HEALTH LITERACY IN KIDNEY DISEASE: ASSOCIATIONS WITH QUALITY OF LIFE AND ADHERENCE

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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**

BIODATA

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INTRODUCTION

Chronic kidney disease (CKD) is globally recognised as a major public health problem, and the disease affects >10% of the Norwegian population (Hallan *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; Fructuoso *et al.* 2011; Pagels *et al.* 2012; Nabolsi *et al.* 2015).

It is recommended that patients with CKD lead a healthy lifestyle involving physical activity and avoid smoking (K/DOQI 2002). They often have a high pill burden (Bailie *et al.* 2005; Chiu *et al.* 2009; Levey *et al.* 2009; Whaley-Connell *et al.* 2011; Levey & Coresh 2012; Tangkiatkumjai *et al.* 2017), and patients with advanced 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 health care 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 Sorensen *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 behaviour, 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; Kazley *et al.* 2015; Lambert *et al.* 2015; Demian *et al.* 2016; Dodson *et al.* 2016; Taylor *et al.* 2016). However, 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 *et al.* 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 S2 (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-QoL). 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 (K/DOQI 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, MSC-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 χ^2 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 $p > 0.05$. $p \leq 0.05$ 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.

	Total group (no = 187)	Low-level (no = 27)	Mid-level (no = 106)	High-level (no = 52)
Age in years, mean ± SD	67 ± 13	69 ± 11	67 ± 13	66 ± 13
Male sex, no (%)	122 (65)	11 (40)	73 (70)	37 (71)
Education level, no (%):				
Low = ≤ higher secondary school	113 (60)	22 (81)	62 (59)	28 (53)
High = > higher secondary school	73 (40)	5 (19)	43 (41)	24 (46)
Household income in NOK, no (%):				
Low = ≤ 300,000	37 (20)	9 (33)	21 (20)	7 (13)
Average = >300,000	147 (80)	18 (67)	83 (80)	44 (85)
Living alone, no (%)	49 (26)	11 (40)	28 (27)	9 (13)
DCI score, no (%):				
0	66 (35)	8 (30)	34 (32)	24 (46)
1	88 (47)	13 (48)	50 (47)	25 (48)
2	33 (18)	6 (22)	22 (21)	3 (6)
Stage of CKD, no (%):				
3	80 (43)	10 (13)	48 (60)	22 (28)
4 and 5, not on dialysis	81 (43)	11 (14)	44 (54)	24 (30)
Haemodialysis patients,	26 (14)	6 (23)	14 (54)	6 (23)
BDI-SF, median (range)	2 (0–29)	3 (0–29)	2 (0–25)	0 (0–19)
Medications, mean (SD)	7.5 ± 3.7	9.1 ± 3.2	7.7 ± 3.8	6.1 ± 3.2
Renal diagnosis, no (%):				
Hypertensive nephropathy	62 (33)	7 (26)	31 (29)	22 (42)
Glomerulonephritis	40 (22)	6 (22)	22 (21)	12 (23)
Diabetic nephropathy	23 (12)	5 (19)	14 (13)	4 (7)
Other	62 (33)	9 (33)	39 (37)	14 (38)
Time with CKD in months, median (range)	46 (1–515)	81 (1–270)	41 (1–516)	50 (2–278)

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.

	Low-level HL N = 27	Mid-level HL N = 106	High-level HL N = 52	P-values
PCS-12				Low vs. high = 0.002
Median (range)	33.5 (16.3–55.3)	34.5 (13.2–60.0)	42.9 (18.7–59.9)	Low vs. mid = 0.524
				Mid vs. high < 0.001
MCS-12				Low vs. high = 0.003
Median (range)	46.7(15.4–60.7)	49.5 (23.8–66.1)	57.1 (27.4–65.0)	Low vs. mid = 0.012
				Mid vs. high = 0.520
VAS-QoL				Low vs. high = 0.001
Median (range)	50 (10–100)	68 (9–100)	82 (19–100)	Low vs. mid = 0.044
				Mid vs. high = 0.002
MARS-5				
Median (range)	24 (14–25)	24 (13–25)	24 (18–25)	0.852
VAS-adherence				Low vs. high = 0.300
Median (range)	90 (36–100)	85 (20–100)	92 (48–100)	Low vs. mid = 0.393
				Mid vs. high = 0.012

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.

HL: health literacy; MARS-5: Medical Adherence Rating Scale 5; MCS-12: mental component score; Nonparametric tests: Kruskal–Wallis to find differences between three different groups and Mann–Whitney as post hoc tests to identify where the differences are located. PCS-12: physical component score; QoL: quality of life; VAS-adherence: Visual Analogue Scale for adherence to lifestyle recommendations; VAS-QoL: Visual Analogue Scale for Quality of Life.

QOL AND ADHERENCE IN PATIENTS WITH DIFFERENT HL LEVELS

By using Wards' 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 high-level group and 106 (57%) were in the mid-level group (Table 1) (Støtmer *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 (49/82) 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 ($p < 0.001$) and patients on haemodialysis ($p < 0.001$). 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

	PCS-12			MCS-12			VAS-QoL		
HLQ scales	Uni p	MA p	MaB p (beta)	Uni p	MA p	MaB p (beta)	Uni p	MA p	MaB p (beta)
Healthcare provider support	0.370	0.210		0.463	0.687		0.045	0.815	
Have sufficient information	0.025	0.570		0.060	0.685		0.024	0.661	
Actively managing health	0.043	0.027		0.317	0.677		0.600	0.734	
Social support	0.412	0.686		0.119	0.352		0.010	0.044	
Critical appraisal	0.436	0.202		0.120	0.810		0.104	0.901	
Actively engaged	0.010	0.970		0.007	0.972		0.003	0.939	
Navigating the healthcare system	0.001	0.491		0.001	0.661		0.001	0.964	
Find good health information	0.002	0.150		0.001	0.134		0.003	0.130	
Understand health information	0.000	0.007	<0.001 (4.733)	0.001	0.688		0.000	0.002	<0.001 (9.238)
Adjusted R^2			0.221						0.278

Table 3a: Multiple linear regression analysis to identify associations between quality of life (SF-12 and VAS-QoL) and Health Literacy Questionnaire scales.

beta: unstandardised coefficient; MA: multiple regression analysis with all independent variables, MaB: multiple regression analysis after including independent variables if univariate analysis $p < 0.2$ and stepwise backward elimination if $p > 0.05$; MCS-12: mental component score-12; PCS-12: physical component score-12; VAS-QoL: Visual Analogue Scale-quality of life, Uni: univariate regression analysis,

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

	MARS-5			VAS-adherence		
HLQ scales	Uni p	MA p	MaB p (beta)	Uni p	MA p	MaB p (beta)
Healthcare provider support	0.303	0.726		0.003	0.423	
Have sufficient information	0.179	0.167		0.001	0.349	
Actively managing health	0.389	0.740		0.000	0.000	<0.001 (11.198)
Social support	0.634	0.941		0.001	0.343	
Critical appraisal	0.508	0.309		0.296	0.132	
Actively engaged	0.719	0.237		0.026	0.053	0.016 (5.357)
Navigating the healthcare system	0.254	0.161		0.564	0.086	
Find good health information	0.754	0.252		0.064	0.147	0.008 (−6.308)
Understand health information	0.578	0.552		0.787	0.355	
Adjusted R^2						0.219

Table 3b: Multiple linear regression analysis to identify associations between adherence to long-term therapy (MARS-5 and VAS-adherence) and Health Literacy Questionnaire scales.

beta: unstandardised coefficient; MA: multiple regression analysis with all independent variables; MaB: multiple regression analysis after including independent variables if univariate analysis $p < 0.2$ and stepwise backward elimination if $p > 0.05$; MARS-5: Medical Adherence Rating Scale-5; Uni: univariate regression analysis; VAS-adherence: Visual Analogue Scale 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 (Stømer *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 measurements 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

patient 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 (Trezona *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 seems 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.

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AUTHOR CONTRIBUTIONS

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

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