ORIGINAL RESEARCH

Common Needs of Patients with Diabetic Kidney Disease: Qualitative Analysis Based on Disease-Specific Social Media Platforms

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Background: Diabetic kidney disease (DKD) patients require comprehensive disease education and mutual support to cope with various challenges. Social media platforms provide opportunities for DKD patients to access information and interact with peers. However, qualitative analysis of DKD patients' real-world concerns and needs on social media is lacking.

Methods: A qualitative study was conducted to analyze DKD patients' posts on Facebook and Baidu DKD-specific forums from June 2013 to June 2023. Posts were retrieved, and the forum with the most DKD-related posts from each platform was selected using stratified random sampling. Thematic analysis was performed to identify common themes, which were categorized and quantified.

Results: In total, 746 DKD-related posts were analyzed, generating 203 keyword categories with 954 tags. Three main themes emerged: Diagnosis and Comorbidities (50.2%), Treatment and Prevention (29.7%), and Lifestyle and Psychology (20.1%). Patients were most concerned about DKD diagnosis, staging, comorbidities, and interpreting diagnostic indicators. They also sought information on treatment advancements, medications, renal replacement therapies, and traditional Chinese medicine. Diet, exercise, work-life balance, family planning, and mental well-being were key lifestyle and psychological concerns.

Conclusion: This study reveals DKD patients' primary needs and concerns on social media, which can guide healthcare professionals in providing targeted education and support. Meeting patients' needs through comprehensive education and counseling can improve treatment adherence and prognosis, though challenges remain in addressing all issues in real-world practice.

Keywords: diabetic kidney disease, qualitative research, patient education, social media

Introduction

Diabetic kidney disease (DKD) is a common and severe complication of diabetes, affecting about 40% of patients.[1] As DKD progresses, patients face various physical, psychological, and social challenges that necessitate comprehensive disease education and peer support.[2] The internet, particularly social media platforms, has become a crucial source of health information and social interaction for chronic disease patients, including those with DKD.[3,4] Previous studies have shown that online health communities can provide valuable disease knowledge, emotional support, and self-management strategies for patients with diabetes.[5,6] However, research specifically focusing on DKD patients' use of social media to seek information and support is scarce. Understanding patients' real-world concerns and needs is essential for healthcare professionals to deliver patient-centered care and education.[7] To address this gap, we conducted a qualitative analysis of DKD patients' posts on disease-specific social media forums. By identifying common themes in patients' discussions, we aimed to gain insights into their key concerns, unmet needs, and preferences for information and support. These findings

can inform the development of targeted educational interventions and support programs to improve DKD patients' self-management and quality of life.

Methods

We performed a qualitative study using publicly available data from Facebook and Baidu, two popular social media platforms with active DKD patient communities. Facebook is a global platform with a diverse user base, while Baidu is widely used in China, allowing for a broader representation of DKD patients' perspectives. A systematic search was conducted to identify DKD-specific forums on each platform using the keywords "diabetic kidney disease" and "DKD treatment" between June 2013 and June 2023. Inclusion criteria were: (1) open forum with no registration required for viewing posts; (2) active forum with at least one new post per month; (3) forum content primarily focused on DKD. The forum with the highest number of DKD-related posts on each platform was selected for analysis.

Stratified random sampling was used to select posts for inclusion. The selected forums were first stratified by year of posting (2013–2023). Within each year stratum, posts were further stratified by month. A random sample of 10% of posts from each month was then selected using a random number generator. This process was repeated for each year stratum, ultimately yielding a total of 746 posts for analysis across the 10-year period (Figure 1). The stratified random sampling approach ensured a representative sample of posts across different time points while accounting for potential seasonal variations in post content.

Thematic analysis was conducted to identify common themes in patients' posts.[8] Two researchers independently coded the posts using an inductive approach, generating initial codes and themes. A third researcher reviewed the codes and themes, and discrepancies were resolved through discussion until consensus was reached. Codes were organized into higher-order themes and subthemes. The frequency of each theme was quantified to provide an overview of the relative importance of different topics to DKD patients (Table 1). Representative quotes were selected to illustrate key themes. This study used publicly available data and did not involve direct interaction with human subjects. However, to protect users' privacy, all personally identifiable information was removed from the data before analysis. The study protocol was approved by the Ethics Committee of West China Hospital, Sichuan University.

Results

Sample Characteristics

A total of 746 DKD-related posts were analyzed, generating 203 unique keyword categories with 954 tags (Figure 1). Posts were primarily written by DKD patients (85%), with some participation from caregivers (12%) and healthcare professionals (3%). User demographics were not consistently available. Three main themes emerged from the analysis: (1) Diagnosis and Comorbidities, (2) Treatment and Prevention, and (3) Lifestyle and Psychology. Table 1 presents the frequency of each theme and subtheme.

Diagnosis and Comorbidities

The most common theme was Diagnosis and Comorbidities (50.2%), with patients expressing concerns about DKD diagnosis, staging, comorbidities, and interpreting diagnostic indicators. Many patients sought information on the diagnostic criteria for DKD and how to differentiate it from other kidney diseases. For example, one patient asked: "I have type 2 diabetes and my urine albumin is slightly elevated. Does this mean I have DKD? What other tests should I get to confirm the diagnosis?" Patients also frequently discussed comorbidities such as hypertension and dyslipidemia, and their impact on DKD progression. One patient shared: "I have had diabetes for 10 years and recently found out I also have high blood pressure. I am worried about my kidneys. What can I do to prevent further damage?"

Treatment and Prevention

The second most common theme was Treatment and Prevention (29.7%), with patients seeking information on pharmacological and non-pharmacological management of DKD. Many posts discussed the latest advancements in DKD treatment, such as SGLT2 inhibitors and GLP-1 receptor agonists. Patients also frequently mentioned traditional
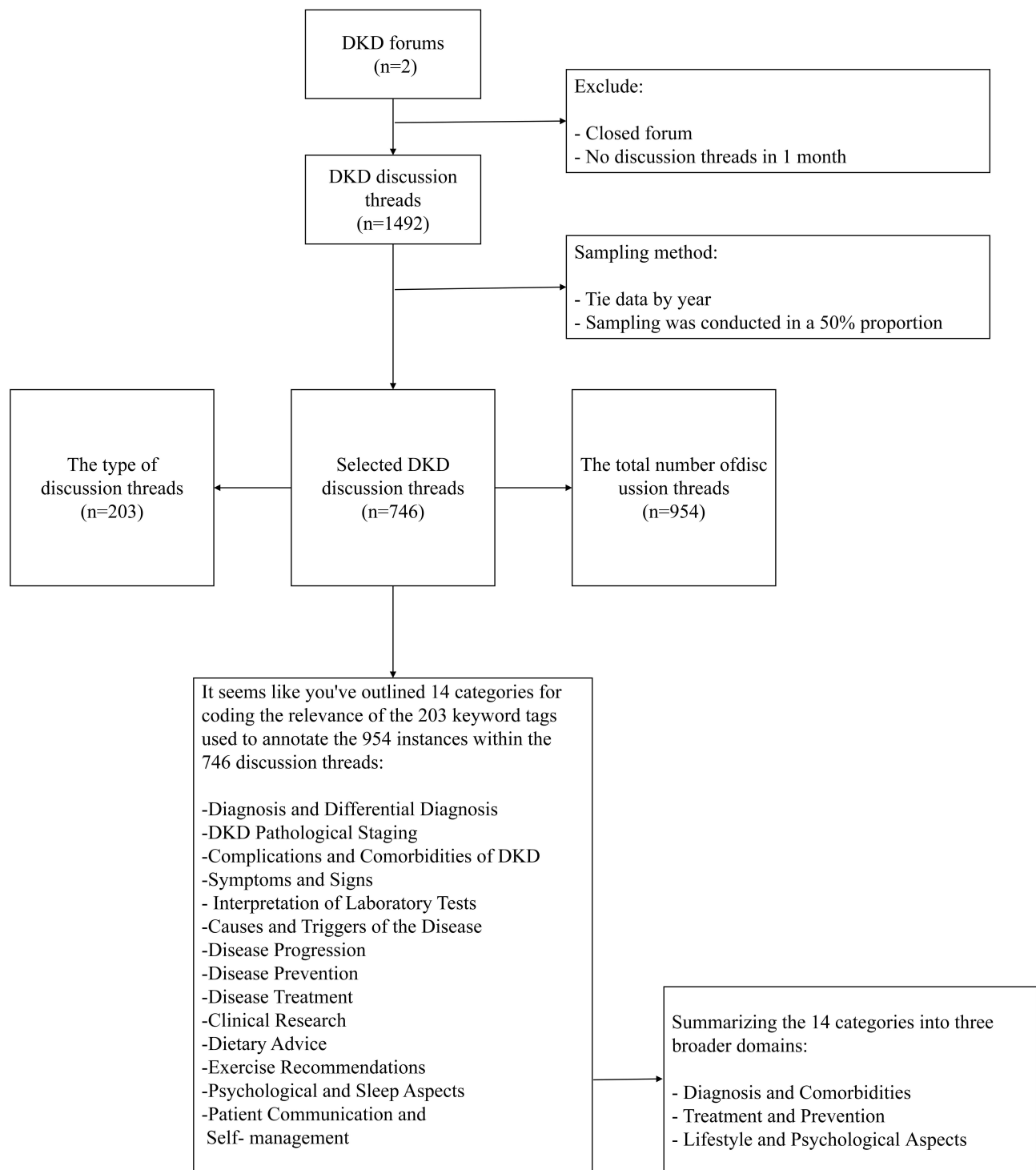
Figure 1 Research Workflow of Qualitative Analysis on Common Needs of DKD Patients Based on Disease-Specific Social Media Platforms.
Notes: *This is the flowchart of the current study. The preliminary scope screening was conducted on DKD-related resources on Facebook and Baidu social media platforms from June 2013 to June 2023. Terms such as "Diabetic kidney disease" and "DKD treatment" were used in social platform search engines to retrieve DKD-related forums. 746 DKD-related posts were included, establishing 203 categories of keyword tags, totaling 954 tagged keyword labels. Statistical analysis was performed using natural language processing methods, utilizing the jieba database for Chinese text segmentation and the nltk database for English text segmentation, to compute the frequency of each segmented word, thereby deriving word frequency.

Chinese medicine as a complementary approach. For instance, one patient commented: "I heard that SGLT2 inhibitors can help protect the kidneys in people with diabetes. Has anyone tried them? What was your experience?" Renal replacement therapies, including dialysis and transplantation, were another common topic of discussion, with patients

Table 1 Qualitative Analysis Results of Common Needs Among DKD Patients

Category (N, %)	Word Frequency Analysis (N, %)
Diagnosis and Comorbidities (479, 50.2%)	Diagnosis and Differential Diagnosis (82, 8.6%)
	DKD Pathological Staging (130, 13.6%)
	Complications and Comorbidities of DKD (93, 9.8%)
	Symptoms and Signs (83, 8.7%)
	Interpretation of Laboratory Tests (88, 9.2%)
	Causes and Triggers of the Disease (3, 0.3%)
Treatment and Prevention (283, 29.7%)	Disease Progression (81, 8.5%)
	Disease Prevention (45, 4.7%)
	Disease Treatment (155, 16.3%)
	Clinical Research (2, 0.2%)
Lifestyle and Psychological Aspects (192, 20.1%)	Dietary Advice (85, 8.9%)
	Exercise Recommendations (20, 2.1%)
	Psychological and Sleep Aspects (15, 1.6%)
	Patient Communication and Self-Management (72, 7.5%)

Notes: *The qualitative analysis of all posts was categorized into three main groups: Diagnosis and Comorbidities, Treatment and Prevention, and Lifestyle and Psychological aspects.

asking about the indications, benefits, and risks of these treatments. One patient asked: "My doctor said I might need dialysis in the future if my DKD progresses. What are the different types of dialysis, and how do I choose which one is right for me?"

Lifestyle and Psychology

The third theme was Lifestyle and Psychology (20.1%), encompassing patients' concerns about diet, exercise, work-life balance, family planning, and mental well-being. Many patients sought practical advice on managing their diet and physical activity while living with DKD. For example, one patient asked: "What are some kidney-friendly recipes for people with diabetes? I struggle with finding tasty and healthy food options". Patients also discussed the emotional burden of living with DKD and strategies for coping with stress and anxiety. One patient shared: "Some days I feel really down about my health and the future. How do you stay positive and motivated to take care of yourself?"

In addition to the three main themes, we also summarized 28 frequently mentioned questions by DKD patients (Table 2). These questions provide a more concrete representation of patients' specific concerns and information needs, covering various aspects of diagnosis, treatment, and daily management of DKD. Finally, a word cloud was generated using the high-frequency keywords to visualize the main topics discussed by DKD patients (Figure 2).

Table 2 High-Frequency Needs Mentioned by DKD Patients

Questions	Frequency (N, %)
Which stage is my kidney disease at now?	(62, 6.5%)
I hope the patients can muster up courage to face difficulties bravely.	(46, 4.8%)
What is DKD? How is DKD diagnosed?	(41, 4.3%)
Is there any new treatment?	(26, 2.7%)
What signs indicate a worsening condition?	(25, 2.6%)
How to prevent DKD development and progression?	(24, 2.5%)
What are the effects of dialysis treatment? What should I pay attention to if I am receiving dialysis treatment?	(16, 1.7%)
I am a patient with DKD, how can I manage my blood pressure?	(15, 1.6%)
I feel tired and have back pain.	(13, 1.4%)
Today, I re-examined my blood indicators, and there are changes in serum creatinine and eGFR compared with the last time.	(12, 1.3%)

(*Continued*)

Table 2 (Continued).

Questions	Frequency (N, %)
Is kidney transplantation a reliable treatment?	(12, 1.3%)
What effect does hyperlipidemia has on my kidney disease?	(10, 1.0%)
I am not sure if I have microalbuminuria.	(10, 1.0%)
Which type of fruits and vegetables should be avoided?	(9, 0.9%)
The doctor suspects I have DKD, and is it necessary to do the renal biopsy?	(8, 0.8%)
After being diagnosed with DKD, how long can I live?	(8, 0.8%)
I am really anxious and always feel depressed.	(8, 0.8%)
How to prevent the progression of the disease to the end stage renal disease?	(7, 0.7%)
Are there specific limitation for salt and sugar intake?	(7, 0.7%)
What exercise program can be recommended?	(7, 0.7%)
What are SGLT2 inhibitors?	(6, 0.6%)
In what situations can ACEI and ARB be used in DKD patients?	(6, 0.6%)
Have you ever tried traditional Chinese medicine treatment?	(5, 0.5%)
Can I eat seafood?	(5, 0.5%)
Can I get pregnant in my current state?	(5, 0.5%)
How should I manage my water intake?	(4, 0.4%)
I hope to find a platform for communication.	(4, 0.4%)
How much does it cost to treat DKD?	(4, 0.4%)

Notes: *Through word frequency analysis of the original text record of DKD patients' communication, we summarized and categorized 28 questions with frequencies greater than 4. These questions cover three major categories: Diagnosis and Comorbidities of DKD, Treatment and Prevention of DKD, and the Lifestyle and Psychological problems of DKD patients. This compilation is a concrete embodiment of the real needs of DKD patients.

Discussion

This qualitative study provides valuable insights into the real-world concerns and needs of DKD patients as expressed on social media forums. The three main themes identified—Diagnosis and Comorbidities, Treatment and Prevention, and Lifestyle and Psychology—reflect the multifaceted nature of living with DKD and the diverse range of information and support needs of this patient population.

Our findings highlight the importance of patient education on disease diagnosis, staging, and monitoring, as well as the management of common comorbidities such as hypertension and dyslipidemia (Table 1). Patients also expressed a strong interest in learning about the latest treatment advancements and the role of traditional Chinese medicine in DKD management. These Results suggest that healthcare professionals should prioritize providing clear, up-to-date, and evidence-based information on these topics to support patients' self-management and decision-making. Similar findings were reported in a qualitative study by Lo et al,[9] where patients with chronic kidney disease emphasized the need for timely and reliable information on disease progression, treatment options, and self-care strategies.

Furthermore, the prominence of lifestyle and psychological concerns underscores the need for comprehensive support services that go beyond medical management. Patients face significant challenges in adopting and maintaining healthy lifestyles, balancing work and family responsibilities, and coping with the emotional burden of living with a chronic illness. Incorporating nutrition counseling, physical activity promotion, and mental health support into DKD care can help address these unmet needs and improve patients' overall well-being. This is consistent with the findings of a systematic review by Clarke et al,[10] which highlighted the importance of psychosocial support interventions in improving quality of life and treatment adherence among patients with DKD.

Our study also sheds light on the potential of social media as a platform for patient education and peer support. By analyzing patients' spontaneous Discussions in a natural setting (Figure 1), we were able to capture their perspectives and priorities in a way that may not be possible through traditional research Methods. Healthcare professionals can leverage these insights to develop targeted educational content and support programs that resonate with patients' real-world experiences and preferences. A recent study by Zhai et al[11] demonstrated the feasibility and acceptability of a social

Figure 2 Word Cloud of Qualitative Analysis on Common Needs Among DKD Patients.
Notes: *To further illustrate the demands of DKD patients, we generated a word cloud resembling the contour of a kidney. The size of words in the cloud represented their frequency in the dataset, with larger font sizes indicating higher frequency and smaller font sizes indicating lower frequency. This visual representation allowed a visual portrayal of the key concerns of DKD patients, offering a vivid and valuable insight into their needs for further comprehension.

media-based peer support intervention for patients with DKD, suggesting that such approaches can be effective in promoting self-management and emotional well-being.

However, it is important to acknowledge the limitations of this study. As an analysis of online posts, our findings may not be representative of the broader DKD patient population, particularly those who do not use social media or have limited internet access. The anonymity of social media users also prevents us from collecting detailed demographic data, which could provide additional context for interpreting the results. Future research should explore the needs and experiences of DKD patients using other methods, such as in-depth interviews or focus groups, to gain a more comprehensive understanding.

Conclusion

This qualitative analysis of DKD patients' posts on social media forums reveals three key domains of patient needs and concerns: Diagnosis and Comorbidities, Treatment and Prevention, and Lifestyle and Psychology. These findings can inform the development of patient-centered education and support services that address the diverse medical, practical, and emotional challenges of living with DKD. While our study suggests that comprehensive education and counseling

may improve treatment adherence and prognosis, further research is needed to evaluate the effectiveness and feasibility of specific interventions in real-world settings. Moreover, given the exploratory nature of this qualitative study, the themes identified should be viewed as a starting point for understanding DKD patients' needs rather than a definitive or exhaustive list. Ongoing engagement with patients through various channels, particularly social media, is essential for continuously optimizing DKD management in the face of evolving patient needs and therapeutic landscapes.

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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Disclosure

The authors declare that there are no conflicts of interest in this work.

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