#### **ORIGINAL ARTICLE**



# How do patients experience chronic kidney disease? A mixed-methods study among patients in Sweden

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#### Abstract

**Background** Advanced chronic kidney disease (CKD) severely impacts patients' lives. Nevertheless, little is known about patients' own experiences of living with CKD in Sweden. The objective of this study was to describe the patient's perspective on CKD—including diagnosis, treatment journey, and healthcare interactions—and how CKD impacts patients' health-related quality of life (HRQoL) and work capacity.

**Subject and methods** A mixed-methods approach was used that incorporated (i) a quantitative online survey with study-specific questions and assessments of HRQoL and work impairment among 178 patients with CKD in Sweden, and (ii) 40 qualitative interviews to gain an in-depth understanding of the patient experience.

**Results** HRQoL and work capacity were notably impacted by CKD and deteriorated with advancing disease stage. Patients experienced numerous symptoms long before diagnosis, but still found diagnosis unexpected. Fatigue was the most frequently reported symptom impacting all areas of patients' lives. In the interviews, patients reported that they worried what their future life would be like, a dread of dialysis and organ transplantation, and how they implemented lifestyle changes to mitigate progression. In primary healthcare, patients struggled to have their symptoms taken seriously. Once referred to kidney specialists, patients were satisfied with healthcare. Patients wished they had been diagnosed sooner in their disease journey. **Conclusion** These findings highlight an unmet need from the patient's perspective in primary healthcare, driven primarily by lack of early CKD diagnosis. In Sweden, there is a need for increased education on CKD in primary care, and a need for increased availability of specialized kidney care.

Keywords Chronic kidney disease  $\cdot$  Patient experience  $\cdot$  Primary healthcare  $\cdot$  Patient-reported outcomes  $\cdot$  Qualitative interviews  $\cdot$  Health-related quality of life

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# Introduction

Chronic kidney disease (CKD) is a common, progressive, and costly disease that is increasing in prevalence worldwide (GBD Chronic Kidney Disease Collaboration 2020). In the early stages of CKD, patients are asymptomatic and thus unaware of the disease (Webster et al. 2017). Once CKD progresses, patients start experiencing symptoms and, if left untreated, there is a risk of their disease progressing towards kidney failure. The risk of cardiovascular comorbidity increases already in moderate CKD (Eckardt et al. 2013). Early diagnosis and intervention is therefore vital (Group KDIGOKCW 2013; NICE 2021) to slow CKD progression, reduce the risk of severe cardiovascular disease, and reduce the number of patients reaching kidney failure with associated excessive healthcare costs and health-related quality of life (HRQoL) impairment.

Chronic kidney disease impacts HRQoL in many ways (Plantinga et al. 2008). The diagnosis itself might cause fear or anxiety in patients, and the multifaceted symptomatology and treatment side effects may negatively affect their wellbeing and everyday life (Pagels et al. 2012). Some patients with advanced CKD report levels of HRQoL equivalent to patients with a terminal malignancy (Webster et al. 2017) and, as for most patients living with chronic and progressive illnesses, maintaining a good HRQoL is as vital as survival. Awareness of the patient perspective is important for diseases like CKD, which requires lifestyle changes to both decrease risk of progression and improve the chance of treatment success. Beneficial changes include increasing physical activity, food and fluid restrictions, and adherence to medication regimens throughout the CKD continuum (Levey et al. 2009).

Patient-centred research in CKD is increasingly common and recognized (Amir et al. 2021; Tong et al. 2014). In a systematic review of qualitative CKD studies published from 2000 to 2018, 260 studies from 30 countries were identified (Roberti et al. 2018); however, the very few studies that related to Scandinavia focused on the dialysis and organ transplantation phases, and none focused on how patients in earlier stages live with CKD and associated treatments. Our objective was, therefore, to focus on CKD patients in Sweden who have not progressed in their disease to a need for dialysis or organ transplantation, and investigate firstly how they experience the disease, including their treatment journey and interactions with healthcare providers (HCPs) from diagnosis and throughout the entire disease continuum, and secondly the impact of CKD and consequent treatment regimens on HRQoL and work productivity. Many of the patients were recruited in collaboration with a patient advocacy organization, which may have shifted the sample into patients with more advanced disease stages, albeit self-reported as CKD stages 3-5. Most importantly, however, none of the patients included had undergone dialysis or transplantation.

# Methods

#### Study design and participants

This was a cross-sectional, non-interventional, mixedmethods study (Amir et al. 2021) in which a quantitative online survey and subsequent qualitative interviews with a subset of survey respondents was adopted. Patients were recruited in collaboration with the Swedish Kidney Patient Advocacy Organization (Njurförbundet) and via advertisements in social and traditional media that informed respondents on how to access the study online, general information about the study, its eligibility criteria, and providing informed consent. Eligible respondents had to declare an age  $\geq$  18 years, CKD diagnosed at stages 3, 4, or 5, no history of dialysis or organ transplantation, and no concurrent clinical trial participation. The survey unlocked for eligible and consenting patients. At the end of the survey, patients were asked to indicate their willingness to participate in a follow-up interview, for which they would be reimbursed with a  $\notin$ 50 electronic gift card.

#### Survey structure

The online survey, which launched in July 2021 and remained open for 16 weeks, comprised (i) a study-specific questionnaire with 14 closed-response questions on demography, comorbidities, medications, symptoms, CKD impact, the patient's diagnosis experience, and interactions with HCPs; (ii) the RAND 36-Item Health Survey 1.0 (RAND-36v1), a generic patient-reported outcome (PRO) instrument that measures HRQoL (RANDa 2022); and (iii) the Work Productivity and Activity Impairment questionnaire (WPAI), a generic PRO that measures disease impact on work and activity impairment (WPAI Coding 2019).

Results for the eight RAND-36 subscales were compared to reference values from the Swedish general population (Ohlsson-Nevo et al. 2021). The minimal clinically important difference for the subscales ranges between 3 and 5 points (Samsa et al. 1999). A detailed description of RAND-36v1 and WPAI can be found in Methods of the Online Resource 1.

#### Qualitative, in-depth, one-to-one interviews

Individuals who volunteered to participate were grouped according to their CKD disease stage (3/4/5) (Group KDIGOKCW 2013) and RAND-36 general health score (low/ medium/high), and subsequently selected randomly based on the survey completion timestamp (every second, third, or fourth patient was selected depending on the number of patients per profile). In total, 40 patients were recruited.

Before being interviewed, patients had to provide formal proof of diagnosis and disease stage by either a certification form from their HCP or a screenshot from their electronic health journal. Trained interviewers conducted telephone interviews that lasted approximately 60 minutes using a standardized, semi-structured discussion guide (see Online Resource 1). This contained open-ended and prompted questions to explore patients' experiences with CKD disease and treatments. Interviews were audiorecorded and transcribed for coding and analysis.

#### Data analysis

The RAND-36 and WPAI questionnaires were scored according to their scoring guidelines (RANDb 2022; WPAI

Table 1	Demographics,	medical treatments,	comorbidities, and	chronic kidney	disease stage,	all self-reported	by survey	respondents
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	CKD <sup>a</sup> stage (self-r				
	Undefined <sup>b</sup> n = 29 (16%)	Stage 3 n = 32 (18%)	Stage 4 n = 76 (43%)	Stage 5 n = 41 (23%)	Total N = 178 (100%)
Demographics					
Age: Mean (SD <sup>c</sup> )	58.4 (15.2)	56.4 (12.6)	60.4 (15.3)	61.2 (14.9)	59.5 (14.7)
Female, n (%)	16 (55)	22 (69)	39 (51)	19 (46)	96 (54)
Comorbidities					
Hypertension, n (%)	18 (62)	30 (94)	59 (78)	34 (83)	140 (79)
Anaemia or iron deficiency, n (%)	7 (24)	10 (31)	24 (32)	22 (54)	62 (35)
Hyperkalaemia, n (%)	5 (17)	3 (9)	20 (26)	22 (54)	50 (28)
Diabetes, n (%)	7 (24)	7 (22)	12 (16)	7 (17)	34 (19)
Heart failure, n (%)	4 (14)	0 (0)	7 (9)	4 (10)	14 (8)
None of the listed comorbidities, $n$ (%)	7 (24)	2 (6)	6 (8)	2 (5)	18 (10)
Current treatments					
Anti-hypertensive medication, n (%)	26 (90)	31 (97)	70 (92)	36 (88)	164 (92)
Sodium bicarbonate, n (%)	7 (24)	9 (28)	39 (51)	28 (68)	84 (47)
Diuretics, <i>n</i> (%)	12 (41)	9 (28)	39 (51)	21 (51)	82 (46)
Phosphate binder, $n$ (%)	2 (7)	2 (6)	9 (12)	17 (42)	30 (17)
Potassium binder, n (%)	4 (14)	0 (0)	9 (12)	16 (39)	28 (16)
Corticosteroids, n (%)	9 (31)	2 (6)	8 (10)	7 (17)	27 (15)
$ESA^{d}$ injection, $n$ (%)	1 (3)	1 (3)	10 (13)	8 (20)	20 (11)

<sup>a</sup> chronic kidney disease; <sup>b</sup> patients in the undefined disease stage group responded that they were in CKD stage 3–5 yet unsure of the exact stage; <sup>c</sup> standard deviation; <sup>d</sup> erythropoiesis-stimulating agent

Coding 2019). Verbatim interview transcripts were translated into English, and coded and analysed using MAXQDA qualitative research software (Rädiker and Kuckartz 2020). Two coders coded the transcript aggregates, with inter-rater agreement evaluated between coders to ensure consistent and satisfactory coding.

#### Results

# Demographics, comorbidities, and current treatments

In total, 786 individuals accessed the link, of whom 438 (56%) aborted without completing the screener, 170 (21%) were not eligible, and 178 (23%) completed the survey. Of the latter, 118 (66%) declared an interest in interview participation.

The patient sample was well balanced as regards gender in all groups except CKD stage 3, where a larger proportion was female. The mean sample age was 59.5 years, with males being slightly older than females (61.8 years, SD = 14.8 vs 57.6, SD = 14.4, respectively) and stage 3 CKD patients being younger than patients in later disease stages (Table 1).

The majority of patients suffered from hypertension (79% of patients stated that they had been diagnosed, but

92% were taking anti-hypertensive medication) followed by anaemia/iron deficiency, diabetes, and heart failure, while 10% reported none of the comorbidities. The second most commonly used medication was sodium bicarbonate (47%), indicating that the responding group had more advanced CKD (Table 1).

#### Main symptom experience

Fatigue was the most commonly reported symptom, followed by reduced physical ability and sleeping problems. Results confirmed that stage 3–5 CKD has multifaceted symptomology: at least 50% of patients experienced up to 8 of the 16 listed symptoms and at least 20% experienced all listed symptoms. On average, patients experienced 7.6 of the 16 listed symptoms, with those in later stages experiencing more symptoms than patients in earlier stages (means for stages 3, 4, and 5 were 7.1, 7.4, and 8.7, respectively) (Table 2).

#### At the time of diagnosis

Table 3 shows the results for survey questions related to the time of diagnosis. Twenty-four percent of patients were diagnosed during a routine visit or through occupational healthcare, 40% when in contact with HCPs for other health

Table 2 Frequency of main chronic kidney disease symptoms currently experienced by survey respondents based on self-reported disease stage

	CKD <sup>a</sup> stage (self-					
	Undefined <sup>b</sup> n = 29 (16%)	Stage 3 n = 32 (18%)	Stage 4 <i>n</i> = 76 (43%)	Stage 5 n = 41 (23%)	Total N = 178 (100%)	
CKD symptoms						
Fatigue, n (%)	24 (83)	26 (81)	60 (79)	38 (93)	148 (83)	
Reduced physical ability, n (%)	17 (59)	24 (75)	54 (71)	36 (88)	131 (74)	
Sleeping problems, $n$ (%)	17 (59)	20 (62)	45 (59)	27 (66)	109 (61)	
Reduced muscle strength, $n$ (%)	12 (41)	17 (53)	43 (56)	33 (80)	105 (59)	
Feeling frozen, <i>n</i> (%)	13 (45)	14 (44)	49 (64)	27 (66)	103 (58)	
Drier skin, $n$ (%)	16 (55)	18 (56)	44 (58)	22 (54)	100 (56)	
Lowered libido, $n$ (%)	14 (48)	17 (53)	38 (50)	26 (63)	95 (53)	
Oedema, n (%)	15 (52)	15 (47)	41 (54)	18 (44)	89 (50)	
Gastrointestinal issues, n (%)	12 (41)	13 (41)	38 (50)	24 (58)	87 (49)	
Itchy skin, $n$ (%)	15 (52)	12 (38)	31 (41)	21 (51)	79 (44)	
Twitching legs, $n$ (%)	11 (38)	12 (38)	30 (39)	20 (49)	73 (41)	
Impaired concentration, n (%)	12 (41)	8 (25)	30 (39)	18 (44)	68 (38)	
Nausea, <i>n</i> (%)	8 (28)	9 (28)	19 (25)	15 (36)	51 (29)	
Lack of appetite, $n$ (%)	6 (21)	7 (22)	17 (22)	10 (24)	40 (22)	
Food tasting different, n (%)	6 (21)	6 (19)	15 (20)	12 (29)	39 (22)	

<sup>a</sup> chronic kidney disease; <sup>b</sup> patients in the undefined disease stage group responded that they were in CKD stage 3–5 yet unsure of the exact stage

problems, and only 36% were diagnosed during a healthcare visit triggered by experiencing CKD symptoms. The vast majority (93%) reported having been diagnosed by a kidney specialist and in hospital (97%) rather than primary health-care, which indicates a population of more advanced CKD. Only 33% of patients received any type of written disease information at the time of diagnosis.

Nineteen percent of patients claimed having been asymptomatic at diagnosis. More than 50% reported having experienced CKD symptoms for > 3 years before diagnosis, while 16% had experienced symptoms for > 10 years. The top five symptoms that patients declared having experienced before diagnosis were drier skin (29%), fatigue (22%), feeling frozen (22%), sleeping problems (21%), and gastrointestinal issues (19%).

#### **Treatment perception**

Table 4 summarizes patients' understanding of CKD-related healthcare. Most patients received routine CKD treatment at a hospital from a kidney specialist (100% for stages 4 and 5, 94% for stage 3, and 83% for undefined stage). This indicates that the patients in CKD stage 3 had more advanced disease, i.e., CKD stage 3b. Most patients (93%) clearly understood how to take their CKD medications as prescribed and 90% claimed they were being compliant. When asked whether they considered treatment efficacious for symptom relief, 24% did not know, and fewer (21%) reported being helped only partially or not at all, whereas a majority (56%) experienced moderate to significant symptom relief.

#### Lifestyle changes

Improved prognosis of CKD requires lifestyle changes. However, 17 patients (10%) claimed no need to implement any changes, while the remainder (n = 161, 90%) adopted on average 3.66 of the 9 listed changes. Patients in later stages implemented more changes than those in earlier stages (means for stages 3, 4, and 5 were 3.3, 3.4, and 4.6, respectively). Four changes were adopted by more than half of the patients: increased physical exercise (60%), weight control (59%), restricted salt intake (59%), and restricted protein intake (51%) (Table 5).

# Health-related quality of life and work productivity and activity impairment

Survey results for HRQoL were compared with scores from the Swedish general population. For all subscales, patients' scores were much lower than the reference values. The differences, ranging from 7.7 (emotional well-being) to 29.9 (role-functioning/physical), underscore the detrimental impact of CKD on HRQoL (Fig. 1).

The RAND 36-Item Health Survey 1.0 is a generic PRO tool to measure HRQoL. Data for the eight RAND-36

Table 3Responses of patientto questions concerningtheir chronic kidney diseasediagnosis: survey data

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<sup>a</sup> chronic kidney disease

subscales were compared to reference values from the Swedish general population (normal). The minimal clinically important difference range for the subscales ranges is 3–5 points, and for all depicted subscales, higher scores indicate better patient status.

Eighty-one patients (46%) were employed. They reported a 22% absenteeism work loss and also a 24% presenteeism work loss due to CKD during the past 7 days. Taken together, they reported a total work productivity loss of 34%. Irrespective of employment status, all patients reported an average every-day activity loss of 43%. All measures of activity impairment increased with disease severity (Table 6).

# Qualitative interviews<sup>1</sup>

#### Demographics

Of the 40 randomly selected patients who were interviewed, 22 (55%) were male and aged 32–82 years, and 21 (53%), 9 (22%), and 9 (22%) had CKD stage 4, 3, and 5, respectively, with stage unknown in one patient. Eighteen (45%)

<sup>&</sup>lt;sup>1</sup> All interviews were conducted in Swedish and translated into English; thus, some have been slightly altered from a language perspective to improve readability with no detriment to the original meaning.

Table 4Responses of patientto questions concerning theirperception on their chronickidney disease treatment andunderstanding: survey data

Question/answer(s)	n (%)
What type of clinic mainly manages your CKD <sup>a</sup> treatment?	
Hospital seeing a kidney specialist	170 (96)
Primary healthcare clinic	4 (2)
Hospital, but not seeing a kidney specialist	4 (2)
Do you understand how to take your CKD medications as prescribed?	
Clearly understand	165 (93)
Somewhat understand	11 (6)
Do not understand	2(1)
Do you think you take your CKD medications according to the prescription?	
Strictly according to the prescription	160 (90)
Somewhat according to the prescription	16 (9)
Not according to the prescription	2(1)
To what extent do any of the medications you take relieve your CKD symptoms?	
Don't know	43 (24)
Not at all	18 (10)
A little bit	20 (11)
Moderately	25 (14)
Quite a bit	44 (25)
Significantly	30(17)

<sup>a</sup> chronic kidney disease

Table 5 Lifestyle changes adopted by survey respondents to adapt to chronic kidney disease

	CKD <sup>a</sup> stage (self-reported)				
	Undefined <sup>b</sup> n = 29 (16%)	Stage 3 n = 32 (18%)	Stage 4 <i>n</i> = 76 (43%)	Stage 5 n = 41 (23%)	Total N = 178 (100%)
Lifestyle changes					
Increase physical exercise, $n$ (%)	20 (69)	17 (53)	46 (61)	24 (59)	107 (60)
Control weight, $n$ (%)	16 (55)	19 (59)	42 (55)	28 (68)	105 (59)
Restrict salt intake, n (%)	15 (52)	17 (53)	47 (62)	26 (63)	105 (59)
Restrict protein intake, n (%)	12 (41)	7 (22)	41 (54)	31 (76)	91 (51)
Restrict potassium intake, n (%)	7 (24)	10 (31)	31 (41)	27 (66)	75 (42)
Restrict intake of phosphate-rich foods, n (%)	8 (28)	2 (6)	18 (24)	21 (51)	50 (28)
Restrict water intake, n (%)	2 (7)	6 (19)	4 (5)	9 (22)	21 (12)
Stop smoking, <i>n</i> (%)	2 (7)	1 (3)	9 (12)	4 (10)	16 (9)
Other, $n$ (%)	4 (14)	6 (19)	6 (8)	3 (7)	20 (11)
Don't need to change anything, $n$ (%)	3 (10)	6 (19)	5 (7)	3 (7)	17 (10)

<sup>a</sup> chronic kidney disease; <sup>b</sup> patients in the undefined disease stage group responded that they were in CKD stage 3–5 yet unsure of the exact stage

patients were retired and 16 (40%) were employed. Twentyone (53%) patients lived with their spouse, 10 (25%) lived alone, and 8 (20%) lived with their family.

#### Diagnosis and disease progression

A striking commonality amongst patients was their experience that CKD had been diagnosed by chance or unexpectedly during a routine visit to the doctor's office or a visit for a comorbidity (e.g., diabetes or hypertension). Many patients sought medical care in response to blood in the urine or a urinary tract infection, abdominal pain, or migraines, and

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underwent a battery of tests before CKD could eventually be established. Typical patient descriptions are as follows:

I was at a pretty standard check-up that you do once in a while when the very young and new doctor... $[...]^2$ ... saw some test results that he didn't think were that great... The creatinine and the cholesterol were a bit too high...[...]... That's how it started. (Male, CKD stage 4<sup>3</sup>)

 $<sup>^2</sup>$  "[...]" denotes that words have been cut from quotes without altering the message. "..." denotes silent pauses.

<sup>&</sup>lt;sup>3</sup> Seventeen patients contributed to the reported 23 quotes (1, 2, and 3 quotes each from 12, 4, and 1 patient(s)).

Fig. 1 RAND-36 mean subscale scores of the study sample of patients with chronic kidney disease compared to the normal population in Sweden



The RAND 36-Item Health Survey 1.0 is a generic patient-reported outcome tool to measure health-related quality of life. Data for the eight RAND-36 subscales were compared to reference values from the Swedish general population (normal). The minimal clinically important difference range for the subscales ranges is 3–5 points and for all depicted subscales, higher scores indicate better patient status.

They noted a lot of blood in the urine during the general check-up at the clinic... I hadn't been feeling unwell from this until the last six months when I started becoming more tired. So I never felt anything. If nobody had taken any samples ... I wouldn't have known anything. (Female, CKD stage 5)

Only 9 (23%) patients reported experiencing no symptoms before diagnosis. Of 31 (77%) patients who experienced pre-diagnosis symptoms, fatigue (n = 12, 30%) was most frequently mentioned, followed by hypertension (n = 11, 28%), leg or abdominal swelling (n = 8, 20%), and urinary tract infection (n = 7, 18%).

I couldn't really do anything. And if I was to do anything at home, for example, work on a project... I could work for one minute and then had to rest for five minutes. (Male, CKD stage 4)

I started to have headaches a lot. So in February I went to the health clinic and they said come back

another day and we'll see if it's better. And it wasn't the day after... They sent me straight to hospital. Then my blood pressure was 260/125. (Male, CKD stage 4)

It started when I got recurring urinary tract infections, for which I got antibiotics. ...[...]... Then I got the same urinary tract infection again...[...]... That all happened to me for around two and a half, three years before healthcare staff discovered that one of my kidneys wasn't functioning anymore. (Male, CKD stage unknown)

Twenty-three (58%) patients had concerns about the diagnosis process, the most pronounced disappointments relating to lack of information and/or support from HCPs, and a feeling that the doctor did not take them seriously.

Eventually I got to see a dietician who told me what I should and shouldn't eat... It took over a year before that happened. (Female, CKD stage 3)

Table 6 Work productivity and activity impairment data by disease stage

	CKD <sup>a</sup> stage (self	CKD <sup>a</sup> stage (self-reported)				
	Undefined <sup>b</sup> n = 14 (17%)	Stage 3 n = 15 (18%)	Stage 4 n = 33 (41%)	Stage 5 <i>n</i> = 19 (23%)	Total $N = 81^{c} (100\%)$	
WPAI <sup>d</sup> scores						
Absenteeism $(n = 81)$	20%	7%	20%	39%	22%	
Presenteeism $(n = 81)$	21%	15%	24%	33%	24%	
Work productivity loss $(n = 81)$	34%	17%	30%	53%	34%	
	n = 29 (16%)	n = 32 (18%)	n = 76 (43%)	n = 41 (23%)	$N = 178^{\rm e} (100\%)$	
Activity impairment $(n = 178)$	41%	32%	44%	52%	43%	

<sup>a</sup> chronic kidney disease; <sup>b</sup> patients in the undefined disease stage group responded that they were in CKD stage 3–5 yet unsure of the exact stage; <sup>c</sup> 81 (46%) patients were employed and responded to the work-related items; <sup>d</sup> Work Productivity and Activity Impairment; <sup>e</sup> irrespective of employment status, all responded to the activity impairment item

Patients experienced mixed emotions in response to their diagnosis, most frequently worry (n = 16, 40%) followed by feeling sad or depressed (n = 8, 20%). Five (13%) patients reported feeling shocked, while five (13%) reported feeling relieved at finally having received a diagnosis.

There's always a worry that the kidneys will stop working. That's always there since I first found out. (Male, CKD stage 4)

... Of course there has been a worry deep down, such as, where is this leading and how is it going to affect my future. At the time, I didn't have any children so really I didn't know if I even should have kids. (Male, CKD stage 5)

*I just felt happy... because there was finally someone who focused on this, who was interested.* (Male, CKD stage 5)

## Disease journey and treatment experiences

Patients were appreciative of the help they received from their HCP. Seventeen (43%) and 12 (30%) patients reported discussing treatment options and lifestyle changes with HCPs, respectively. Many revealed that having struggled to receive a diagnosis, subsequent care was excellent. Patients also noted that when discussing treatments with HCPs, they were advised to prepare for the future when they might need additional treatments, such as dialysis or transplants.

Patients were familiar with various current treatments. Of the 29 (73%) patients who responded to questions concerning whether the treatments alleviate the symptoms, only 2 (7%) reported no symptom relief (angiotensin-converting enzyme inhibitors), while the rest reported symptom relief. Most satisfied patients had received angiotensin receptor blockers (n = 14, 48%), calcium channel blockers (n = 11, 38%), and diuretics (n = 10, 34%). All patients reported doing their best to adhere to treatment.

... If I don't take my blood pressure medicines, I get stressed... Antihistamine, for itching and furosemide when taking it I feel very thirsty, but if I don't take it, I gain weight ... I gain liquid. ... I notice it if I don't take my medicines. (Male, CKD stage 4)

## Disease impact

Chronic kidney disease impacts patients in many different ways. Interviewed patients spontaneously mentioned 22 unique and different ways in which CKD affected them, of which only seven were mentioned by  $\geq 5$  patients and only three (fatigue, worry, and reduced ability to enjoy leisure activities) were mentioned by > 10 patients (see Table 1, Online Resource 1).

Fatigue was the key impact for most patients, affected most aspects of their lives, and was described as constant, causing an endless need to rest in order to cope yet still preventing participation in work and social activities. Their inability to enjoy leisure activities was also fatigue-related, and many reported that fatigue worsened over time.

The fatigue is constant. Constant fatigue... I could sleep for 24 hours actually, it's that bad. (Male, CKD stage 4)

Constantly, I wake up [fatigued]. I sleep 12 hours per night yet I wake tired... I feel drained, that I don't have energy for anything. (Female, CKD stage 5)

...It's been so many years so it's difficult because it's been a slow process of getting worse... It's hard to see a clear trend, but the way things are now...[...]...when I get tired the only solution is to sleep or lie down. You endure throughout the daytime because later you're drained. A little marathon every day. (Male, CKD stage 5)

...The friends I have aren't the same. I can't keep up and don't have the stamina to do what they do... That's really difficult actually. (Male, CKD stage 5)

I can't do...or keep going as much as I'd like... I've always sung in choirs all my life, but I've had to quit. Some nights I might force myself to go out to do something, but not regularly, one day a week. No, it just doesn't work. (Female, CKD stage 5)

Patients had concerns and worries; knowing that CKD would deteriorate with no real recovery hugely impacted their lives. They reported anxieties about a future with CKD, particularly the potential need for dialysis and transplantation.

... The knowledge that I won't ever get better, that it gets worse with each year. Of course, I'm not exactly looking forward to having dialysis, for example. (Male, CKD stage 4)

I fear, a little, the dialysis thing that I realize is coming any year now. And I know that... dialysis ... will limit, well, my life, on a whole different level than it's done before. (Male, CKD stage 5)

## Managing disease with lifestyle changes

The top three lifestyle changes patients had implemented to adapt to CKD were dietary (n = 39, 98%), increased physical activity (n = 18, 45%), and weight loss/management (n = 17, 43%). Dietary changes included reduced intake of protein, salt, dairy food, alcohol, potassium, and fast food. Patients

also tended to eat out less often and cooked at home to better control ingredients.

Many patients described being physically active prior to diagnosis and increasing their activities after diagnosis, particularly walking. This, by far, was the most commonly reported form of physical activity primarily because fatigue and CKD-related pain prevented patients from doing more strenuous activities. Weight control was the primary goal of increased physical activity.

#### Quality of healthcare and suggested improvements

Thirty patients (75%) were treated by a nephrologist at a kidney clinic, although patients also received healthcare from non-kidney specialty physicians (n = 11, 28%), dieticians (n = 9, 23%), nurses (n = 7, 18%), and urologists (n = 4, 10%). Many patients revealed not having received specialized kidney healthcare until their CKD had deteriorated; before their situation had become more serious, they only received care at primary healthcare centres and local hospitals rather than at kidney clinics.

When I later became worse, I got in contact with the kidney department and that was a great improvement. Suddenly you get personnel who are engaged in you. (Male, CKD stage 5)

Patients spoke highly of specialized kidney clinics, with 22 (73%) being very satisfied with the associated healthcare. Over half (55%) of patients currently treated by non-kidney specialists expressed a preference to be treated by kidney specialists rather than primary HCPs. Many noted receiving unsatisfactory initial primary healthcare; when this changed to a kidney clinic with dedicated staff, patients were happy with the healthcare quality.

...At the health centres I went to first, I didn't receive support and help... They ignored the urinary tract infection. I was given tablets and they thought that they'd help, but it all went wrong. After that I've had nothing to complain about. They're really good here they're absolutely incredible. (Female, CKD stage 4)

Patients described similar attributes when explaining why they were satisfied/unsatisfied with healthcare. Satisfied patients had access to HCPs, received good information about CKD and its treatment, and experienced feelings of trust and safety as regards the HCP, as well as continuity with their healthcare team. In contrast, the minority of unsatisfied patients highlighted inconsistencies with their HCPs causing them to feel distrust and unsafe. As regards the treatment journey prior to referral to kidney clinics, patients reported experiencing a lack of knowledgeable staff, which triggered frustration and a constant drive to be their own advocate. They felt that HCPs could have taken their symptoms more seriously and revealed that they could have started taking better care of themselves earlier. They also mentioned that it was "madness" to have had to wait for the disease to deteriorate for referral to a kidney clinic.

... Not safe, not as safe as if I'd had the same doctor the entire time. In that way there is a level of uncertainty—you don't know who you'll be seeing. Is it a good doctor, is it a bad doctor? You don't know if it'll be the same doctor as the last time—in that way you're not safe. (Female, CKD stage 3)

What has been less good was...[...]...the filter to get to specialists and get proper care... But then the problem was that I wasn't taken seriously. I felt very bad. But when I came to the kidney clinic it was wonderful. It was the primary care that was lacking. (Male, CKD stage 5)

It's also strange that you should have to wait for something to get worse; it's complete madness. (Female, CKD stage 3)

As regards improvements, patients wanted complaints of recurrent urinary tract infections to be taken seriously early on to enable earlier potential diagnosis of CKD.

... To have not received a diagnosis earlier so that you can be more aware because I know how to work with a diet and maybe could've worked with it earlier. ...One shouldn't ignore the people who have urinary tract infection, but one should take them seriously and check all of them. (Female, CKD stage 4)

Additional quotes illustrating patients' experiences of healthcare received in primary and specialized kidney healthcare settings can be found in Table 2 of Online Resource 1.

# Discussion

We set out to address a knowledge gap: how do CKD patients in Sweden experience their disease and healthcare? Previous qualitative research from Scandinavia has only focused on patients in the dialysis or transplantation phases of treatment, whereas our ambition was to shed light on patients at earlier stages of CKD treatment (Roberti et al. 2018). Our study describes how some patients diagnosed with CKD in Sweden experience their disease, treatment journey, and the impact of CKD on their daily life. The results demonstrate the obstacles that many patients have had to cope with, particularly related to the diagnosis stage. Based on their experiences, many patients declared having experienced symptoms for many years prior to being diagnosed, yet the diagnosis was still unexpected.

Patients had difficulty living with CKD, causing a profound and negative impact on their HRQoL and daily functioning both at work and beyond. Even those patients who tried to persevere with normal activities reported reduced work productivity and missing almost half of their everyday activities beyond work due to CKD. Fatigue often constant—was the main symptom contributing to HRQoL losses that prevented patients from living life to the full both before and after diagnosis. Patients were also worried by their long-term prognosis—they understood that CKD deteriorates, and treatment options may terminate in dialysis or organ transplantation, both of which they dreaded.

Importantly, patients revealed that they were concerned by the lack of early diagnosis. Although CKD should predominantly be diagnosed in the primary healthcare setting, almost all (93%) patients reported having been diagnosed at specialist kidney clinics. Although this is their perspective, they may have been diagnosed, albeit tentatively, by primary HCPs with subsequent confirmation by kidney specialists without realizing this. Both the survey and interview results were congruent in demonstrating that patients had symptoms long before CKD was diagnosed, and many reported a need for more attentive HCPs to ensure earlier diagnosis. In epidemiological studies, under-diagnosis of CKD has been found to be common and widespread (Sundström et al. 2022), and in a recent study from Sweden, profound sex differences in CKD detection, recognition, and monitoring that persisted over time were observed: women were less likely than men to receive a diagnosis, visit a nephrologist, have their creatinine and albuminuria measured, and receive guidelinerecommended therapies (Swartling et al. 2022). The patient perspective on the diagnosis stage, as revealed in our study, demonstrates patients' struggles to receive an early diagnosis and appropriate treatment, as well as their perspective on how frequent changes in healthcare staff influenced their general dissatisfaction with primary healthcare. In contrast, once patients were eventually diagnosed by nephrologists, specialized kidney healthcare was well received by them. This highlights the need for improved early diagnosis and treatment initiation for CKD in the Swedish primary healthcare setting. It also indicates the need for earlier intervention by kidney specialists to mitigate CKD progression.

In our patient group that was very concerned about CKD, we found a high ambition for a healthy lifestyle, including physical exercise and recommended food intake. This lifestyle, however, should be effectuated early when there is still good kidney function to preserve.

Despite the small survey sample that may also have been affected by selection bias towards more advanced CKD, as patients were recruited predominantly via a patient advocacy organization, the main strength of this study is its 40-patient interview sample group. This is large for a qualitative interview study. The RAND-36 results, however, were compared to those published in the annual report of the Swedish Kidney Registry (SNR 2021) comprising 791 patients. Although the sample scores in the study were higher for some domains and lower for others, overall results were comparable, thereby supporting our objective to shed light on the patient perspective of living with CKD in Sweden.

# Conclusions

This study fulfils our study objectives to gain a better understanding of patients' own perspectives of CKD and associated healthcare in Sweden. It highlights the need (i) to improve the diagnosis and early treatment of CKD, including patient-driven changes for a healthy lifestyle, (ii) to enhance the provision of patient information in primary healthcare in Sweden, and (iii) for more nephrologists to intervene earlier in the CKD continuum to help mitigate disease progression. Necessary measures include educating primary healthcare staff on the most important signs of CKD, basic diagnosis and treatment strategies, and correct referral to specialized kidney clinics. In addition to advocating formal, national guideline requirements (i.e., the targeted screening of people with diabetes, hypertension, and heart failure) (National Healthcare Programme for CKD 2021), we suggest that patients presenting in primary healthcare with symptoms known to be CKD-related, such as fatigue, unspecific skin problems, feeling frozen, and sleep problems, should be listened to and examined for potential CKD, including appropriate testing of estimated glomerular filtration rate and proteinuria (Group KDIGOKCW 2013).

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**Data Availability** Data underlying the findings described in this manuscript may be obtained in accordance with AstraZeneca's data sharing policy described at https://astrazenecagrouptrials.pharmacm.com/ST/Submission/Disclosure.

Code Availability Not applicable.

#### Declarations

**Ethics approval** The study was approved by the Swedish Ethical Review Authority (reference number 2021-01968).

**Consent to participate** All patients provided informed consent to participate in the study.

**Consent for publication** Not applicable.

**Conflicts of Interest** Elisabeth Z. Wolpert has a minor consultancy position with AstraZeneca. Sara Norman is a full-time employee at the Swedish Kidney Association, which received a minor, financial compensation from AstraZeneca for patient recruitment. Daniel Eek is a full-time employee of the study sponsor AstraZeneca and owns stock in the company. Carina Holmesson reports no conflicts of interest. Anders Fernström reports consulting fees from Vifor Pharma, Alnylam, and AstraZeneca; payment/honoraria for lectures, presentations or educational events from Otsuka; and participation on an advisory board for Vifor Pharma and AstraZeneca.

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