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Barriers to and Facilitators of Sustained Employment: A Qualitative Study of Experiences in Dutch Patients With CKD

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Rationale & Objective: Although patients with chronic kidney disease (CKD) are at risk for work disability and loss of employment, not all experience work disruption. We aimed to describe the barriers to and facilitators of sustained employment experienced by Dutch patients with CKD.

Study Design: Qualitative study using semi-structured interviews.

Setting & Participants: 27 patients with CKD glomerular filtration rate categories 3b-5 (G3b-G5) from 4 nephrology outpatient clinics in The Netherlands.

Analytical Approach: Content analyses with constant comparison of interview data based on the International Classification of Functioning, Disability and Health framework.

Results: Participants were 6 patients with CKD G3b-G4, 8 patients receiving maintenance dialysis, and 13 patients with functioning kidney transplants. We identified health-related barriers (symptoms, physical toll of dialysis/transplantation, limited work capacity) and facilitators (few physical symptoms, successful posttransplantation recovery, absence of comorbidities, good physical condition), personal barriers (psychological impact, limited work experience) and facilitators (positive disposition, job satisfaction, work attitude, person-job fit), and environmental barriers and facilitators. Environmental barriers were related to nephrology care (waiting time, use of a hemodialysis catheter) and work context (reorganization, temporary contract, working hours, physical demands); environmental facilitators were related to nephrology care (personalized dialysis, preemptive transplant), work context (large employer, social climate, job requiring mental rather than physical labor, flexible working hours, adjustment of work tasks, reduced hours, remote working, support at work, peritoneal dialysis exchange facility), and support at home. Occupational health services and social security could be barriers or facilitators.

Limitations: The study sample of Dutch patients may limit the transferability of these findings to other countries.

Conclusions: The wide range of barriers and facilitators in all International Classification of Functioning, Disability and Health components suggests great diversity among patients and their circumstances. These findings underline the importance of personalized nephrology and occupational health care as well as the importance of individually tailored workplace accommodations to promote sustained employment for patients with CKD.

Complete author and article information provided before references.

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Work is a central organizing structure of adult life and is generally beneficial to people's health and well-being.[1] During the chronic kidney disease (CKD) trajectory, patients experience limitations in everyday activities because of diminished functional capacity and endurance.[2]

Editorial, p. 772

Patients may face reduced work ability, work absence due to sickness, and work disability.[3-5] From the patients' perspective, labor market participation is highly valued, as it enhances quality of life and provides a sense of identity.[6,7] However, patients with CKD may experience work-related problems like loss of career, financial problems, difficulty in returning to work, and illness stigma at work.[8]

Although many patients experience loss of work, others manage to stay at work as CKD progresses. Available literature shows high variability in employment rates across studies and countries (range of 18%-82%[9-11]). In-depth understanding of barriers and facilitators affecting sustained employment as perceived by patients with CKD is lacking, and qualitative research is scarce. McQuoid et al[12] reported that patients expressed the importance of workplaces with employee-oriented flexibility and flexible health services. A study on home dialysis found that patients receiving peritoneal dialysis (PD) experienced less disruption of work because they could perform dialysis outside working hours and could continue working.[13] Other than these limited findings on environmental factors, we found no literature regarding personal factors from the perspective of patients with CKD. Insight into barriers and facilitators based on qualitative research may enhance future person-centered health care in nephrology.[14] This is relevant because patients' increased life expectancy, including longer work life, confronts them with significant work-related problems related to their disease.

This qualitative study explores the experiences of patients with different stages of CKD regarding barriers to

PLAIN-LANGUAGE SUMMARY

Work is beneficial for people's health and well-being. Symptoms and treatment (dialysis, kidney transplant) of chronic kidney disease (CKD) limit patients' physical health, and many cannot maintain their job. Interviews with patients showed multiple factors that hindered sustained employment, such as fatigue, decreased concentration, dialysis, transplant waitlist, psychological impact, and issues at work. However, patients also expressed factors that were believed to help them remain at work, such as personalized dialysis, transplant before the need to start dialysis, having a positive attitude, job satisfaction, supports at work, and work accommodations. Clinicians can support patients by monitoring work-related problems and support needs, offering treatment (dialysis/transplant) that fits patients' work circumstances and referring patients for occupational counseling when needed.

and facilitators of sustained employment. The International Classification of Functioning, Disability and Health (ICF[15,16]), which integrates biological, individual, and societal perspectives on health, is used as a framework to distinguish between barriers and facilitators that are health- and body functioning–related, personal, and environmental.

Methods

This qualitative study used semistructured interviews to explore CKD patients' experiences of barriers and facilitators regarding sustained employment. We used the Consolidated Criteria for Reporting Qualitative Health Research (COREQ[17]).

Participant Selection

Participants were eligible for inclusion if they were aged 18-65 years and had chronic kidney disease (CKD) of glomerular filtration rate categories 3b-4 (G3b-G4), G5D, or G5T for at least 1 year. We included patients with relevant CKD-related experiences regarding work situation or work history (ie, maintenance of employment, loss of work, sick leave, work disability, return-to-work trajectory, voluntarily quitting work or pursuing early retirement, seeking a job), whereas patients without a work history were excluded (eg, homemakers, full-time students). Participants were recruited from nephrology, dialysis, and transplantation departments in 4 centers geographically dispersed over The Netherlands and from the Dutch Kidney Patients Association. We used purposeful sampling strategy[18,19] to ensure maximum variation in employment status, sociodemographic variables (sex, age, socioeconomic status), and clinical characteristics (CKD severity, dialysis and transplant modality). The medical ethics review board of University Medical Center Groningen approved the study (M15.169470). All participants indicated their informed consent by signing a written consent form.

Data Collection

We collected data using semistructured in-depth interviews with a topic-based interview guide consisting of open-ended questions about the impact of CKD on work and circumstances and factors that enabled or hampered sustained employment (Item S1). In consultation with the research team, a preliminary interview guide was developed and evaluated after the first interview. Interviews were conducted by 2 researchers (SFvdM and MAA) who were trained and experienced in qualitative research. Researchers and participants were not acquainted before the study. Interviews were audiotaped and transcribed verbatim, and field notes were written after each interview. Interviews (duration, 30-154 min) took place between June 2015 and July 2019 at participants' homes (n = 23), at another place of their choice (n = 2), or by telephone (n = 2). Data collection stopped after reaching saturation (ie, when no new concepts emerged during additional interviews).

Data Analysis

In accordance with guidelines for qualitative data analysis, we combined content analyses with constant comparison, ie, the data-analytic process of ongoing comparison and contrasting of interview data and emerging categories and themes.[20-22] The process of (re)reading transcripts led to brief narrative summaries of participants' experiences in response to the research questions, ensuring holistic understanding of each interview. SFvdM and AV independently read and coded the first transcript, discussed and compared their findings, and generated a first draft of a codebook, which was adapted during the coding process. SFvdM and MAA coded the remaining transcripts using ATLAS-ti version 8.4 (ATLAS.ti Scientific Software Development). They kept memos to record reflections, achieve abstraction, and conceptualize data. Broader review identified categories and (sub)themes to be discussed within the research team and interpreted according to the ICF framework regarding barriers and facilitators related to (1) health and body functioning, (2) personal factors, and (3) environmental factors. Data analysis began after 10 interviews and continued until additional interviews delivered no new concepts and data were considered saturated. The validity of the results was discussed during a meeting of experts (n = 7): 3 occupational health professionals (occupational health physician, insurance physician, labor expert), 1 occupational health researcher with a qualitative research background, and 3 research team members (SFvdM, MAA, AEdR). In addition, study results were discussed with a social advisor from the Dutch Kidney Patients Association. Finally, SFvdM and MAA selected illustrative quotations; these were translated by an external bilingual translator and reviewed by SFvdM to ensure adequacy.

Results

Overview of Participants

Of the 27 study participants, 17 (63%) were employed (≥30 h/wk, n = 9; 12-29 h/wk, n = 4; <12 h/wk, n = 4; Table 1). Most employed participants had mentally demanding jobs (n = 11), 4 had physically demanding jobs, and 2 had jobs with mixed tasks. Of those employed, 5 participants received wages and additional partial work disability benefits. Of the 10 nonworking participants, 4 received work disability benefits. Seven participants were (partially) work-disabled because of CKD, and 2 reported disability due to a combination of CKD with other conditions (ie, spinal stenosis, "burnout").

Six patients (22%) had CKD G3b-G4 (CKD duration, 2-19 years), and 8 (30%) had G5D (continuous ambulatory peritoneal dialysis, n = 4; in-center hemodialysis, n = 4; dialysis vintage, 16-34 months). Two of the patients with CKD G5D had returned to dialysis after kidney transplant failure. Thirteen patients (48%) had undergone kidney transplant (CKD G5T; deceased donor, n = 3; living donor, n = 6; preemptive living-donor transplant, n = 4; time since transplantation, 1-11 years). Four of these had received a repeat transplant.

We organized the identified barriers and facilitators according to the ICF framework into (1) health- and body functioning–related barriers and facilitators, (2) personal-related barriers and facilitators, and (3) environmental-related barriers and facilitators.

Health- and Body Functioning–Related Barriers and Facilitators of Sustained Employment

Participants experienced barriers to and facilitators of health and body functioning related to 4 themes: physical symptoms, cognitive symptoms, kidney replacement therapy (KRT), and general health and functioning. Box 1 presents illustrative quotations.

Physical Symptoms

Fatigue and lack of energy were expressed as important barriers and sometimes resulted in complete inability to work. Even after successful transplant, patients experienced fatigue. Patients with polycystic kidney disease explained that symptoms (eg, infection, pain, hematuria) compelled them to call in sick. However, some patients experienced few or no physical symptoms, which facilitated sustained work functioning.

Cognitive Symptoms

Some patients specifically reported that poor concentration and focus, memory problems, and difficulties with calculating and reading were barriers to working.

Table 1. Characteristics of Study Participants

Characteristic	Total (N = 27)	CKD G3b-G4 (n = 6)	Dialysis (n = 8)	Transplantation (n = 13)
Male sex	18 (67%)	4	5	9
Age, y[a]	46.2 ± 10.2	46.7 ± 11.2	44.6 ± 11.7	46.9 ± 9.7
Age group				
18-29 y	3 (11%)	1	1	1
30-39 y	6 (22%)	1	2	3
40-49 y	6 (22%)	–	2	4
50-59 y	9 (33%)	4	2	3
60-65 y	3 (11%)	–	1	2
Born in The Netherlands	24 (89%)	5	6	13
Educational status				
Primary or lower secondary	5 (19%)	2	2	1
Upper secondary	13 (48%)	3	5	5
Tertiary	9 (33%)	1	1	7
Employment status				
Full-time, ≥30 h/wk	9 (33%)	2	3	4
Part-time, 12-29 h/wk	4 (15%)	2	–	2
Part-time, <12 h/wk	4 (15%)	1	1	2
Not employed	10 (37%)	1	4	5
Receiving work disability benefit	9 (33%)	3	1	5
Primary kidney disease				
Glomerulonephritis	7 (26%)	2	2	3
Renal vascular disease/diabetes	3 (11%)	–	3	–
Polycystic kidney disease	5 (19%)	2	–	3
Other/unknown	12 (44%)	2	3	7

Abbreviation: CKD, chronic kidney disease.
[a]Mean ± standard deviation.

Box 1. Health Condition and Body Functioning–Related Barriers and Facilitators of Sustained Employment, With Exemplar Quotations

Physical symptoms

Barrier: Fatigue

"The tiredness, that wears you out. Even if you've had a transplant, you still feel tired." (Male, age 51 y, DDKT)

"You get up in the morning and you're tired already. So, you do something, then you need to rest again... This has made work totally impossible for me." (Male, age 39 y, PD)

Barrier: Symptoms caused by kidney cysts

"I had a lot of bleeding and infections, so I often had considerable pain and had to call in sick. Sometimes I couldn't even walk." (Male, age 61 y, PLDKT)

Facilitator: No or few physical symptoms

"I don't feel sick and I do everything... I don't feel anything, so then you just keep going, don't you?" (Female, age 59 y, non-KRT CKD)

Cognitive symptoms

Barrier: Poor concentration/memory

"The most important reason why I stopped working was that I just couldn't concentrate or remember things... I made mistakes... When I had to calculate a price... I just couldn't manage" (Male, age 49 y, non-KRT CKD)

"I can hardly read books anymore... In my [profession], it is handy to be able to concentrate and remember things." (Male, age 33 y, non-KRT CKD)

Toll of KRT

Barrier: Physical toll of dialysis

"I was on dialysis for almost 6 years, and, in the beginning, it really went pretty well... but the longer it went on, the harder it got." (Male, age 47 y, DDKT)

Barrier: Side effects of immunosuppressive medication

"After a transplant, it's not over... You still have a lot of residual complaints, and, for me, this probably comes from the medication. If you have a lot of stomach and bowel problems, they really make you tired." (Male, age 61 y, PLDKT)

"I had the problem of severe tremors caused by the antirejection medication. I thought, 'Oh no, if this is lasting, then I will have a big problem.' Luckily, they substantially reduced this medication and increased the other one. I have hardly any problems anymore... At one point, I couldn't even send a text message." (Male, age 36 y, PLDKT).

Facilitator: Successful recovery posttransplantation

"In the hospital, I had a [donor] kidney function of 76%... After I was home for 14 days, I felt fitter and had more energy... I had my transplantation in March and I started work again in June, just a few hours... I gradually increased my hours, and, in July, I was back to work full time." (Male, age 60 y, LDKT)

General health and functioning

Barrier: Limited work capacity

"I was there half-time, and maybe I functioned about 40%. You had good days and bad days." (Female, age 47 y, RLDKT).

Facilitator: No comorbidities

"Because I don't have diabetes or cardiovascular problems or whatever... I do sports and whatever I want to do." (Female, age 47 y, RLDKT)

Facilitator: Good physical condition

"Because, up until the transplant, I just kept working, my muscles remained strong, and 14 days after the transplantation, I was able to go up and down the stairs." (Male, age 36 y, PLDKT).

Abbreviations: DDKT, deceased-donor kidney transplant; LDKT, living donor kidney transplant; non-KRT CKD, chronic kidney disease not requiring kidney replacement therapy; PD, peritoneal dialysis; PLDKT, preemptive living-donor kidney transplant; RLDKT, repeat living-donor kidney transplant.

Toll of KRT

Many participants described the physical toll of dialysis and transplant. As barriers to work participation, they reported dialysis side effects, complications related to dialysis catheters, frequent surgical procedures for dialysis access, and long-term dialysis. Barriers named by transplant recipients were side effects of immunosuppressive medication and decreased functional capacity, whereas successful transplant without complications was described as enabling a return to work.

General Health and Functioning

Some participants described that having good days and bad days affected their work capacity. Having no other chronic illnesses and being in good physical condition were described as enabling work participation before and after transplant.

Comparison Between Nonemployed and Employed Participants

Analysis showed that nonemployed participants reported physical and cognitive symptoms and limited work capacity as barriers. Employed participants described lack of

Box 2. Personal-Related Barriers and Facilitators of Sustained Employment, With Exemplar Quotations

Psychological impact

Barrier: Nonacceptance of CKD

"...Could not at all accept that I was sick. Stubbornness, anger, you name it... Just not to be labeled as 'sick' because that felt like failure." (Male, age 33 y, non-KRT CKD).

Barrier: Ignoring limits

"I think that has been my pitfall, that I actually always just kept going on, keeping at it, and then, at some point, you notice that you're actually very sick." (Female, age 51 y, PLDKT)

Barrier: Negative emotions and stress

"You walk in there and then you look at all those dialysis patients. I've had quite a lot of trouble with that... and sitting at home for 2 years... The confrontation with thinking about my future, the psychological strain it puts on me." (Male, age 50 y, non-KRT CKD).

"It [occupational support] was a mess. I thought, 'what do I do now?'... 'Who will help me? There are all sorts of organizations, but who should I call on?'... I couldn't do it anymore, I was like: 'I just don't know what to do'." (Female, age 51 y, PLDKT).

Positive disposition

Facilitator: Perseverance

"How do you deal with the situation? Is your glass always half empty or half full? That makes a lot of difference. You can just give up, and then you won't come to anything, or you try to keep going." (Male, age 61 y, PLDKT).

Facilitator: Willpower

"Willpower... I just wanted to get back on my feet... I just want to live a normal life again" (Male, age 44 y, PD)

Perception of work

Facilitator: Job satisfaction

"I like the work... I am glad to go to work. I think, if I had had worthless work and found it annoying, I would have handled things differently." (Male, age 61 y, PLDKT)

Attitude toward work

Facilitator: Openness at workplace

"I thought, 'now I'm going to tell you.' She [the manager] will say... 'That won't work, because they [employer] have fired so many people.' I thought, 'I'm next'... She says, 'I also have people around me who have had kidney failure. They now have a [donor] kidney and it's going really well. We are also going to support you'... 'Take all the time you need, don't feel rushed about going back to work. When you're ready, let me know'." (Female, age 42 y, HD)

Facilitator: Willingness to work

"Right after the transplantation, I said, 'I really intend to go back to work for 36 hours'... I wanted to go back to work again as much as possible." (Male, age 46 y, DDKT)

Facilitator: Flexibility

"I think it's up to yourself too. Are you willing to do something else?... If you, as an employee, say, 'this is my job and that is what I want to do and nothing else,' then it becomes very difficult. So I think it's give and take from both sides." (Female, age 47 y, RLDKT)

Person-job fit

Barrier/Facilitator: Work experience

"Then I started a new work situation... You actually had to do 200 percent, and, of course, I had very little percent left... That created a lot of tension." (Female, age 51 y, PLDKT)

"The fact that I've been doing the job for a long time, that you can run a little more on routine... can fall back on certain basic skills... more on autopilot. I think, if I had really had to do entirely new things, it would have been difficult." (Male, age 47 y, DDKT)

Facilitator: Professional expertise

"I did have a certain input that others didn't have. A way of looking, talking, and acting. I was always more innovative." (Male, age 57 y, RLDKT).

Abbreviations: DDKT, deceased-donor kidney transplant; HD, hemodialysis; LDKT, living-donor kidney transplant; non-KRT CKD, chronic kidney disease not requiring kidney replacement therapy; PD, peritoneal dialysis; PLDKT, preemptive living-donor kidney transplant; RLDKT, repeat living-donor kidney transplant.

physical symptoms and favorable general health and functioning as facilitators.

Personal Factor–Related Barriers and Facilitators of Sustained Employment

Personal barriers and facilitators incorporated 5 themes: psychological impact, positive disposition, perception of work, attitude toward work, and person-job fit (Box 2).

Psychological Impact

Some participants expressed having difficulty accepting their CKD status. They ignored symptoms and limitations and exceeded personal boundaries by pushing themselves to the limit. For some patients, being confronted with CKD and the prospect of dialysis imposed an enormous psychological burden, making them unable to work for long periods. Some patients felt overwhelmed and stressed by

complex procedures involved in obtaining social security support.

Positive Disposition

Participants referred to general personal assets that were believed helpful to maintain employment: having a positive outlook, perseverance, focusing on possibilities, and willpower to live a normal life.

Perception of Work

Participants expressed that having a job they liked and enjoying being at work were important facilitators.

Attitude Toward Work

Some patients reported that their openness about their disease, in explaining its symptoms and limitations to others, ensured support in the workplace. Some reported that maintaining contact with the workplace during sick leave helped them to keep their jobs. Some believed their willingness and positive intention to work, cooperative attitude toward the employer in showing initiative at work, and being flexible had been helpful.

Person-Job Fit

Some participants indicated that long work experience made them able to do their job as a matter of routine. Others found new jobs or new work tasks more demanding. Some participants believed that valued contributions and specific professional expertise and skills made them an asset to their employers.

Comparison Between Nonemployed and Employed Participants

Although factors did not differ between the nonemployed and employed participants, the direction of their experiences differed. Nonemployed participants experienced the psychological impact of having CKD and lack of person-job fit as barriers. Employed participants reported having a positive disposition and attitude toward work and having a good person-job fit as facilitators.

Environmental Factor–Related Barriers and Facilitators of Sustained Employment

Environmental barriers and facilitators could be divided into 8 themes: nephrology care, occupational health services, social security system, employer characteristics, work characteristics, work accommodations, support at work, and support at home (Box 3).

Nephrology Care

Nephrology care–related barriers included long wait times for transplant and limitations imposed by CKD treatment, such as a hemodialysis central venous catheter that prohibited working in an industrial workplace because of possible infection. With respect to dialysis preference, patients reported the importance of being able to integrate dialysis into their work schedule. Some patients preferred automated PD, which allowed flexible scheduling and independence. Others preferred in-center hemodialysis because this modality offered treatment-free days or the possibility of flexible scheduling permitting changes to treatment days, as facilitated by the dialysis center. Preemptive transplant recipients reported advantageous post-transplant recovery compared with patients who had undergone dialysis, and mentioned their ability to stay at work before the transplant.

Occupational Health Services

Most patients valued the expertise and advice of their occupational physician. Some, however, described a lack of continuity in occupational health physicians, and that receiving inappropriate advice reduced the feeling of being supported toward sustained employment.

Social Security System

Only a few participants reflected on the effect of the social security system. Some believed that their partial disability or young handicapped status stimulated employers to reintegrate or hire them, whereas others were afraid to lose a substantial part of benefits when returning to work.

Employer Characteristics

Patients reported company reorganizations that made their jobs redundant. Those working in large companies indicated that their employers had opportunities and resources to achieve the necessary work accommodations. Some experienced a social climate in which individuals' contributions were valued, thereby facilitating return to work.

Work Characteristics

Participants believed that long working hours, temporary employment contracts, and high physical demands contributed to their dropping out of work. Work characteristics that were considered helpful in maintaining work were having a job requiring mental rather than physical labor and flexible working hours.

Work Accommodations

Patients reported helpful adaptation of work tasks, such as fewer physical and mental work demands, more routine work activities, fewer extra duties, and working at a slower pace. Another facilitating adjustment was reduction in daily working hours to allow patients to recover. Working a split shift allowed patients time to rest between shifts, and avoiding evening and night shifts helped patients to keep their jobs. One patient found it helpful to reduce external appointments and to minimize commuting by working at 1 location. Patients undergoing dialysis indicated that the opportunity to work from home or during in-center hemodialysis enabled them to continue working.

Box 3. Environmental-Related Barriers and Facilitators of Sustained Employment, With Exemplar Quotations

Nephrology care

Barrier: Long wait time for transplantation

"The donor list [6 y] is a limiting factor. I would have preferred to have had a donor kidney a little earlier... Then, the damage would probably have been more limited. Financially, but also medically." (Male, age 47 y, DDKT)

Barrier: HD catheter–related risk for infection

"Because of rejection of my donor kidney, I had a tunneled central line for a while... At most companies, things are not always clean, and, in the hospital, they preferred not to allow that... that's a big risk. So then they said: 'Working? No'." (Male, age 25 y, PD)

Facilitator: Personalized dialysis

"When I got the catheter for peritoneal dialysis, I went back to work... What makes that [working full time in shifts] possible is that I do peritoneal dialysis... You have fewer ups and downs [compared with HD]... I'm very glad that I can do this form of dialysis and that I can just do it at home every night... You're not so bound to fixed times, like having to be somewhere then and then." (Male, age 25 y, PD)

"Because of my work, I can't [dialyze] every day. I do irregular work, which makes it very difficult for me. That is why I opted for hemodialysis. I dialyze on Monday, Wednesday, and Friday afternoons, as late as possible... I change quite a lot, also in terms of days. Because of my work, I have to switch Fridays with Saturdays, or Mondays with Sundays, or sometimes I have to go in the morning. They [dialysis center] are very flexible in that." (Male, age 50 y, HD)

Barrier: Preemptive transplantation

"There were men who had been on dialysis, and they weren't able to go up and down the hall. Of course, I was also weakened after 2 weeks in the hospital, but then you already have such a huge advantage over people who have been on dialysis. That's why I think it's just very important to avoid dialysis." (Male, age 36 y, PLDKT)

Occupational health services

Barrier/Facilitator: Occupational advice

"The [Social Security Institute] is focused on getting you started... The work coach thought I could start my own company... but not everyone is an entrepreneur... they didn't take that into account... With your own business, you're never really done... In fact, a business of your own is even more demanding than just a normal job." (Male, age 47 y, DDKT)

"...Those changes of these [occupational health] physicians... Then, my employer also changed their Occupational Health and Safety office, and I lost the one [occupational health physician] I had already been to twice before." (Female, age 51 y, PLDKT)

"My occupational health physician also helped me a lot. He didn't want to send me back to work so soon... he was very careful. He had a friend who was a nephrologist, and he got a lot of information from him." (Male, age 60 y, LDKT)

Social security system

Barrier/Facilitator: Disability pension

"I've been lucky that I've been declared completely work-disabled, and have only had to lose a fifth [of my income]... If, for example, you have to find a job for 20%... then employers are not standing in line to get you. And then your income [benefits] gets hit, and, before you know it, you've lost half... The risk is too great... If I go to work now, I'll stand a chance of losing my safe income." (Male, age 51 y, DDKT)

"The Wajong status [disablement assistance for handicapped young persons]... takes away the threshold for them [employer]... First of all, they get a bit of wage dispensation... and, if I drop out, they don't have to pay my wages. Then I just fall back on the [Social Security Institute]." (Male, age 28 y, non-KRT CKD)

Employer characteristics

Barrier: Reorganization

"There was a reorganization... Then a thousand people were laid off in one go... and I was one of them." (Male, age 47 y, DDKT)

Facilitator: Large employer

"It was a factory, so you had the office, with sales office, administration, logistics department, financial administration, automation... There were opportunities [for work adjustment]." (Female, age 47 y, RLDKT)

Facilitator: Workplace social climate

"It's also a company with a social impact. They look at your input, at who you are as a person... Colleagues had also been sick... Everyone was actually treated very well." (Male, age 57 y, RLDKT)

Work characteristics

Barrier: Temporary employment contract

"You worked there with annual contracts... and then I stayed at home sick... At the end of the contract period, you had an evaluation interview... Then they [employer] said: 'Your contract won't be renewed'." (Male, age 33 y, non-KRT CKD)

Barrier: Long working hours

"I was there 10 hours a day; that really got to me." (Female, age 38 y, HD)

(Continued)

Box 3 (Cont'd). Environmental-Related Barriers and Facilitators of Sustained Employment, With Exemplar Quotations

Barrier: Physically demanding job

"I had houses to clean... but 2 bathrooms, a huge house, that was so demanding that I just said, 'No, I have to stop'." (Female, age 65 y, PD)

Facilitator: Job requiring mental rather than physical labor

"...This work takes a lot of thinking; it doesn't take a great physical effort. If it had, I would have had to stop working much sooner. I was able to keep up because it wasn't so physically strenuous." (Male, age 61 y, PLDKT)

Facilitator: Flexible working hours

"If I was a bit more tired from time to time, especially in the morning... I would come to work a little later. The advantage was that I could do that... as long as I made my 8 hours... My working hours were a bit flexible." (Male, age 47 y, DDKT)

Work accommodations

Facilitator: Adjustment of work tasks (fewer demands)

"I was able to move to the control room. I just had the luck to be able to keep working. But I couldn't do any other work activities... Because of the adjustments with the help of the occupational health physician, I was able to keep on working... I had light jobs." (Male, age 60 y, LDKT)

"That I don't do certain things anymore, that there is space for that... That we just decided among ourselves that my core task is teaching... That's pretty routine... Whereas, when you do projects, you have to dive in completely—the contacts, lots of conversations... things that demand extra energy." (Male, age 44 y, PD)

Facilitator: Reduction of working hours

Interviewer: "What is the impact of working half a day?" Patient: "You noticed that you could keep going... I noticed that I could handle things better in my private life at night. I can't handle everything yet, but it gives you a bit more air." (Male, age 61 y, PLDKT)

"It's not continuous [but working in split shift]. I think that, if I was going to clean for 5 hours in a row, I wouldn't be able to keep that up." (Female, age 36 y, PLDKT)

Facilitator: Working in 1 location

"At the time I had 2 work locations… When my kidney function dropped so much that I got anemia, I said, 'I can't handle the other location anymore, the travel time and all the hassle.' Then I started working completely at 1 location again." (Male, age 61 y, PLDKT)

Facilitator: Remote working

"I just work 100%, full time, 2 or 3 days at work or 2 or 3 days at home. I also take a lot of my work with me to dialysis... I put some documents on my laptop and can work them out nicely there... So I consider it as if I go to work in the afternoon... On the days when I dialyze, I usually work at home in the morning." (Male, age 50 y, HD)

Support at work

Facilitator: Supportive employer

"All the room I got at work, and all the consultations ... It's never a problem if I have to go see a doctor in between." (Male, Age 44, PD)

"We built it up very slowly. After less than a year, I was completely back to work. That was thanks to my employer, that he said, 'Just pick things up slowly'." (Male, age 36 y, PLDKT)

Facilitator: Supportive manager

"I also have an unbelievably nice supervisor who really takes me into account... Every now and then, she comes to talk and asks how I am doing... When I'm in the hospital, she is worried and asks how my kidney is doing." (Female, age 36 y, PLDKT)

"It's so positive, the support of your manager... I felt that he was really involved and that he was concerned that I was doing well... 'Just see for yourself what you can handle'." (Male, age 46 y, DDKT)

Facilitator: Supportive coworkers

"...That adjustments are made and that colleagues also accept this. Because the work I did is now being distributed among others. That also takes some consideration." (Male, age 44 y, PD)

Facilitator: Facilitating PD exchange at work

Interviewer: "What helped you most?" Patient: "Well, that I could do peritoneal dialysis at work.... If you can't do that, then you'll work fewer hours because then you'll go home sooner... That special room in the office building, that also gives you more motivation to keep on working." (Male, age 60 y, LDKT)

Support at home

Facilitator: Support from partner

"My husband has supported me a lot... He just helps a lot... Four days a week, he cleans up, does the laundry, before he goes to work. When I come back from my dialysis, the house is completely tidied up. That day, all I have to do is cook... And the day I work, too... He vacuums, empties the dishwasher, does all the usual jobs... and that's why it just goes well." (Female, age 42 y, HD)

Abbreviations: DDKT, deceased-donor kidney transplant; HD, hemodialysis; LDKT, living donor kidney transplantation; non-KRT CKD, chronic kidney disease not requiring kidney replacement therapy; PD, peritoneal dialysis; PLDKT, preemptive living-donor kidney transplant; RLDKT, repeat living-donor kidney transplant.

Support at Work

Participants who worked reported that employers granted the necessary space for a gradual return to work and accommodated medical appointments after periods of sick leave. Managers facilitated patients' return to work by being considerate and attentive, fostering open communication, and accommodating work adjustments. Coworkers were described as understanding when they offered help and took over job duties, enabling participants to remain at work. One patient mentioned that being able to perform PD exchanges in a clean area at work helped to increase his working hours.

Support at Home

Patients expressed that their partner's support enabled them to manage daily life and stay at work. Partners gave practical support (eg, with household tasks) and also gave emotional support.

Comparison Between Nonemployed and Employed Participants

Environmental factors differed between nonemployed and employed participants. Barriers for nonemployed participants were related to employer and work characteristics. Facilitators for employed participants were personalized KRT, occupational advice, a job requiring mental rather than physical labor, a flexible workplace with accommodations, and support at work and at home.

Synthesis of Perceived Barriers to and Facilitators of Sustained Employment

Analysis of patients' perceptions indicated a complex set of barriers and facilitators unique to each individual patient and related to multiple sociodemographic, clinical, and personal characteristics and a variety of work-related contexts and dynamics. Figure 1 integrates these findings according to the ICF framework. Environmental and personal factors were organized into "work-related" factors and "other" environmental and personal factors.

Discussion

This study aimed to explore barriers to and facilitators of sustained employment from the perspective of patients with different stages of CKD. This qualitative in-depth interview study indicates that the health conditions and CKD treatment of individual patients greatly vary, as do their personal and work characteristics. Patients identified a complex variety of barriers and facilitators in all components of the ICF framework, indicating that sustained employment is affected by multiple interacting factors. Along with health-related and personal factors, environmental barriers and facilitators appear to play a significant

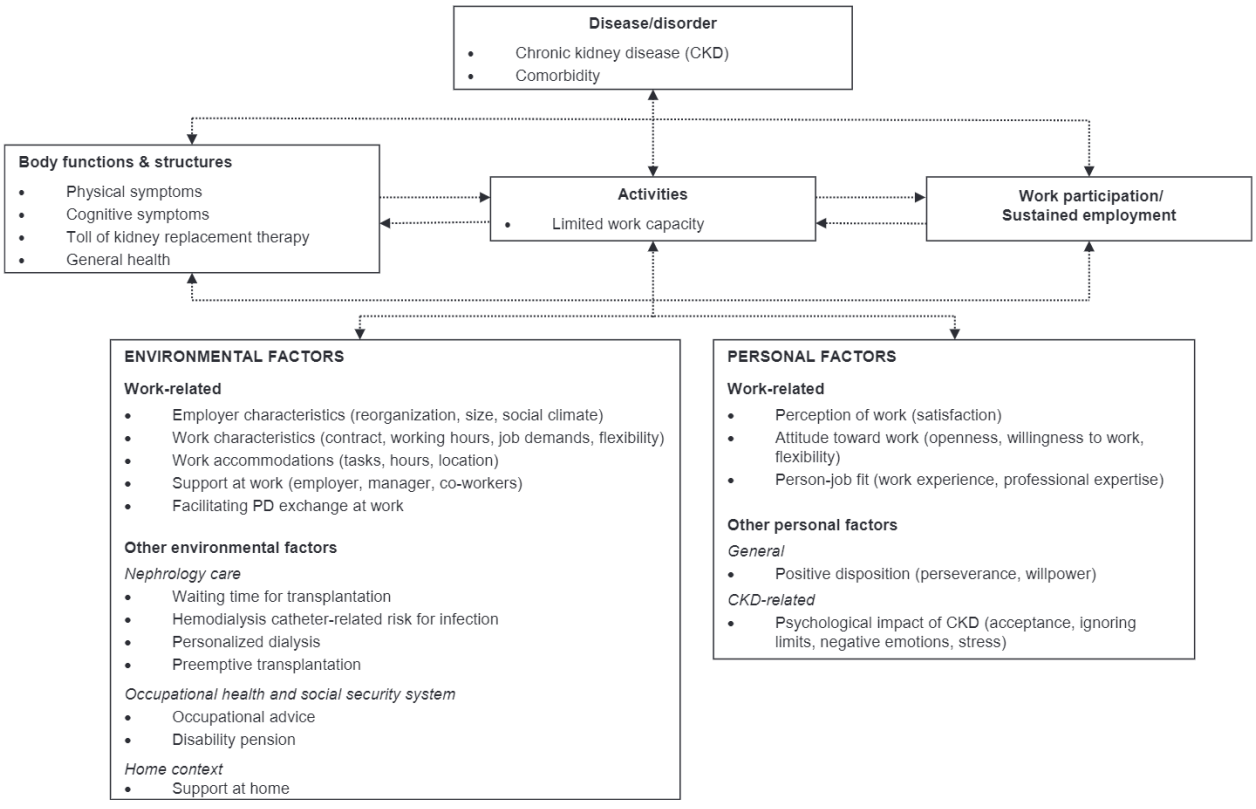

Figure 1. Factors (barriers/facilitators) of sustained employment classified according to the International Classification of Functioning, Disability and Health.[15,16]

Box 4. The Dutch Social Insurance System

In The Netherlands, the health care system and health insurance are separated from the social insurance system. Treating physicians are not allowed to write sick notes for their patients. Instead, accredited occupational physicians hired by employers or accredited insurance physicians working for the Dutch Social Security Institute (SSI) check the legitimacy of sickness absences and long-term work disability (ie, not being able to work because of a medical condition, regardless of its cause). Employers have a large responsibility regarding sickness absence guidance and payment. The incentive to promote labor participation includes a sick leave of 2 years, with the employer having to pay ≥70% of the salary instead of paying premiums or other contributions to a sickness absence fund. This Extended Payment of Income Act reduces the role of the state in controlling work disability. Further, the Gatekeeper Improvement Act requires employers, employees, and occupational physicians to fulfill certain tasks during workers' sickness absence to promote prompt reintegration into work.[45] After a sickness absence of 2 years, the Work and Income Act, executed by the SSI, allows employees to apply for a disability benefit. Insurance physicians assess applicants' functional limitations, and labor experts determine residual earning capacity. Work disability can be full or partial and granted permanently or temporarily. Partially disabled individuals with residual earning capacity are expected to reintegrate into paid (part-time) work at their employer or enroll in other more appropriate (part-time) jobs.

The Dutch social insurance system and the central role of employers offer patients with chronic kidney disease opportunities such as work adaptations, temporary sickness absence, or work disability with (gradual) return to work in case of improved health (eg, after successful transplant), and the possibility of combining permanent partial work disability with a part-time job. Despite differences in social policies between countries, employers have an important role in the dynamic process of sustained employment among patients with chronic diseases.[46]

role in the process of maintaining work throughout the uncertain and unpredictable CKD trajectory. Even after successful transplant, sustained employment is a challenge; patients continue to be at risk of an episode of progressive graft failure and recurrent dialysis. To promote sustained employment, a biopsychosocial approach with personalized health care and support seems to be a key factor.

Our study integrated findings of previous qualitative studies on barriers and facilitators in other chronic disease populations into a comprehensive framework. Fatigue and concentration problems limited the capability to work.[23,24] In addition, our study identified absence of comorbidities and good physical condition as relevant facilitators. A systematic review of personal-related factors of work participation identified optimism, self-efficacy, motivation, coping, and feelings of control.[25] Other studies indicated the importance of acceptance,[26,27] disclosure,[27,28] perseverance, and setting boundaries.[28,29] Regarding type of job, the advantage of having a job with mental rather than physical demands, as expressed by our study participants, was also reported by patients with breast cancer.[24] Our study added the insight that participants saw the role of their own flexibility regarding work and person-job fit as important.

Regarding the environmental context, support at work,[23,26,27,29] at home,[30] and by occupational physicians[23] were facilitative. Two studies identified barriers related to the attention of health care professionals for employment, occupational health service provision, and complexity of social security regulations.[24,28] Our study also identified temporary employment contracts as a barrier; thus, the recently increased proportion of temporary workers resulting from employment protection legislation reforms may be a risk for workers with CKD.[31]

In addition to generic barriers and facilitators, we identified others that are specific to CKD. Dialysis is an invasive and time-consuming therapy that often interferes with participation in work.[12,32,33] In transplant recipients, we found that side effects due to immunosuppressive medication and prolonged fatigue interfered with work participation.[34] Patients indicated that decreasing the period of dialysis by timely transplant, or even completely avoiding dialysis by preemptive transplant, helped them to stay at work.[35] Our results confirm the importance of appropriate treatment-job fit, that is, if KRT fits individual patients' situations and preferences.[36] Being able to self-administer PD at the workplace and to work during in-center hemodialysis indicates that the degree of control, independence, and flexibility in dialysis scheduling affects patients' ability to integrate dialysis with work participation.

Our study identified a range of facilitative work accommodations that correspond with previous qualitative studies.[26,27,29,37] Adjustment of work tasks into less demanding duties, reduction of weekly working hours, flexibility in work tasks and working hours, and job control addresses CKD effects like lack of energy and fatigue, limited cognitive functioning, and time needed for dialysis. Work accommodations can be temporary, as during the gradual return to work posttransplant; long-term in case of lengthy waiting lists for a transplant; or permanent in patients with persisting limitations. In patients with CKD G3b-G5, preventive supportive intervention may initiate timely customized workplace adjustments to reduce sickness absence and work disability.[38] Clearly, job demands must correspond with patients' individual work ability, that is, person-job fit.[39]

One implication for nephrology health care arising from our study is the need for specific attention to work-related issues, a development also seen in other medical specialties.[40,41] This requires medical staff to have a proactive attitude to assess a patient's working situation, optimize the treatment-job fit, monitor work-related problems and support needs, and refer for occupational counseling when needed. Occupational health care should be helpful in optimizing the person-job fit. Along with patient-centered

information, early identification of work-related problems and implementation of strategies to empower patients may support and optimize the integration of CKD treatment and work.[42] A short period of dialysis with flexible schedules, home dialysis, and preemptive transplant may also be helpful, as may the minimization of side effects of immunosuppressive regimens.[43,44] Some individual characteristics or context-related factors, however, are difficult to modify. For example, patients reflected how lucky they felt having certain circumstances (eg, office work and/or a supportive employer/partner) that made it easier to stay at work. Future development and evaluation of interventions aimed at mitigating barriers and promoting facilitators are needed, with the ultimate aim of assisting patients in sustained employment.

Our study provides an in-depth, comprehensive exploration into the barriers to and facilitators of sustained employment for patients with CKD. Strengths of the study are its inclusion of patients with a long history of CKD across all stages, representing a wide variety of backgrounds, treatments, and work experiences. In addition, the exploratory study design promoted in-depth reflection by patients. The study was performed in The Netherlands, which has a social insurance system designed to foster (re)employment; this involves a large responsibility for employers regarding sickness absence guidance and payment (Box 4). This key role for Dutch employers may have resulted in an overestimation of employer-related facilitators and may limit the transferability of some findings to other countries. Moreover, our study sample was predominantly composed of men, and participants were generally well educated, possibly resulting in fewer experiences typical of female or less educated patients. Nevertheless, participants had diverse employment outcomes, CKD stages, and treatment trajectories, and data included varying positive and negative experiences.

On the level of the ICF domains, results indicated that the experiences of many factors were bidirectional, ie, either a facilitator or a barrier, which indicates a strong relation with sustained employment. According to the principle of analytical induction,[22] support for a relation is strongest when evidence is found in both directions. Although we found only unidirectional relations in some factors (eg, cognitive symptoms, work accommodations, support at work/home, psychological impact, positive disposition, perception, attitude toward work), these factors can still be considered as influential in the process of sustained employment.

In conclusion, patients with CKD reported a wide range of barriers to and facilitators of sustained employment; this indicated a great diversity in individual patient, health care, and work characteristics, and the complexity with which these multiple interacting factors influence maintenance of work throughout the CKD trajectory. Besides health-related and personal factors, environmental factors related to CKD treatment and nephrology care, occupational health care, and workplace and home context were experienced as playing significant roles. Specific attention to work-related issues in nephrology health care, as well as personalized CKD treatment and individual tailoring of workplace accommodations, seem to be key factors for patients of working age with CKD to promote their sustained employment.

Supplementary Material

Supplementary File (PDF)

Item S1: Interview guide.

Article Information

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