical implications and further research. The discordance in what patients and healthcare professionals mean by their HLQ scores reported in a previous study
with other patients [24], also suggests that we need more research to understand the complexity of the concept HL.

Implications for practice and future research

In a long-term perspective and at an organizational level, creating organizations that are HL responsive (HLR) might facilitate better HL in CKD patients. HLR refers to the flexibility in an organization to adapt the healthcare services to meet the different needs of the individual patients as well as the populations they serve [51]. For example, our findings indicate that continuity of care is essential for the CKD patients’ HL; hence, an HLR organization can ensure that they organize their outpatient clinic with sufficient time and staff to provide continuity of care. More research is necessary to further explore HL in the context of CKD, for instance, the importance of healthcare providers’ communicative skills for the CKD patients’ HL, and whether the level of HL is responding to interventions aimed to improve HL in CKD patients. Besides, a discussion about healthcare systems’ expectations of the patient role seems to be timely as the healthcare system is continually evolving.

Strengths and limitations

A strength in this study is the inclusion of patients with different levels of HL based on a quantitative assessment with the HILQ, which ensured diversity in the study sample. There are some limitations to this study. It is a small-scale, single-center study, and hence, the results should be interpreted with caution. More extensive research, including more participants from different healthcare institutions and patients with different ethnicities, may have given other results. Another limitation is the limited age spread, with no participant under 40 years. However, the current study is highly hypothesis-generating and raises timely questions in an evolving healthcare system.
Conclusion

CKD patients have different approaches to health information. To limit or avoid health information can be a strategy to cope with the disease and does not necessarily mean that health information is inaccessible or difficult to understand. Comorbidity and a fragmented healthcare system can make it challenging to navigate. A good and trusting relationship with healthcare providers seems to promote several aspects of HL and should be endeavored to optimize the CKD patients’ HL.

List of abbreviations

CKD: chronic kidney disease

ESRD: end-stage renal disease

F: female

GP: general practitioner

HL: health literacy

HLQ: Health literacy questionnaire

M: male

WHO: World Health Organization

Declarations

Ethics approval and consent to participate
All the participants signed informed consent before inclusion in the study, including information about the publication of the results.

The study was approved by the Personal Protection Officer at Stavanger University Hospital, ID number 2017/1.

Consent for publication

Not applicable

Availability of data and materials

The dataset generated and analyzed during the current study is not publicly available due to the individual privacy of the participants, but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

No funding was received.

Authors contributions

UES: Project Leader, conceived study, collected and analyzed the data, drafted the manuscript, coordinated the co-authors, read, and approved the final manuscript.

AKW: Participated in design, helped to analyzed data, contributed in drafting the manuscript, read and approved the final manuscript.
Paper III

LGG: Participated in design, helped to analyze data, draft manuscript, read and approved the final manuscript.

KHU: Participated in design and coordination, helped to analyze data and draft the manuscript, read and approved the final manuscript.

All the authors have read and approved the manuscript.

Acknowledgments

The authors would like to thank the patients who generously participated in this study. We also would like to thank the staff at the Nephrology Department at the Stavanger University Hospital for their cooperation during the data collection period.

References


Paper III


Table 2. Semi-structured interview guide.

<table>
<thead>
<tr>
<th></th>
<th><strong>Starting question</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>- What do you think of your knowledge of CKD?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>About gaining and using health information</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>- How do you get information about your kidney disease?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>About understanding and appraising health information</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>- What do you do if you cannot understand the information you get?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- How do you appraise health information/ consider if health information is relevant for you?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- What do you do if you get conflicting recommendations from healthcare providers/ others with relevance for your health?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>About navigating the healthcare system and managing health</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>- Can you describe how you navigate the healthcare system?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- How do you know when to seek medical assistance?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- How do you know who/where to contact?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- How do you manage your kidney disease daily? (i.e., diet, medications, lifestyle)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>About cooperation and support from healthcare providers</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- How do you experience collaboration with healthcare professionals in general?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- What do you think about the importance of support from healthcare professionals to manage your disease?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th><strong>About social support</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>- Can you explain which role family and friends have concerning you living with CKD? Others with relevance (peers, others)?</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td><strong>Closure question</strong></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Is there anything we should talk about with relevance for how you are handling CKD that we have not talked about already?</td>
<td></td>
</tr>
</tbody>
</table>

*Legend Table 2. CKD = chronic kidney disease*
Appendices
Appendix A – Questionnaires

Spørreskjema knyttet til helseforståelse hos pasienter med kronisk nyresykdom

Deltaker id:
Informasjon


Takk for ditt bidrag!
Del A: Spørreskjema om forståelse av helse og helsetjenester

Takk for at du tar deg tid til å svare på dette spørreskjemaet. Vi håper at resultatene vil hjelpe oss til å forbedre våre helsetjenester.

Vi ønsker å få informasjon om hvordan du søker, forstår og anvender informasjon om helse, hvordan du håndterer dine egen helse og hvordan du samarbeider med leger og annet helsepersonell.

I denne sammenhengen omfatter begrepet helsepersonell leger, sykepleiere, fysioterapeuter, ernæringsfysiologer og andre helsearbeidere du søker råd og behandling fra.
Appendix A

Informasjon om utfylling av spørreskjemaet
Spørreskjemaet inneholder to deler.
I del 1 blir du bedt om oppgi hvor stor grad du er uenig eller enig i ett sett av utsagn.
I del 2 blir du bedt om å oppgi hvor vanskelig eller lett ett sett med oppgaver er for deg. For hvert utsagn eller oppgave, skal du sette ett kryss i bolken som best beskriver deg nå.
Vær vennlig å sørge for at du setter et kryss for hvert utsagn eller oppgave.

Ett eksempel

1. Jorden er flat

Fru Janne Olsen har signalisert at hun er veldig uenig i dette utsagnet.

Del 1 av spørreskjemaet starter her
Vennligst oppgi i hvor stor grad du er uenig eller enig i følgende utsagn. Husk å krysse av for kun ett alternativ.

Kryss av i en av bolksene på denne måten:

<table>
<thead>
<tr>
<th>1. Jeg synes jeg har god informasjon om helse</th>
<th>2. Jeg har minst én helsearbeider som kjenner meg godt</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Når jeg føler meg syk forstår virkelig folk rundt meg hva jeg gjennomgår</td>
<td>6. Jeg bruker ganske mye tid på aktivt å ta vare på helsen min</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Når jeg kommer over ny informasjon om helse sjekker jeg om det er sant eller ikke</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix A

**Delt 1 fortsetter**

Vennligst oppgi i hvornår du er **unken** eller **enken** i følgende utsagn. Husk å krysse av for kun et alternativ.

<table>
<thead>
<tr>
<th>Nummer</th>
<th>Utsagn</th>
<th>Vælg</th>
<th>Uken</th>
<th>Enken</th>
<th>Igen</th>
<th>Iuenk</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Jeg har minst én helsearbeider som jeg kan diskutere helseproblemene mine med</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Jeg legger planer for hva jeg trenger å gjøre for å ha god helse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Jeg har nok informasjon til å ta hånd om helseproblemene mine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Hvis jeg trenger hjelp har jeg mange mennesker jeg kan stole på</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Jeg sammentligner alltid helseinformasjon fra ulike kilder og avgjør hva som er best for meg</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Til tross for andre ting som skjer i livet mitt, setter jeg av tid til å ta vare på helsen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Jeg er sikker på at jeg har all den informasjonen jeg trenger for å ta vare på helsen min på en god måte</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Jeg har minst én person som kan bli med meg når jeg har avtaler hos helsepersonell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Jeg vet hvordan jeg skal finne ut om den helseinformasjonen jeg får er riktig eller ikke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Jeg har de helsearbeiderne jeg trenger til å hjelpe meg å finne ut hva jeg trenger å gjøre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Jeg setter mine egne mål for å opprettholde helse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Jeg har stor støtte fra familie eller venner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Jeg spør helsearbeidere om kvaliteten på den helseinformasjonen jeg finner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Det er ting jeg gjør regelmessig for å bli sunnere</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Jeg kan stole på minst én helsearbeider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Jeg har all den informasjonen jeg trenger for å ta vare på helsen min</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix A

**Del 2 av spørreskjemaet starter her**
Vennligst oppgi hvor vanskelig eller lett følgende gjøremål er for deg nå. Husk å kryss av for kun ett alternativ.

**Kryss av i en av boksene på denne måten:**

<table>
<thead>
<tr>
<th></th>
<th>Finne den riktige helsehjelpen</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Forsikre deg om at helsearbeiderne forstår problemene dine ordentlig</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Finne informasjon om helseproblemer</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Føle at du kan diskutere dine helsebekymringer med en helsearbeider</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Fylle ut skjema med helseopplysninger på en riktig måte</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Finne helseinformasjon fra flere ulike steder</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Ha gode diskusjoner om helsen din med leger</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Få treffe de helsearbeiderne jeg trenger</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Folge instruksjoner fra helsearbeidere nøyde</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Få informasjon om helse slik at du er oppdatert med den beste informasjonen</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Bestemme hvilken helsearbeider du trenger å treffe</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Lese og forstå skriftlig helseinformasjon</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Være sikker på at du finner det rette stedet for å få den helsehjelpen du trenger</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix A

**Del 2 fortsetter**

Vennligst oppgi hvor vanskelig eller lett følgende gjøremål er for deg nå. Husk å krysse av for kun **ett** alternativ.

<table>
<thead>
<tr>
<th></th>
<th>Klare ikke å gi det</th>
<th>Giblet vis av vanskelig</th>
<th>Vanligvis vanskelig</th>
<th>Vanskelig vis til</th>
<th>Vanskelig lett</th>
<th>Alltid lett</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Få helseinformasjon med ord du forstår</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>15</td>
<td>Diskutere ting med helsearbeidere til du forstår det du trenger</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>16</td>
<td>Finne ut av hvilke helsetjenester du har krav på</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>17</td>
<td>Lese og forstå all informasjon på medisinforpakninger</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>18</td>
<td>Få tak i helseinformasjon på egen hånd</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>19</td>
<td>Finne ut av hvilken helsehjelp som er best for deg</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>20</td>
<td>Stille spørsmål til helsearbeidere for å få den helseinformasjonen du trenger</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
<tr>
<td>21</td>
<td>Forstå hva helsearbeidere vil at du skal gjøre</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
<td>☐ ☐ ☐ ☐ ☐</td>
</tr>
</tbody>
</table>
## Appendix A

### Del B: Spørsmål om din helse

Spørsmålene under handler om hvordan du oppfatter helsen din. Disse opplysningene vil hjelpe oss til å forstå hvordan du føler deg og hvor godt du er i stand til å utføre dine vanlige aktiviteter. Hvert spørsmål skal besvares ved å sette et kryss (X) i den boksen som passer best for deg.

1. **Stort sett, vil du si at helsen din er:**
   - Utmerket
   - Veldig god
   - God
   - Nokså god
   - Dårlig

2. **De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er helsen din slik at den begrenser deg i utførelsen av disse aktivitetene nå?**
   Hvis ja, hvor mye? (Kryss (X) en boks på hver linje.)
   - Moderate aktiviteter som å flytte et bord, støvsuge, gå en spastur eller drive med hagearbeid
   - Gå opp trappen flere etasjer

3. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av din fysiske helse?**
   - Fått gjort mindre enn du ønsket
   - Vært begrenset i type arbeidsoppgaver eller andre aktiviteter

4. **I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av følelsesmessige problemer (som å føle seg engstelig eller deprimert)?**
   - Fått gjort mindre enn du ønsket
   - Utført arbeid eller andre aktiviteter mindre grundig enn vanlig
5. **I løpet av de siste fire ukene, hvor mye har smerte påvirket det vanlige arbeidet ditt (gjelder både arbeid utenfor hjemmet og husarbeid)?**

<table>
<thead>
<tr>
<th>Ikke i det hele tatt</th>
<th>Litt</th>
<th>Moderat</th>
<th>Ganske mye</th>
<th>Ekstremt mye</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. **De neste spørsmålene handler om hvordan du føler deg og hvordan du har hatt det i løpet av de siste fire ukene.** For hvert spørsmål, ber vi deg velge det svaret som best beskriver hvordan du har følt deg.

**Hvor ofte i løpet av de siste fire ukene:**

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Mesteparten av tiden</th>
<th>En god del av tiden</th>
<th>Noe av tiden</th>
<th>Litt av tiden</th>
<th>Aldri</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Har du følt deg rolig og avslappet?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. Har du hatt mye overskudd?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. Har du følt deg nedfor og deprimert?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

7. **I løpet av de siste fire ukene, hvor mye av tiden har den fysiske helsen din eller følelsesmessige problemer påvirket dine sosiale aktiviteter (som å besøke venner, slektninger osv.)?**

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Mesteparten av tiden</th>
<th>En del av tiden</th>
<th>Litt av tiden</th>
<th>Aldri</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Del C: Spørsmål om din livskvalitet

Sette et kryss på linjen som du mener representerer din **livskvalitet** for tiden (de siste 4 ukene).

Verst tenkelig livskvalitet
Best tenkelig livskvalitet
Appendix A

**Del D: Spørsmål om depressive tanker**

I listen nedenfor skal du i hver gruppe finne den setningen som passer best til din tilstand *akkurat nå* og sette et kryss i ruten som står foran setningen.

Vennligst les gjennom alle setningene i hver gruppe før du setter kryss for en av dem.

**A.**  
0.....0 Jeg føler meg ikke trist.  
1.....1 Jeg er lei meg eller føler meg trist.  
2.....2 Jeg er lei meg eller trist hele tiden og kan ikke komme ut av denne tilstanden.  
3.....3 Jeg er så trist eller ulykkelig at det gjør vondt.  
4.....4 Jeg er så trist eller ulykkelig at jeg ikke holder det ut.

**B.**  
0.....0 Jeg er ikke særlig pessimistisk eller motløs overfor fremtiden.  
1.....1 Jeg føler meg motløs overfor fremtiden.  
2.....2 Jeg føler at jeg ikke har noe å se frem til.  
3.....3 Jeg føler at jeg aldri vil komme over mine vanskeligheter.  
4.....4 Jeg føler at fremtiden er håpløs og at forholdene ikke kan bedre seg.

**C.**  
0.....0 Jeg føler meg ikke som et mislykket menneske.  
1.....1 Jeg føler at jeg har sviktet mer enn andre mennesker.  
2.....2 Jeg føler at jeg har utrettet meget lite av verdi eller som betyr noe.  
3.....3 Når jeg ser tilbake på livet mitt, ser jeg ikke annet enn svikt.  
4.....4 Jeg føler at jeg har mislykkes fullstendig som menneske (far/mor, ektefelle).

**D.**  
0.....0 Jeg er ikke særlig utilfreds.  
1.....1 Jeg kjøder meg for det meste.  
2.....2 Jeg har ikke samme glede av noe som før.  
3.....2 Ingenting gir meg tilfredsstillelse lenger.  
4.....3 Jeg er utilfreds med alt.
Appendix A

E. 0....0 Jeg føler meg ikke særlig skyldbetyg.
   1....1 Jeg føler meg slett eller verdiøs en stor del av tiden.
   2....2 Jeg føler meg svært skyldbetyg.
   3....2 Jeg føler meg slett eller verdiøs nesten hele tiden nå.
   4....3 Jeg betrakter meg som svært slett eller verdiøs.

F. 0....0 Jeg har ikke følelsen av å bli straffet.
   1....1 Jeg har en følelse av at noe vondt kan komme til å hende meg.
   2....2 Jeg føler at jeg blir eller vil bli straffet.
   3....3 Jeg føler at jeg fortjener å bli straffet.
   4....3 Jeg vil ha straff.

G. 0....0 Jeg føler meg ikke skuffet over meg selv.
   1....1 Jeg er skuffet over meg selv.
   2....1 Jeg er ikke fornøyd med meg selv.
   3....2 Jeg kan ikke utstå meg selv.
   4....3 Jeg hater meg selv.

H. 0....0 Jeg føler ikke at jeg er noe dårligere enn andre.
   1....2 Jeg er svært oppmerksom på mine egne svakheter eller feiltakelser.
   2....2 Jeg bebreider meg mine feil.
   3....3 Jeg bebreider meg selv alt galt som skjer.

I. 0....0 Jeg tenker ikke på å gjøre meg noe.
   1....1 Jeg har tanker om å gjøre meg selv noe, men kommer ikke til å gjøre det.
   2....2 Jeg føler at det ville være bedre om jeg var død.
   3....2 Jeg føler at det ville være bedre for min familie om jeg var død.
   4....3 Jeg har klare planer om å begå selvmord.
Appendix A

J. 0....0 Jeg gråter ikke mer enn vanlig.
  1....1 Jeg gråter oftere enn vanlig.
  2....2 Jeg gråter hele tiden nå og klarer ikke å stoppe.
  3....3 Jeg pleide å kunne gråte, men nå kan jeg ikke gråte i det hele tatt selv om jeg gjerne vil.

K. 0....0 Jeg er ikke mer irritert nå enn ellers.
  1....1 Jeg blir lettere ergelig eller irritert enn vanlig.
  2....2 Jeg føler meg stadig irritert.
  3....3 Jeg blir ikke irritert i det hele tatt over ting som pleide å irritere meg.

L. 0....0 Jeg har ikke mistet interessen for andre mennesker.
  1....1 Jeg er mindre interessert i andre mennesker nå enn jeg pleide å være.
  2....2 Jeg har mistet nesten all interesse for andre mennesker nå enn jeg pleide å være.
  3....3 Jeg har mistet all interesse for andre mennesker og bryr meg ikke om dem i det hele tatt.

M. 0....0 Jeg kan ta avgjørelser like lett som ellers.
  1....1 Jeg forsøker å utsette å ta avgjørelser.
  2....2 Jeg har store vanskeligheter med å ta avgjørelser.
  3....3 Jeg kan ikke ta avgjørelser i det hele tatt lenger.
Appendix A

Del E: Spørsmål om hvordan du tar medisiner

- Mange finner en måte å bruke sine medisiner på som passer dem.
- Dette kan avvike fra instruksjonene på etiketten eller fra hva legen deres har sagt.
- Vi vil gjerne stille deg noen få spørsmål om hvordan du bruker dine medisiner.

Her er noen måter folk har sagt de bruker medisinenene sine på. For hvert av utsagnene, vennligst kryss av i den ruten som passer best for deg.

<table>
<thead>
<tr>
<th></th>
<th>Alltid</th>
<th>Øfte</th>
<th>Noen ganger</th>
<th>Sjelden</th>
<th>Aldri</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg glemmer å ta medisiner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg endrer dosen av medisinene</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg stopper å ta medisinenene for en stund</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg bestemmer meg for å utelate en dose</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg tar mindre enn jeg har fått beskjed om</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Del F: Spørsmål om etterlevelse av livsstil

Sett et kryss på linjen som beskriver i hvilken grad du etterlever anbefalinger om livsstil du får fra helsepersonell i forhold til din nyresykdom

Følger ingen anbefalinger
Følger alle anbefalinger
**Appendix A**

**Del G: Spørsmål om deg selv**

Vennligst sett kryss i boksen som beskriver deg

<table>
<thead>
<tr>
<th>Sivil status</th>
<th>Sett kryss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gift/samboer</td>
<td></td>
</tr>
<tr>
<td>Enslig/skilt/separert/enke/enkemann</td>
<td></td>
</tr>
<tr>
<td>Bor sammen med noen</td>
<td></td>
</tr>
<tr>
<td>Bor alene</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fullfort utdanning</th>
<th>Sett kryss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barne- og ungdomsskole</td>
<td></td>
</tr>
<tr>
<td>Videregående/ yrkesskole</td>
<td></td>
</tr>
<tr>
<td>Universitet/ hoyskole mindre enn 4 år</td>
<td></td>
</tr>
<tr>
<td>Universitet/ hoyskole mer enn 4 år</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Arbeidssituasjon</th>
<th>Sett kryss</th>
</tr>
</thead>
<tbody>
<tr>
<td>I arbeid</td>
<td></td>
</tr>
<tr>
<td>Uforetrygd/ pensjonert</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td></td>
</tr>
<tr>
<td>Arbeidsledig</td>
<td></td>
</tr>
<tr>
<td>Hjemmearbeidende</td>
<td></td>
</tr>
<tr>
<td>Annet</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Inntekt i husstanden pr. år</th>
<th>Sett kryss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mindre enn 300 000 kroner</td>
<td></td>
</tr>
<tr>
<td>300 000-600 000 kroner</td>
<td></td>
</tr>
<tr>
<td>600 000-900 000 kroner</td>
<td></td>
</tr>
<tr>
<td>Mer enn 900 000 kroner</td>
<td></td>
</tr>
</tbody>
</table>

**Hvor lenge har du bodd i Norge**  

<table>
<thead>
<tr>
<th>Antall år</th>
</tr>
</thead>
</table>

**Takk for ditt bidrag!**
Appendix A

Intentionally left blank
Appendix B – Interview guide

Intervjuguide: Hvordan pasienter med KNS innhenter, forstår og anvender informasjon om helse.

Innledende spørsmål
Hva tenker du om din kunnskap i forhold til nyresykdom?

1. Om å innhente og bruke informasjon/kunnskap
Hvordan får du tilgang på informasjon/kunnskap om din nyresykdom?
   - Muntlig eller skriftlig?
   - Eks. fra sykehuset, fastlege, internett, spørre andre?
   - Hvordan opplever du at informasjonen du har fått har vært til nytte for deg i håndteringen av din sykdom? Kan du gi eksempler?

2. Om å forstå og vurdere helseinformasjon
   - Hva gjør du dersom du ikke skjenner den informasjonen du har fått/innhentet?
   - Kan du gi eksempler på noe som er vanskelig å forstå i forbindelse med din nyresykdom?
   - Hvordan vurderer du om helseinformasjonen du får/innheter er riktig for akkurat deg?
   - Hva gjør du dersom du opplever å få motstridende anbefalinger fra helsepersonell/andre som angår din helse?

3. Om å navigere i helsesystemet og styre egen sykdom
Kan du beskrive hvordan du finner frem i helsesystemet?
   - Hvordan vet du når du skal ta kontakt?
   - Hvordan vet du hvor du skal henvende deg?

Hvordan tar du hensyn til nyresykdommen din i hverdagen?
   - Eks. Kosthold, medisinbruk, livsstil/trening?

4. Om samarbeid og støtte av helsepersonell
   - Hvordan opplever du samarbeidet med helsepersonell generelt?
   - Erfaring / eksempler?
   - Hva tenker du om betydningen av støtte fra helsepersonell til å håndtere sykdommen? Hvilke erfaringer har du? Eksempler?

5. Om sosial støtte
Kan du fortelle litt om hvilken rolle familie og venner har i forhold til du lever med kronisk nyresykdom? Evt. andre som har betydning: medpasienter, andre?

Avslutningsspørsmål:
6. Er det noe vi ikke har snakket om som du mener har betydning for din håndtering av nyresykdommen?
Appendix B

Intentionally left blank
Appendix C – Informed consent, quantitative studies (Paper I and II)

Appendix C – Informed consent, quantitative studies (Paper I and II)

Helseforståelse hos pasienter med kronisk nyresykdøm


Hva innebærer prosjektet?


Mulige fordelers og ulemper

Det er ikke forventet at deltakelse i denne studien vil føre med seg noen ulemper utover bruk av tid for å fylle ut de aktuelle spørreskjemaene. Vi regner med at det tar ca 30-40 minutt å svare på spørreskjemaet. På sikt vil det kunne medføre en fordel ved at informasjonen og veiledningen som gis fra helsevesenet er bedre tilpasset ditt behov.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi grunn trekke ditt
Helseforståelse hos pasienter med kronisk nyresyklom 1, 21/10-2016


HVA SKJER MED INFORMASJONEN OM DEG?


OPPFOLGINGSPROSJEKT

Noen deltakere i studien vil på et senere tidspunkt bli invitert til å delta i et intervju. Det er helt frivillig, og intervjuet vil bli brukt for å få en dypere forståelse av noen av spørsmålene.

GODKJENNING

Prosjektet er godkjent av Personvernombudet ved Stavanger Universitetssjukehus.
Appendix C

Helseforståelse hos pasienter med kronisk myresykdom 1, 21/10-2016

<table>
<thead>
<tr>
<th>SAMTYKKE TIL DELTASELSE I PROSJEKTET</th>
</tr>
</thead>
<tbody>
<tr>
<td>JEG ER VILLIG TIL Å DELTA I PROSJEKTET</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sted og dato</th>
<th>Deltakers signatur</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deltakers navn med trykte bokstaver</td>
<td></td>
</tr>
<tr>
<td>Jeg bekrefter å ha gitt informasjon om prosjektet</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sted og dato</th>
<th>Signatur</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rolle i prosjektet</td>
<td></td>
</tr>
</tbody>
</table>
Appendix C

Intentionally left blank
Appendix D – Informed consent qualitative study  
(Paper III)

Helseforståelse hos pasienter med kronisk nyresykdom

Universitetet i Stavanger, Stavanger universitetssjukehus

Forespørsel om deltaking i forskningsprosjektet

Helseforståelse hos pasienter med kronisk nyresykdom

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å gi oss kunnskap om hvordan pasienter med kronisk nyresykdom innhenter, forstår og vurderer helseinformasjon om sin sykdom. Du har tidligere samtykket til og fylt ut et spørreskjema som handlet om din helseforståelse. Som en del av den opprinnelige studien ønsker vi å intervjuere deg for å få belyst noen punkter bedre.

Hva innebærer prosjektet?

Vi ber deg om å delta i et intervju som vil vare i omtrent 1 time. Intervjuet vil bli tatt opp på lydbånd dersom du ikke har noen innvendinger mot det. Du vil bli intervjuet av en prosjektmedarbeider og intervjuet vil foregå i et dertil etegnet rom på sykehuset en dag det passer for deg. I intervjuet vil du bli invitert til å reflektere rundt spørsmål som handler om hvordan du innhenter, forstår og vurderer helseinformasjon som handler om din kroniske nyresykdom.

Mulige fordele og ulemper

Appendix D

Helseforståelse hos patienter med kronisk nyresykdom 2, 24/10-2016

HVA SKJER MED INNFOMASJONEN OM DEG?

GODKJENNING
Prosjektet er godkjent av Personvernombudet ved Stavanger Universitetssjukehus.

Samtykke til deltakelse i PROSJEKTET

JE ER VILSIG TIL Å DELTA I PROSJEKTET

<table>
<thead>
<tr>
<th>Sted og dato</th>
<th>Deltakere signatur</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Deltakere navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet.

<table>
<thead>
<tr>
<th>Sted og dato</th>
<th>Signatur</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Rolle i prosjektet

Side 2 / 2

160
Appendix E – Regional Ethics Committee (REK) response

Kristin Hjortug Urstad
Samfunnsvitenskapelig fakultet, Institutt for helsefag

2016/2060 Helseforståelse hos pasienter med kronisk nyrevsikt stadium 3-5.

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 24.11.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig institusjon: Universitetet i Stavanger
Prosjektleder: Kristin Hjortug Urstad
Prosjektleders projekttomtale:

Framleggsplikt
De prosjekter som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (b) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virkomhet som utføres med vitenskapelig metodikk for å skaffe til visse ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgir om et prosjekt skal anses som framleggspliktig for REK eller ikke.

I den vedlagte protokollen står det at "The study will give a description of HL as associated to demographic and clinical variables and investigate the associations between HL and HRQoL, self-efficacy, depressive symptoms and adherence to medical treatment. The study will also explore how CKD patients understand, seek for and appraise health information. This will add new knowledge to the concept of HL and might contribute to developing new strategies for increased self-care. A descriptive, cross-sectional survey study design will be used to investigate HL in CKD patients. The study will be based on self-reported data and clinical information from the medical journals."

Protokollen har tre deler, under del to står det at "investigating the associations between HL and quality of
Appendix E

life, depressive symptoms, self-efficacy and adherence to medical treatment in patients with CKD. “What are the associations between HL and HRQoL, depressive symptoms, general self-efficacy, and adherence to medical treatment in patients with CKD?”

Det er vedlagt to informasjonsskriv. Når det gjelder informasjonsskrivet mener at hendelsen fremgår av at «Vi ber deg om å bevare et spørreskjema som er utarbeidet for å kartlegge helseforståelse, livsstil, trø på egen evne til å mestre utfordringer samt etterlevelse av medisinsk behandling. I tillegg spør vi etter noen opplysninger om deg selv. Opplysninger fra din sykejournal vil bli brukt som grunnlag i dette konteksten, hvilken type nyresykdom du har, grad av nyresvikt, svar på blodprøver som tidligere er tatt og hvilke medisiner du eventuelt bruker og henter fra apotek.»

Slik prosjektet er beskrevet, fremstår det slik at det er helseforståelsen som skal måles og det er bare denne som er beskrevet som det målbar endepunktet. Selv om dette er en helsefaglig studie og fem medlemmer i studien indirekte vil kunne gi en helsemessig gevinster faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Godkjening fra andre instanser
Det påtider prosjektdelen å undersøke hvilke eventuelle godkjenninger som er nødvendige fra eksempelvis personvernombudet ved den aktuelle institusjon eller Norsk senter for forskningsdata (NSD).

Vedtak

Klageadgang

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder
Appendix F 

Appendix F – Personal Protection Officer approval of PhD project 

<table>
<thead>
<tr>
<th>Intern ID</th>
<th>Bjørneste saknr</th>
<th>Saksbehandler</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017/1</td>
<td>2017/549</td>
<td>Personvernombud Ina Trane</td>
<td>17.01.17</td>
</tr>
</tbody>
</table>

Tilbakemelding på melding om behandling av personopplysninger i forbindelse med prosjektet; «Health literacy in patients suffering from chronic kidney disease»

Det vises til innsendt melding om behandling av personopplysninger av 14.12.16, med vedlegg.

Behandling og utlevere av person-/helseopplysninger i denne saken meldes til personvernombudet med hjemmel i Personopplysningsforskriften § 7-12, jf. Personopplysningsloven § 31 første ledd.

Formålet med prosjektet er;

Prosjektet er et samarbeidsprosjekt mellom Helse Stavanger HF og Universitetet i Stavanger (UiS) der Une E. Stønner ved dialyseavdelingen har permisjon for å gjennomføre et PhD-prosjekt med midler fra UiS. I prosjektet ønsker en å kartlegge helseforståelsen hos pasienter med kronisk nesyndrom. Tidligere forskning har funnet redusert helseforståelse hos pasienter med KNS. En ønsker å gjøre en kartlegging av helseforståelsen til pasientgruppen i et videre perspektiv ved hjelp av spørreskjemaer og intervjuer. En ønsker å få en dypere forståelse av hvordan pasientene innhenter, forstå og vurderer helseinformasjon.


Personvernombudet tar stilling til om prosjektet skal tillås med hjemmel i Personopplysningsforskriften § 7-27, som omhandler behandling av personopplysninger i forbindelse med forskningsprosjekter.

Personvernombudet tillåt prosjektet med hjemmel i personopplysningsforskriften § 7-27 under følgende forutsetninger:

1. At prosjektet godkjennes av klinikkdirektør.


Helse Stavanger HF, Besøksadresse: Armbein Hansnesvei 30, Postadresse: Postboks 8100, 4068 Stavanger E-postadresse: ppo@helse-stavanger.no, Telefon 0 55 51, www.helse-stavanger.no, organisationsnummer 983 974 678
3. Prosjektet gjennomføres i tråd med personopplysningsloven og helseregisterloven med forskrifter.

4. I henhold til personopplysningsloven § 8 skal den som personopplysningene omhandler samtykke til behandlingen av opplysningene. I henhold til personopplysningsloven § 2 nr. 7, skal et samtykke være: Frivillig, uttrykkelig og informert, hvorav vedkommende godtar behandlingen av opplysningene om seg selv.

5. For at et samtykke skal være gyldig må det samtidig informeres om hvor lenge personopplysningene skal oppbevares. Opplysninger om dette må innstå i informasjonsskrivet til pasienten.

6. Prosjektet må sørge for at informert samtykke som innhentes fra pasienten, også omfatter oppslag i pasientens journal, og bruk av grunnlagsdata som hentes derfra.

7. Tilgangen til opplysningene skjer i overensstemmelse med taushetspliktbestemmelsene.

8. Prosjektets data skal oppbevares forsvarlig og i henhold til personopplysningsforskriften kap. 2.

9. Det kreves i utgangspunktet at en følger UIUs sin rutine for lagring av data.

10. Lydopptakene transkriberes uten unødvig opphold. Lydfilen oppbevares inneløst i skap på UIUs etter transkribering.

   Øvrige innsamlede prosjekt data lagres aidentifisert på Helse Stavanger HF sin kvalitetsserver.

11. Koblingsnøkkel som kobler aidentifiserte data med personopplysningene lagres på kvalitetsserver på eget lagringsområde.

12. Samtykkeskjema oppbevares nedløst med to hindringer, separat fra det øvrige prosjektmaterialet.


   Det skal ved prosjektslutt sendes slipmelding og bekreftet sletting til personvernombudet.

Med hilsen

Ina Trané
Personvernombud

Kopi:
Klinikkdirektør