

Experiences and Disease Self-Management in Individuals Living With Chronic Kidney Disease: Qualitative Analysis of the National Kidney Foundation's Online Community

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Research Article

Keywords: Chronic kidney disease (CKD), information support, emotional support, online forum, qualitative research, self-management

Posted Date: December 14th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-1125087/v1>

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Version of Record: A version of this preprint was published at BMC Nephrology on March 4th, 2022. See the published version at <https://doi.org/10.1186/s12882-022-02717-7>.

Abstract

Background: Self-management of chronic kidney disease (CKD) is one of the keys in improving CKD outcomes and quality of life. There has been an increased use of online health communities to share the experiences of those living with CKD. By analyzing the CKD online forum data, this study aims to: 1) understand the experiences and challenges of individuals living with CKD, and 2) explore how online communities may help CKD patients in improving CKD self-management.

Methods: Publicly available posts of peer interactions on the National Kidney Foundation's online community for people affected by CKD were extracted in April 2021 using computer programming. A total of 20,436 posts were collected, of which 400 posts were analyzed using inductive thematic analysis, and saturation was reached. Two researchers coded each post independently, and discrepancies were discussed to reach consensus.

Results: The analysis identified seven themes: 1) *Dynamics of CKD status*, 2) *CKD comorbidities*, 3) *Managing CKD and symptoms*, 4) *Life participation and outlook*; 5) *Navigating healthcare and clinical needs*, 6) *Medical tests and results*; and 7) *Support on the forum*. The results revealed that comorbidities were common in CKD patients and early-stage CKD was not communicated in a timely manner to patients by the health care community; living with CKD challenged both CKD and caregivers; some common challenges included but were not limited to the management of a diet for CKD and co-morbidities (especially co-morbid diabetes), CKD dynamics and symptoms, and fear of/ways to prevent progression. Individuals living with CKD primarily used the online forum to share and seek information and emotional support for managing CKD (including co-morbidities).

Conclusions: Challenges of living with CKD were found not only in those with advanced kidney disease and those on dialysis, but also in those with early and middle stages. Information and emotional support from the online forum serves as a platform to empower CKD patients with the knowledge, skills and confidence for CKD self-management. Proactive and innovative strategies with a combination of virtual and real settings to improve self-management for individuals with all-stage CKD needs to be explored and tailored.

Background

Chronic kidney disease (CKD) is a major public health concern worldwide. The estimated prevalence of CKD is 13.4% (11.7-15.1%) globally. In the United States, approximately 15% adults are estimated to have CKD in 2021(1). CKD is progressive and classified as stages from 1 to 5, with stage 5 being end-stage kidney disease requiring renal replacement therapy (e.g., dialysis, transplantation). CKD raises the risk of various medical complications (e.g., cognitive impairment, cardiovascular disease), poor quality of life, early death, and heavy health care burden (1–4). Therefore, strategies to prevent CKD complications, slowdown/prevent progression, and improve quality of life are needed.

Self-Management of CKD is the key to improving CKD outcomes and quality of life. It is the active participation in managing one's CKD conditions, which includes but is not limited to setting goals, monitoring and assessing the condition, adhering to treatment (e.g., medication compliance, lifestyle modification), coordinating care, decision making, and resource utilization (5–7). An in-depth understanding of the experiences, challenges, and needs of patients with CKD is essential in improving self-management of CKD. However, this may not always be conveyed in clinical settings (8). Qualitative research is a useful approach to collect detailed evidence on patients' priorities, goals, and needs to change and improve practice and policy (8). The experience of individuals living with CKD has been explored using qualitative studies. However, there is always limited information in those living with early or middle stage kidney disease (9). Additionally, the sample size is usually small (9). Furthermore, oftentimes, patients' opinions are not well captured either due to study designs, data collection approaches, or recall bias.

There has been an increased creation of online health communities to support those living with certain diseases, so people can access such support anytime from anywhere. For example, the National Kidney Foundation (NKF) looks to support individuals with kidney disease by offering education, support, and resources (10). To fulfill this, the NKF offers online communities for patients with CKD of any stage and caregivers alike to participate in a supportive forum for individuals to share experiences, communicate and ask questions (10). The current study aims to understand the experiences, challenges, unmet needs, goals and preferences of individuals living with CKD by analyzing the NKF CKD online forum data, and 2) explore the approaches empowering individuals with CKD for actively engaging in self-management.

Methods

Publicly available posts of peer interactions on the NKF's online community for people affected by CKD were extracted in April 2021 using computer programming. A total of 20,436 posts were collected. All extracted posts were imported into an Excel (Microsoft) file for analysis. The study was determined exempted from approval by the institutional review board of the University of Texas Health Science Center at San Antonio because it is not human research as defined by HHS regulations at 45 CFR 46 and FDA regulations at 21 CFR 56 (Protocol number: 20210332NHR).

Inductive thematic analysis strategy, in which no predetermined theory, structure or framework is applied, was used to analyze the data (11). Two researchers with qualitative study experience coded each post independently from the beginning of the posts listed in the excel sheet. Each researcher used an open coding analysis strategy to seek unique or similar/repeated ideas of each post, and coded them accordingly. Following their independent coding, the two researchers met to compare, contrast, and refine existing codes until they reached consensus on codes and code definitions. Frequent repetition of codes occurred for each of the researchers after analyzing around 350 forum posts. They then continued to analyze another 50 posts and determined that saturation had been reached at 400 posts. The 400 analyzed posts were posted on the NKF forum between March 3, 2021, to April 1, 2021. A senior qualitative researcher was brought in for further analysis and consulted throughout the process as

needed. The three researchers grouped the codes into subthemes and themes, and findings were discussed and agreed upon within the research team.

In addition, two trained junior research assistants independently reviewed the same 400 posts. They independently categorized CKD stage/status into 8 categories: CKD stage 1 through 5 based on the definition of Improving global outcomes 2012 clinical practice guideline (12), on dialysis, after transplantation, and stage unknown. They discussed and reconciled their categorization to reach agreement.

Results

Descriptive Results

Descriptive analysis found that the 400 posts were generated from 94 unique forum users (either patients or caregivers) encompassing 50 threads. Based on the descriptions of the posts (e.g., self-reported stage, lab results), the estimated CKD stage/status of these users or users' care recipients are shown in table 1. Specially, 3 living with stage 1, 4 with stage 2, 20 with stage 3, 9 with stage 4, 1 with stage 5, 4 on dialysis, and 6 after transplantation. We were not able determine the CKD stage/status for 47 individuals. Demographic information, such as age, gender, region of residency of the forum users is not publicly available and therefore could not be identified.

Table 1. Estimated CKD stage/status for forum users of the included posts.

CKD Stage/Status	Number
1	3
2	4
3	20
4	9
5	1
On dialysis	4
After transplantation	6
Stage unknown (Stage cannot be determined from posts)	47
Total	94

Themes

The analysis of the 400 posts identified seven themes: 1) *Dynamics of CKD status*, 2) *CKD comorbidities*, 3) *Managing CKD and symptoms*, 4) *Life participation and outlook*; 5) *Navigating healthcare and clinical needs*, 6) *Medical tests and results*; and 7) *Support on the forum*. The themes and corresponding codes are shown in table 2.

Table 2. Themes and corresponding codes.

Themes

1. Dynamics of CKD status

- Current health/ disease status
 - Decline in health/progression of CKD
 - Kidney transplant
 - Dialysis
 - Improvement in overall health and CKD
-

2. CKD Comorbidities

- Controlling comorbidities
 - Uncontrolled comorbidities
 - Underlying causes of CKD
 - Mistaking CKD and comorbidity symptoms
-

3. Managing CKD and symptoms

- CKD symptoms
 - Medications and supplements
 - Diet
 - Exercise
 - Other Lifestyle management
-

4. Life participation and outlook

- CKD and work or family
 - Stress
 - Fearful or negative feelings
 - Future with CKD
 - Optimistic/positive outlook or motivated to change health
 - Being unsure or resources not applying (or under support on forum for CKD benefit?)
-

5. Medical tests and results

- Lab results
 - Medical tests/procedures
 - Unexpected test results or worrying from doctor visit
 -
-

6. Navigating healthcare and clinical needs

- Medical history
- Healthcare differences and resources
- Not aware of early-stage CKD
- Dissatisfied with care or not getting adequate care

- Change in care
 - Positive remarks for doctor or healthcare
 - Medical specialists
 - COVID and CKD
-

7. Support on the forum

- Seeking advice or support on forum
- Information Support on forum
- Emotional Support on forum
- Consulting with or knowing what to ask doctors (other users telling others what to ask)
- Slowing or preventing progression of CKD (users sharing their own or telling others on ways to slow the progression – could instead be under strategies?)
- Strategies for increasing CKD recommendation adherence
- Caregivers

1. Dynamics of CKD status

This theme focused on the dynamic range in health status and changes occurring for CKD and comorbid conditions. These included an overall improvement, decline or progression in CKD or comorbidities, such as an increase or decline in eGFR over time. It also included the dynamic thoughts and needs for procedures impacting CKD status such as dialysis and kidney transplants, including opinions on dialysis and navigating the inactive vs active transplant list. Example quotes of this theme are displayed below:

“My GFR was 28 last Feb, 2020... My GFR is up to 56 and will hopefully continue to improve.” (CKD stage 3)

“It’s always sobering when one goes on dialysis but it does save lives. My husband, who was very ill at the time, is now on dialysis and it has improved his quality of life significantly.” (Caregiver of dialysis patient)

“They put my son on the inactive list at 16 so he could claim pediatric points and time accrued since he would most likely be an adult when the kidney was needed. I thought it was a good thing for him. Can be upgraded to active at anytime and reviewed at least once per year.” (Caregiver of CKD stage 4)

2. CKD comorbidities

This theme focused on the interplay and connections between CKD and comorbidities or the impacts that one can have on the other. Users discussed trying to control comorbidities through methods such as medication, to ultimately have a positive impact on CKD. Users also discussed uncontrolled comorbidities or those chosen not to be managed to focus attention on CKD. The connections between CKD and comorbidities were also seen in relation to underlying causes for CKD, such as hypertension and diabetes, as well as mistaking CKD and comorbidity symptoms for that of the other condition which could delay treatment of the proper cause. Example quotes of this theme are displayed below:

"My HBP [high blood pressure] is also controlled by meds and the diabetes is controlled with my diet and exercise." (CKD stage3)

"I'm a caregiver to my husband, a Diabetic Type 2, who is now on dialysis. Unfortunately, diabetes destroys the small blood vessels inside your kidneys. In turn, that erosive force can also create heart disease, drive up blood pressure, and more." (Caregiver of dialysis patient)

"My BP, CKD, diabetes, Osteoporosis, IBS, detached upper arm muscles, high cholesterol and brain fade from suspected MS are all untreated. As yet I have not found it necessary to mitigate my health issues." (CKD stage unknown)

As these posts were originally posted on the forum during the COVID pandemic, some posts discussed COVID related matters, including but not limited to getting the vaccine while having CKD and comorbidities.

"Ckd and covid vaccine!?? Anybody here got the covid shots? is it safe for diabetic and ckd patient? what do you feel after the shots? Thank you !" (CKD stage unknown)

3. Managing CKD and symptoms

This theme focused on CKD symptoms, as well as the strategies and challenges of their management. CKD symptoms shared through the forum were dynamic and varied between individuals. Discussed symptoms included but were not limited to fatigue, edema, stress, anxiety, exhaustion, itchy skin and general discomfort associated with CKD. Users often shared their own ways of how to manage symptoms that others were experiencing, such as advice on managing itchy skin by using a moisturizer or taking a bath before bed.

"I'm extremely tired and have no energy, foamy cloudy urine, back pain, abdominal pain, dizziness, brain fog, weakness, just feeling so exhausted." (CKD stage unknown)

"I am stage 3 B and feel so tired that I have to take caffeine pill in the morning to get going. I also have Ulcerative colitis so that contributes. But the fatigue is debilitating. I just sit the rest of the day. Everyday I try to use a recumbent bike. I rarely can do more than a few minutes at a time. Does this sound like your experiences," (CKD stage 3)

"Sorry to hear your dad is having this problem [skin itchiness interfering with sleep]. The best thing I found was to have a nice warm bath before bedtime. While in the bath I would rub my legs with an abrasive sponge. Then I would pat them dry before applying simple moisturiser. It used to help me sleep better." (CKD stage unknown)

Management of CKD incorporated a range of challenges, approaches and techniques individuals used or recommended to others such as diet, exercise, medications, supplements, and lifestyle; amongst other strategies. Diet was the most frequently discussed, which also had its own challenges and strategies.

Challenges included diet recommendations for CKD and diet recommendations for other comorbid conditions conflicting, while strategies for managing CKD with diet ranged from a vegetarian diet, no added salt diet, to using whole grains over white starches, and what the optimal level of protein consumption is.

"Taking certain meds that work at cross purposes is a difficult situation. For me it's aspirin. NSAIDs are not recommended for anyone with CKD." (CKD stage 2)

"I'm in stage 3 [CKD]... The things that they recommend on the kidney disease diet such as white bread and white rice are an absolute NO on the diabetic diet. Everything contradicts each other..." (CKD stage 3)

"My meal plan was designed specifically for me based on my diabetes, kidney disease, and hypertension. Low sodium foods and I use herbs and spices for flavor instead of salt. ... No sweets and nothing that turns into bad carbs when digested. ... Portion control is critical and by far the largest portion on my plate is the veggies. If you can, obtain a referral to meet with a renal dietitian and bring your previous lab reports, and design something for you." (CKD stage 3)

4. Life participation and outlook

As there are many challenges and aspects to managing CKD, this theme focused on how an individual's life or outlook on life was affected by living with CKD, both positively and negatively. Life participation topics included CKD impacts on work, stress, emotions and family. Examples included needing to take time off from work due to not feeling well from CKD symptoms or side effects and dealing with stress directly from CKD management or from external sources.

"In the last six months in my opinion my health has decreased considerably such as not having any energy and not appetite which has caused me to take a period of time off work." (CKD stage 4)

"...I'm often too tired to do anything more and my 40 hr/wk job. I argue with my family about my lethargy and lack of motivation for activity. I doubt I'm alone in this. Thank you for being here." (CKD stage 3)

Life outlook included past, present or imagined future feelings, such as negative or fearful emotions around diagnosis or living with CKD, outlook on the future with CKD, and being unsure of what one should do for their own CKD care. Other topics included having an optimistic outlook on life with CKD, being motivated to change one's own health or feeling as though health is within one's own control.

"It's just that I'm worried everytime I see foam in my urine, I get all these negative thoughts about my kidney not lasting long." (CKD stage unknown)

"We can each maximize our own situations. Regardless of treatment approach, doing this will improve our quality of life." (CKD stage unknown)

"I learned that GFR decreases at a rate of 1 every year after the age of 40 even for normal healthy people. I'm 43 years old now and my GFR is 56, although everything is stable. Do I get to live to 70? Do I get to see

my grandchild? My daughter is only 3....Will I be on dialysis in my 60s?... All these questions just keep lingering in my minds..." (CKD stage 3)

5. Navigating healthcare and clinical needs

This theme included discussions, statements, and navigation of medical and clinical needs an individual with CKD experiences. These clinical needs included any type of healthcare professional or specialist as well as generalized to specialized needs, which could be impacted based on an individual's specific comorbidities, challenges with management, life participation or outlook, and needs during the COVID pandemic. Both positive and negative remarks in relation to clinical needs as well as users discussing questions or giving advice based on their own experiences for medical and clinical needs were found within this theme. Examples included healthcare differences such as how care differs across country borders, an individual being dissatisfied with their care or not getting adequate care, being pleased with healthcare or doctor and using medical specialists such as a dietician or nephrologist to guide them within their CKD journey.

"I'm in the UK so things are a bit different over here - the USA seem much more proactive about CVD, CKD etc. I wish I could get more answers - I emailed the cardio but he has just ignored it... I've never been so frightened in my life - I've tried reading everything ... Thanks for your help - even just hearing from someone helps to be honest!" (CKD stage 3)

"Nephrologist's in many states in the USA refuse to see you until stage 4. I got in because I played the hey i only have one kidney card, and I earned it. She was dismissive, rude, and seemed to think I was overreacting to a grf gone from 60 to 44, repeatedly, after a full pulmonary embolism." (CKD stage 4)

"With COVID I've had several telemedicine (phone) appointments too. I am able to show my physicians not only my face but also my hands, ankles, lower legs, etc, during these appointments. It's not as good as a physical exam where my doctors can actually feel for edema, but it has worked. They also have me send them a table with my weight and BP readings." (CKD stage unknown)

Another frequently discussed topic was individuals not being aware of early-stage CKD, in which users described not having been told about being in early-stage CKD until it had progressed farther, reducing the early ability for progression prevention. They also discussed that some health specialists may not adopt a proactive approach for

"Found out i had CKD stage 3b from my labs and office visit report. I believe this has happened to many people on this forum. Not sure why primary doctors don't address this condition earlier so we can start trying to delay the progression." (CKD stage 3)

"I'm somewhat angry because I've been diagnosed as CKD Stage 3a and my primary care doctor very nonchalantly said "oh you're Stage 3 kidney disease. You've been having some high creatinine and low GFR a couple times in the past couple years." For goodness sake! I went from not knowing anything about CKD to Stage 3a. Cripes. What happened to Stage 1 and 2?" (CKD stage 3)

"... I'm a mess. I was diagnosed 2 years ago with diabetes 2 and that and the fact that I have high blood pressure (although now very controlled) lead me to kidney disease. I'm in stage 3. The thing is, I didn't even know that I was in stage 1 or 2. A million specialists and nobody said a word. I'm terrified and confused" (CKD stage 3)

6. Medical tests and results

This theme focused on the medical and lab tests which individuals with CKD frequently require to manage and monitor CKD. This included lab results, in which users would often post their recent lab results to give others indication to their health and open the floor to advise on how to better manage. It also included medical tests and procedures such as biopsies, as well as individuals receiving unexpected test results such as seeing renal failure indicators or being worried about health or CKD after a doctor's office visit or while waiting on test results.

"Has anyone else had this? When I was diagnosed with CKD I had a kidney biopsy and they advised they would take 2-3 samples. Unfortunately the samples were all fragmented and they ended up taking 12 samples... I am concerned my kidneys are totally destroyed as they couldn't get one clear sample." (CKD stage 3)

"I have received a lab work but I do have question on the range. So my albumin was normal 4.9 (4.0-5.0). So even though it is in normal range but it went up from 4.4 (previous lab) to 4.9 (current lab). Is that a sign of concern that it went up and hovering around closer to 5 and eventually be out of range?" (CKD stage unknown)

"It sounds like your Doctor is doing the right thing by stopping some of your meds. Unfortunately, I think that you have just got to wait and see what your latest blood results say"(CKD stage unknown)

7. Support on the forum

This theme encompasses the many types of support between peers communicating within the online forum. Support was often bidirectional as users both gave advice and went to the forum to seek advice from others, in addition to sharing stories, experiences and tips for living with CKD. Support came in many forms and included both individuals with CKD and caregivers for someone with CKD alike. Information support included providing specific information within a post, such as specific books, websites or specialists to look see, while emotional support included supporting or empathizing with others' emotional journey, frustrations, or successes. Examples included users educating others in knowing what to ask doctors during their next appointment, expressing plans or recent consultations with doctors, as well as strategies for slowing progression of CKD, and strategies for increasing CKD recommendation adherence. Example quotes from this sub-theme are displayed below:

"I need help with finding a cookbook or website with recipes for unimaginate cooks. Also, any ideas on what are good replacements: say, recipe calls for beans, what would be a good substitution." (CKD stage 4)

“When you meet with a nephrologist ask for a referral to meet with a Renal Dietitian and bring as many hard copies of your labs with you and together you and the RD can develop a kidney-friendly meal plan based on your preferences and needs. Once you know where you stand, come back as often as you need for advice and support...” (CKD stage unknown)

“No thanks ever needed; my pleasure. You have come to a community of wonderful, compassionate and knowledgeable people who are happy to share and support.” (CKD stage unknown)

Discussion

By qualitatively analyzing the posts of the CKD online forum, our study found that the experiences and challenges of individuals living with CKD depended on many factors (e.g., CKD status and comorbidities, symptoms, clinical and health care needs), all of which are impacted by situation specific needs and goals throughout an individual’s journey. The online forum provides a convenient platform for CKD patients and their caregivers to share experiences and challenges of living with CKD and seek information and emotional support on demand, and in a flexible timeframe. Individuals expressed, relayed, and gained knowledge through supporting each other on the forum, looking to ultimately have a positive impact on and improvement in CKD management. We acknowledge that the CKD online forum plays a significant role in educating, engaging, and empowering CKD patients and their caregivers to manage CKD and ease anxiety and stress. Meanwhile, more proactive strategies are needed in the real setting for early CKD detection, communication, and management advice and consultation. Although there are some general, common needs CKD patients at different stages share, there are also many unique needs, symptoms, and personal characteristics. Therefore, individualized and tailored approaches to improve self-management should be recommended.

Based on the discussions on the forum, people living with CKD often have one or more comorbidities, which may be risk factors for CKD progression and increase the treatment and self-management burdens on CKD patients. This phenomenon has been reported by prior quantitative studies (13–15). Diabetes and high blood pressure are the most common comorbidities of CKD, and the Kidney Disease: Improving Global Outcomes (KDIGO) practice guidelines have been issued periodically to improve the management of the comorbid conditions (16, 17). Despite the available guidelines, forum users frequently discussed the challenges of managing CKD comorbid with diabetes and/or high blood pressure regarding medication and/or lifestyle management. Therefore, understanding each CKD patient’s health conditions and their challenges of living with CKD and comorbidities is essential to develop tailored and effective management strategies.

Diet management was one of the most challenging self-management tasks revealed by this study. It has been widely evidenced that diet regimen in CKD patients vary by an individual’s CKD stage or remaining kidney function. For example, depending on one’s lab results, some food items high in potassium or phosphorus might be limited. On the forum, the meaning of lab results were also frequently discussed, which were sometimes attributed to diet choices. This may highlight that managing CKD diet may require

a higher level of health literacy, reflected in the forum by high frequency of lab result discussions. Meanwhile, peers in the forum also suggested to bring lab results to a dietitian for an individualized diet plan, especially for those living with comorbidities. Living with CKD and comorbidities further complicates the diet regimen. For example, forum users discussed the conflicting diet regimen of diabetes and CKD. Due to the increasing needs of managing comorbid diabetes and CKD, in 2020, the KDIGO issued the first version of practice guidelines of managing diabetes in CKD patients involving both pharmacological and lifestyle management. In the guideline, the complexity of diet management is acknowledged. The guideline points out that individualized and tailored diet regimen should be implemented. However, how to individualize and tailor diet regimen is not conveyed, and still needs to be explored further.

Their symptoms and lab results (renal function) may independently or jointly influence patients' life participation and outlook. Individuals with CKD often experience a variety of symptoms, especially as CKD progresses. As reported previously, fatigue, anxiety and depression symptoms are particularly prevalent in those with end-stage renal disease and/or on dialysis (18, 19). The various symptoms may interact and influence on each other, and impact one's life participation and outlook for future. For example, fatigue leads to sedentary lifestyle and social participation, which may cause depression and further renal function decline. However, as relayed by forum users, whether the symptoms are caused by CKD and/or its comorbidities is often hard to determine by patients themselves, as well as by health professionals (20). Therefore, clustering CKD symptoms and correlating symptoms with various health conditions may help improve CKD symptom management, and improve patients' health outcomes and quality of life. In addition, the current study found that CKD patients of earlier stages (e.g., stage 3 and 4) also suffer from various CKD symptoms, which calls the scientific and clinical's attentions to promote interventions for symptom management in earlier CKD stages.

Notably, our study revealed that CKD patients experience a wide array of problems, but felt unheard, ignored, and misunderstood by their healthcare professionals. Forum users also frequently complained that they were not informed about CKD when it was in early stages. According to the CDC, as much as 9 in 10 adults in the US with CKD don't know they have it, and around 2 in 5 adults with severe CKD are not aware that they have CKD (21). This is a serious problem since if not managed, CKD may progress into later, more severe stages, and the subsequent cost and burden to both the individual and the healthcare system would be much higher compared to taking action in earlier stages (22, 23). Actions for early CKD detection and prevention should be taken not only by the primary health providers, but also by public health professionals, to encourage earlier CKD detection and communication about the diagnosis with patients in a timely manner. Furthermore, early action and education can help raise awareness of CKD severity, which is important as patients can be symptom driven when managing health conditions, and consequently those newly diagnosed with early-stage CKD may not care about their conditions due to seeing minimal or no symptoms at the time. Shared decision making between health care providers and CKD patients is the cornerstone of eliciting self-management. Patients share information about their experiences of illness, values, and preferences while clinicians complement with information and recommendations with each individual patient in mind (24). CKD will continue to be a major public health

concern, as the aging population living with diabetes and hypertension, the two major risk factors of CKD, are rapidly increasing (1). Proactive strategies to detect and communicate early-stage CKD, improve decision making to initiate CKD self-management and empowering patients to manage their CKD are urgently needed.

Similar to other online health communities, our study found that CKD forums have become an important community to empower CKD patients for CKD self-management through various support. Our findings suggest that despite from various regions around the world, the forum commutations may empower forum users in improving the fundamental self-manage skills such as problem-solving, decision making, and communicating with healthcare professionals. The forum also empowers forum users with knowledge and efficacy through information and emotional support to improve the skills and confidence of managing their CKD. These findings suggest that forum users are actively seeking ways to improve patient activation in CKD self-management. To be noted, this may lead to further health disparities as those highly educated may access to more resources to improve their health conditions. Future interventions to improve CKD self-management may consider a combination of in person and online strategies which tailored to individual factors such as CKD status, individual and clinical needs, and demographics.

Limitations

There are several limitations of the study. First, the forum users were from across the world. The results might not be applicable to a specific country or region. However, this is also a strength of this study of assessing the experiences and challenges of CKD patients from a very diverse background globally. Second, the online forum is in English, so the transferability of our findings to non-English speaking CKD patients is uncertain. Third, the size of datasets is too big to be all analyzed manually. We may have missed information from the forum by only selected a small number of posts to analysis. Lastly, since it is not required when registering for an online forum account, we were not able to directly obtain data such as age, gender, region of residence or CKD stage of forum users we were unable to relay our findings for a more specific group. Making some data information required when registering for an account to post a topic or comments may further improve and facilitate future research using forum resources.

Conclusion

By analyzing the user interactions on the CKD online forum, we found that not only those with end-stage kidney disease, those with earlier CKD also struggle with various challenges of living with CKD and comorbidities. The online CKD community provides a great platform for CKD patients to improve patient activation for CKD self-management through sharing information, exchanging management skills and health care coordination, and encouraging and comforting each other. Proactive intervention programs to improve CKD self-management with a combination of in person and online strategies which tailored to the characteristics of each CKD patient are needed.

Abbreviations

CKD = chronic kidney disease

HHS = Department of Health and Human Services

NKF = National Kidney Foundation

Declarations

Ethics approval and consent to participate

The study was determined exempted from approval by the institutional review board of the University of Texas Health Science Center at San Antonio because it is not human research as defined by HHS regulations at 45 CFR 46 and FDA regulations at 21 CFR 56 (Protocol number: 20210332NHR).

Consent for publication

Not Applicable

Availability of data and materials

The datasets generated and/or analyzed during the current study are available in the National Kidney Foundation's online community repository, <https://www.kidney.org/online-communities>

Competing interests

The authors declare that they have no competing interests

Funding

Not Applicable

Authors' contributions

YD and JW contributed to study conceptualization and methodology. CL extracted the dataset for this study. BD and VR qualitatively analyzed posts from the online forum. YD, BD and VR contributed to analyzing and categorizing final codes. YD and BD wrote the original draft, with help from VR. JW and CM provided critical feedback to the manuscript. All authors reviewed and edited to create the final version of the manuscript.

Acknowledgements

We would like to thank Deanna Hu and Lisa Quan for their input for data analysis and their effort for categorizing the CKD stages and status.

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