Changes in Health Literacy during the first year following a kidney transplantation: Using the Health Literacy Questionnaire

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A B S T R A C T

Objectives: The study aimed to identify changes in health literacy (HL) and associated variables during the first year following a kidney transplantation.
Methods: A total of 196 transplant recipients were included in a prospective follow-up study. The patients answered the Health Literacy Questionnaire (HLQ) at 5 days, 8 weeks, 6 and 12 months following the kidney transplantation. Mixed linear models were used to analyze changes in HL and backward elimination was used to identify variables associated with HL.
Results: Two main patterns of change were identified: a) HL increased during the first 8 weeks of close follow-up and b) in several domains, the positive increase from 5 days to 8 weeks flattened out from 5 days to 6 and 12 months. Self-efficacy, transplant-related knowledge, and general health were core variables associated with HL.
Conclusions: Overall, HL increased during the 8 weeks of close follow-up following the kidney transplantation, while 6 months seem to be a more vulnerable phase. Furthermore, low self-efficacy, less knowledge, and low self-perceived health may represent vulnerable characteristics in patients.
Practical implications: Future kidney transplant care should take into account patients' access to and appraisal of health information and social support, and draw attention to potentially vulnerable groups.

1. Introduction

A kidney transplantation represents a major change in the life of kidney recipients and their families. The recipients depend on lifelong immunosuppressive medications, and must cope with side effects and monitor symptoms of infections and organ rejections [1,2]. Being able to find, use, and understand health information, to communicate with healthcare providers, and to navigate the healthcare system are therefore essential skills. Such skills are also known as health literacy (HL). According to the World Health Organization (WHO), HL has been defined as "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" [3].

During the first year post-transplantation, the kidney recipient moves through several phases. In the Norwegian center these represent the postoperative phase at the surgical ward; the rehabilitation phase at the outpatient ward (consisting of eight weeks with close follow-up and patient education [4]); and the transition from a highly controlled setting to the home context with local follow-ups. According to Sørensen et al. [5], individuals needs different HL-related competences in the process of accessing, understanding and applying health-related information in different phases; being a patient in the health care system, and being a person at risk of disease. Available studies of HL in the context of kidney transplantation are mostly cross-sectional, meaning that there is a lack of knowledge about how HL-needs might change following a kidney transplantation.

Furthermore, most studies focuse on functional HL (basic reading and writing skills), and have found HL limitations to be associated with reduced access to transplantation [7–10], medication non-adherence [11,12] and socioeconomic factors like lower levels of education [13,14], lower income, ethnicity, and language barriers [12,14,15]. Studies have also identified associations between HL and

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health outcomes, such as lower levels of creatinine [12,14], early graft failure, increased rejections, and frequent hospital readmissions [16]. Few studies have used multidimensional measures to map a more detailed picture of HL and associated variables. Exceptions are the studies of Demian et al. [12] and Dahl et al. [17]. Demian [12] found an association between medication adherence and several aspects of HL, in particular social support and having sufficient information. Demian et al. [12] and Dahl et al. [17] found that kidney transplant recipients had the lowest scores in critical appraisal of health information, an HL skill that is becoming even more important in a society with increasing access to a wide range of information sources.

As we lack insight considering multidimensional aspects of HL in kidney transplant recipients, there is consequently lack of knowledge about important variables associated with different domain. Especially about personal assets like transplant related knowledge, and self-efficacy, both being important abilities following a kidney transplantation. A cross-sectional study focusing on eight weeks post transplantation found that several domains of HL had a positive association with self-efficacy, transplant related knowledge, and better general health [17]. In the present study, we follow the same population through the first year after the transplantation.

The present study aimed to answer the following research questions:

- What are the patterns of change in HL during the first year following a kidney transplantation?
- To what extent is HL associated with selected sociodemographic and clinical variables, self-efficacy, transplant-related knowledge, and general health during the first year post-transplantation?

2. Methods

2.1. Study design and data collection

This single-center, prospective study was conducted in Norway, where all transplant surgery is localized at one nationwide transplant center with approximately 250–300 kidney transplantations performed each year. The research project was approved by the Norwegian Regional Ethical Committee (#2016/1485), and the University Hospital Data Protection Officer (#2016/14592).

Recruitment took place February 2016 to August 2017. Transplant nurses invited patients to participate in the study three to five days post transplantation. Inclusion criteria were:

- ≥ 18 years of age
- Ability to read Norwegian well enough to fill out the questionnaire
- Ability to participate in patient education

Four patients who were isolated due to contagious deceases were excluded from participation, since the questionnaires were distributed on paper for self-administration.

The patients answered the questionnaire at 5 days, 8 weeks, 6 months and 12 months following kidney transplantation. All questionnaires were handed out during the hospital consultations, except for the questionnaires at six months that were sent by mail to the patients.

During the recruitment phase, 357 patients received a kidney transplant, of whom 217 were invited to take part in the study. A total of 196 were included and received the questionnaire (Fig. 1). Of these, 176 patients also gave
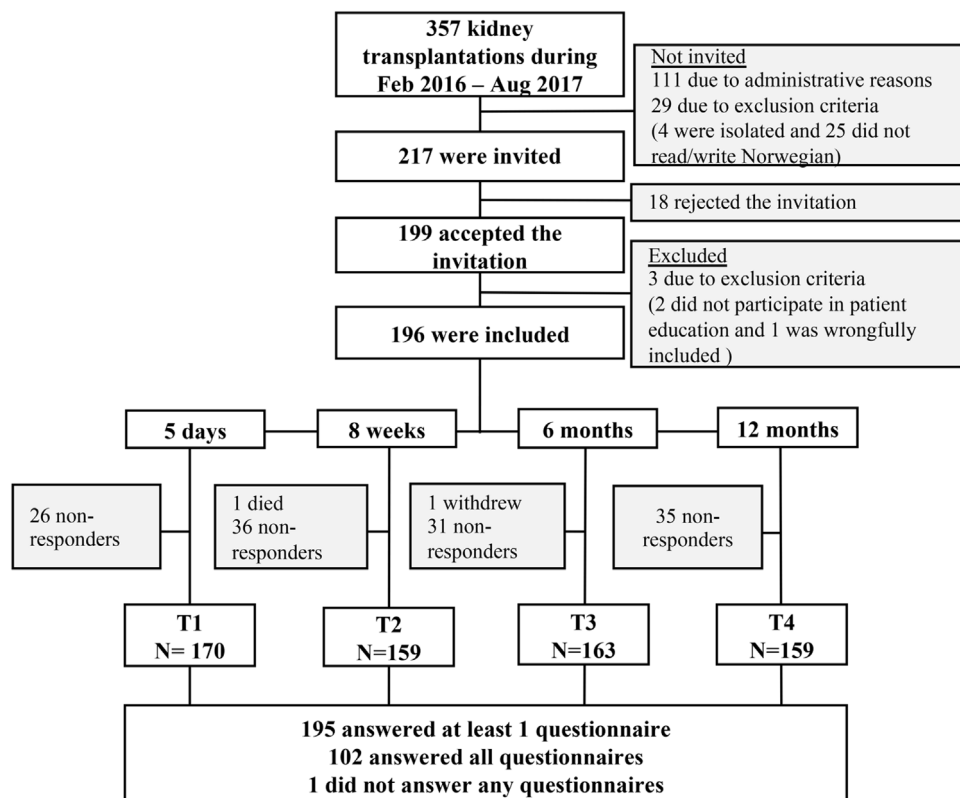

Fig. 1. Flowchart.

permission to withdraw clinical information from the electronic patient journal.

2.2. Measurements

HL, transplant-related knowledge, self-efficacy, and general health were measured at all four time points. The time points reflect critical phases for transplant recipients the first year following transplantation (postoperative phase at 8 weeks, everyday life at home at 6 months, and a long-term perspective at 12 months).

2.2.1. Health literacy

HL was assessed using the Health Literacy Questionnaire (HLQ) [18]. The questionnaire contains 44 questions across 9 independent domains of HL, where each domain includes four to six statements (Table 2). WHOs definition of HL was used as a stepping stone in the development of the HLQ [18]. In the first five domains, the respondents chose one of four answering categories from "strongly disagree" to "strongly agree." In the last four domains, the answer categories ranged from one to five: "cannot do or always difficult" to "very easy." The calculation of scores are described elsewhere [17]. A higher score indicates higher levels of HL.

The questionnaire has been translated into and adapted for Norwegian according to the principals of translation developed by the authors of the HLQ [19]. The Norwegian translation has further been validated and found to be a robust measure of HL with high internal consistency [20,21].

2.2.2. Transplant-related knowledge

Transplant-related knowledge was measured using the Knowledge Questionnaire for Renal Recipients [22], comprising 14 statements about immunosuppressive medication, organ rejection, and lifestyle. The questionnaire was developed and validated in a Norwegian setting [22]. Each statement has five possible responses from "totally disagree" to "totally agree." Respondents are given a score from 0 to 14, where higher scores indicate a higher level of transplant-related knowledge. Description and use of the questionnaire is described in detail elsewhere [17].

2.2.3. Self-efficacy

Self-efficacy was assessed by the General Perceived Self-Efficacy Scale (GSE). The GSE contains 10 statements related to the respondents' belief in their ability to cope with novel, unexpected or difficult situations, and to achieve certain goals [23]. Each statement has a 4-point response scale, ranging from "not at all true" to "exactly true." The scores for each item give a total GSE score between 10 and 40 points, and higher scores indicate higher self-efficacy [23]. The questionnaire has been used world-wide [24,25], and was validated in a Norwegian setting [23]. In the present study's sample, the measure was found to have an acceptable internal consistency with a Cronbach's alpha ranging between .90–.93 at the four measurement points.

2.2.4. General health

The single item question "In general how would you say your health is?" was used to assess self-perceived evaluation of general health [26]. The possible responses are "excellent," "very good," "good," "fair" or "poor." The scores were reverse-coded when analyzed with higher scores representing higher levels of general health.

2.2.5. Sociodemographic and clinical variables

Sociodemographic variables like education, civil status, length of kidney disease, and donor status were collected at 5 days. Self-reported information about rejection episodes were collected at 6

and 12 months. Clinical data concerning episodes of rejection at eight weeks, status of dialysis pre-transplantation, comorbidity, and glomerular filtration rate (eGFR) were retrieved from the electronic patient journal. eGFR, a proxy for kidney function, was collected at 12 months since kidney function is more stable at this point in time and the value should reflect the general kidney function thorough the first year. The Charlson comorbidity index [27] was used to register comorbidity. Points were not given for kidney disease, and age was omitted due to high collinearity with the variable age in the multivariable model.

2.3. Statistical analysis

Descriptive data are presented with frequencies and proportion, mean and standard deviation (SD), and median and range. The HLQ domains are presented in full sentence in the result section and throughout the manuscript referred to in short form.

The HLQ were scored according to the scoring algorithm of the HLQ user manual, using IBM SPSS© Statistics version 25 (IBM Corp, Armonk, New York). Missing variables in the HLQ were treated with the expectation maximization algorithm [6]. Domains with four to five questions allowed for two missing values to be imputed. Domains with six questions allowed for three missing values to be imputed. Cronbach's alpha was calculated for all nine domains at each of the four time points.

HLQ scores are presented as margin values with SD. The margin values were calculated using linear mixed-effect models (see details below) with time as the only fixed variable. P-values from the test of significant change in HLQ follow-up scores from 5 days were given.

Linear mixed-effect models were used to analyze variables associated with changes in HL over time, using Stata© version 15.0 (StataCorp LP, College Station TX) [28]. The nine HL domains were used as dependent variables and time was used as a fixed, categorical variable. Stepwise backward elimination was used to identify variables associated with change in the nine HL domains. Sociodemographic variables (sex, age, civil status, and education), clinical variables (length of kidney disease, time in dialysis pre-transplantation, eGFR, rejections, comorbidity, and general health), transplant-specific knowledge, and self-efficacy were considered for inclusion. Variables with a p-value < 0.2 in univariate analysis were included in the multivariable analysis as fixed variables. The least significant variable was excluded from the analysis until all variables had a p-value < .05. Variables with p-values >.20 in the univariate analysis were then added back to the model, one by one, and included in the final model if the p-value <.05, but none became significant. In all models, ID was included as a random effect, meaning that each participant was given a random intercept. Interaction effects between time and the fixed variables were tested one at a time. Due to a large number of tests, a significance level of .01 was chosen. No significant interactions were observed. Results were presented as unstandardized beta coefficients (β) and p-values to describe the strengths of associations between the fixed factors and the HLQ-domains.

Several of the sociodemographic variables, clinical variables, and general health variables were incomplete, thus missing data were imputed before inclusion in the analyses. We performed multiple imputation with chained equations, using the *mi impute* procedure in Stata©. This procedure involves creating multiple "complete" data sets. The imputations are based on existing observations for each individual in addition to observed values for other responders. The procedure creates multiple predictions for each missing data and considers the uncertainty in the imputations [29]. Results of analysis without imputation are provided as supplementary file (S1).

To evaluate the clinical significance of changes in HL, we calculated the standardized response mean (SRM) when the HLQ score changed significantly (p < 0.05) from 5 days. SRM was calculated using the formula SRM= (ESp/√2)/(√(1-correlation) [30]. ESp is the difference between the margin value for HL at 8 weeks, 6 months and 12 months from the margin value at 5 days, divided by the pooled standard deviation of the specific HL domain. *Correlation* is the corresponding correlation between the margin value at 5 days and follow-up. An SRM of 0–0.20 was interpreted as trivial effect, while a SRM ≥ 0.20–< 0.60 was interpreted as small effect [30]. A positive SRM indicated decline and a negative SRM indicated an improvement in HLQ scores.

3. Results

A total of 196 patients were included in the study, and 195 responders answered at least one questionnaire during the first year following the transplantation. Characteristics of the participants are described in Table 1. The mean age of the participants was 56 years and 33% of the participants were women.

Table 2 provides an overview of descriptive characteristics related to the nine domains of the HLQ. The Cronbach's alpha ranged from .76 to .89, indicating acceptable internal consistency.

3.1. Changes in HL during the first year

Table 3 and Fig. 2 illustrate changes in HLQ during the first year post-transplantation. In the HLQ domain "feeling understood and supported by healthcare providers (HCP)," there was a significant increase from 5 days to 8 weeks post transplantation (p=.02; SRM=−0.31). There were no significant changes between 5 days and 6 months, but a significant increase reappeared from 5 days to 12 months (p=<.01; SRM=−0.33). In "having sufficient information to manage my health," there was a significant increase from 5 days to 8 weeks (p=<.001; SRM=−0.52). From 5 days to 6 and 12 months, there was no significant change. In "actively managing health," there was a significant increase from 5 days to 8 weeks (p=<.01; SRM=−0.46). From 5 days to 6 and 12 months, there was no significant change and the scores were the same at 12 months as they were at 5 days. Studying "social support for health," there was no change from 5 days to 8 weeks, but we found a significant decrease from 5 days to 6 months (p=<.01; SRM = 0.32). There was no significant change from 5 days to 12 months. "Appraisal of health information" was the only domain with no significant change during the first year following the kidney transplantation. In "ability to actively engage with HCP," there was a significant increase from 5 days to 8 weeks (p = .01; SRM=−0.30), 6 months

Table 1
Sample characteristic of kidney transplant recipients.

Variables	N	Missing	n (%)	Mean (SD)	Median (min–max)
Age at time of transplantation	196	0		56.0 (13.9)	58 (20–81)
Sex	196	0			
Women			64 (32.7)		
Men			132 (67.3)		
Civil status	189	7			
Married/living with a partner			139 (73.5)		
Single/divorced/separated/widow(er)			50 (26.5)		
Education	178	18			
Completed lower education			102 (57.3)		
Higher education			76 (42.7)		
Years of kidney disease	166	30		16.4 (13.6)	11 (1–55)
History of transplantation	191	5			
First time			156 (81.7)		
Being transplanted before			35 (18.3)		
Donor status	191	5			
Deceased donor			139 (72.8)		
Living donor			52 (27.2)		
Number of comorbidities	174	22		1.25 (1.36)	1 (0–6)
Dialysis status before the transplantation	174	22			
Pre-emptive dialysis			68 (39.1)		
Peritoneal dialysis			32 (18.4)		
Haemodialysis			74 (42.5)		
Time in dialysis (months)	103			19.13 (13.0)	18 (0.25–74)
Kidney function					
Glomerular filtration rate at one year	166	30		56.7 (19.2)	55.5 (11–112)
Rejections					
Organ rejection 8 weeks	188	8	25 (13.3)		
Organ rejection 6 months	181	15	31 (17.1)		
Organ rejection 12 months	161	35	38 (23.6)		
General health score [Scale range 1–5]					
At 5 days	170	26		3.1 (.9)	3 (1–5)
At 8 weeks	157	39		3.4 (.9)	3 (1–5)
At 6 months	160	36		3.2 (.9)	3 (1–5)
At 12 months	158	38		3.3 (.9)	3 (1–5)
Total knowledge score [Scale range 0–14]					
At 5 days	172	24		10.0 (2.6)	10 (1–14)
At 8 weeks	158	38		10.3 (2.6)	11 (0–14)
At 6 months	163	33		9.9 (2.8)	10 (0–14)
At 12 months	160	36		9.9 (2.7)	10 (1–14)
Total self-efficacy score [Scale range 10–40]					
At 5 days	166	30		32.2 (5.00)	32 (13–40)
At 8 weeks	155	41		32.5 (4.58)	33 (22–40)
At 6 months	161	35		32.0 (5.26)	32 (13–40)
At 12 months	160	36		31.8 (4.86)	30.5 (18–40)

Table 2
The Health Literacy Questionnaire, with short form, description of the nine domains, answer options and Cronbach alpha.

Health literacy domains	Range	Answer options	Number of items	Cronbach's alpha			
Short form Description				T1	T2	T3	T4
1. Feeling understood and supported by healthcare providers 'Feeling supported by HCP' Having at least one health care provider that you trust, and knows you well, and that can assist in decision making.	1–4	1. strongly disagree 2. disagree 3. agree 4. strongly agree	4	.82	.84	.82	.86
2. Having sufficient information to manage my health 'Having sufficient information' Have enough good information to look after your health	1–4		4	.83	.80	.84	.84
3. Actively managing my health 'Managing health' Spending time on actively managing health. Making plans and actively engage in healthy activities.	1–4		5	.84	.84	.78	.82
4. Social support for health 'Social support' Feel understood and supported in relation to health. Have access to people that can help if necessary.	1–4		5	.81	.76	.78	.76
5. Appraisal of health information 'Appraisal of health information' Check the quality of information and compare different sources.	1–4		5	.80	.77	.80	.82
6. Ability to actively engage with healthcare providers 'Engaging with HCP' Healthcare providers understand your problems and you are able to have meaningful and good discussions with healthcare providers.	1–5	1. cannot do or always difficult 2. usually difficult 3. sometimes difficult 4. usually easy 5. very easy	5	.87	.86	.89	.87
7. Navigating the healthcare system 'Navigating' Find the healthcare you need, what the best care is and what you are entitled to	1–5		6	.87	.86	.86	.85
8. Ability to find good health information 'Finding good health information' Find up to date and understandable information from different sources.	1–5		5	.81	.82	.87	.86
9. Understand health information well enough to know what to do 'Understanding health information' Correctly filling out forms, understand and follow instructions from healthcare professionals, read and understand medical labels and other health information	1–5		5	.80	.80	.81	.83

T1 = 5 days, T2 = 8 weeks, T3 = 6 months and T4 = 12 months.

(p=.02; SRM=−0.28), and to 12 months (p=<.01; SRM=−0.29). In "navigating the healthcare system," we found an increase from 5 days to 8 weeks (p=.01; SRM=−0.33), where the scores stabilized. In "ability to find good health information," there was a significant increase from 5 days to 8 weeks (p=<.01; SRM=−0.33), but no significant change from 5 days to 6 or 12 months. Finally, "understanding health information well enough to know what to do" had a significant increase from 5 days to 8 weeks (p=<.001; SRM=−0.53), 6 months (p=<.001; SRM=−0.51), and 12 months (p=<.001; SRM=−0.42).

Table 3
Fluctuations in the nine Health Literacy Questionnaire (HLQ)-domains with pooled standard deviation (SD) for each time point, statistical significance, effect size measure standardized response mean (SRM)[*]. The p-value and effect size describe the change in HLQ-score from 5 days. An SRM of .20–.60 was interpreted as a small effect, while <0.2 was considered as trivial effect.

	Domain 1 Feeling supported by HCP	Domain 2 Having sufficient information	Domain 3 Managing health	Domain 4 Social support	Domain 5 Appraisal of health information	Domain 6 Engaging with HCP	Domain 7 Navigating	Domain 8 Finding good health information	Domain 9 Understanding health information
	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]	Margin score [SD] (p-value) [SRM]
5 days	3.34 [0.4]	3.11 [0.31]	3.12 [0.28]	3.20 [0.37]	2.76 [0.44]	4.0 [0.41]	3.69 [0.41]	3.70 [0.44]	3.83 [0.42]
8 weeks	3.43 [0.4] (.02) [−0.31]	3.26 [0.31] (<.001) [−0.52]	3.23 [0.28] (<.001) [−0.46]	3.22 [0.37] (.53)	2.80 [0.44] (.25)	4.10 [0.41] (.01) [−0.30]	3.80 [0.41] (.01) [−0.33]	3.81 [0.44] (<.01) [−0.33]	3.99 [0.42] (<.001) [−0.53]
6 months	3.42 [0.4] (.06)	3.14 [0.31] (.42)	3.15 [0.28] (.52)	3.09 [0.37] (<.01) [0.32]	2.77 [0.44] (.78)	4.10 [0.41] (.02) [−0.28]	3.80 [0.41] (.01) [−0.28]	3.75 [0.44] (.24)	4.01 [0.42] (<.001) [−0.51]
12 months	3.45 [0.4] (<.01) [−0.33]	3.17 [0.31] (.12)	3.12 [0.28] (.85)	3.15 [0.37] (.17)	2.77 [0.44] (.87)	4.12 [0.41] (<.01) [−0.29]	3.80 [0.41] (.01) [−0.29]	3.77 [0.44] (.08)	3.99 [0.42] (<.001) [−0.42]

[*] SRM = ((followup−5days/pooled SD)/$\sqrt{}$)/($\sqrt{}$(1−correlation).
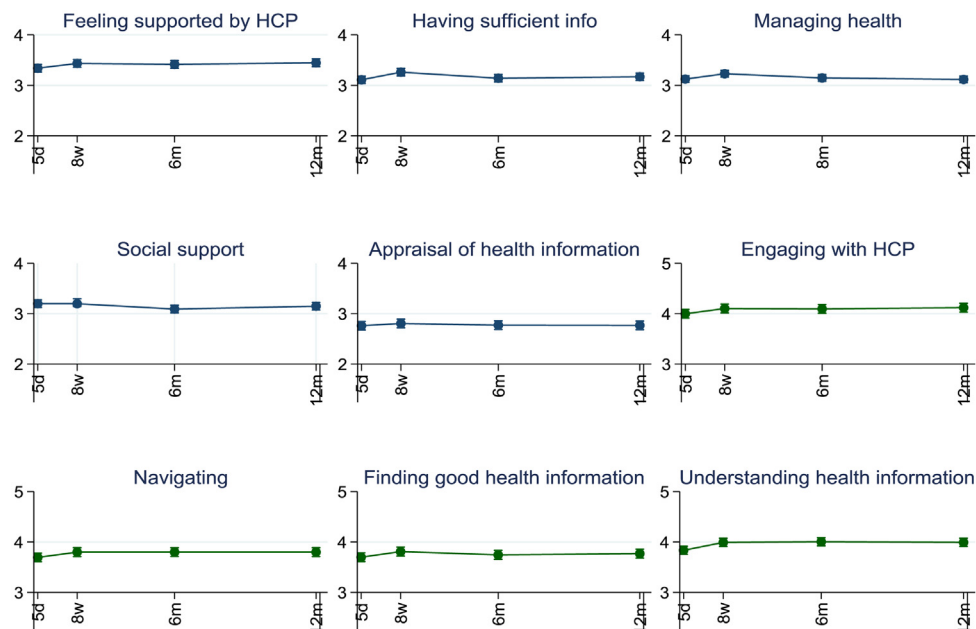
Fig. 2. Fluctuations in the nine Health Literacy Questionnaire (HLQ) domains during the first twelve months following kidney transplantation. All HLQ scores were over the critical scores ≥ 2 in domains 1-5, involving answering "agree" or "strongly agree." In domain 6-9, scores ≥ 3 involve answering "usually easy," or "always easy.".

3.2. Variables associated with health literacy

Self-efficacy (GSE) and transplant-related knowledge were positively associated with all the nine domains of HLQ over the first year post-transplantation, and the single item general health was positively associated with all domains, except "appraisal of health information" and "understanding health information," indicating that these factors are important for explaining variation in the HLQ domains (Table 4).

Longer time with kidney disease was positively associated with "feeling supported by HCP," "navigating," and "finding good health information." More comorbidity was negatively correlated with "having sufficient information." With regards to demographic variables, higher education had a positive association with "understanding health information" and "finding good health

information." Being female was positively associated with "having sufficient information" and "actively managing health." Having a status as married or living with a partner was positively associated with "social support for health." Higher age had a negative association with "appraisal of health information" and "finding good health information."

Results of analysis without imputation supported the main results (Supplementary file S1).

4. Discussion and conclusion

4.1. Discussion

From the results, two main patterns seem to describe changes in HL during the first year post transplant: a) HL seem to increase

Table 4
Variables associated with the nine domains of health literacy (with imputed data). *Significance level <.05 **Significance level <.01 ***Significance level <.001.

Independent variable	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9
	Supported by HCP	Having sufficient information	Managing health	Social support	Appraisal of health information	Engaging with HCP	Navigating	Finding good health information	Understanding health information
	β	β	β	β	β	β	β	β	β
5 days (ref.)									
8 weeks	.069	.121**	.077*	−.006	.039	.076	.073	.085*	.147***
6 months	.077*	.023	.019	−.109**	.018	.098*	.105*	.045	.176***
12 months	.115**	.061	−.010	−.050	.021	.132**	.113**	.079*	.176***
Sex (0=male 1=female)		.147**	.110*						
Age (years)					−.007**				
Education (0=primary and secondary school, 1=higher education)								.154*	.205**
Civil status (0=married/partner, 1=divorced/ widowed/ alone)				.140*					
Comorbidity		−.058**							
Duration of kidney disease (years)	.004*						.006**	.006**	
General health	.049*	.079***	.082***	.095***		.066**	.073**	.058*	
Knowledge	.041***	.023**	.017*	.026**	.008**	.040***	.041***	.032***	.034***
Self-efficacy	.020***	.026***	.016***	.018***	.006***	.031***	.030***	.029***	.029***
Number of patients (n)	**194**	**194**	**194**	**194**	**194**	**193**	**193**	**194**	**193**

during the first eight weeks after the transplantation and b) six months might seem like a more demanding phase as the positive increase from five days to eight weeks flattened out in four domains.

Two domains had different patterns of change: "social support" was the only domain with a negative development from five days to six months and "appraisal of health information" had no significant change. Self-efficacy, transplant-related knowledge and general health stood out as core variables significantly associated with HL during the first year post transplantation.

Using SRM to evaluate the effect size of change in HL, we found *small* clinically significant changes in eight out of the nine HLQ-domains. However, in the context of measuring HL with the HLQ, there is no consensus related to minimal important change. More research is therefore needed to be able to evaluate clinically significant changes using the HLQ.

In the HL domains "having sufficient information" and "finding good health information," the significant changes disappeared at 6 and 12 months. The transition from the specialist hospital to everyday life may challenge patients' experience of having sufficient information and their ability to find information of good quality. Nielsen et al. [31] found that patients had a higher threshold for calling the hospital once they returned home after a kidney transplantation and Dahl et al. [32] found that reduced availability, lack of continuity, and personal factors like low self-esteem could result in the use of other information sources over healthcare providers. It might not be possible to maintain the same close follow-up beyond eight weeks post-transplantation, nevertheless, these results call for more available health information of high quality in transplant care.

"Managing health" had a significant decrease from 8 weeks to 6 and 12 months. We know that the motivation to manage one's health and change one's lifestyle often decreases with time [33–35]. It is vital that transplant recipients take care of their new kidney and prevent adverse effects of immunosuppressive medications [1,36]. Managing one's own health is therefore a key element in kidney care and should be a priority in future interventions.

"Social support" was the only domain with a significant decrease from five days to six months. Pre-transplantation, many patients might feel that their lives are controlled by their diagnoses and requirements of the healthcare system [37], and both the kidney transplant recipient and their family might expect more flexibility and independence post transplantation. Schmid-Mohler et al. [38] found that kidney recipients experienced living with the discrepancy between feeling ill while others perceived them as healthy. As such, this could result in feeling misunderstood and not experiencing social support [38]. Schultz et al. [39] found that nearly half of the patients on the waiting list for a kidney transplantation overestimated their post-transplant physical, social and psychological quality of life (QoL). These findings imply that expectations about life after the transplantation might be unrealistic and may perhaps impact patients' experience of "social support." However, social support is recognized as a key element in health literacy [40], medication adherence [12], and managing chronic disease [41]. In the present clinical setting, patient education and follow-up normally takes place without next of kin being present. As such, involving both the transplant recipient and their families may be an important part of pre- and post-transplant follow-up.

"Appraisal of health information" was the only domain with no significant change during the first year, and with the lowest overall scores. Several other studies involving patients with chronic conditions have also found this domain to be the most challenging [12,42–45]. The current patient education program focuses too little on critical appraisal of health information, and future practice

should emphasize these skills. Furthermore, the respondents may not feel the need to critically assess the quality of the information if the main source of information is a trusted healthcare provider. The higher overall scores in "feeling supported by HCP" and "engaging with HCP" might support this assumption. In the context of kidney transplant recipient, we might therefore need more knowledge of how the patients interpret the questions related to "appraisal of health information."

In a cross-sectional study based on the same study sample as that of the present study, self-efficacy, transplant-related knowledge, and general health were found to be core variables explaining variance in HLQ scores at eight weeks post transplantation [17]. The present prospective study supports these results. Self-efficacy has also been found to influence self-care behavior and medication adherence in kidney transplant recipients [46,47]. As such, it might be important to assess the transplant recipients' own expectations related to self-efficacy following the transplantation.

Lower levels of transplant-specific knowledge were associated with lower HLQ scores in all domains. Although the education provided at the hospital aims to be tailored to the patients' needs, recent evaluations of the educational program show that the teaching-situations may be more standardized, as the nurse must also ensure that all relevant information is given [48,49]. As such, both the nurses providing the education and the patients may benefit from using tools like teach-back [50], in which patients explain the information they have been given in their own words. This technique may be a helpful tool to avoid misunderstandings and reveal knowledge gaps in all patients regardless of their levels of HL.

Self-perceived general health was associated with "having sufficient information," "managing health," and "social support." These were all domains with decreasing scores after eight weeks. The general health variable showed a significant increase from 5 days to 8 week and 12 months post transplantation, but no significant change from 5 days to 6 months. As studies have shown that transplant recipients might overestimate their physical QoL post transplantation [39], expectations might be a contributing factor influencing lower self-perceived health at six months. We found general health at one year to be positively associated with eGFR but none of the other objective measures of health. This study did not include the burden of side-effects, which may impact levels of self-perceived health.

4.2. Strengths and limitations

The use of a multidimensional measure of HL and a prospective design is an important strength in this study, and add novel insight into how different aspects of HL change following the transplantation. The patients included in the study were recruited from the nationwide transplant center. This strengthens the external validity of the results. However, a possible weakness is that a total of 111 transplant recipients were not invited to participate in the study due to administration faults. Since we did not have the permission to collect information from non-participants, we do not know whether the uninvited patients deviated from the study population. However, there are no indications that the administration faults were non-random. An important weakness in our study is that 25 patients unable to read Norwegian were excluded from participation. This might have excluded a vulnerable group that face challenges regarding several aspects of HL.

We used five days post transplantation as the baseline time point for comparing changes in HL. This is a vulnerable phase, as the patients are affected by the recent surgery. However, it is challenging to find an appropriate point in time to answer a questionnaire before the transplantation as 70–80% of the transplantations are with deceased donor and not possible to plan.

4.3. Conclusion

Overall, HL increased during the close follow-up at the hospital the first eight weeks following the kidney transplantation. However, this positive increase seemed to flatten out from five days to six months, revealing aspects of HL that may need closer attention as the transplant recipients return to their home context. Self-efficacy, transplant-related knowledge and general health stood out as core variables significantly associated with HL during the first year post transplantation.

4.4. Practice implications

The results from the present study could inform future interventions to improve kidney transplant care. It seems that six months post transplantation represents a more challenging phase regarding several HL domains, and may be a key point for follow-up with regard to HL. Access to good health information and the ability to actively manage one's health seem to be especially vulnerable domains. Social support was the only domain with a significant decline from five days to six months, and appraisal of health information had no significant fluctuation during the first year. As such, future kidney transplant care should have an increased focus on including next of kin and enhancing patients' ability to critically appraise information.

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CRediT authorship contribution statement

Kari Gire Dahl: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Resources, Software, Validation, Visualization, Writing - original draft, Writing - review & editing. **Astrid Klopstad Wahl:** Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Resources, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Kristin Hjorthaug Urstad:** Conceptualization, Funding acquisition, Investigation, Methodology, Resources, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Ragnhild S. Falk:** Conceptualization, Formal analysis, Investigation, Methodology, Resources, Software, Validation, Visualization, Writing - original draft, Writing - review & editing. **Marit Helen Andersen:** Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at https://doi.org/10.1016/j.pec.2020.12.028.

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