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ORIGINAL RESEARCH

Patients with Chronic Kidney Disease: Background Factors Associated with Experienced Health Status and Life Satisfaction

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Purpose: The prevalence of chronic kidney disease (CKD) is increasing and CKD often goes undiagnosed and untreated until its later stages when irreversible damage has occurred. Patients with CKD have been reported to have lower quality of life than the general population, but the patient-reported outcome data on CKD patients in Finland are limited.

Patients and Methods: The primary outcome of this structural, multiple-choice survey study was to assess life satisfaction and experienced health status in Finnish patients with CKD. The results were presented as numbers (n) and percentages (%). The secondary outcome was to identify patient groups using the K-means clustering method based on preselected response variables and to assess the associated background factors.

Results: In total, 558 patients with CKD responded to the electronic survey. Of the 395 patients who completed the whole survey, 39.7% reported their health status as good, pretty good, or excellent, and 59.9% were fairly or very satisfied with their life. Two clusters of patients could be identified based on their health status and life satisfaction: patients with (1) poorer or (2) better well-being. Patients with poorer well-being were more likely to have at least 3 comorbidities (66.8% vs 44.3%) and lack follow-up visits entirely (10.5% vs 1.9%), compared with patients with better well-being. The patients with poorer well-being were less often knowledgeable about the disease, its causes (35.5% vs 48.1%), and its care (30.7% vs 20.3%) than patients with better well-being, and they showed weaker adherence to lifestyle interventions such as following dietary instructions (30.3% vs 40.5%).

Conclusion: Screening for CKD to enable early diagnosis, early commitment to treatment, and empowering the patient by providing education are key for improvement of health and life satisfaction in patients with CKD. Therefore, resources should be allocated to these measures of action.

Keywords: Chronic kidney disease, health status, life satisfaction, patient-related outcome measure, survey

Introduction

Chronic kidney disease (CKD) is defined by abnormalities of kidney function that have lasted for three months or longer.[1] CKD is classified by the estimated glomerular filtration rate (eGFR) and albuminuria,[1] and an eGFR of lower than 60 mL/min/1.73 m^2 constitutes a CKD.[1,2]

On average, every tenth adult is affected by CKD worldwide, but the disease remains widely underdiagnosed.[3–6] For Finland, data on prevalence of CKD are limited,[7] but it can be assumed that along with the aging of the general population and with the metabolic syndrome becoming more common, the prevalence of CKD has increased in Finland similarly to the trend observed worldwide.[5,6,8]

Common complications of CKD include eg cardiovascular disease and anemia.[2,9,10] Psychiatric disorders associated with CKD can also contribute to the overall life satisfaction of the patient.[11,12] The quality of life (QoL) of patients with CKD has been examined in studies covering varying numbers of patients and facilities[13–19] and conducted via general

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QoL instruments[13–16,19] and disease-specific instruments.[17,18] Patients with CKD have been reported to have lower QoL compared with the general population[20,21] or patients with other chronic diseases such as cancer or heart failure.[22–24] The stage of CKD, depression, dialysis treatment, and several comorbidities have been reported as factors decreasing the QoL in studies spanning several nationalities or populations.[13,15,16,19] Female sex and socioeconomic factors such as low levels of education or income or lack of a life partner also contribute to lowered QoL.[13,14,16,17,19]

Beyond QoL, the other subjective experiences of well-being by CKD patients have been evaluated more rarely, but observations on life and health satisfaction have been reported eg by studies from Spain,[25] Australia,[26] Poland,[27] and the United States.[28] Yet, the health status or life satisfaction of Finnish patients with CKD has thus far not been extensively assessed. Here, we have conducted an electronic survey study which examined the physical and psychological health (experienced health status and life satisfaction) of patients with CKD in Finland as the primary outcome. Participation in the survey was open to any patient with CKD in Finland, thus potentially spanning all regions and facilities across the country. Furthermore, as a secondary outcome, patient groups of poorer or better overall well-being were identified via clustering analysis and the associated background factors were assessed.

Methods

Study Population

The open survey study was designed and conducted as a collaboration between Boehringer Ingelheim Ky and the Finnish Kidney and Liver Association. The responses were collected between February 1st and February 28th, 2022.

Participants were recruited via advertising in newspapers, on patient organization's mailing list, on the Finnish Kidney and Liver Association's website, and on social media and the sample was thus a convenience sample. Capture of participants via the patient organization might have led to a potential preselection of patients. Participants were informed of the purpose of the study and consent was given by completing the voluntary survey. The only eligibility criteria for participating in the survey was the presence of CKD; if a respondent reported not having CKD, the survey form closed. Patients who had received an organ transplant were excluded from the study.

The survey was web-based (Qualtrics), conducted in Finnish, and consisted of 32 items which were structural, multiple-choice questions. There were 4–5 items per page and 7 pages in total. The investigators (Finnish Kidney and Liver Association and Boehringer Ingelheim), the purpose of the study, and the estimated time to complete the survey were listed at the top of the survey. Depending on the question, the participants were able to choose one or several answers, and go back and change answers if needed. The items were not randomized or alternated. No completeness check before submission was performed, but the metadata of the survey included information on whether the patient had completed the whole survey. As missing data were relevant in the evaluation of the associated factors, the main analyses were limited to participants that had completed the whole survey (n=395 patients). All participants were included in the sensitivity analysis (n=558 patients). No personal information of the participants was collected. The survey was not validated. Unique site visitors were determined by IP address and multiple responses were not allowed.

The variables of the survey are presented in Table S1. The variables were classified into background variables (eg, age and sex), treatment variables (eg, medical treatment and dialysis treatment), information variables (where the patient had received information on the disease and its treatment), and response variables (eg, life satisfaction and experienced health status). In addition to the original variables, a variable describing the total number of comorbidities was derived from the question "What additional diseases do you have?", and resulting in a subsequent classification of the answers into 0, 1–2, 3–4, or >5 comorbidities.

Outcomes

The primary outcome of the study was the life satisfaction and experienced health status of the patients with CKD. The secondary outcome was to identify patient groups that were similar with regards to the response variable, and to describe background, treatment, and information variables in the identified groups.

Statistical Analyses

The number (n) and proportion (%) of responses were used in the visualization of the descriptive data. No weighting of items was performed to adjust for potential non-representative sample. To assess multidimensional associations, patients were clustered using the K-means clustering method based on preselected response variables (Table S1). The number of clusters was decided in a data-driven manner. The difference in distributions between groups was assessed using standardized mean difference (SMD) which describes how much the distribution of variables differs between two groups. In addition, the statistical differences between groups were tested using the χ^2-test. No pooled scores were calculated.

Ethical Considerations

No ethical evaluation was required according to the Finnish regulations regarding survey studies. The study was conducted in accordance with the principles outlined in the Declaration of Helsinki.[29]

Results

Demographics and Characteristics of Survey Participants

The background information on the survey participants and the summary of all survey responses in all groups are presented in Table S1. In total, 558 patients with CKD responded to the electronic survey and 395 patients completed the whole survey.

There were more women (73.0%, n=285) than men (27.0%, n=106) among the participants (Figure S1). The proportion of participants who were over 75 years of age was higher among men (29.3%) than among women (17.5%). Most participants were retired (74.7%, n=293) and lived with a partner or a family member (67.9%, n=267) (Table S1). Most often, the patient had been diagnosed on a hospital visit (34.9%, n=138) or on a health center visit due to a routine control for another disease (27.1%, n=107).

Medication was received by almost half (46.3%, n=183) of the patients and dialysis treatment by one in seven (14.4%, n=57) of the patients (Table S1). The patients were followed up most often at a hospital outpatient clinic (47.6%, n=188) or by a health center physician (27.8%, n=110) and more than half of the patients (57.2%, n=223) had a follow-up at least twice a year. However, one in seven (15.9%, n=62) of the patients had a follow-up only when needed or not at all. Regarding the awareness or information regarding the disease, less than a fifth of patients (18.0%, n=71) were aware of their written plan of care, more than half of the patients (58.3%, n=229) felt that they had not been listened to when preparing the plan of care, and only one in ten patients (9.2%, n=36) had had a close family member involved in the planning. A little over a quarter of the patients (26.6%, n=105) experienced uncertainty about their disease and its treatment.

Experienced Health Status and Life Satisfaction

Of all patients, 39.7% (n=156) described their experienced health status as good, very good, or excellent (Table 1 and Figure 1A). Regarding life satisfaction, 59.9% (n=236) of the patients reported being fairly satisfied or very satisfied with their life (Table 1 and Figure 1B). Patients who had follow-up visits only when in need or never, described their health status as good, very good, or excellent, more rarely (Figure 2A). Similarly, patients who had regular follow-up visits were more satisfied with their lives (Figure 2B).

Identification of Groups of CKD Patients with Poorer or Better Well-Being

As a secondary outcome, the study examined the possibility of using cluster analysis to identify groups of patients whose responses resembled each other. Based on all the 11 response variables, two main groups of patients could be identified (Table S1). The first group comprised patients who reported poorer well-being (Group 1, n=241) and the second group of patients who reported better well-being (Group 2, n=158). In addition, a third cluster was identified consisting of those patients who did not answer the response variable questions (Group 3, n=159).

Table 1 Results for Variables in Which a Statistically Significant Difference Was Observed Between Groups 1 and 2. The Groups Were Identified According to Response Variables Using Cluster Analysis. Statistically Significant Differences Between Groups 1 and 2 Were Assessed Using the χ^2-Test. Group 3 Consisted of Patients Who Did Not Answer the Response Variable Questions. Results for All Variables are Shown in Supplementary Table 1

Variable	Patients completing the whole survey (n=395)	All patients (n=558)	Cluster analysis			P value[a]
			Group 1: Patients with poorer well-being (n=241)	Group 2: Patients with better well-being (n=158)	Group 3: Did not respond to response variable questions (n=159)	
Response variables						
Experienced health status, n (%)						<0.001
Information not available	1	159				
Poor	37 (9.4)	38 (9.5)	38 (15.8)	0 (0.0)	No response	
Satisfactory	170 (43.1)	171 (42.9)	171 (71.0)	0 (0.0)	No response	
Varies	31 (7.9)	33 (8.3)	30 (12.4)	3 (1.9)	No response	
Good	98 (24.9)	98 (24.6)	2 (0.8)	96 (60.8)	No response	
Very good	53 (13.5)	54 (13.5)	0 (0.0)	54 (34.2)	No response	
Excellent	5 (1.3)	5 (1.3)	0 (0.0)	5 (3.2)	No response	
Life satisfaction, n (%)						<0.001
Information not available	1	159				
Very dissatisfied	9 (2.3)	9 (2.3)	8 (3.3)	1 (0.6)	No response	
Fairly dissatisfied	37 (9.4)	38 (9.5)	36 (14.9)	2 (1.3)	No response	
Not satisfied but not dissatisfied	112 (28.4)	114 (28.6)	97 (40.2)	17 (10.8)	No response	
Fairly satisfied	192 (48.7)	194 (48.6)	93 (38.6)	101 (63.9)	No response	
Very satisfied	44 (11.2)	44 (11.0)	7 (2.9)	37 (23.4)	No response	
Experience of loneliness, n (%)						<0.001
Information not available	2	160				
Constantly	13 (3.3)	14 (3.5)	13 (5.4)	1 (0.6)	No response	
Quite often	46 (11.7)	46 (11.6)	40 (16.7)	6 (3.8)	No response	
Sometimes	134 (34.1)	136 (34.2)	91 (37.9)	45 (28.5)	No response	
Rarely	130 (33.1)	130 (32.7)	68 (28.3)	62 (39.2)	No response	
Never	70 (17.8)	72 (18.1)	28 (11.7)	44 (27.8)	No response	
CKD has not affected mood, n (%)	76 (19.2)	78 (14.0)	31 (12.9)	47 (29.7)	No response	<0.001
Disease has caused sadness, n (%)	67 (17.0)	67 (12.0)	49 (20.3)	18 (11.4)	No response	0.020
Disease causes fear, n (%)	73 (18.5)	73 (13.1)	53 (22.0)	20 (12.7)	No response	0.019
Has been depressed, n (%)	50 (12.7)	51 (9.1)	43 (17.8)	8 (5.1)	No response	<0.001

Need of assistance in understanding laboratory test results, n (%)						0.021
Information not available	2	109				
Does not need help, has understanding	73 (18.6)	88 (19.6)	45 (18.7)	30 (19.1)	13 (25.5)	
Does not need help, but knows how to access it if needed	119 (30.3)	128 (28.5)	63 (26.1)	57 (36.3)	8 (15.7)	
Needs and has received help	151 (38.4)	171 (38.1)	94 (39.0)	59 (37.6)	18 (35.3)	
Needs help but does not know how to access it	50 (12.7)	62 (13.8)	39 (16.2)	11 (7.0)	12 (23.5)	
Non-response variables						
Time from diagnosis, n (%)						0.015
Not diagnosed	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
<1 year	50 (12.7)	76 (13.6)	35 (14.5)	17 (10.8)	24 (15.1)	
1–5 years	159 (40.3)	201 (36.0)	91 (37.8)	67 (42.4)	43 (27.0)	
6–10 years	76 (19.2)	97 (17.4)	47 (19.5)	29 (18.4)	21 (13.2)	
>10 years	110 (27.8)	184 (33.0)	68 (28.2)	45 (28.5)	71 (44.7)	
Number of comorbidities, n (%)						<0.001
0	15 (3.8)	119 (21.3)	3 (1.2)	12 (7.6)	104 (65.4)	
1–2	151 (38.2)	186 (33.3)	77 (32.0)	76 (48.1)	33 (20.8)	
3–4	150 (38.0)	167 (29.9)	95 (39.4)	57 (36.1)	15 (9.4)	
>4	79 (20.0)	86 (15.4)	66 (27.4)	13 (8.2)	7 (4.4)	
Comorbidities						
Heart failure, n (%)	55 (13.9)	62 (11.1)	45 (18.7)	10 (6.3)	7 (4.4)	<0.001
Cancer, n (%)	63 (15.9)	73 (13.1)	49 (20.3)	16 (10.1)	8 (5.0)	0.007
Arthritis, n (%)	46 (11.6)	49 (8.8)	38 (15.8)	8 (5.1)	3 (1.9)	0.001
Type 2 diabetes, n (%)	115 (29.1)	132 (23.7)	84 (34.9)	33 (20.9)	15 (9.4)	0.003
Thyroid disorder, n (%)	112 (28.4)	124 (22.2)	78 (32.4)	35 (22.2)	11 (6.9)	0.027
Lung disease, n (%)	80 (20.3)	87 (15.6)	59 (24.5)	21 (13.3)	7 (4.4)	0.006
Musculoskeletal disorder, n (%)	111 (28.1)	117 (21.0)	80 (33.2)	31 (19.6)	6 (3.8)	0.003
Ophthalmopathy, n (%)	34 (8.6)	38 (6.8)	26 (10.8)	8 (5.1)	155 (97.5)	0.045
No comorbidities, n (%)	29 (7.3)	38 (6.8)	12 (5.0)	18 (11.4)	8 (5.0)	0.018
Frequency of follow-up visits, n (%)						0.004
Information not available	5	151				
Never	27 (6.9)	30 (7.4)	25 (10.5)	3 (1.9)	2 (16.7)	

(*Continued*)

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Table 1 (Continued).

Variable	Patients completing the whole survey (n=395)	All patients (n=558)	Cluster analysis			P value^a
			Group 1: Patients with poorer well-being (n=241)	Group 2: Patients with better well-being (n=158)	Group 3: Did not respond to response variable questions (n=159)	
Only when in need	35 (9.0)	37 (9.1)	22 (9.3)	13 (8.2)	2 (16.7)	
Approximately every other year	16 (4.1)	17 (4.2)	6 (2.5)	11 (7.0)	0 (0.0)	
Annually	89 (22.8)	91 (22.4)	49 (20.7)	41 (25.9)	1 (8.3)	
Two or more times per year	223 (57.2)	232 (57.0)	135 (57.0)	90 (57.0)	7 (58.3)	
Knows what causes the disease and how it can be treated at home, n (%)	159 (40.3)	165 (29.6)	85 (35.3)	76 (48.1)	4 (2.5)	0.011
Feels taken care of, n (%)	136 (34.4)	139 (24.9)	74 (30.7)	64 (40.5)	1 (0.6)	0.044
Has uncertainty over the disease and its care, n (%)	105 (26.6)	111 (19.9)	74 (30.7)	32 (20.3)	5 (3.1)	0.021
Measures blood glucose levels, n (%)	118 (29.9)	119 (21.3)	81 (33.6)	38 (24.1)	0 (0.0)	0.041
Has daily activity, n (%)	222 (56.2)	223 (40.0)	108 (44.8)	115 (72.8)	0 (0.0)	<0.001
Adheres to dietary instructions, n (%)	135 (34.2)	137 (24.6)	73 (30.3)	64 (40.5)	0 (0.0)	0.036
Aims to avoid excess intake of salt, n (%)	287 (72.7)	289 (51.8)	163 (67.6)	126 (79.7)	0 (0.0)	0.008
Life situation, n (%)						0.024
Information not available	3	165				
Retired	293 (74.7)	294 (74.8)	189 (79.1)	105 (68.2)	No response	
Student	3 (0.8)	3 (0.8)	2 (0.8)	1 (0.6)	No response	
Employed	87 (22.2)	87 (22.1)	41 (17.2)	46 (29.9)	No response	
Unemployed	9 (2.3)	9 (2.3)	7 (2.9)	2 (1.3)	No response	
Economic situation, n (%)						<0.001
Information not available	3	165				
Very good	39 (9.9)	40 (10.2)	21 (8.8)	19 (12.3)	No response	
Quite good	123 (31.4)	123 (31.3)	55 (23.1)	68 (43.9)	No response	
Decent	162 (41.3)	162 (41.2)	107 (45.0)	55 (35.5)	No response	
Quite poor	48 (12.2)	48 (12.2)	39 (16.4)	9 (5.8)	No response	
Poor	20 (5.1)	20 (5.1)	16 (6.7)	4 (2.6)	No response	

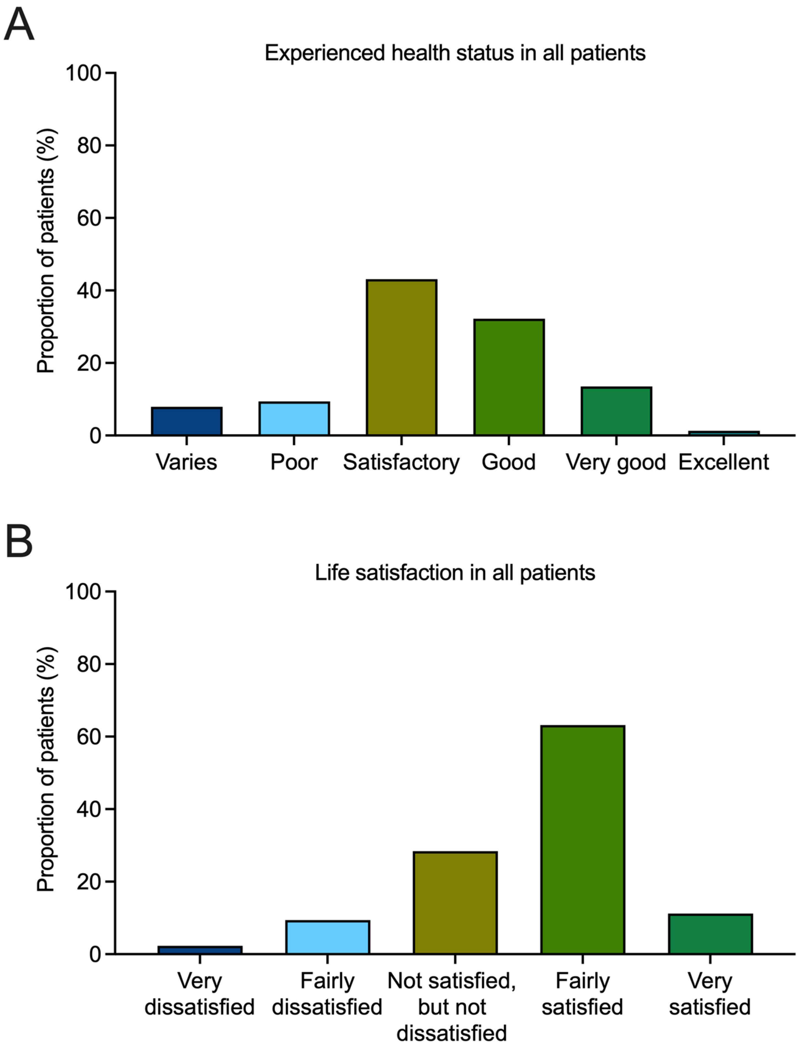

Figure 1 (**A**) Experienced health status and (**B**) life satisfaction in Finnish patients with CKD. Only patients who completed the whole survey were included in the analysis (n=394).

The age distribution did not differ between the two main groups. A significantly smaller proportion of patients in the group of poorer well-being (0.8%, n=2) described their experienced health status as good, very good, or excellent, compared with patients in the group of better well-being (98.2%, n=155; p<0.001, Table 1 and Figure S2A). Correspondingly, fairly good or very good life satisfaction was described by 41.5% (n=100) of the patients with poorer well-being and 87.3% (n=138) of the patients with better well-being (p<0.001, Table 1 and Figure S2B). Additionally, the patients with poorer well-being experienced loneliness (Table 1 and Figure S2C), sadness, depression, and fear of the disease more often and they felt that CKD had affected their mood (Table 1). Of the patients with poorer well-being, one in ten (10.5%, n=25) replied that they never had follow-up visits, whereas among patients with better well-being, the same was reported by only 1.9% (n=3) (Table 1).

Background Factors Associated with Experienced Health Status and Life Satisfaction

Overall, the patients with a larger number of comorbidities described their health status as good, very good, or excellent more rarely (Figure 3A) and were less satisfied with their life (Figure 3A and B). In the two identified clusters, 66.8% (n=161) of the patients with poorer well-being had three or more comorbidities, while the same was true for 44.3% (n=70) of the patients with better well-being (Table 1 and Figure S2D). There were also more individual comorbidities, such as heart failure and T2D, present in patients with poorer well-being (Table 1 and Figure S2E).

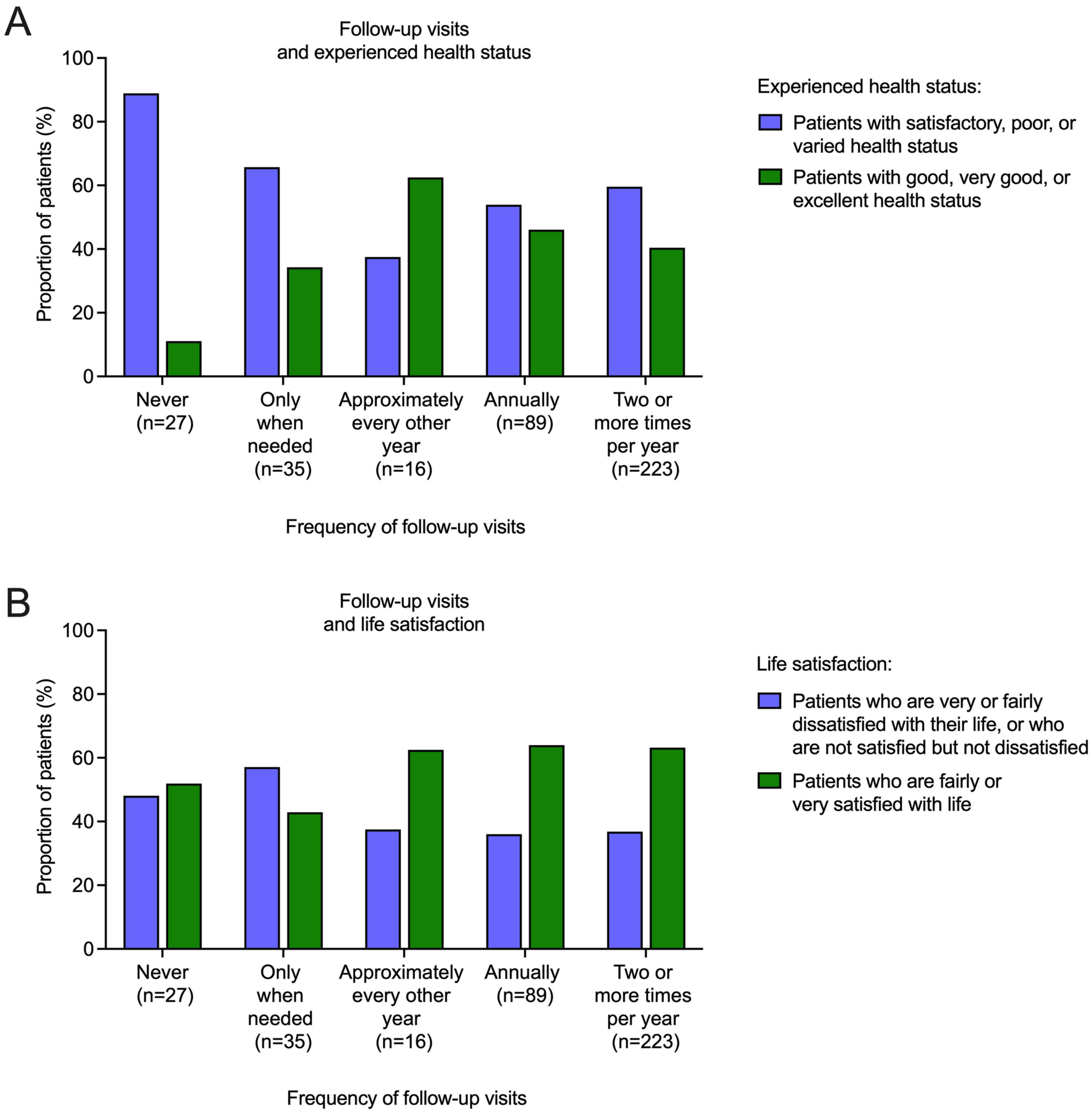

Figure 2 (**A**) Experienced health status and (**B**) life satisfaction of patients according to the frequency of follow-up visits. Only patients who completed the whole survey were included in the analysis (n=390).

Regarding awareness of the disease and its care, the patients who were involved in preparing their plan of care, were more certain and/or aware of the disease, its causes and treatment, and about their medication targets (Figure 4A). Furthermore, patients who were involved in the planning of their care (Figure 4B) or had knowledge of the causes and treatment of the disease (Figure 4C), attended follow-up visits more frequently than patients who were less involved or less knowledgeable. In the two identified clusters, the patients with poorer well-being were more often uncertain about the disease and its treatment than the patients with better well-being (30.7% vs 20.3%, p=0.021, Table 1 and Figure S2F). There were more patients who had received their CKD diagnosis less than a year ago in the group of poorer well-being than in the group of better well-being (14.5% vs 10.8%, p=0.015, Table 1). The patients with poorer well-being knew less often what causes the disease and how it can be treated (35.3% vs 48.1%, p=0.011, Table 1 and Figure S2F) and experienced more rarely that they were being taken care of (30.7% vs 40.5%, p=0.044, Table 1 and Figure S2F). The patients with poorer well-being also showed weaker adherence to lifestyle interventions such as blood glucose measurements, commitment to daily activity, or following dietary instructions, including avoidance of excess intake of salt (Table 1).

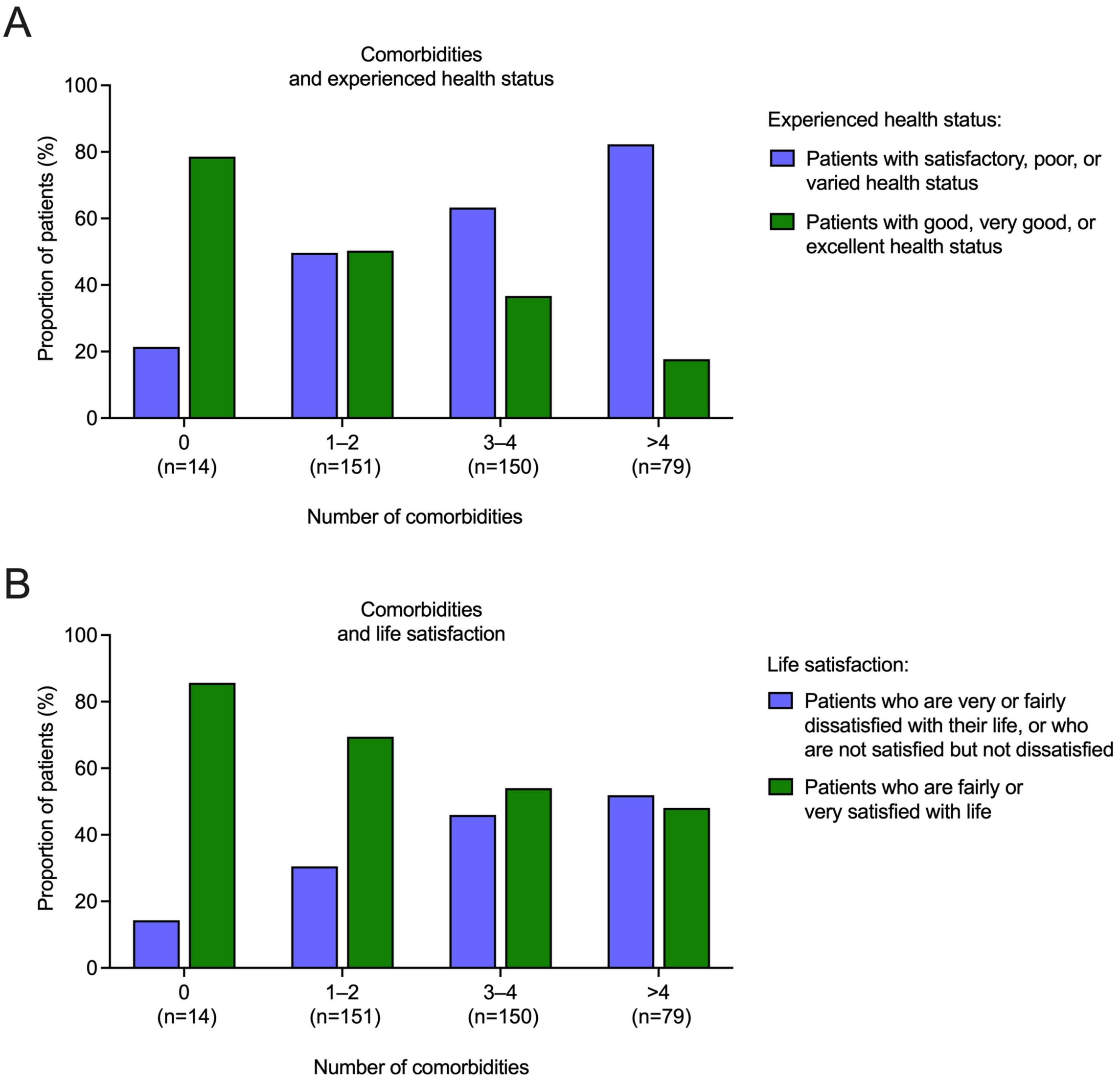

Figure 3 (**A**) Experienced health status and (**B**) life satisfaction of patients according to the number of their comorbidities. Only patients who completed the whole survey were included in the analysis (n=394).

In addition to the factors mentioned above, the two clusters also differed from each other with regards to socio-economic background factors (Table 1). The patients with better well-being were more often employed (29.9% vs 17.2%, Table 1 and Figure S2G) and more often described their economic situation as quite good or very good (56.2% vs 31.9%, Table 1 and Figure S2H) compared with the patients with poorer well-being.

Discussion

This patient survey study examined the experienced physical and psychological health status, life satisfaction, and associated factors of Finnish patients with CKD and to our knowledge, this study is the first one that represents the heterogeneous patient population in Finland.

In this study, less than half (40%) of the studied 395 patients with CKD described their health status as good and more than half (60%) reported good life satisfaction. Furthermore, the patients clustered into two groups whose survey responses differed from each other regarding experienced health status and life satisfaction in particular. The two identified groups also differed from each other with regards to several other factors. For example, the patients with poorer well-being had comorbidities more often, and while this study did not assess QoL directly with an instrument, the finding overall aligns with previous reports which have shown the association between comorbidity and QoL.[30] The

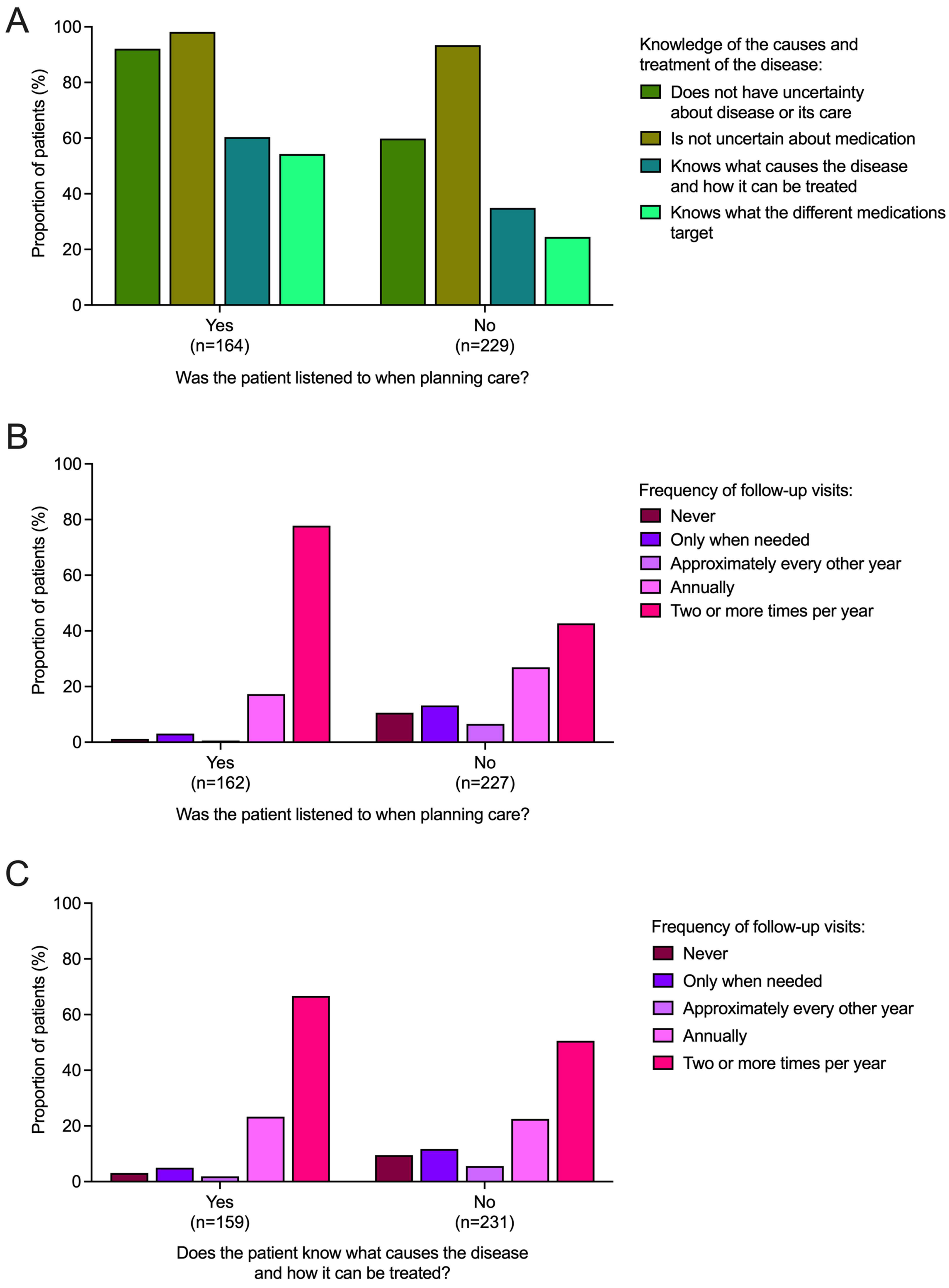

Figure 4 Associations between follow-up frequency, patient involvement in their care, and patient knowledge of the causes and treatment of the disease. (**A**) The knowledge of the causes and treatment of the disease in patients, according to their involvement in planning of care (n=393 patients). (**B**) Frequency of follow-up visits, according to the patient involvement in planning of care (n=389 patients). (**C**) Frequency of follow-up visits, according to the patient knowledge of the causes and treatment of the disease (n=390 patients).

patients with poorer well-being were also more often without any follow-up, were less committed to the lifestyle interventions, and reported more often uncertainty about how to treat the disease than patients with better well-being. Loneliness and depression were more prominent in the group of patients with poorer well-being, and they were more often in dialysis care or had received their diagnosis more recently. The results reflect a multifaceted situation, where several interconnected factors predispose the patient to poorer well-being and general dissatisfaction and can decrease the patient's sense of control of the disease as well as weaken their commitment to care. Supporting the multifaceted nature of factors affecting life satisfaction, a previous study of CKD patients also found an association with personality style and personal coping mechanisms.[25] Lower general life satisfaction has been reported for patients with end-stage kidney disease on haemodialysis compared with the general population,[26] but interestingly, no differences in life satisfaction were observed in a study that compared patients treated by hemodialysis vs kidney transplant.[25,27]

The results of this study suggest that the main action measures for supporting patients with CKD are early diagnosis and support, provided already before complications appear. Moreover, the measures should be tailor-made in that resources should be particularly focused on the identification and care of patients who are under the risk of becoming part of the group with poorer well-being. The progression of CKD is typically slow and asymptomatic, and patients with a mild form of the disease usually do not consider themselves ill, so an early CKD can only be detected via laboratory tests.[2,31] Screening of patients with diabetes or hypertension for their kidney values has increased in Finland recently, but healthy individuals are currently still not screened and thus, many early CKD cases remain undiagnosed. In addition, there are further aspects that need to be taken into account when diagnosing CKD: eg, remarkably only half of the Finnish patients with T2D whose laboratory tests indicate CKD, had a CKD diagnosis listed in their health records.[5] A British study conducted in an ethnically and socially diverse cohort also found a high prevalence of underdiagnosed CKD.[32] In the results of our survey, it was notable that only 38% of the patients had been diagnosed during a health examination and about a third (35%) on a hospital visit. Thus, more efforts should be focused on the screening and diagnosis of CKD, and especially at-risk individuals should be screened systematically. In addition to screening, a systematic charting of diagnosed patients' experienced life satisfaction could also be a tool in catching at-risk individuals at an early stage.

The patient's awareness of the disease and early commitment to care play a central role in their future well-being after a CKD diagnosis. A great number of patients with a mild form of the disease (eGFR 30–60 mL/min/1.73 m^2) are treated in primary care and thus, the improvement efforts should be directed at primary care practices, along with the development of standardized protocols for the treatment and follow-up of the disease. In this survey, less than a fifth of the participants were aware of whether they had a written plan of care. In the group of patients with poorer well-being, less than a third (31%) felt taken care of. Therefore, the data from this survey study suggest that it is crucial that the patients receive information and support already during the mild phase of the disease. This finding is supported by earlier reports emphasizing education and empowerment of the patient.[33,34] Patients with CKD should also be identified in health care systems as patients with a chronic disease and they should receive care that is comparable to other chronic diseases. Currently, their QoL has been reported as lower than patients with other chronic conditions such as cancer or heart failure,[22–24] but patient-centered care has been suggested to improve self-reported health related QoL (HRQOL).[35]

The frequency of follow-up visits differed greatly between the two clusters, with the patients of poorer well-being showing poorer commitment to consistent care. According to the current Finnish guidelines, eg CKD patients with T2D are recommended to have a follow-up visit at least once a year.[36] In this survey study, approximately every tenth patient in the group of poorer well-being reported never having follow-up visits, whereas the same was reported by less than 2% of the patients of better well-being. Overall, only a little over a half of the patients (56%) reported always receiving an invitation for the visit, so inviting all patients for follow-up visits on a systematic basis could potentially improve commitment to follow-up care. This could be achieved by eg increasing awareness of the importance of follow-up among physicians and/or employing an automated system for follow-up visit invitations.

Limitations of this survey study include the potential bias in the selection of the participants and by the uncertainties involving the reporting itself, such as patients' reporting of the frequency of their follow-up visits. Regarding the potential bias, the patients who participate in surveys are typically more aware of and interested in their disease and well-being and are active individuals in general. The study may have therefore missed the patients with the poorest health, resulting in a bias towards a more positive description of the health and life satisfaction status of the CKD patient population compared to the heterologous patient population in the real-life setting. In addition, 73% of the participants were women, which is a higher proportion than expected based on the prevalence of CKD[3] and patients from the catchment area of Helsinki University Hospital were overrepresented compared with other catchment areas. Finally, this study used k-means clustering as the identification method of the patient groups. In future studies, also other methods such as population segmentation could be considered if applicable.[37,38]

Conclusion

This survey study sheds light on the patient's perspective on the burden of CKD in Finland. The patients clustered into two groups based on life satisfaction and experienced health status: one group reports better well-being and the other group poorer well-being. Furthermore, the patients in the group of poorer well-being more often have uncertainty regarding their disease and are less committed to treatment. The results of this study showed that the main approaches for improving the experienced health status and life satisfaction of patients with CKD are: early diagnosis, increased screening, improvement of primary care practices along with development of standardized protocols for treatment, systematic follow-up of the disease, and the empowerment of the patient already in the mild phase of the disease by identifying individual needs and providing access to support and education.

Abbreviations

CKD, chronic kidney disease; GFR, glomerular filtration rate; HRQoL, health-related quality of life; QoL; quality of life; SMD, standardized mean difference; T2D, type 2 diabetes.

Data Sharing Statement

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

This survey study did not require an ethics approval or signed consent to participate. Participants gave their informed consent by participating in the voluntary survey.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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