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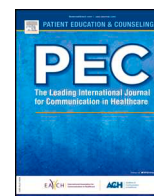
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# A longitudinal qualitative study to explore and optimize self-management in mild to end stage chronic kidney disease patients with limited health literacy: Perspectives of patients and health care professionals

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## ABSTRACT

**Objectives:** Limited health literacy (LHL) is associated with faster kidney deterioration. Health care professionals (HCPs) promote self-management to maintain kidney function, which is difficult for patients with LHL. Evidence lacks on perceived barriers and best strategies to optimize their self-management. Our study aims to explore experiences with and barriers for self-management from the perspectives of LHL patients and HCPs to identify strategies to optimize self-management.

**Methods:** We performed a longitudinal qualitative study with semi-structured in-depth interviews and focus group discussions among CKD patients and LHL (n = 24) and HCPs (n = 37) from general practices and hospitals.

**Results:** Four themes arose among patients: (1) CKD elusiveness, (2) suboptimal intake of knowledge (3) not taking a front-seat role, and (4) maintaining change. Among HCPs, three themes emerged: (1) not recognizing HL problems, (2) lacking effective strategies, and (3) health care barriers.

**Conclusion:** We suggest three routes to optimize self-management: providing earlier information, applying person-centered strategies to maintain changes, and improving competencies of HCPs.

**Practice implications:** HCPs need to explain CKD self-management better to prevent kidney deterioration. New interventions, based on behavioral approaches, are needed to optimize self-management. HCPs need training to improve recognition and support of LHL patients.

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## 1. Introduction

In 2017, 697.5 million people were diagnosed with Chronic Kidney Disease (CKD) of whom 1.2 million died [1]. The latter is expected to rise to 2.2–4.0 million in 2040 [2]. An estimated 25% of CKD patients with limited health literacy (LHL) are at risk [3], since they experience faster kidney deterioration and higher mortality [4,5]. Health literacy (HL) is defined as the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts to promote and maintain good health across the life course [6]. To

prevent and slow down the rise of CKD, actions that support patients with LHL are needed.

Health care professionals (HCPs) promote self-management to maintain kidney function [7–9]. Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition [10], and is difficult for patients with LHL. These difficulties are illustrated by an association of LHL with worse treatment knowledge [11,12], lifestyle [4,13–16] and medication management [9,12]. The self-management experiences and barriers of CKD patients with LHL remain largely unknown.

Communication barriers between HCPs and patients with LHL may influence self-management, but evidence in CKD is scarce. For example, HCPs often overestimate patients and lack competencies to communicate with them effectively [17–19]. Additionally, patients often hide their LHL [20] and struggle to take part in decision-

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making [19,21,22]. In general, CKD patients consider information during consultations [23–25] or in self-help materials [26] as insufficient or difficult. A deeper understanding of these communication barriers is essential to identify strategies to optimize self-management.

It is important to know if common strategies to promote self-management are effective for patients with LHL. In the Netherlands, every inhabitant has a general practitioner (GP), who delivers primary care in case of illness, and is gatekeeper of the more specialized secondary care. The GP increases CKD awareness and stimulates lifestyle changes to stabilize kidney function [27]. The GP will refer to hospital care when patients experience moderate to severe CKD. There, nephrology specialists discuss stricter lifestyle and medications [28,29], and, if needed, renal replacement therapies [30]. In end stage CKD, the psychological consequences and disease burden play a more prominent role in consultations [31,32]. Evidence lacks on whether the above strategies suit the needs of patients with LHL.

This longitudinal, qualitative study aims to identify strategies to optimize self-management by exploring experiences with and barriers for self-management, from the perspectives of both patients with mild to end stage CKD and LHL and HCPs. This method provides the opportunity to learn how experiences of people develop [33,34], and supports reflection upon and confirmation of results from earlier phases of data collection [35].

## 2. Methods

The Consolidated criteria for REporting Qualitative research (COREQ) checklist was used during the development and reporting of the study [36].

### 2.1. Study design

We performed a longitudinal, qualitative research with semi-structured, in-depth interviews with CKD patients with LHL (n = 24) and in-depth interviews and focus group discussions (FGDs) with

HCPs (n = 37). In line with guidelines[37], we used purposive sampling until data saturation was met [38]. Interviews and FGDs were recorded, transcribed and analysed following the principles of thematic analysis [39]. However, within the concepts of interest, we used a grounded theory approach [40]. Additionally, we administered a questionnaire on background characteristics and, for patients, the All Aspects of Health Literacy Scale (AAHLS) [41]. The Medical Ethical Committee of the University Medical Centre Groningen (UMCG) approved the study (number: 201800346).

### 2.2. Participant recruitment

Participants were recruited from three general practices (primary care), two nephrology clinics and two dialysis centers (secondary care) in Groningen, the Netherlands. Patients were eligible if they: (1) were adult, (2) experienced > 3 months of mild to end stage CKD, and (3) had LHL, based on a total score ≤25 (max. 30) or a critical HL domain score ≤7 (max. 12) on the AAHLS. Inability to speak Dutch, major cognitive problems and terminal illness were reasons for exclusion. We aimed for sample heterogeneity by recruiting (1) native and non-native Dutch speakers, and (2) patients with and without co-morbidities. We accepted an overrepresentation of people with lower education and males, since these are predictors of LHL [3] and risk factors for becoming dialysis dependent [42]. For HCPs, we included GPs and specialized nurses in primary care, and nephrologists, specialized nurses, dieticians and social workers in secondary care. Together these are responsible for Dutch CKD care.

Fig. 1 gives details on our recruitment and study procedure. We first approached HCPs by e-mail and phone to ask for informed consent. First, we included ten HCPs representing every professional background. Second, we recruited twelve new representative HCPs for the FGDs in phase 2. Last, we approached all previous participants to contribute to three final FGDs, of which ten refused with reasons, i.e. lack of time, new profession, and personal circumstances. Therefore, additionally, we recruited four GPs, two nephrologists, three nurse specialists and one nurse to join the FGDs.

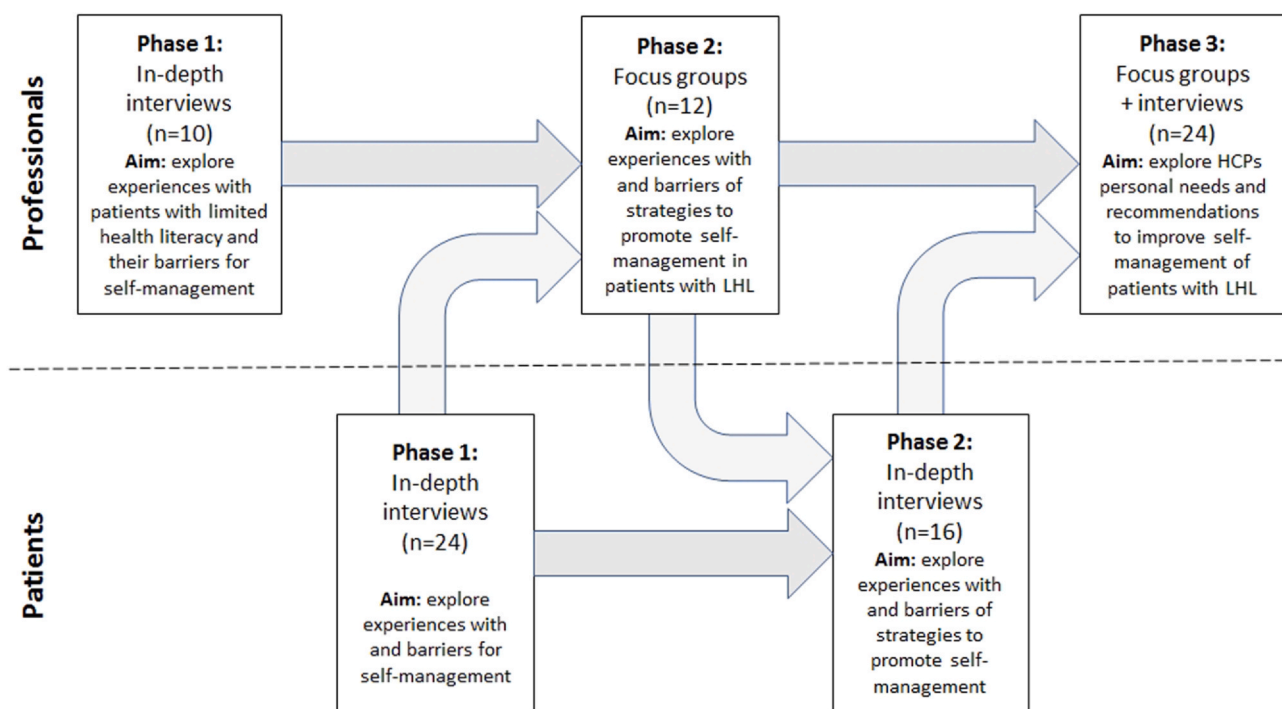


Fig. 1. Overview of consecutive interviews and focus group discussions with professionals and patients. Arrows indicate that results of earlier phases were validated during later phases.

Patients were recruited via seven participating HCPs to participate in both in-depth interviews. These HCPs received a checklist, explaining predictors and signs of LHL [3,43]. They approached 47 eligible patients by phone or during consultations. Patients with interest received an information letter. The main researcher (MDB) called them to give additional information. 28 patients provided informed consent of whom four with adequate HL were excluded, based on the AAHLS [41]. Nineteen patients did not consent with reasons, i.e. not interested in participation, disease burden or uncertainty about their ability to contribute. Participating patients received a gift card of 10 Euros.

### 2.3. Study procedure

Interviews and FGDs took place between May 2018 and August 2019. Between subsequent phases of data collection was 4–6 months. This ensured that patients likely had met with the HCP again or had new experiences in their self-management or treatment. It also supported the study phases, illustrated in Fig. 1. The first phase explored experiences with self-management among patients and HCPs. In the second phase, we explored experiences with strategies to promote self-management. The third phase focused on the HCP's personal needs to support patients with LHL. In subsequent phases, preliminary results were confirmed or validated.

#### 2.3.1. Health care professionals

Interviews and FGDs were in Dutch and took place in the HCP examination room or a meeting room of the UMCG. Interviews lasted 30 min and FGDs 120 min and were audio or video recorded. In phase 3, the interviewer (MDB) ensured both new and known HCPs equally contributed to FGDs, for example by asking to first note their thoughts and then collect and discuss them.

#### 2.3.2. Patients

In-depth interviews were in Dutch, took 30–70 min, and were audio-recorded. To provide a safe environment, the same interviewer (MDB) met with the patients each time. They could bring a significant other to support them during the interview, for example, when they found it difficult to express themselves. All patients could choose where to meet. Interviews took place at home, in a GP's or nephrology specialist's examination room, or in the researcher's office.

### 2.4. Study instruments

#### 2.4.1. Interview guides

For each study phase, we used an interview guide with open-ended questions based on existing research [44,45]. MDB developed the first drafts. These were adjusted several times, based on discussion between the researchers (MDB, AFW, JV), and an advisory board of patients, HCPs and a representative of the Dutch Kidney Patient Association. Each guide contained questions tailored to the aim of the phase. In later phases, the guides contained probes derived from the results of earlier interviews or FGDs to confirm or validate preliminary results. During the patient interviews, we brought prints of a drawn timeline and written words, for example 'diet' or 'doing activities', by which patients shared their experiences. Additional files A and B contain the interview guides.

#### 2.5. Online questionnaires

Patients answered ten items of the AAHLS, consisting of 3-point Likert scales [41]. Patients could score 1, 2 or 3 points for each item. We deleted items on empowerment at the community level, because we considered these difficult and irrelevant. Patients were considered to have LHL when they scored a maximum of 85% of the

possible AAHLS score or 60% of the critical HL domain score, as a precondition for self-management according to definitions [46]. Additionally, we asked questions on background characteristics, such as education and co-morbidities. HCPs answered questions on their profession, age and gender.

### 2.6. Data handling and reporting

All recordings were transcribed ad verbatim in F4 Transkript and analysed line-by-line in Atlas.ti 8.4. Two pairs (MDB and JV for patient data, MDB and JT for HCP data) analysed the transcripts. First, both pairs fully read ten transcripts, created two preliminary codebooks and discussed those to increase uniformity. Second, the pairs coded three transcripts independently, while constantly discussing and revising the codebook, until a Krippendorff interrater agreement [47] above 0.65 was reached. The analysts divided and separately coded the remaining transcripts; new codes were added during analysis. During several bilateral and group discussions, the researchers (MDB, JV, JT, AFW, SMR, GN and RW) discussed the final codes and organized them into main- and subthemes. Codes and themes, with illustrative quotes in Dutch and English, were debated until consensus was reached. The final themes and codes are in Additional File C and D.

In our synthesis, we compared the themes of patients and HCPs to identify strategies to optimize self-management, and sought for consensus and contrasts. We also determined if common approaches of HCPs to promote self-management met the needs of patients with LHL. Last, we compared what patients and HCPs considered effective and ineffective strategies to promote self-management to seek for discrepancies between their opinions. Based on this synthesis, we formulated promising strategies to optimize self-management of patients with LHL.

## 3. Results

### 3.1. Characteristics

Table 1 shows the participants' characteristics. Patients had a mean age of 68.5, 71% was male. HCPs had a mean age of 46, 24% was male. Patients had mean scores of 21.1 on total HL and 6.7 on critical HL. The latter indicates that patients experienced problems to search and reflect on information. Eight patients were lost to follow-up: five departed or reported severe illness and three lost interest.

### 3.2. Experiences with and barriers for self-management

Table 2 provides the main- and subthemes with illustrative quotes. Although participants also shared positive experiences, we focused mainly on barriers. Interviews with patients yielded four themes: (1) CKD elusiveness, (2) suboptimal intake of knowledge (3) not taking a front-seat role and (4) maintaining change. From the interviews with HCPs, three themes emerged: (1) not recognizing HL problems, (2) lacking effective strategies and (3) health care barriers.

### 3.3. Perspectives of patients

#### 3.3.1. Theme 1: CKD elusiveness

Many patients mentioned how CKD was or had been elusive, so they were not fully aware of the need for self-management. In earlier disease stages, CKD was often not identified by the GPs, or they solely shared how lab values indicated some kidney deterioration without discussing the exact meaning of kidney disease. Patients receiving care from nephrology specialists still did not always experience symptoms nor felt ill. Many patients did not see the need to self-manage until they experienced a sudden drop in kidney function or were warned by a HCP.

**Table 1**  
Baseline characteristics of patients and of health care professionals.

Patients (n = 24)		Professionals (n = 37)	
<b>Age, mean ± stdev (range)</b>	68.5 ± 16.0 (28–90)	<b>Age<sup>#</sup>, mean ± stdev (range)</b>	46.0 ± 12.0 (28–63)
<b>Male sex, n (%)</b>	17 (71)	<b>Male sex, n (%)</b>	9(24)
<b>Educational level<sup>p</sup>, n (%)</b>		<b>Health setting and profession, n (%)</b>	
Low education	11 (46)	<b>General Practices</b>	<b>16(43)</b>
Middle education	11 (46)	General practitioner	10(27)
High education	2 (8)	Specialized nurse	4(11)
<b>Living situation, n (%)</b>		Educators	2(5)
Alone	16 (67)	<b>Hospital care</b>	<b>21(57)</b>
With partner	8 (33)	Nephrologist	5(14)
<b>Nationality n (%)</b>		Specialized nurse	5(14)
Dutch	20 (83)	Dialysis nurse	6(16)
Non-native Dutch	4 (17)	Social worker	1(3)
<b>Type of treatment, n (%)</b>		<b>Method of data collection, n (%)**</b>	
General Practice (CKD-stage 1–3)	7 (29)	<b>General Practices</b>	
Ambulatory CKD-care (CKD-stage 3–4)	7 (29)	In-depth interview	6(11)
Dialysis/transplantation (CKD-stage 5)	10 (42)	Focus group discussion	11(30)
<b>Co-morbidities, n (%)</b>		<b>Hospital care</b>	
Diabetes	11 (46)	In-depth interviews	8(22)
Hypertension	12 (50)	Focus group discussions phase 2	12(32)
Cardiovascular Diseases	8 (33)	Focus group discussions phase 3	9(24)
Other	8 (33)		
None	2 (8)		
<b>Years of kidney disease, mean ± stdev*</b>	11.7 ± 16.1		
<b>Health literacy (AAHLS)</b>			
Total HL score, mean ± stdev (range)	21.1 ± 3.0 (14–26)		
Total Funct. HL <sup>†</sup> , mean ± stdev (range)	6.8 ± 1.5 (3–9)		
Total Comm. HL <sup>†</sup> , mean ± stdev (range)	7.6 ± 1.4 (4–9)		
Total Critical HL <sup>†</sup> , mean ± stdev (range)	6.7 ± 1.7 (4–10)		
<b>Relatives present during the interview n (%)</b>			
Yes	12 (50)		
No	12 (50)		

n = the number of participants.

<sup>p</sup> = Low = only primary or secondary school; mid = middle-level tertiary education; high = university or university of applied sciences, according to Statistics Netherlands (CBS) [48].

\* = Two participants from GPs were not included in this calculation, since they were only aware of having proteins in the urine, but unaware of having damaged kidneys. During the interviews, we followed their level of awareness and knowledge. For example, if patients said they believed something was not applicable for them, we did not ask further questions.

HL = health literacy. Funct = functional, Comm = communicative. Maximum possible AAHLS scores: total: 30, funct: 9, comm: 9, critical: 12.

<sup>†</sup> = calculation based on n = 36, because of missing data.

\*\* = As some professionals were included in two phases of data collection the n and % exceeds the n of total participants.

### 3.3.2. Theme 2: suboptimal uptake of knowledge

Most patients reported suboptimal knowledge uptake from both written information and consultations, leading to struggles with their self-management. Some patients said information was limited; especially GPs did not extensively discuss CKD self-management or provide additional written information. Regarding later CKD stages, patients considered oral and written information from the nephrology specialists overwhelming. Patients did not always use written information, because of lacking reading skills or considering it to be too confronting. Patients also described situations of over-estimation by the HCPs in all settings. For example, HCPs discussed too many topics or assumed patients had basic knowledge about kidneys. In these situations, patients struggled to ask for clarification or express their needs.

### 3.3.3. Theme 3: not taking a front-seat role

Over time, patients with moderate to severe CKD became aware of the importance of self-management, although they did not always succeed to take a front-seat role and meet the HCP's expectations. The patients' negative emotions, limited ability to act on risks and leaving the responsibility to others influenced their self-management negatively.

Negative emotions, such as hopelessness, fear and loneliness, were common and caused by the burden of treatment, having multiple diseases, or life events, such as the loss of a partner. As a result, patients said to lack energy or motivation to follow-up on HCP's advices in all health settings. Daily life itself was already enough to deal with.

Patients also shared problems to act on risks. For example, they were unaware of noteworthy symptoms, such as fatigue, and treatment risks. Some patients had past experiences that made them more alert. For example, a patient was hospitalized because of medication side effects. Since that moment, she read medication prescriptions.

Additionally, many patients left the responsibility for self-management to others. Partners or family members monitored their diet, prepared medication, and asked questions during consultations.

### 3.3.4. Theme 4: maintaining change

Even when patients, on the short-term, took a front-seat role, maintaining self-management was difficult. Patients resigned to self-management because they felt to have made too many adaptations in their lives already. The joy of food, smoking, or alcohol helped to enjoy or deal with life and therefore they reverted to old habits. Or, they were unable to combine lifestyle changes for multiple diseases. For example, patients said it was difficult to eat less sugar and salt when they had diabetes and CKD. As a result, their self-management had shortcomings. Older patients believed 'age comes with flaws' and were unwilling to adapt habits much at this point in life.

Patients also shared to fall for temptations or lacked social support. Some of these patients did not live very healthy before, making it more difficult to fulfill all the needed changes. A lack of rewards was another reason maintaining self-management was difficult. On the short-term, self-management led to losing weight or stabilization of lab values. On the long-term, when kidney function kept

Table 2

Overview of the main- and subthemes with exemplary quotations for CKD patients with limited health literacy and health care professionals.

Themes from interviews with CKD patients with LHL	Example quotations
<b>Themes</b>	
<b>Theme 1: CKD elusiveness</b>	
<b>Unawareness of CKD</b>	<b>Female, 86 years, GP care:</b> 'That dietician for my sugar, who is here, she said that about kidney function, yes, that must be it, I believe that she once said something about that being checked.' <b>Male, 79 years, hospital care, about CKD diagnosis:</b> 'It is a, how do I say that, a bothersome disease. Well, diseases are always, but before they had found out what was wrong, years had passed by.'
<b>Lack of symptoms</b>	<b>Male, 84 years, hospital care:</b> 'In the beginning you tend to say, so be it. Actually, at that point, you don't see the problem of it [having CKD] yet. It is not much of a burden. You don't notice anything.'
<b>Limited sense of urgency</b>	<b>Male, 63 years, hospital care:</b> 'I had no idea it [CKD] could be very severe, so to say. And then, later, that nephrologist said I was very close to needing dialysis. Then I thought, wait a minute, maybe it is bad after all. But then it was already too late, so it doesn't matter anymore. Well.'
<b>Theme 2: Suboptimal uptake of knowledge</b>	
<b>Struggle with the details</b>	<b>Female, 72 years, dialysis care:</b> 'Last time, she [the dialysis nurse] said 'Packed your bag yet?' and I said: 'Where should I have packed my bag for?'. She answered: 'After 7 months, you might receive a call [when a kidney is available]. I said: 'No way, the doctor said it would be after 2 years'. Then she said 'Well, the 2 years started last year'. <b>Female, 74 years, GP care:</b> 'They told me I had something in the urine and they took a piece of...I can't remember what it was. I went to the hospital. No, I don't remember. Something I had in the urine.'
<b>Absence of information</b>	<b>Female, 71 years, GP care:</b> 'The fact that I have some protein in my urine makes me wonder. Where does that come from, proteins in the urine? No further explanation is given about this. Maybe it is comparable to the sugar? That had gone up again.'
<b>Overwhelming information</b>	<b>Male, 72 years, dialysis care:</b> 'The one time potassium is high, the other time there is too much iron. In the end, you don't know what to eat anymore. Well, at least we tried, right?'
<b>Limited skills</b>	<b>Female, 46 years, dialysis care:</b> 'If a leaflet lies there [at the hospital], I will check what I might find interesting. Attractive stories, for example. I would read the leaflet a bit. But I will not read everything, because when I start reading at the beginning of the text, then suddenly my eyes will go somewhere halfway the page.'
<b>Overestimation by the HCPs</b>	<b>Female, 86 years, GP care: [about the number of topics during a consultation]:</b> 'First, she had the results for the blood tests, just for the sugar. Then she measured my blood pressure. Next, she checked my feet. Well, that was not very good. Then we talked about my bladder. I could be that she said something about the kidneys. That something is going on. I have no idea what she said exactly.'
<b>Theme 3: Not taking a front-seat role</b>	
<b>Negative emotions</b>	<b>Female, 74 years, GP care:</b> 'I do try to think along and force myself to be less lazy. However, last week, I was alone all the time. At half past seven in the evening, I went to bed. I was very tired, probably also because of my blood sugar levels. Yes, some periods I am terribly tired.'
<b>Not signaling and solving problems</b>	<b>Female, 46 years, dialysis care:</b> 'In the past, I did eat pizza and fries, and I drank cola. I think that I am to blame a bit for, uh, a faster deterioration of my kidneys. If I could do it over, I think I would do it differently. Eating healthier, for example cooked potatoes and vegetables.'
<b>Leaving responsibility with others</b>	<b>Male, 28 years, transplant care:</b> 'They do everything for me. My girlfriend organizes my medications and my mom checks it afterwards. My mom and dad even gave me a kidney.' <b>Female, 72 years, dialysis care:</b> 'Especially when it is about group education. For yourself, you are a bit stuck with it. What should I do? Where should I pay attention to? And then others are asking questions. Like my daughter in law, she dived into it and came along with me to ask the questions.'
<b>Theme 4: Maintaining change</b>	
<b>Resignation</b>	<b>Male, 49 years, hospital care:</b> 'Now, they [HCPs] also start about alcohol. Well, at some point you are not allowed anything. If you need to quit everything that is bad, I think it is better to commit suicide. Because everything is bad, this is bad, that is bad. Let me smoke my cigarette. I am okay with that.' <b>Female, 74 years, GP care:</b> 'I think that I have reached an age that justifies: 'Do I like to eat snacks? Then I will bring tasty snacks! Do you have tapas in the evening? Who can judge me? Right?''
<b>Failed attempts to change</b>	<b>Male, 63 years, hospital care:</b> 'I received a book 'life with less salt'. It was full of things [to do]. I had to buy all kind of products I almost would never use and the recipes were for two persons. I needed to find out a lot. I prefer to cook the way I am used to.' <b>Male, 90 years, GP care:</b> 'Careful with sugar and drink enough. That are two important rules. But I am a snatch. So, uhm, I try to persist, but at the same time I have my cookie jar close. I know it is bad, but I have that since I was a child.'
<b>Importance of rewards</b>	<b>Male, 72 years, GP care:</b> 'Actually, with things [drinking alcohol], I need an extra reason to lessen. If, that is, for example, related to the kidneys and the liver, and I see the function is decreasing, that would be a good reason to drink less alcohol.' <b>Male, 49 years, hospital care:</b> 'Yeah, if they will now tell me what I can do to protect my kidneys, then I wonder and think: 'You are a bit too late now, I have kidney problems for 7 years. You found out too late and if you give me information now about how to protect the kidneys, I will lay it aside.'
<b>Importance of rewards (continued)</b>	
<b>Conflict with others</b>	<b>Female, 74 years, GP care:</b> 'In the past I had to go to someone in the general practice. She started: 'You have to change this and change that'. The words 'have to' constantly came first. Then I said to her: 'Now you have to listen to me. As a child I had to listen to my parents and since I am old, it seems I have to listen to my children, but I am done. I don't have to do anything and I won't.'
<b>Themes from interviews and focus group discussions with health care professionals</b>	
<b>Theme 1: Not recognizing HL problems</b>	
<b>Difficulties to identify LHL</b>	<b>Female, 32 years, general practitioner (INT):</b> 'I think I can learn a lot about identification because I find this difficult, mostly for the group in between. The very extremes, I think I am aware of them.'
<b>Difficulties to comprehend barriers of people with LHL</b>	<b>Female, 56 years, dialysis nurse (INT):</b> 'They [patients] don't have interest for their health. I cannot understand that. I try to explain what happens with his or her body. What all healthy people do is exercise and eat healthy. The patients, they should do that as well, but they do not do that. Also, the medications - they don't know how to take it sometimes. I think that's a problem.' <b>Female, 56 years, dietician (FGD):</b> 'I tried to make it easy. They had a dog, but the partner was walking it. And I said, try to come along once a day, but the patient did not do it. I did not know what to do next.' <b>Male, 61 years, general practitioner (FGD):</b> 'When patients are not following advices, it activates a fatherly role in yourself. If that is the best way to help people, I am not sure, but it happens. Me, taking over responsibility!'

(continued on next page)

Table 2 (continued)

Themes from interviews with CKD patients with LHL	
<b>Theme 2: Lacking effective strategies</b>	
<b>Common strategies do not work</b>	<b>Female, 44 years, general practitioner (FGD):</b> 'We are may be too focused on the final goals and give less attention to the steps in between. For example, we say that someone needs to exercise more, so that he can use the bicycle again and do all kind of activities. And that he thinks: 'I won't reach that anyways and I can't even make it to the end of the driveway.' Then biking is of course not an option.' <b>Female, 52 years, specialized nurse dialysis (FGD):</b> 'They receive a book with information on dialysis. Almost no-one will have a proper look. People who do that, are an exception. 1 out of 25 people.'
<b>Emphasis on medical information</b>	<b>Male, 31 years, general practitioner (FGD):</b> 'To understand something is bad, you need to understand something about your body. We always try to explain that to the patients. But I think, in some cases this is absolutely pointless, because these patients don't want to know the full function of the kidneys. And then, they become totally, uhm, they are unable to have overview, and become stressed.'
<b>Problems with tailoring of strategies</b>	<b>Male, 53 years, nephrologist (FGD):</b> 'It's an art to differentiate with whom you can do that and with whom you cannot [communicating consequences such as death clearly]. And there is a group that you have to follow for longer until you know, okay, I really need to make this clear. Weeks go by.' <b>Female, 39 years, nephrologist (FGD):</b> 'With some [patients] you pay more attention than with others. For some it is quite clear what they understand. Just name it and you are set. Others need extra time. But you don't always know, for example when someone is heavily nodding 'yes' when you ask if it is understood.'
<b>Limited use of beneficial strategies</b>	<b>Female, 32 years, general practitioner (FGD):</b> I always find it difficult to ask patients to repeat what I just told. It feels like, uhm, like I am interrogating them. <b>Female, 44 years, general practitioner:</b> Yeah, I also experience a barrier to ask that. I think, well, I just told you, and you are here to listen, so.....' <b>Female, 55 years, specialized GP nurse (INT):</b> 'Providing information and using tools to find out if they really got the message or using more pictures, I think that is something to work on.'
<b>Theme 3: Health care barriers</b>	
<b>CKD not a topic in GPs</b>	<b>Male, 61 years, general practitioner (FGD):</b> 'I am thinking, but during my whole career, I never said to a patient you have a kidney disease, despite the fact that there are dozens of people with reduced kidney function. I just stick to there are some proteins in your urine.'
<b>Less time for consultations</b>	<b>Female, 39 years, specialized nurse nephrology (FGD):</b> 'You can't do everything in 20 min. So, you have to feel a bit if you need to do something at that moment with that patient or not. I don't think you need to ask and discuss this [integrating self-management in the patient's life] with every patient but with some you should.'
<b>Decreasing accessibility to health services</b>	<b>Female, 39 years, nephrologist (FGD):</b> 'I recently had a patient who said I am not going to the dietician and I can also not go to the physiotherapist because the insurance just doesn't cover it. And yes, I also couldn't think of anything. I understand that patients make these decisions out of financial considerations and there is nothing I can do about it.'
<b>Professional cooperation</b>	<b>Female, 55 years, specialized GP nurse (INT):</b> 'I think it's important that when a patient sees several different professionals, that they all say the same. Because, for the patient it is very confusing if the dietician says: 'You shouldn't eat raw fish!', and the doctor says, "Well, if you take some salmon once in a while, that's not bad." We should try to express the same vision. But I think it's not always done at the moment.'

FGD = participant of focus group discussion, INT = participant of interview.

decreasing, patients could lose motivation. Treatment or life aims helped to succeed in self-management. For example, one woman stated to live healthier to qualify for transplantation.

Some patients ended up in arguments, for example if HCPs kept trying to advice on lifestyle when patients wanted to discuss other problems, or when relatives repeatedly tried to convince patients to follow doctor's advices.

### 3.3.5. Perspectives of professionals

**3.3.5.1. Theme 1: not recognizing HL problems.** HCPs were unsure if they were able to identify patients with LHL. They based identification on clearly manifesting clues, such as weak language ability, or on information, that was part of their basic patient assessment, such as hygienic impression. They were concerned on knowing all indicators of LHL, and on missing patients who hide their LHL. They also said identification of HL problems could take several consultations.

Especially nephrology specialists mentioned to have problems to understand why LHL patients, even after serious warnings, did not self-manage well. They mostly mentioned lacking knowledge or motivation as barriers for self-management. They shared to pay less attention to lacking social support, mental barriers or the feasibility of advices. All HCPs said self-management problems triggered their doubts, because they were risky for the patient's health. Stories emerged about risk behaviors, such as not picking up medications or maintaining a dangerously high weight. As a result, HCPs sometimes felt powerless or took over responsibility.

**3.3.5.2. Theme 2: lacking effective strategies.** Common strategies applied by HCPs from all settings, such as education or

motivational interviewing, did not always lead to change. GPs mentioned how consultations often were about multiple other topics, such as diabetes or metabolic syndrome, and not about CKD. Nephrology specialists were uncertain on whether they explained kidney functioning or lab results in too much detail. Physicians from both settings indicated they gave priority to medical issues rather than discussing lifestyle. If strategies were ineffective, HCPs struggled in applying person-centered strategies. For example, they found it difficult to determine if patients needed practical guidance, strong confrontation or a comforting style to improve self-management. HCPs knew effective strategies, such as asking patients to repeat information, but felt untrained or reluctant to apply them.

**3.3.5.3. Theme 3: health care barriers.** HCPs mentioned various health care barriers that potentially disadvantage patients with LHL. They thought cooperation between GPs and nephrology specialists, or within a care team, needed improvement. GPs, for example, struggled to determine when kidney problems needed discussion. Better collaboration with nephrology specialists could improve their support of CKD patients. Within hospital nephrology teams, members sometimes gave different health advices to one patient, causing confusion. All HCPs believed this is more disadvantageous for patients with LHL, who have problems to seek clarification if information is absent or contradictory.

HCPs mentioned to lack time during consultations. As a result, they used most time to inform about the medical condition, instead of teaching about self-management. HCPs considered this a risk for patients with LHL, who have more problems to self-manage effectively. Last, HCPs feared decreased accessibility of health services.

**Table 3**  
Recommendations to optimize self-management of patients, derived from the results of the interviews and focus group discussions.

Recommendation	From theme(s):	Description of the problem	Strategy to improve
<i>Recommendations related to optimize the patients' understanding</i>			
Improve CKD awareness in earlier stages	<b>Patients:</b> CKD elusiveness (T1) <b>HCPs:</b> Health care barriers (T3)	Patients are often unaware of the existence and seriousness of CKD. GPs pay limited attention to CKD and mainly explain it as 'a value from the lab' without teaching self-management skills.	Educate patients about the meaning of CKD, long-term risks, the relation with co-morbidities and lifestyle.
Simplify information and check understanding	<b>Patients:</b> Suboptimal uptake of knowledge (T2) <b>HCPs:</b> Lacking effective strategies (T2)	Information is mainly provided orally or with (simple) text. This is not always suitable for patients with LHL. Patients' understanding of information is not consistently checked.	Provide simple information and use images, video's and animations during education. Also visualize CKD lab values (with graphs). After explanation HCPs should explicitly ask patients to repeat information to check understanding.
Provide practical step-wise guidance	<b>Patients:</b> Suboptimal uptake of knowledge (T2), Not taking a front-seat role (T3) <b>HCPs:</b> Lacking effective strategies (T2)	Patients perceive information as overwhelming or self-management as unfeasible. They struggle to translate advices into daily life self-management. HCPs focus too much on medical theory and the aims of treatment, leaving out 'the steps in between'. They think information is often too much.	HCPs should focus consultations on one or two main topics, instead of discussing many. For these topics, they should provide step-wise advice and reflect during the next consultation if the patient succeeded.
<i>Recommendations to optimize the patients' long-term self-management</i>			
Motivate using life aims instead of health aims	<b>Patients:</b> Maintaining change (T4) <b>HCPs:</b> Lacking effective strategies (T2)	HCPs often motivate by emphasizing the importance of 'being healthy', while patients with LHL see no or only short-term health benefits. For them life aims seem to have higher potential to improve self-management	Apply consultation strategies aiming to truly understand what drives patients in their daily lives. Translate these drives with the patient into treatment or life aims to support self-management and provide rewards.
Target barriers of patients with LHL	<b>Patients:</b> Maintaining change (T4) <b>HCPs:</b> Lacking effective strategies (T2), Health care barriers (T3)	Patients mention multiple barriers for self-management, such as resignation, negative emotions and socio-economic problems. HCPs pay limited attention to these self-management barriers.	Apply strategies to truly understand the barriers hindering the patients to change and maintain self-management. Translate these barriers into solutions, in cooperation with the patient, to overcome them.
Involve the social network	<b>Patients:</b> Not taking a front-seat role (T3), Maintaining change (T4) <b>HCPs:</b> Lacking effective strategies (T2)	According to both the patients and the HCPs the social network can either support or counteract self-management. Involvement of the social network in the treatment is often insufficient.	Involve the social network better by inviting them for consultations, providing them with information and explaining them how they can support the patient without fully taking over responsibility.
<i>Recommendations to optimize the capabilities of the health care professional and health system</i>			
Train the professional	<b>Patients:</b> All themes (T1, T2, T3, T4) <b>HCPs:</b> Not recognizing HL problems (T1), Lacking effective strategies (T2)	HCPs mention that they have problems to recognize HL problems and to truly understand the barriers of LHL patients. Patients and HCPs mention how strategies to improve self-management not always meet the needs of patients with LHL.	Train professionals to improve their abilities to recognize LHL and to apply patient-centered, tailored strategies to optimize self-management of patients with LHL. Incorporate the strategies mentioned above in the training.

Costs for medications, physiotherapy and dieticians are rising, causing problems for patients with LHL, who often have lower incomes.

### 3.3.6. Strategies to optimize self-management

Comparison of the results of patients and HCPs yielded seven promising strategies to optimize self-management of patients with LHL. Table 3 gives a description of the identified strategies, the problem they aim to overcome, and their relation to the main- and subthemes. First, to improve the patients' understanding, GPs need to inform patients earlier about CKD and self-management. Second, a better use of visually attractive information, and third, stepwise guidance combined with teach-back, will help patients to understand the details of self-management better. To optimize the patients' long-term self-management, HCPs need to employ new strategies, tailored to the needs of patients with LHL. The use of life aims, instead of health aims, to motivate patients, and an explicit focus on reducing barriers for self-management are a promising fourth and fifth strategy. Sixth, better cooperation with the social network is needed to optimize the chance of successful lifestyle improvements. Seventh, HCPs need training to identify LHL and acquire competencies and strategies to overcome self-management barriers.

## 4. Discussion and conclusions

### 4.1. Discussion

Our study yielded several barriers that influence self-management of CKD patients with LHL. Patients lack awareness and have suboptimal knowledge about CKD, which affects self-management, especially in primary care. Patients also mentioned problems to take a front-seat role in self-management and to maintain behavior change. Additionally, HCPs experienced problems to identify and support LHL patients and mentioned barriers in the health care system that potentially disadvantage patients with LHL. We identified strategies to optimize competencies of patients with LHL and of the HCPs who support them.

Both GPs and patients reported information on CKD self-management to be scarce, leading to unawareness and suboptimal knowledge. These findings align with other studies, showing that GPs discuss CKD insufficiently [27,49], many patients have limited CKD awareness and knowledge [50–52], and LHL is hindering consultations and self-management [12,53–55]. Our findings provide insight in the underlying reasons. Patients point out that discussing CKD lab values is not enough to make them aware of having a disease. They did not receive much information on self-management, and struggled to derive meaning from the consultations. GPs



explained the consultation is often about diabetes and cardiovascular risks, but less about CKD. These findings call for earlier education on CKD and its risk factors to overcome patients' lacking awareness and knowledge.

Patients mentioned barriers to take a front-seat role and maintain self-management on the long-term, such as negative emotions, not seeing risks, missing rewards, and leaving the responsibility with others. This confirms previous findings, e.g. that many CKD patients have problems to accept and act on their CKD diagnosis and that adherence on the long-term is negatively influenced by LHL, conflicting treatment regimens for co-morbid diseases, and age [24,44,56]. Since LHL is associated with worse self-management [9,13,14] and psychological problems [3], we hypothesize these barriers are prominent among people with LHL. Our study helps to understand. First, we show that HCPs often respond to self-management barriers by educating patients on expected behaviors. That may be hardly effective, as addressing the experienced barriers is a precondition to be open for information from HCPs [57]. Second, patients reported problems to express their needs and to make decisions that contradict with HCP's advises, but have benefits for their life quality. This shows a need of more person-centeredness in health care, characterized by partnerships between patients, HCPs and family and active patient participation.

HCPs reported barriers related to the health system and their competencies to recognize and support patients with LHL. They reported to take over responsibility sometimes. This confirms other studies, showing that HCPs overestimate patients [17] and adopt a more paternalistic style in consultations with patients with LHL [21]. HCPs in our study added interpretations. First, they said to doubt if they overwhelmed patients with medical information, but felt this was necessary to motivate them for self-management. Second, HCPs acknowledged their inability to apply strategies that are beneficial for LHL patients, such as visually attractive information or teach-back. Third, they shared worries about the risk behaviors of some patients. This indicates the need to improve HCPs' competencies regarding effective strategies aiming at patients with LHL.

Our study has several strengths. First, with our longitudinal design, we checked results from patients and HCPs and defined critical moments, heightening the credibility and validity of our results. This design also led to more openness about experiences in subsequent interviews. A second strength is our mixed methodology among various HCPs. During FGDs, sometimes all HCPs consented on certain experiences, but we also found contradictions. During interviews, we could address the more sensitive topics, such as personal doubts. A risk of the FGDs was that physicians and specialized nurses, from their hierarchic roles, led the discussion, but the interviewer could ensure an equal contribution from all HCPs. Additionally, our interpretation of the data may have been too generic. If so, specific profession related barriers in the care for patients with LHL might have been missed. Third, we believe our recruitment, with help of HCPs, is a strength. By offering strong guidance, such as oral explanation on the research, we managed to include a representative sample of LHL patients, who are often underrepresented in research [58,59]. A last strength is that the joint inclusion of the patient and a significant other added more detail on certain self-management barriers. This asked from the interviewer to direct questions towards the patient first, and then ask the other for additions.

Our study also has limitations. First, the Dutch health system is very accessible and has a universal health insurance coverage, which may have resulted in fewer experienced barriers related to care access than may occur in other countries. Second, two patients and six nephrology specialists knew the interviewer from his previous job as communication advisor in their dialysis centre. This familiarity could have resulted in self-censoring but this seems rather unlikely, as he was not involved in direct patient care. Last, our sampling via HCPs, mentioned as strength, can also cause selection bias. When HCPs

only recruited patients with clearly visible LHL or patients failed to attend an appointment, and fill out a consent form, this could have led to underestimation of the challenges for the group with very low HL.

#### 4.2. Conclusions

We can advise three routes with seven strategies to optimize self-management, targeting both patients with LHL and HCPs. We recommend providing earlier information on CKD and self-management, developing and using patient-centered HL strategies aiming to enable and maintain the patient's self-management, and strengthening various competencies of HCPs to tailor communication towards patients with LHL. Interventions that include these strategies are currently largely absent in CKD care. Therefore, we suggest developing new interventions and test their effectiveness in LHL CKD patients and HCPs.

#### 4.3. Practice implications

We show both GPs and nephrology specialists fail to provide patients with a complete overview on CKD, and its relation with comorbidities and self-management. To improve, nephrology specialists should share their knowledge with GPs, e.g. in refresher courses. Specialists need to look beyond their specialism (i.e. nephrology, diabetes, cardiovascular diseases) to truly support patients with LHL and multiple diseases.

Our study also indicates a need for the development of person-centered strategies, based on behavioral approaches. Existing HL interventions predominantly target the patient's knowledge and communication competencies [60–63], but strategies aimed at eliminating barriers or strengthening competencies to maintain health behaviours are missing. Since multi-component interventions are absent, but according to other studies most effective [64] to optimize self-management and health [65,66], we suggest researchers to develop and pilot-test these interventions for CKD settings.

Our study also calls for interventions to improve the HCPs' competencies to recognize and support patients with LHL. A recent review showed learning objectives for HCPs to deliver person-centered care for patients with LHL [67], which suit the three routes we suggest. Researchers need to adopt these objectives in a training for HCPs in CKD care, and test the effect on competencies and skills of the HCP, but also on self-management and health outcomes of patients with LHL.

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#### CRediT authorship contribution statement

**Marco D. Boonstra (MDB)** and **Andrea F. de Winter (AFW)** designed the study in line with the COREQ-checklist. The study design was discussed with **Sijmen A. Reijneveld (SAR)**, **Gerjan Navis (GN)** and **Ralf Westerhuis (RW)**. Additionally, **MDB** and **AFW** were responsible for preparing the documents needed for the approval of the Medical Ethical Committee.

**MDB** was the main researcher and, therefore, responsible for the conduct of the study. He reached out to the health care organizations where patients and HCPs were recruited. He developed the research information letters, HL checklist for HCPs, and informed consent forms, which were checked by **AFW**. **MDB** ensured the participation

of sufficient and eligible patients and HCPs, until data saturation was met and reached out to participants for the planning of FGDs and in-depth interviews. As described in the manuscript, **MDB** was also responsible for the development of the questionnaires and interview guides. These were discussed with both **AFW** and **Johanna P.M. Vervoort (JV)** multiple times and based on this discussion adapted until they were considered final. In close cooperation, **MDB** and **JV** transcribed the recorded data for patients in F4 Transkript and, afterwards, analysed the transcripts in Atlas.ti, following the procedure described in the manuscript. For the recorded data regarding the HCPs, **MDB** cooperated with **Janne M. Tullius (JT)** in the process of transcribing and analysing. **MDB** was responsible for the analysis of the questionnaires in SPSS, which was checked by **AFW**. Both pairs (**MDB** and **JV**, **MDB** and **JT**) prepared the codebooks and organized the codes into main and sub themes.

During several bilateral and group discussions between all authors the themes and codes were debated until consensus was reached. The synthesis that was derived from the final themes was also discussed between all authors to ensure that these reflected our results well.

**MDB** set up drafts of the manuscript, which were discussed four times with **SR**, **GN**, and **RW**. All authors added comments to the manuscript and did in-text suggestions for improvement. After

consent from all authors above, the final manuscript was submitted by **MDB**.

### Declaration of Competing Interest

Each author has read and has no actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within 3 years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work.

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## Appendix A: Questions for the phases of data collection among health care professionals

Appendix A1: In-depth interviews.

Below you find questions for the in-depth interviews with HCPs during the first phase of the research, which aimed to identify the experiences of HCPs with patients with LHL and which barriers these patients have in their self-management.

### Opening question:

1. Have you ever heard of the term health literacy?
  - a. Can you shortly tell what it is?
  - b. What are in your opinion the main consequences of low health literacy?

### Personal experiences with patients with LHL:

2. Do you see patients in daily practice that you consider as low health literate?
  - a. What are your experiences?
  - b. Do you change your approach?
  - c. How do you identify this group of patients?
  - d. What are their main problems during consultations?
    - i. Does LHL influence providing information?
    - ii. Does LHL influence how patients share about their own problems?
    - iii. Does LHL influence decision making processes?
    - iv. Does LHL affect building a relationship of trust?

### Barriers of patients with LHL:

3. Self-management (such as treatment adherence or visiting appointments) might be harder for patients with LHL.
  - a. What do you think are common barriers for patients with LHL?
  - b. What are your experiences in supporting the barriers of patients with LHL-patients?
4. Do you also see other barriers hindering patients with LHL in their self-management?
  - a. What is the role of the social network?
  - b. What is the role of life events / socio-economic factors?
5. In treatment of patients with LHL, do you experience other barriers? If so, what kind of barriers are those?

### Closing question:

6. Based on this interview, do you have suggestions which barriers of patients with LHL need to be supported?
  - a. What do you need to learn / improve?

Appendix A2: Focus group discussions.

Below you find questions for the focus group discussions with HCPs during the second phase of the research, which aimed to identify the experiences with applied and potential strategies to support patients with LHL. Barriers in the care for patients with LHL were explored.

### Opening question:

1. Could you first please describe what you think of when you hear 'patient with low health literacy'? Feel free to share every thought you have.

### Recognizing Limited Health Literacy

First, we showed the definition of limited health literacy and then we asked:

2. Within your team, do you pay attention to health literacy and how?

3. What are your experiences in recognizing / identifying patients with limited health literacy?
  - a. What is your approach?
  - b. Where do you pay attention to?  
Then we showed some examples of strategies to recognize limited health literacy with screening questions, during consultations and based on predictors / behaviors. We asked:
4. Which of the strategies to identify patients with limited health literacy do you apply and what are your experiences?
5. Which of these strategies do you not use yet, and how useful do you consider them?
6. Do you have other ideas to recognize limited health literacy?

#### **Informed patient**

Introduction: an important aspect of health care is giving information to the patient and treatment. This helps the patient to contribute to the treatment and delaying/preventing kidney decline. The next questions are about strategies to give information.

7. What are your experiences in giving information during consultations or with additional information sources (like leaflets, medicine lists, lab values etc.)?
8. Do you see barriers related to health literacy in how they receive, use or respond to information?
9. If you encounter barriers related to understanding information, in a consultation or otherwise, how do you act or what do you do?
  1. Do you use tools / drawing or other aids?
  2. What are your experiences when you try to explain in simple language?  
During interviews with patients and in scientific literature we encountered some examples of barriers related to giving and understanding information. We would like to reflect with you on these examples:
10. *'I never read or I don't read much. It is too much and confronting. I rely on health care professionals telling me what to do'*
  1. What do you think when you see this. What are your experiences?
  2. Does this lead to problems or risks? If so, how?
  3. Do you have suggestions to improve this situation?
11. *'I do not always understand what health care professionals tell me. I might ask clarification, but perhaps not always'*
  1. What do you think when you see this. What are your experiences?
  2. Does this lead to problems or risks? If so, how?
  3. Do you have suggestions to improve this situation?

#### **Advising and motivating patients to improve self-management**

Introduction: Often the aim of giving information is to support patients to contribute to their treatment by living healthy, taking medication and by dealing with the multiple aspects of their CKD. The next questions are about advising and motivating patients for self-management.

Then we shared a definition of self-management with the Powerpoint presentation.

12. Let's make a quick round. What are important topics you advice or inform the patient about, when it comes to self-management?
13. Thinking of people with limited health literacy. What are your experiences when providing advices on or informing patients about self-management?
  1. What are common reactions of the patient?
  2. What barriers do you see if it comes to applying or adhering to the self-management advices you give?
  3. Do you have explanations for that?
14. What barriers do you encounter with the strategies you use to inform and motivate patients about self-management?
15. Do you change anything in your approach or strategies when you expect limited health literacy and if so, what do you change?
16. Do you have suggestions what could help to improve self-management of patients with limited health literacy?
  1. Do you have succes stories to share that might help?  
Now, I would like to focus on self-care behaviors, namely lifestyle and medication adherence.
17. What are your experiences in adherence of patients with limited health literacy?
  1. For lifestyle?
  2. For medication?
18. Do you have strategies to optimize the adherence of patients?
  1. What are your experiences with these strategies in patients with limited health literacy?
19. Do you have suggestions for strategies that would help to improve adherence in patients with limited health literacy?
  1. Do you have succes stories to share that might help?  
To conclude, we would like to share a story of patients from the interviews we did earlier:
20. *"Lately I went to the doctor. I had a painful back. I sat down and we discussed things. Suddenly the doctor started about living healthy again and that I really should stop smoking. I became frustrated and angry. We discussed that so many times and I can't manage. By the way, I was there for my back! Do you recognize that at some point, when much is done, it becomes difficult to discuss lifestyle or other parts of treatment when nothing seems to change?"*
  1. How does it influence in consultations?
  2. What does it do with your personal style/strategies in consultations?
21. Do you have suggestions for strategies that would help to overcome these kind of long-term difficulties to adapt lifestyle?

#### **Patient participation in consultations**

Introduction: Before, we mainly discussed strategies to inform patients and to motivate them for self-management. However, patients also contribute to an effective consultation. For example by sharing their symptoms and problems and asking questions. The next questions are on patient's participation during consultations.

22. What are your experiences when it comes to the way patients participate during consultations when you consider them limited health literate?
  1. Do you have stories that illustrate how patients typically contribute?

2. What kind of barriers does this bring during consultations from your perspective as a professional and the strategies you need to apply?
3. What are the risks for the patient if they are not actively participating?
23. Do you have strategies to improve the participation of patients during consultations?
  1. How effective are these in patients with limited health literacy?
24. If we focus more on moments that a decision needs to be made, for example in the treatment.
  1. What are your experiences in the decision making process, when it comes to patients with limited health literacy?
  2. How does it affect your approach during a consultation or the strategies you need to apply?
  3. What are the risks?
25. Do you have ideas for strategies that might help to improve participation of patients with limited health literacy?  
Now, we would like to share two examples from patient interviews, we conducted earlier. These examples relate to communication during consultations. We would like to reflect with you on these examples.
26. *'During consultations, it is mainly about lab results and medication. Some other topics, such as my emotional well-being or if I am satisfied with the way my treatment and life is, are less discussed'*
  1. Who would like to respond? What do you think of this?
  2. Is this a bad thing? Is it important to change that?
  3. Do you have ideas for strategies to improve that situation?
  4. Do you feel responsible for this kind of problems? Where does your responsibility end?
27. *'Professionals have studied very long. Therefore, I let them decide what is needed for me, for example when it comes to deciding on treatment options. I will mainly listen!'*
  1. Who would like to respond? What do you think of this?
  2. Is this a bad thing? Is it important to change that?
  3. Do you have ideas for strategies to improve that situation?
  4. Do you feel responsible for this kind of problems? Where does your responsibility end?

#### **Other experiences**

To conclude this focus group discussions, we have some additional questions. These relate to the trajectory of the patient within the health system and the role of the social support system / background of patients.

28. Patients with kidney problems, potentially receive care from multiple settings over time. First in the general practice, then the nephrology department and dialysis/transplant care.
  1. Do you see differences between patients with adequate and limited health literacy in their kidney disease care trajectory?
  2. What does that mean for your role as a health care professional?
  3. Do you have ideas for strategies to improve the trajectory for patients with LHL?  
During the patient interviews, we notices that in earlier stages patients are often not very aware of CKD or do not feel much urgency. Two exemplary quotes are:
29. *'From what the general practicionist told me, I thought almost every older person has some kidney problems. I thought: it can't be that bad!'*

*'For a long time I had no symptoms of CKD, until a point that I almost needed dialysis. That was so unexpected, I did not think of treatment options.'*

1. Do you recognize these stories of patients?
2. How is this possible? What is the role of the health care professional?
3. Do you have recommendations / strategies to improve this situation?

To conclude we have a question on social support:

30. What are your experiences with the role of a social support network in patients with limited health literacy?
  1. How do you currently involve the social network in the treatment?
  2. Do you have ideas what could be improved?
31. Did we miss anything, do you have something on your mind that is relevant for our research?

#### Appendice A3: Focus group discussions.

Below you find questions for the focus group discussions with HCPs during the third phase of the research, which aimed to identify their personal needs to support patients with LHL better.

#### **Opening question.**

1. From earlier interviews and focus group discussions, we learned how difficult it can be to recognize patients with limited health literacy. Can you think of factors from both the patient and health system perspective that make it difficult to identify patients with limited health literacy?
  1. Do you have suggestions what health care organizations to identify them better?
  2. What do you like to learn yourself?

#### **Access to health care**

Introduction: from earlier interviews and focus groups, we learned that patients not always see the risks of symptoms and seek help in time. We also learned that they sometimes do not have the financial resources or competences to seek additional professional help if needed.

2. Do you have ideas about the causes of these kind of reduced access to care?
  1. Do you have ideas how hospitals or general practices can act to change that?

2. What could be your role?
3. What do think HCPs need or have to learn to improve this situation?  
We also found that patients with CKD and limited health literacy: 1) felt their CKD was diagnosed late, 2) thought CKD was not that important or 3) lacked symptoms.
3. Do you recognize this? What is the reason that this happens?
  1. Do you have suggestions how this situation can be improved?
  2. What do you think HCPs need or have to learn to improve this situation?

#### **Informed patient**

Introduction: From the interviews with patients we learned some barriers for you as a health care professional when you are providing information. Patients for example told that sometimes information could be too medical or theoretical and that they lacked information that teaches them practical skills.

4. What is your first reaction on this finding? Do you have examples when this might occur?
  1. What could be the consequences when patients have limited health literacy?
  2. What is needed to improve that situation?
  3. What do you think HCPs need or have to learn to improve this situation?  
Patients also mentioned, related to this topic, that they did not always want to know how the kidneys function or understand what all the precise lab values meant. For them, the lab values were sort of a mystery. They could not derive meaning from it. They were not always sure why you had to know them and what you could do to improve them. They also shared how sometimes a lab result is only shared shortly by phone.
5. What is your first reaction on this finding? Do you have examples when this might occur?
  1. What could be the consequences when patients have limited health literacy?
  2. Do you pay attention to these kind of numeracy problems of patients when you explain lab results?
  3. What do you think is needed to improve this situation?
  4. If you work in a team, what could be the role of specific team members?
  5. What does the team need or have to learn?

#### **Potential solutions**

Patients also shared their solutions to improve their understanding of information. They shared that the social network could help, that reminders would help, that they needed take home messages in the end of the consultations and they said that sometimes time in consultations was too short. They also valued visually attractive information, such as animations or drawings.

6. What do you consider as possibilities from these options and why?
  1. What are the barriers to implement these in health care?
  2. What do you need or have to learn to adopt the solutions that patients suggested?
7. How can the patient or you as HCP benefit when information providing is improved?

#### **Gathering information from the patient**

Introduction: Compared to patients with adequate health literacy, patients with limited health literacy experience more communication barriers. They find it difficult to distinguish main from sideproblems, ask less questions and also to express themselves. They also experience feelings of hierarchy.

8. What is your first reaction on this finding? Do you recognize it?
  1. What does this mean for the quality / your strategies during consultations?
  2. Do you have strategies to meet the needs of these patients? If so, which?
  3. How do you think current health care can be improved to meet the needs of these patients?
  4. What do HCPs need or have to learn to improve this situation?  
Patients also value an emotional connection or relation with HCPs and find it more important to talk about daily life and their problems there. This is also the consequence of more socio-economic problems in this group.
9. Do you meet this need of patients? If so, which strategies do you use?
  1. Do you think it is important to pay attention to these themes, if so why?
  2. How can it contribute to the health care you deliver?
  3. What do you think HCPs need or have to learn to improve this situation?

#### **Potential solutions**

We have collected some potential solutions to improve information gathering in consultations. Suggestions are to help patients to recognize important symptoms or problems, that definitely need to be discussed and to teach professionals to stimulate patients to become active in the consultation, such as stimulating to ask questions. Also preparation of consultations by the patient or a role for the support network are potential solutions.

10. What do you consider as possibilities from these options and why?
  1. What are the barriers to implement these in health care?
  2. What do HCPs need or have to learn to adopt the solutions that patients suggested?
11. How can the patient or you as HCP benefit when information gathering is improved?

#### **Self-management of lifestyle and medication**

Introduction: We derived some themes from the interviews with patients related to their self-management of lifestyle and medication. They stated for example that they perceived the needed actions as too much or the steps too big. They also said that they did not change much, because of their high age or emotional well-being. We like to reflect with you on these findings.

12. Who would like to respond? Do you recognize this stories from daily practice?
13. Do you have strategies to find out what are barriers for patients' self-management?
14. These examples of patients show the importance of flexibility in HCP's communication strategies that are needed to optimize self-management, like listening carefully, providing feasible advices, having empathie, asking clarifying questions and solving barriers. How do you perceive your current competencies in communication with patients?

1. What is lacking?
  2. What do you think HCPs need or have to learn to improve this situation?  
Patients also mentioned problems on the long-term with maintaining self-management. Sometimes they started with hope, but under influence of temptations, negativity or social pressure, bad habits would return into their lives. They also mentioned that for kidney disease it is difficult because the kidneys will never be better. It is hard to see the benefits. And once a patient feels he or she failed, it is difficult to start over and over again. Sometimes having perspective in the treatment, like a upcoming transplantation or life aims helped patients to self-manage better.
  15. Do you recognize this stories from daily practice?
  16. Do you have strategies to support patients with these self-management problems?
    1. How do you signal these problems?
  17. Do you encounter barriers when you try to support patients with these problems?
  18. How do you perceive your current competencies in communication with patients?
    1. What is lacking?
    2. What do you think HCPs need or have to learn to improve this situation?  
We now would like to discuss some other factors that might influence self-management of patients.
  19. What is the role of the social context of the patient?
    1. Is that a topic during consultations?
    2. What is lacking?
  20. Do you have ideas what HCPs need or have to learn to take the social context into account?
  21. Patients sometimes stated to have made enough adaptations in their lives. Do you, as a HCP, believe that patients always need to change?
    1. How do you determine? Is there flexibility in your approach?
    2. How do you take the opinion of the patient into account?
  22. Do you see room for improvement?
    1. What do you think HCPs need or have to learn?
- Potential solutions**
23. There are strategies to promote self-management in patients. What would be your strategy to promote self-management? We would like you to give a short opinion on the feasibility and realization of these strategies in daily practice:
    1. Put health behaviors in a relationship to symptom reduction to show the benefits.
    2. Stimulate problem-solving skills by formulating action plans.
    3. Review action plans: Discuss behavioral strategies, questions and problems
    4. Assess individual barriers regarding adherence.
    5. Cooperate with the social network of the patients.

24. What do you consider as possibilities from these options and why?
  1. What are the barriers to implement these in health care?
  2. What do HCPs need or have to learn to adopt the solutions that patients suggested?
25. How can the patient or you as HCP benefit when support of lifestyle and medication adherence is improved?

#### **Health care system and team cooperation**

To conclude, we would like to discuss the role of the organization of health care in the Netherlands and cooperation between health care professionals.

26. Do you have suggestions what the department / organization you are working in can improve to support patients with limited health literacy better?
  1. Do you have ideas for better organization / processes in your department / organization?
  2. Do you have ideas what the health care professionals need to improve?
27. How do you perceive the cooperation with other health settings or your colleagues when it comes to identifying and supporting patients with limited health literacy?
  1. Do you see any problems in cooperation?
  2. What could be the effect of these problems for patients with limited health literacy
  3. What do you want to improve?
28. To conclude, did we miss important topics? Do you have anything to share that is important for patients with limited health literacy?

### **Appendix B: Questions for the phases of data collection among patients with LHL**

Appendix B1: In-depth interviews with patients.

The aim of the first round of in-depth interviews was to retrieve experiences of patients with LHL with self-management of kidney disease and their barriers in self-management. The final questions are below:

1. How did you find out about your kidney disease?
  - a. What did you think about that?
  - b. Can you tell about the diagnosis and the treatment?
  - c. Did you have symptoms?
2. Do you have an idea about the cause?  
We will now show you a time line. By this timeline, we will discuss the trajectory of your CKD.
3. How did your disease and treatment develop over time?

4. Were there anywhere in your disease, treatment or life, moments that you now perceive as negative or positive?
  - a. And which influenced your disease development or treatment
  - b. Which influenced how you could contribute to your treatment?
5. Were there also moments where you discussed CKD with a health care professional? Do you have positive or negative experiences that you remember?  
Now we will discuss your own role in the treatment of CKD.
6. Did you receive any advices on how you could protect your kidneys? Which?
7. What do you currently do to keep the kidneys stable?
8. What do you think of this?  
We will now show you a sheet with topics. These topics can be challenges when you are ill. We want you to take in mind your kidney problems.
9. If you think of your CKD, which of the topics are easy for you? And which are difficult?
  - a. Can you explain why you think the topics you mentioned are easy?
  - b. Can you explain why you think the topics you mentioned are difficult
10. Did you discuss your difficulties with your health care professional?
  - a. What are your experiences with that?
11. What did you do yourself to overcome your difficulties?
  - a. Did you have additional help?  
Next, we would like to discuss how you perceive the way you were supported to deal with your kidney disease and to contribute to your treatment.
12. Did you seek or receive additional information on CKD or your challenges?
  - a. How did you perceive this information?
  - b. Did you encounter any problems to use the information?
13. Do you discuss your CKD and treatment with others?
  - a. With health care professionals?
  - b. With people you know (relatives etc.)?
14. Where do significant others help you with in your treatment?  
To finalize, we have two more questions.
15. Do you have additional topics you would like to discuss about your CKD or the treatment?
16. Do you have advices what health care professionals can do better?

#### Appendice B2: In-depth interviews with patients.

The aim of the second round of in-depth interviews was to retrieve experiences of patients with LHL with the support HCPs offered to optimize their self-management and if they encountered any barriers with these strategies. Additionally, we asked some questions on the development of CKD. The final questions are below:

Based on the interviews with 28 patients we had before, we would like to discuss some topics that were mentioned by patients a lot. We would like to hear your opinions on them and how you are supported in these topics by health care professionals.

1. We first will give you a set of card with topics that were mentioned a lot by patients. These topics are all about 'having CKD' or 'the treatment of CKD'.
  - a. Which are relevant/difficult for you?
  - b. Are there topics for which you believe that you can do things better or that you can learn something?
2. We will now focus on three topics that you mentioned as important in the previous question. For each topic, we have questions. The first topic we would like to discuss is [topic of the patient's choice]:
  - a. What is it that you would like to do better or learn?
  - b. Why do you consider that important?
  - c. What did health care professionals do to support you in that?
  - d. Do you have ideas what health care professionals can change in their approach?
  - e. What was your main lesson over time and, based on that, what would you suggest other patients to do to do things better or learn?
3. We also heard some stories of patients on information from the hospital / general practice. For example in leaflets, letters or spoken during a consultation.
  - a. How do you perceive information providing?
  - b. Is the information comprehensible / understandable?
  - c. Do you have suggestions to improve?
4. When you have a consultation with the health care professional about your CKD:
  - a. How do you feel about the information they give you?
  - b. What is mainly discussed?
  - c. What do you think of their style / the way they tell you things?
  - d. What is your own role / contribution to the consultation?
  - e. Do you have suggestions to improve?
5. If you have consultations with multiple health care professionals:
  - a. Did you ever encounter differences in what they tell you?
  - b. Do you have ideas on their cooperation? Which?  
To conclude, we have a few questions about you. Since the last time we met, for the first interview:
6. Did anything change about the severity of your CKD? Can you explain what that means for you?

7. Did anything change in your treatment? Can you tell how this was discussed with your health care professional and if you encountered any problems?
8. Did you learn new things about your CKD or the treatment?
9. Did you change anything in how you talk with others, both health care professionals and the people close to you, about your CKD or the treatment? Do you do things differently in consultations?
10. If you were the boss of your general practice or the nephrology department, what would you do to improve care for patients with CKD?

### Appendix C: Final main- and subthemes, codes and descriptions derived from the data analysis of the interviews with patients with limited health literacy.

#### Patient theme 1: CKD elusiveness

Unawareness / Lack of symptoms	Belated CKD diagnosis Lack of symptoms Belated awareness	CKD was not checked/mentioned by HCPs or diagnosed late Patients do not experience noticeable symptoms of CKD Often patients became aware late after serious warnings/signs
Limited sense of urgency	CKD is a value from the lab CKD discussed insufficiently CKD is not so serious Keeping distance / denial Many people have it Influence of co-morbidities General view on CKD	Patients do not perceive CKD as an illness but just as lab result Especially in GPs CKD is discussed marginally in consultations Patients perceive CKD as a non-serious problem Patients tend to keep 'being ill' at a distance or deny it Since many people have some kidney damage it can't be bad Patients prioritize (self-management of) other diseases over CKD Patients state that others perceive CKD as a mild problem
<b>Patient theme 2: Suboptimal uptake of knowledge</b>		
Patients' barriers	Reading problems Language problems Overwhelmed Not understanding causation	Patients lack abilities to read written information Patients do not speak Dutch very well which is problematic Severe illness or the amount of information is overwhelming Patients have problems to see cautions between, for example, lab values and being ill, other diseases and (onset of) CKD etc. Patients do not always ask questions to the HCPs if needed If patients don't understand, they do not always clarify that The use of the Internet or other sources to seek information Information is understood, but not remembered after some time
HCPs approach	Not asking questions Not seeking clarification Not using other sources Memory problems Openness for information CKD discussed insufficiently Overestimation Providing / using additional information Wrong information Medical information first Clarifying understanding Being too generic  Personnel changes  Consultation time	Patients are not always open to receive information from HCPs, for example when stressed Especially in GPs CKD is discussed marginally in consultations HCPs explain too many topics/overestimate patients' knowledge HCPs do not always use or provide additional visual, written or digital information during consultations Different HCP's advises can be contradictory / sometimes false HCPs put much emphasize on lab values and medication while lifestyle receives less attention HCPs do not consistently check if patients understood An advice is often generic: 'eat less salt' instead of precise and actionable: 'you can have 6 g salt a day' and 'cheese is bad' Patients in secondary care often see many HCPs which can lead to repetitive or contradictory information Time in consultations is too short to be informed
<b>Patient theme 3: Not taking a front-seat role</b>		
Resignation	Accepting illness Age comes with flaws Adaptability Not following advices Beneficial for well-being Feasibility Expected disease course	Patients do not accept being ill and the fact they need treatment Patients perceive having health problems as normal and don't think self-management will help much Patients struggle to incorporate self-management into their lives and give up. Patients do not follow up on HCP's advises Patients keep unhealthy habits because they prefer living without restrictions over strict adherence Advices (for multiple diseases) are simply too much to follow-up Patients think CKD is unstoppable / perfect adherence useless
Leaving responsibility with others	Doctor in the lead Hierarchy Network is in the lead Network is making it difficult Usefulness of medication Usefulness of lifestyle Role of spirituality / faith	Patient: 'The HCP monitors my kidneys. I can not do much myself' Patients do not dare to speak up to HCPs because of hierarchy The partner or relatives are in the lead in medication / diet etc. When the network is not understanding, it is hard to live healthy In general, medication is considered useful, but not always The positive effect of lifestyle on kidneys is questioned Patients lay their destiny in the hands of Gods (and may feel less urgency to take control into their own hands).
Signaling / solving problems	Character trait Risks of medication use Recognizing unhealthy food Recognizing (severe) symptoms Overestimation of your own health / abilities Lack of problem-solving Learning from past experiences Being confronted by HCPs Ending up in hospital	The patients character influences their ability to self-manage Patients not always recognize side effects or adhere properly Patients not always know which products are bad for them If patients encounter physical problems they do not recognize the ones that serious and act on that Patients overestimate their abilities / health and overstretch themselves in physical activity or show risky behaviors If patients experience self-management problems they let it be If something went wrong in the past, patients change their approach of self-management Patients stated to sometimes need serious warnings to act When serious illness or risky behaviors led to hospitalization
<b>Patient theme 4: Inability to change</b>		
Negative emotions	Disease / treatment burden Losing autonomy Thinking of dead Stress / fear Depression / negativity Loss because of old age	Giving up, because the disease or treatment is too much to bear High age / disease unwantedly leading to dependence of others The fear for or awareness of dead leads to (not) feeling the need to change behaviors Stress or fear causes that patients do not decide on treatment options or feel certain enough to act Depression or negativity influences motivation / ability to act Many people have lost loved ones, influencing life lust



Failed attempts	Maintaining physical exercising Maintaining a diet Addiction / habits Falling for temptations Socio-economic background	Symptoms problemize physical activity. It is difficult to persist Seeing diet as 'a burden' and finding it difficult to persist Patients struggle to overcome addiction / replace habits Falling groceries / social activities there are many temptations causing 'unhealthy decisions' If patients have backgrounds where eating is very important or where living unhealthy is normal change is difficult
Rewards	Putting things into practice Seeing kidney improvement Having life aims Having health/treatment aims	Knowing what to do, does not mean a patient will succeed The importance of seeing the kidneys stable to persist Having life aims is an important motivator to change behavior Preventing dialysis, meeting transplant requirements or losing weight. If patients have health /treatment aims it motivates
Lack of support / conflict with others	People with worse kidneys as motivator Network is making it difficult Changing relation with network Sharing emotions with others Not asking help Problematic relation with HCP HCPs motivational strategies  Taboos Having other support  Lack of cooperation	If patients know stories of other kidney patients who ended up worse it can motivate them to self-manage When the network is not understanding, it is hard to live healthy With severe illness, the relation with others changes. Patients do not always share their problems / emotions Patients want to be strong and solve their own problems When patients fail to change behaviors it can lead to a damaged relationship with the HCP If HCPs choose a paternalistic or unsuitable strategy in consultations it can influence the patients willingness to change Some topics (like smoking) become a taboo to talk about Patients can sometimes rely on support from professionals from nursery homes, municipalities or volunteers. Patients do not always have a good cooperation with their network or HCPs and this is influencing self-management

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