Harnessing Social Media Data to Understand Information Needs about Kidney Diseases and Emotional Experiences with Disease Management: Topic and Sentiment Analysis

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Submitted to: Journal of Medical Internet Research
on: August 02, 2024

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Abstract

Background: Kidney diseases encompass a variety of conditions, including chronic kidney disease, acute kidney injury, glomerulonephritis, and polycystic kidney disease. These diseases significantly impact patients' quality of life and healthcare costs, often necessitating substantial lifestyle changes, especially regarding dietary management. However, patients frequently receive ambiguous or conflicting dietary advice from healthcare providers, leading them to seek information and support from online health communities.

Objective: This study aims to analyze social media data to better understand the experiences, challenges, and concerns of kidney disease patients and their caregivers in South Korea. Specifically, it explores how online communities assist in disease management and examines the sentiment surrounding dietary management.

Methods: Data were collected from "KidneyCafe," a prominent South Korean online community for kidney disease patients hosted on the Naver platform. A total of 124,211 posts from ten disease-specific boards were analyzed using latent Dirichlet allocation for topic modeling and Bidirectional Encoder Representations from Transformers (BERT)-based sentiment analysis. Additionally, efficiently learning an encoder that classifies token replacements accurately (ELECTRA)-based classification was used to analyze posts related to disease management further.

Results: The analysis identified six main topics within the community: Family Health and Support, Medication and Side Effects, Examination and Diagnosis, Disease Management, Surgery for Dialysis, and Costs and Insurance. Sentiment analysis revealed that posts related to Medication and Side Effects topic and Surgery for Dialysis topic predominantly expressed negative sentiments. Both significant negative sentiments concerning worries about kidney transplantation among family members and positive sentiments regarding physical improvements post-transplantation were expressed in posts about family health and support. For Disease Management, seven key subtopics were identified, with inquiries about dietary management being the leading topic.

Conclusions: The findings highlight the critical role of online communities in providing support and information for kidney disease patients and their caregivers. The insight gained from this study can inform healthcare providers, policymakers, and support organizations to better address the needs of kidney disease patients, particularly in areas related to dietary management and emotional support.

(JMIR Preprints 02/08/2024:64838)

DOI: https://doi.org/10.2196/preprints.64838

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Keywords: Kidney diseases; online health communities; topic modeling; sentiment analysis; disease management; patient support

Introduction

Background

Kidney diseases encompass a wide range of conditions, including chronic kidney disease (CKD), acute kidney injury, glomerulonephritis, polycystic kidney disease, and various other renal disorders. These conditions collectively affect a significant proportion of the global population, with CKD alone estimated to affect 13.4% of people worldwide [1]. Kidney diseases increase the risk of other medical complications and significantly impact patients' quality of life and healthcare costs [2,3]. Managing these conditions can require substantial lifestyle changes, particularly in dietary habits, which can be challenging for patients [4]. However, maintaining a healthy lifestyle can reduce the risk of kidney disease progression and lower mortality rates [5].

Despite the critical role of lifestyle modifications in managing kidney diseases, patients often report receiving ambiguous or conflicting information from healthcare providers, leading to confusion and a sense of disempowerment [6]. Moreover, time constraints in clinical settings can limit the extent of guidance healthcare providers can offer. Consequently, many patients turn to online health communities for information and support.

The use of online platforms for health-related information has become increasingly prevalent, with approximately 80% of patients utilizing the Internet to exchange information and over one-third

of adults using social media for health information and social support [7,8]. These online communities serve as valuable resources for patients seeking information about various kidney diseases, treatments, and the experiences of others in similar situations.

While topic modeling has been widely used to extract health-related topics from social media data, studies focusing on public discourses and opinions presented on social media specifically related to kidney diseases are scarce. Additionally, topic modeling primarily allows for the quantitative analysis of the discussed topics but does not easily facilitate qualitative analysis, such as the analysis of sentiments associated with these topics. Therefore, this study aimed to address this gap by analyzing posts from a major online kidney disease community in South Korea. Topic modeling was used for quantitative analysis, and qualitative analysis was used to understand the emotional challenges associated with the topics. These analyses provide insight into the experiences, challenges, and concerns of patients living with various kidney conditions and their caregivers.

Objectives

The main objectives of this study were to:

1. Analyze social media data using topic modeling to better understand the experiences, challenges, and concerns of patients living with various kidney diseases and their caregivers in South Korea.
2. Explore the ways in which online communities can provide assistance, specifically in relation to disease management for different kidney conditions.
3. Examine the sentiment surrounding disease management among individuals affected by kidney diseases.

By achieving these objectives, this study aimed to provide valuable insight that can inform healthcare providers, policymakers, and support organizations in better addressing the needs of patients with a spectrum of kidney diseases and renal conditions.

Methods

Overview

The goals of this study were to identify the challenges faced by patients and determine the key topics related to kidney disease management. We utilized topic modeling for quantitative analysis and sentiment analysis for qualitative analysis to achieve this. Relevant posts were gathered from online communities discussing kidney disease, preprocessing was conducted, and the topics and sentiments were analyzed. Figure 1 provides an overview of the research methodology.

Data Collection and Preprocessing

We collected data from "KidneyCafe," a prominent South Korean online community for kidney disease patients and caregivers hosted on the Naver platform [9]. This community, with approximately 183,545 members, organizes discussions into boards based on specific kidney conditions, allowing for targeted analysis.

The Selenium WebDriver was used to extract 124,211 posts from ten disease-specific boards, dating from the community's inception on December 15, 2003, to the date of data collection (April 20, 2014). The collected data included post titles and content.

Data preprocessing was performed using Python, with the KoNLPy library employed for Korean natural language processing (NLP). This step involved removing punctuation and non-informative words, as well as extracting nouns from the text to prepare for subsequent analysis.

Topic Analysis Using Latent Dirichlet Allocation

We employed latent dirichlet allocation (LDA) topic modeling [10], an unsupervised machine learning model, to uncover latent topics in the collected posts. Topic modeling is a technique widely used in NLP for discovering topics and extracting meaning from large, unstructured documents. LDA is the most popular topic modeling method and is based on statistical probability inference. It assumes that each document can be represented by a probabilistic distribution over latent topics, and each topic is characterized by a probabilistic distribution over the words[11].

We imported LDA models from the Gensim library for this study. When analyzing topics using LDA, the number of topics is typically determined using coherence scores such as U_mass[12,13]. The U_mass coherence score, which relies on word co-occurrence statistics in documents, has been validated to closely align with human labeling results[12,14]. A higher coherence score indicates better topic quality and interpretability. We evaluated the U_mass coherence score for each cluster size on a scale ranging from 3 to 10 and found that the highest coherence score was achieved with six clusters (Supplementary Figure 1).

Using the optimal cluster size, we ran the LDA model to obtain lists of representative words for each cluster. Four food science researchers reviewed these word lists to determine the appropriate topic labels for each cluster. The contribution of each word to a cluster was evaluated using the probability metric derived from the model results. Representative example sentences for each cluster were identified based on the probability that each post belonged to the topic.

Sentiment Analysis

The bidirectional encoder representations from transformers (BERT) method, a machine

learning technique for NLP, was used to identify the sentiment of posts about dietary management—positive, negative, and neutral—to uncover which aspects of dietary management were the most challenging. While word embeddings can be derived from large and unannotated corpora using word co-occurrence statistics, they do not consider the context when creating word vectors [15]. However, BERT is context-dependent; it produces dynamic and context-specific representations of the word by accounting for neighboring words, which helps to interpret the semantics along with the grammatical structure [16].

Sentiment analysis of the posts about dietary management was performed utilizing the Naver CLOVA Sentiment platform, which uses a pre-trained BERT model. Sentiment analysis using BERT provides sentiment classification results (i.e., which sentiment—positive, negative, or neutral—is best represented in the texts) along with the expected probability of each sentiment.

Analysis of the Disease Management Topic Using ELECTRA

The Disease Management topic was investigated by conducting a detailed analysis. One author manually classified the posts categorized under Disease Management by the LDA results into questions and non-questions. Three additional authors independently annotated a subset of 300 posts to establish the annotation rules. The posts were reviewed for seven key sentiments: (1) general dietary management methods, (2) food recommendations, (3) inquiries about the safety of consuming specific foods, (4) requests for dietary evaluations, (5) water management, (6) exercise management, and (7) weight management. After discussion, the annotators agreed on a finalized set of annotation rules and guidelines.

Next, two independent annotators labeled a random set of 1000 posts from the overall dataset. Cohen's kappa coefficient for inter-rater reliability was 0.77, indicating substantial agreement. This annotated data was used for transfer learning. We fine-tuned the efficiently learning an encoder that classifies token replacements accurately (ELECTRA) model, a pre-trained language model that helps the machine learn superior contextual representations of text. We used 1000 manually annotated posts, split into training and test sets at a ratio of 80:20. The evaluation metrics on the test set yielded an F1 score of 0.85, indicating high performance. This fine-tuned ELECTRA model was then used to annotate the question posts related to the topic of Disease Management.

Results

Community Overview

We gathered a comprehensive dataset that included 124,211 posts from various discussion boards in the KidneyCafe community to better understand the experiences, challenges, and concerns

of patients living with kidney disease and their caregivers in South Korea. These posts were written by 34,472 unique users, indicating a highly engaged community. Of these users, 34.92% (12,039 of 34,472) wrote multiple posts, with an average of 3.6 posts per user. This high level of repeated engagement suggests that many users found ongoing value and support within the community. Figure 2 illustrates the monthly distribution of posts, showing a significant increase during the beginning of the COVID-19 pandemic in South Korea.

One of the notable advantages of this community is the categorization of discussion boards according to specific disease conditions. An examination of the number of posts collected per board (Table 1) showed that the highest number of posts was related to kidney transplantation (n = 39,221), followed by kidney dialysis (n = 27,692).

Table 1. Number of posts per board

Board [a]	**Crawled posts (number)**
Hypertension & Diabetes	1,422
Pediatric Kidney Disease	3,271
Others	3,969
Polycystic & Cysts & Lumps	4,011
Kidney Cancer	6,097
Chronic Kidney Failure	8,216
Proteinuria & Hematuria	10,113
Nephrotic syndrome & Glomerulonephritis	20,199
Hemodialysis & Peritoneal Dialysis	27,692
Kidney Transplant	39,221
Total	**124,211**

[a]The KidneyCafe organizes posts into boards according to specific health conditions.

Main Topics within the Kidney Community

We used LDA for topic modeling to identify the common topics discussed by kidney disease patients in the KidneyCafe. Our analysis revealed six distinct topic clusters that represented important discussions within the community. Each cluster was labeled based on the main keywords, as described in Table 2. Figure 3 shows how the following clusters were distributed across the community: Family Health and Support (28.36%), Medication and Side Effects (21.11%), Examination and Diagnosis (20. 12%), Disease Management (11.67%), Surgery for Dialysis (9.71%), and Costs and Insurance (9.03%).

Table 2. Keywords representative of the six discussion clusters in the KidneyCafe

Topic label	**Keywords**[a]

Family Health and Support	mother, father, discharge, mind, preparation, husband, start, family, groom, tomorrow, sibling, call, nurse, life, body
Medication and Side Effects	intake, immunosuppressant, symptoms, side effects, steroids, prescription, cold, treatment, morning, rejection reaction, dose, injection, face, yesterday, head
Examination and Diagnosis	blood pressure, tissue examination, normal, creatinine, blood test, management, creatinine levels, outpatient, professor, maintenance, hematuria, figures, current, diagnosis, function
Disease Management	exercise, water, weight, food, rice, meal, blood sugar, potassium, daily, diet, eat, urine volume, control, diabetes, snack
Surgery for Dialysis	blood vessels, peritoneal dialysis, removal, pain, recommendation, procedure, surgical site, hemodialysis, anesthesia, surgery, peritoneum, machine, arteriovenous fistula, Seoul, endoscopy
Costs and Insurance	application, price, registration, antibodies, usage, insurance, error, Korea, disease, occurrence, brain death transplant, cross-reaction, benefits, treatment, donation

[a]Each keyword represents the top 15 terms for each topic, ranked by their relevance score from the latent Dirichlet allocation (LDA) results, making them the most representative words for each topic.

Topic 1: Family Health and Support

Topic 1, which accounted for 28.36% of the discussions, mainly focused on family members with kidney disease and concerns regarding their health. The key terms included words related to familial relationships, such as “mother,” “father,” “husband,” “family,” “groom,” and “sibling.” These terms appeared frequently in discussions about kidney transplantation within the family context.

Examples of those posts are:

"It seems like my father will donate a kidney to my mother, but I'm worried."

Additionally, concerns and emotions surrounding post-transplant discharge and care were prevalent, with terms like “discharge,” “mind,” and “preparation” appearing frequently in the posts, as shown below.

"I work full-time, so how should I take care of my husband after he is discharged?"

" My sibling offered to donate a kidney, but my mind is very uneasy about it."

Topic 2: Medication and Side Effects

Topic 2 comprised 21.11% of the discussions and included posts about the correct usage, precautions, and dosages of medications. Key terms like “intake,” “immunosuppressant,” “prescription,” “treatment,” “morning,” and “dose” were frequently mentioned, highlighting discussions on the proper way to take specific prescriptions. Examples of those posts appear below.

"I was prescribed Solondo. Can Solondo and immunosuppressants be taken together?"
"Should immunosuppressants be taken on an empty stomach in the morning?"

The community also engaged in discussions on various side effects and their causes, with terms like “symptoms,” “side effects,” “steroids,” “injections,” and “rejection reaction” being commonly mentioned. An example of such a post follows.

"I was prescribed steroid injections and am experiencing side effects."

Topic 3: Examination and Diagnosis

Topic 3, accounting for 20.12% of the discussions, focused on kidney disease tests and diagnostic content. Terms related to specific test items, such as “blood pressure,” “creatinine,” and “hematuria,” as well as test methods such as “tissue examination” and “blood test,” were particularly frequent.

Examples of posts using those keywords are:
"My blood pressure was too low during a blood test."
"Which is more important, creatinine levels or the glomerular filtration rate?"

Additionally, discussions often included receiving a diagnosis from a doctor based on test results, with terms like “normal,” “management,” “outpatient,” “doctor,” “maintenance,” and “current” appearing frequently. Examples of those posts are shown below.

" I came for an outpatient consultation to review my test results.”

“The doctor said that, as of now, my test results showed normal creatinine levels and glomerular filtration rate, but ongoing management will be necessary for maintenance."

Topic 4: Disease Management

Topic 4, accounting for 11.67% of the discussions, focused on the management of kidney diseases, including exercise, water intake, and dietary management. Major keywords like “exercise” and “weight” were prevalent in exercise management discussions, such as the following.

"What exercises should I do to lose weight?"

Keywords such as “water” and “urine volume” were commonly seen in posts related to water intake management, such as *"How much water do dialysis patients typically consume?"*

Keywords such as “food,” “snack,” “meal,” “diet,” “eat,” “potassium,” and “control” were identified in the context of dietary management. Examples of those posts are shown below.

"What are some high-calorie foods or snacks that don’t strain the kidneys?"
"Is it okay to eat snacks after dialysis?"
"I’m following a low-protein, low-potassium diet. What should I be cautious of when planning my meals?"

Topic 5: Surgery for Dialysis

Topic 5, which accounted for 9.71% of the posts, focused on dialysis and pre-dialysis procedures. Major keywords, such as “hemodialysis,” “peritoneal dialysis,” “recommendation,” and “pain,” were prevalent, with many posters seeking advice on the reasons for selecting and transitioning between the two types of dialysis. Examples of those posts are shown below.

"Give me a recommendation on whether I should choose hemodialysis or peritoneal dialysis."
"While undergoing hemodialysis, I experienced pain as the pressure increased."

Additionally, keywords such as “blood vessels,” “procedure,” “surgical site,” “anesthesia,” “surgery,” “arteriovenous fistula,” and “Seoul” frequently appeared in posts related to pre-dialysis surgery, including arteriovenous fistula creation or placement surgery, and peritoneal dialysis

catheter insertion. Examples appear below.

"Can you recommend a good hospital in Seoul for arteriovenous fistula surgery?"
"After an arteriovenous fistula surgery, my blood vessel feels enlarged, and the surgical site is swollen. Is it normal for the vessel to enlarge after the procedure?"

Topic 6: Costs and Insurance

In topic 6, accounting for 9.03% of the posts, the users expressed significant concerns regarding financial and insurance-related issues related to managing their health conditions. The major keywords were “application,” “price,” “registration,” “insurance,” and “benefits.” They appeared in sentences such as the following.

“What documents do I need to prepare for an insurance application and reimbursement for costs?”
"How much compensation do patients undergoing dialysis receive?"
"I am a kidney donor and have registered for insurance. Can I claim insurance benefits?"

Distribution of Topics Across the Boards

We analyzed the distribution of topics across different boards to gain insight into the specific focus areas in each board (Figure 4). Our analysis revealed that the Kidney Transplant board had the highest concentration of posts related to the Family Health and Support topic and also showed a significant focus on the Medication and Side Effects topic. Of note was that the Hemodialysis & Peritoneal Dialysis board had a higher proportion of transplant-related topics than dialysis-specific ones. The Nephrotic Syndrome & Glomerulonephritis' and Proteinuria & Hematuria boards showed a high concentration of posts related to the Examination and Diagnosis topic. The Pediatric Kidney Disease board notably focused on the Medication and Side Effects topic, while the Disease Management topic was particularly prominent in the Hypertension & Diabetes board.

Sentiment Analysis of the Kidney Disease Topics

Posts on each topic cluster were analyzed to determine their sentiment, which was then categorized as positive, neutral, or negative. The results indicated that posts on the Medication and Side Effects topic contained the highest proportion of negative sentiments (Figure 5). This cluster often included discussions about adverse reactions to prescribed medications, concerns about the

impact of other drugs on kidney health, and general anxiety about the side effects of medications used to manage kidney disease. Below are a few posts from the community expressing these sentiments.

"Since starting steroids, my eyes feel very dry, and my legs feel heavy. Is this normal?"
"I took herbal digestive medicine due to severe stomach pain. I'm worried it might stress my kidneys."
"As a polycystic kidney patient, is it safe to be prescribed medication for severe itching from a dermatologist?"

Similarly, the topics Surgery for Dialysis and Examination and Diagnosis mainly received posts with negative sentiments. These topics often discussed difficulties with dialysis, dissatisfaction with diagnostic outcomes related to kidney disease, and other related issues. Here are some examples from each topic:

"I'm currently in my third year of peritoneal dialysis. I'm not anemic, but I feel extremely dizzy. Does anyone have any advice?"
"Last year, I was diagnosed with stage 4 polycystic kidney disease, which was tough. Now, finding out that my son has also inherited it makes it even harder."

The Family Health and Support topic also had posts with many negative sentiments, primarily expressing worries regarding kidney transplantation among family members:

"My sister is insisting on donating immediately, but I'm too worried about her health."

However, alongside these concerns, high proportions of posts about physical improvements after transplantation were also notable among positive sentiments:

"It's been three years since my simultaneous pancreas-kidney transplant. I just tried a urine test kit, and the results are good, which makes me happy."

While the Disease Management topic also had significant negative sentiments, they were relatively fewer compared to other topics. Negative posters often expressed frustration with managing the

disease or feeling overwhelmed by uncertainties in disease management, such as:

"Managing my diet is the hardest part."
"I really want to drink lots of water, but it's sad that I can't."

In contrast, many posts inquiring about disease management strategies were classified as expressing neutral sentiments:

"Is it okay to eat wild mango jelly?"
"Does curry have a lot of potassium?"

In the Costs and Insurance topic, negative and neutral sentiments were expressed in similar proportions. Negative posts often focused on concerns regarding delays or cost issues in insurance paperwork, such as:

"I applied for reimbursement of my cancer diagnosis fee, but the review process is taking too long."
"I currently have workplace group supplemental insurance, but I'm worried about what will happen after retirement."

In contrast, neutral posts mainly shared information regarding the handling of costs or insurance, such as:

"Today, when I visited the local district office, they provided me with an informational leaflet regarding the required documents for registering as a person with kidney disease."
"If my grade 2 renal impairment progresses to grade 5, what changes will occur in my benefits?"

In-Depth Analysis of Disease Management Topics

Given the complexity and importance of self-management for patients with kidney disease, we conducted an extensive analysis of the Disease Management topic. We carefully sorted the posts in this category into two main groups: information sharing and questions, as shown in Figure 6. We used an ELECTRA-based model to further categorize the questions into six specific subtopics. This process allowed us to qualitatively examine which issues were being actively discussed. We also analyzed the sentiments associated with each specific subtopic, which was important for determining

which subtopics were causing more difficulties for the patients (Figure 7).

The number of posts under the Questions category was more than four times higher than those under Information Sharing (Figure 6-7). The Information Sharing category included valuable resources, such as "Recommended information for post-transplant patients" and "Nephrotic syndrome management methods extracted from the Korean Dietetic Association." The majority of posts in the Questions category were related to dietary management (Figure 6), and these topics also contained posts with more negative sentiments (Figure 7). Specifically, 29.5% of the inquiries were about the safety of specific foods, 20.0% sought guidance on dietary management strategies, and 10.9% requested dietary recommendations. Examples of inquiries about the safety of specific foods included:

"Can I eat ginger if I have diabetes or kidney disease?"
"Are low-sodium salt and low-sodium soy sauce sold in stores okay?"

Examples of inquiries seeking guidance on dietary management strategies included:

"How should a single working person manage their weekday diet?"
"How should I manage my diet for proteinuria?"

Examples of inquiries requesting dietary recommendations included:

"Can you recommend low-potassium foods?"

Other popular topics included water intake management (7.9%), exercise management (7.0%), and weight management (6.7%). Examples of these questions included:

"Is it okay to do high-intensity exercises like CrossFit if I have polycystic kidney disease?"
"What should I do if my weight keeps dropping?"
"How many liters of water do you drink per day?"

Discussion

Our study findings provide valuable insight into the concerns and challenges faced by patients with different kidney diseases and conditions across various conditions. The analysis of online community discussions revealed several key points with important implications for patient care, education, and support.

Principal Results

Impact of COVID-19

The analysis revealed a significant increase in community activity during the COVID-19 pandemic. This observed increase underscores the heightened health concerns and information needs of CKD patients during this period. This finding aligns with research highlighting the increased vulnerability of CKD patients to COVID-19 complications [17–19] and emphasizes the importance of online communities as sources of support and information during health crises.

Topic Distribution and Varied Information Needs Across Disease Stages

Our analysis identified six main discussion topics in the kidney disease community: 1) Family Health and Support, focusing on concerns surrounding kidney donation among family members and post-transplantation management; 2) Medication and Side Effects, where conversations centered around medication administration methods and the associated side effects; 3) Tests and Diagnostics, where results from blood tests and tissue examinations were predominantly discussed; 4) Disease Management, which involved advice and shared experiences related to exercise, diet, and fluid intake; 5) Dialysis Surgery, which addressed dialysis methods and surgical procedures; and 6) Costs and Insurance, covering financial burdens related to managing kidney disease and insurance issues.

Early-stage patients, as evidenced by discussions in the Nephrotic Syndrome & Glomerulonephritis and Proteinuria & Hematuria boards, primarily focused on examinations and diagnoses. These posts aligned with the natural progression of the disease, where initial concerns revolve around understanding the condition and its implications. As the disease progressed, we observed a shift in focus toward disease management and treatment-related issues. A higher proportion of transplant-related topics were discussed in the Hemodialysis & Peritoneal Dialysis board, suggesting that many dialysis patients are considering or preparing for future kidney transplants. In the Kidney Transplant board, many discussions were related to Family Health and Support, as well as Medication and Side Effects. These findings are consistent with the complexities faced by transplant recipients, including the need for extensive medical management and coping with medication side effects, which can significantly impact morbidity and the quality of life [20].

Our analysis also sheds light on the unique challenges faced by patients with comorbidities and special populations. The Hypertension & Diabetes board prominently featured Disease Management topics, highlighting the added complexity of simultaneously managing multiple chronic conditions. The findings emphasize the need for integrated care approaches that address the interplay between kidney disease and common comorbidities [21,22]. The Pediatric Kidney Disease board's notable focus on the Medication and Side Effects topic reflects the heightened concern about treatment impacts on children. This underscores the importance of providing stage-specific support and education to patients.

Emotional Challenges and Support

The sentiment analysis revealed that discussions about medication side effects elicited the most negative emotions. The results identified particularly high levels of negative emotions in the themes of Medication and Side Effects and Dialysis Surgery. This underscores the difficulties that kidney disease patients face in pain management, as pain is a significant issue for kidney disease patients and significantly impacts their quality of life. Pharmacological changes associated with kidney disease increase the risk of side effects from pain medications, complicating pain management [23,24]. Specifically, more than 58% of dialysis patients experience pain, with 49% rating it as moderate to severe [25]. Medications typically need to be taken long-term, causing ongoing concerns about side effects, which can lead to heightened negative emotions. Similarly, posts on the Dialysis Surgery topic expressed negative emotions as patients began an indefinite period of dialysis.

The Family Health and Support topic showed a mix of negative sentiments. Negative sentiments regarding kidney transplants and their impact on families were also prevalent, consistent with studies showing that both transplant recipients and their families experience significant stress and concern [26]. However, successful kidney transplants are associated with improved health outcomes and increased life satisfaction, as indicated by the relatively higher proportion of positive sentiments [27,28]. Thus, kidney transplantation, meaning the end of long-term dialysis and dietary restrictions, which can allow patients to return to a more normal lifestyle, can increase positive sentiments.

Financial Concerns

The emergence of costs and insurance as a significant topic indicates that financial burden is a major concern for kidney disease patients. This finding is consistent with previous research highlighting the economic challenges faced by kidney disease patients and their families, especially those with limited financial resources[29]. The economic strain of managing CKD encompasses

expenses for medical supplies, specialized diets, and transportation to medical appointments. These challenges are exacerbated by various factors, including increased costs during hospital stays for transplantation, additional expenses due to delayed graft function, which can cost an additional average of $18,000 [30]and the need for multiple dialysis sessions. The severity of the kidney condition typically correlates with the magnitude of the financial impact [29–31].

The prolonged nature of kidney disease often makes it challenging for patients to maintain stable employment, further contributing to their financial difficulties. The strain of managing a long-term illness can lead to interruptions in careers, thereby increasing economic hardships for both patients and their families. Many patients and caregivers report reduced work hours or job loss, leading to further financial strain [32,33]. The financial burden varies between different countries due to differences in local healthcare systems, yet the impact on work hours and productivity is universally challenging [34].

Disease Management Challenges

Consistent with previous research highlighting the role of online communities in providing a platform for individuals to share information, experiences, and support regarding health issues [35–37], our study found significant engagement in Disease Management topics. Posts related to disease management often included sharing daily experiences and asking for advice, particularly about dietary management, which appeared more frequently compared to exercise, fluid intake, and weight management. Previous studies [22,37–39] identified dietary management as one of the most challenging self-care tasks for kidney disease patients. The dietary regimen for kidney disease patients is complex and varies based on the stage of kidney disease or remaining kidney function, necessitating comprehensive management. Individual differences in taste, including a preference for salty food, pose another challenge for managing the disease.

Patients with comorbid conditions, like obesity or diabetes, experience additional challenges in [21,22]. Because dietary management is different for different kidney disease conditions, the question of whether a food is acceptable for their condition was the most popular among the dietary management questions. This highlights the need for precise and tailored patient education regarding disease management from healthcare providers.

Comparison with Prior Work

Despite the active discussions in kidney disease communities, a notable paucity of research analyzing these communities exists. To our knowledge, the only study that previously analyzed a kidney disease community focused on the National Kidney Foundation’s online community for CKD [37]. However, this study only qualitatively analyzed approximately 20,000 posts without employing

topic modeling techniques. In contrast, our study utilized text mining methods to analyze a larger dataset, capturing more comprehensive insight into the perspectives prevalent in kidney disease communities. Another key advantage of our study was the ability to analyze posts based on disease state, which was not possible in the National Kidney Foundation's online community due to the lack of separate boards for different disease states. The previous study also did not conduct a sentiment analysis.

Other studies exploring the challenges faced by kidney disease patients have relied on surveys or interviews [31,40]. While informative, analyzing communities offers practical and voluntary consumer sentiment insights [41], a benefit highlighted by previous studies [42,43]. Our approach captured a more mainstream perspective due to the vast amount of user-generated content available online over extended periods [43]. Traditional survey methods are limited by resource constraints in analyzing data within specific spatial and temporal boundaries. In contrast, diverse individuals contribute extensive posts on online platforms, making text mining particularly valuable for the qualitative analysis of such large datasets.

Our findings resonate with the themes identified in previous studies. For instance, previous studies [37,40] highlighted themes related to Managing CKD and Symptoms, Medical Tests and Results, Navigating Healthcare and Clinical Needs, translated into Medication and Side Effects, Tests and Diagnostics, and Disease Management in our study. Additionally, Family Health and Support and Dialysis Surgery were similarly categorized under themes like Considering Dialysis and Family and Transplantation, reflecting the dynamics of CKD status. Support on the Forum, a significant theme in previous research [37], was classified in our study under Sharing Information within Disease Management, emphasizing the role of information exchange and communication in disease management.

Limitations

While our study provides valuable insight into the discussions and challenges in online kidney disease communities, it is not without limitations. First, the data were limited to posts from the KidneyCafe community and may not be representative of all kidney disease patients. Also, the specific environment of Korean kidney patients, such as differences in race, lifestyle, economic status, diet, and healthcare systems, may not be fully generalizable to other countries. Expanding the scope to include various communities from different countries would add diverse perspectives and enhance the comprehensiveness of the findings. Second, the topic modeling method, LDA, while effective in extracting main topics, does not determine the optimal number of topics and may not

fully capture semantic relationships between topics. ELECTRA, while efficient for our classification tasks, could benefit from domain-specific pre-training on medical corpora to enhance its performance on health-related text. Third, BERT-based sentiment analysis, though context-aware, is computationally intensive and has token limit constraints, which may affect the processing of longer posts. Also, the analysis might not accurately reflect the true sentiments of the posters, as the context in which words are used can vary. Lastly, the study's reliance on publicly available data excluded private discussions, which might have contained additional valuable insight.

Future research could address these limitations by incorporating multiple online communities, combining qualitative and quantitative methods, and exploring private discussions through surveys or interviews. Researchers might also consider using correlated topic models or expert review processes to refine topic selection. Expanding the scope to include various communities from different countries would also add diverse perspectives and enhance the comprehensiveness of the findings.

Conclusions

Our study offers an in-depth analysis of online discussions among kidney disease patients, highlighting key concerns and informational needs. The findings underscore the importance of online communities in providing support and education to patients and caregivers. These insights can inform healthcare providers and policymakers when developing targeted interventions to address the specific needs of kidney disease patients. Precise and tailored patient education regarding disease management from healthcare providers is clearly needed and can be significantly enhanced through the insight gathered from online community discussions.

Acknowledgments

This work was supported by the Korea Institute of Planning and Evaluation for Technology in Food, Agriculture, and Forestry (IPET) through the High Value-added Food Technology Development Program, funded by the Ministry of Agriculture, Food and Rural Affairs (MAFRA) [grant number 321029-05].

Conflicts of Interest

none declared

Abbreviations

CKD: chronic kidney disease

AKI: acute kidney injury

LDA: latent Dirichlet allocation

NLP: natural language processing

BERT: bidirectional encoder representation

ELECTRA: efficiently learning an encoder that classifies token replacements accurately

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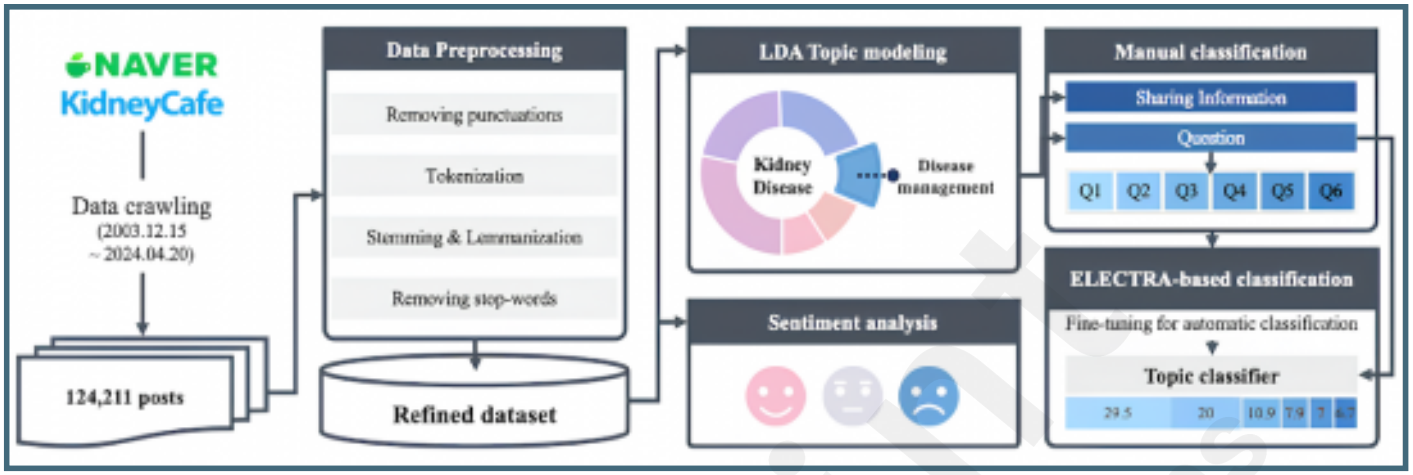
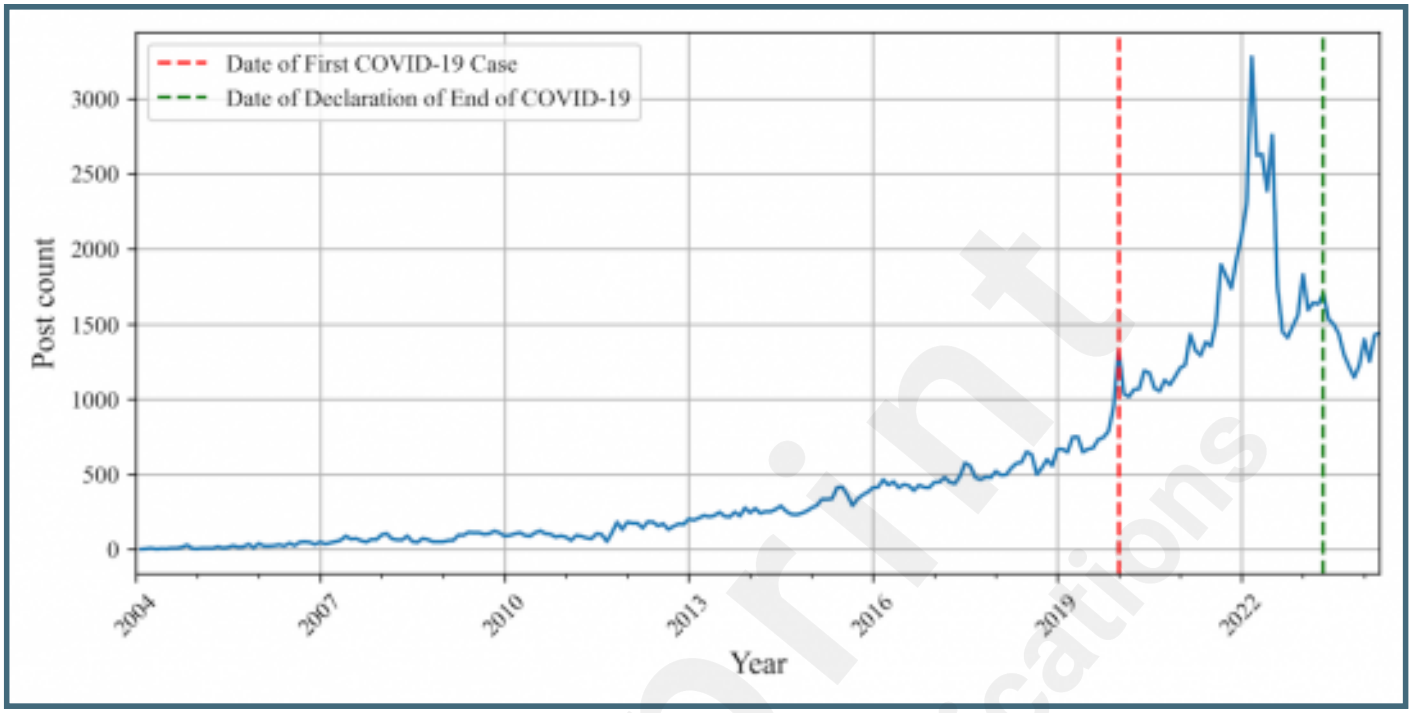
Supplementary Files

Figures

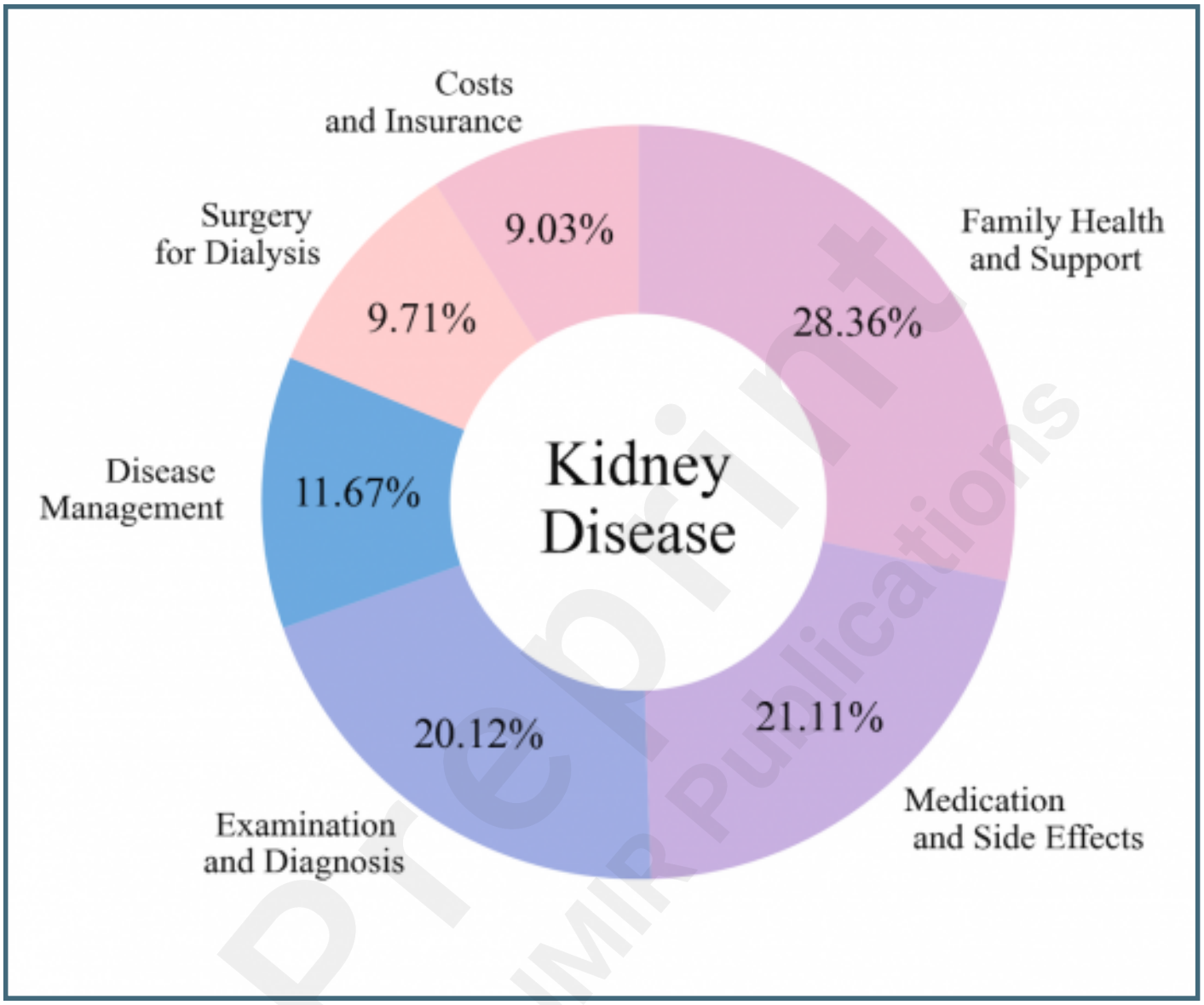
Overall procedures used in the study. The workflow included data crawling from Naver KidneyCafe, data preprocessing, latent dirichlet allocation topic modeling, and sentiment analysis of the total posts, and manual and ELECTRA-based classification related to disease management.



Timeline of the number of posts per month. The red line indicates the first confirmed COVID-19 case in South Korea, while the green line marks the World Health Organization's declaration of the end of the COVID-19 emergency. Monthly post counts were aggregated.

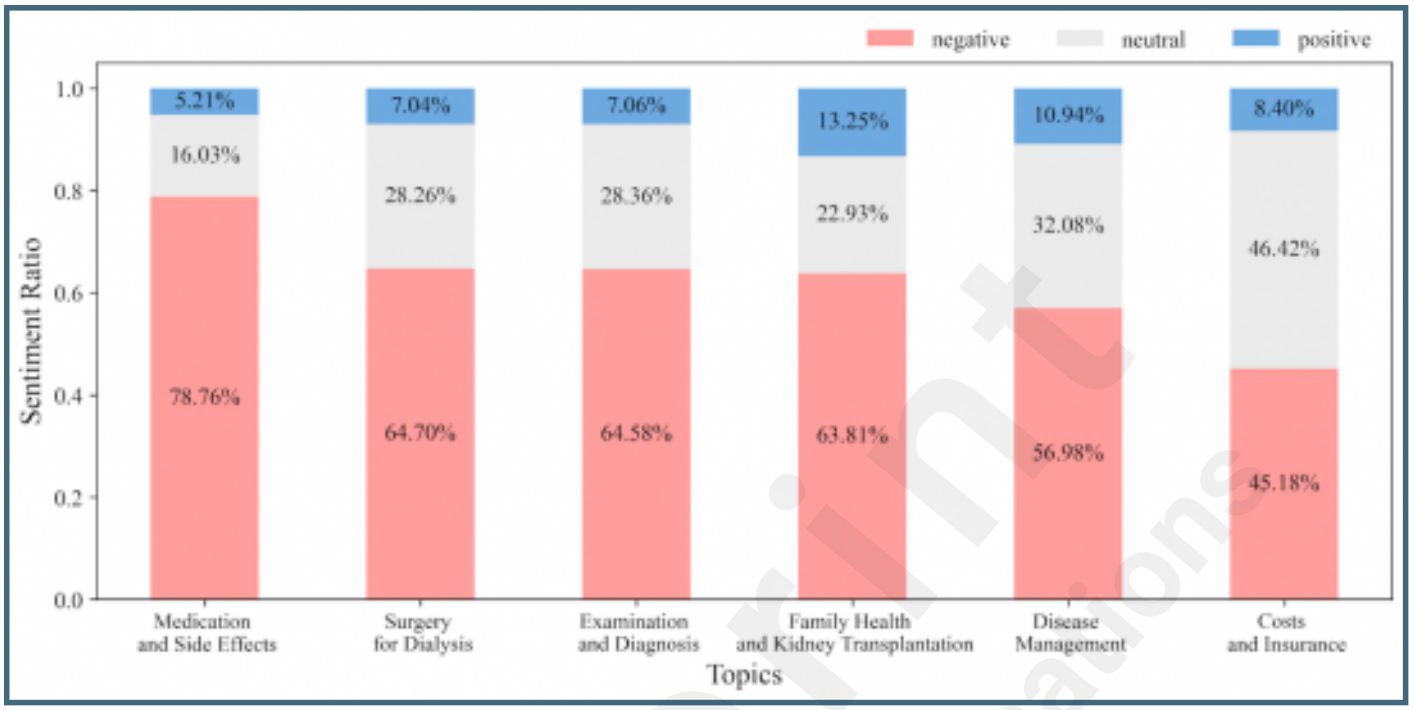


Ratios of the main discussion clusters in the KidneyCafe kidney community. The proportions, indicated as percentages, reflect the prominence of each topic within the community discussions.

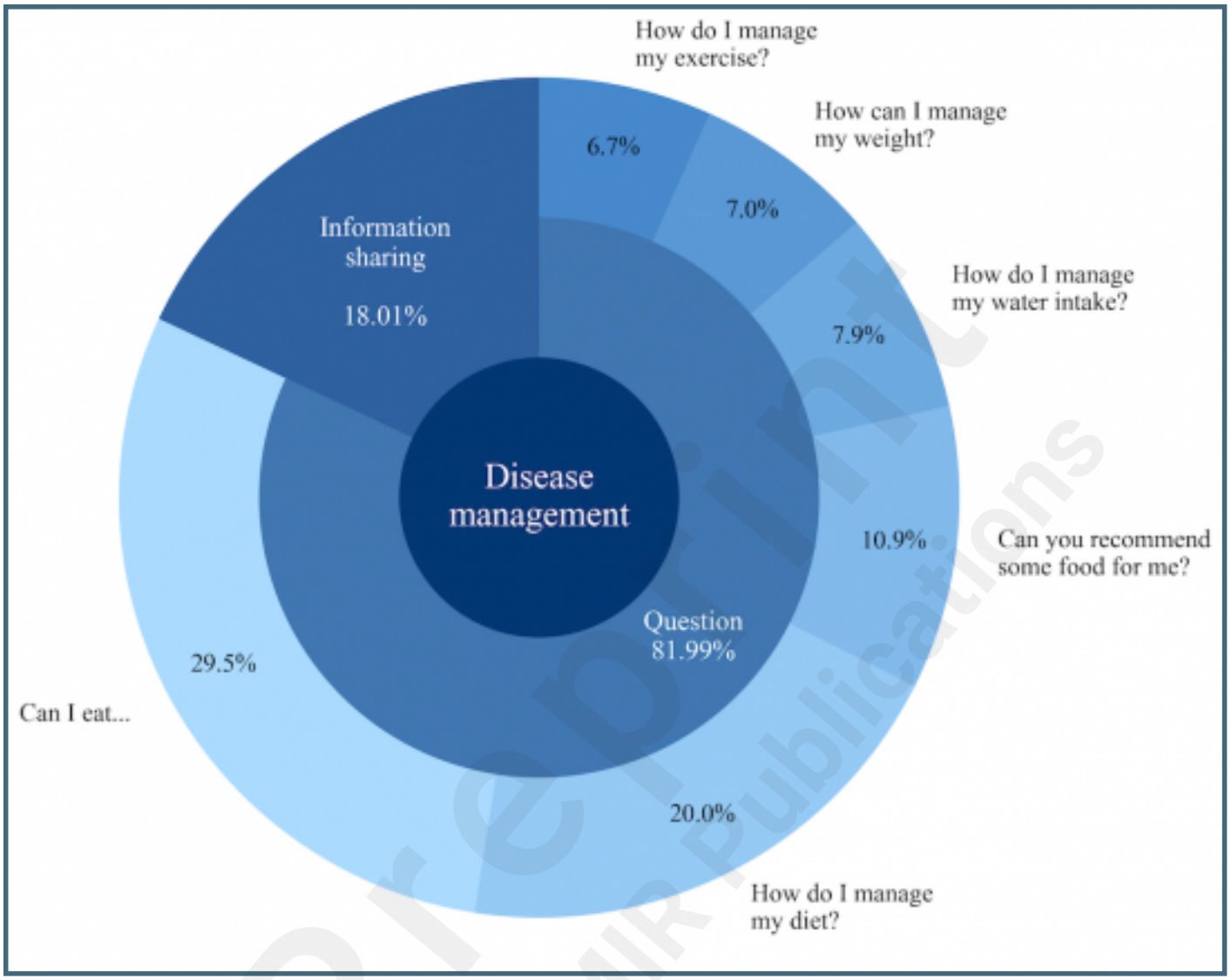


Topic distribution per board. The intensity of the colors in Figure 4 represents the frequency of a particular topic on a board, with darker shades indicating a higher concentration of posts related to that topic. The topics are ordered from left to right in descending order of overall prevalence across all boards. The boards are arranged from bottom to top in descending order of total post count.

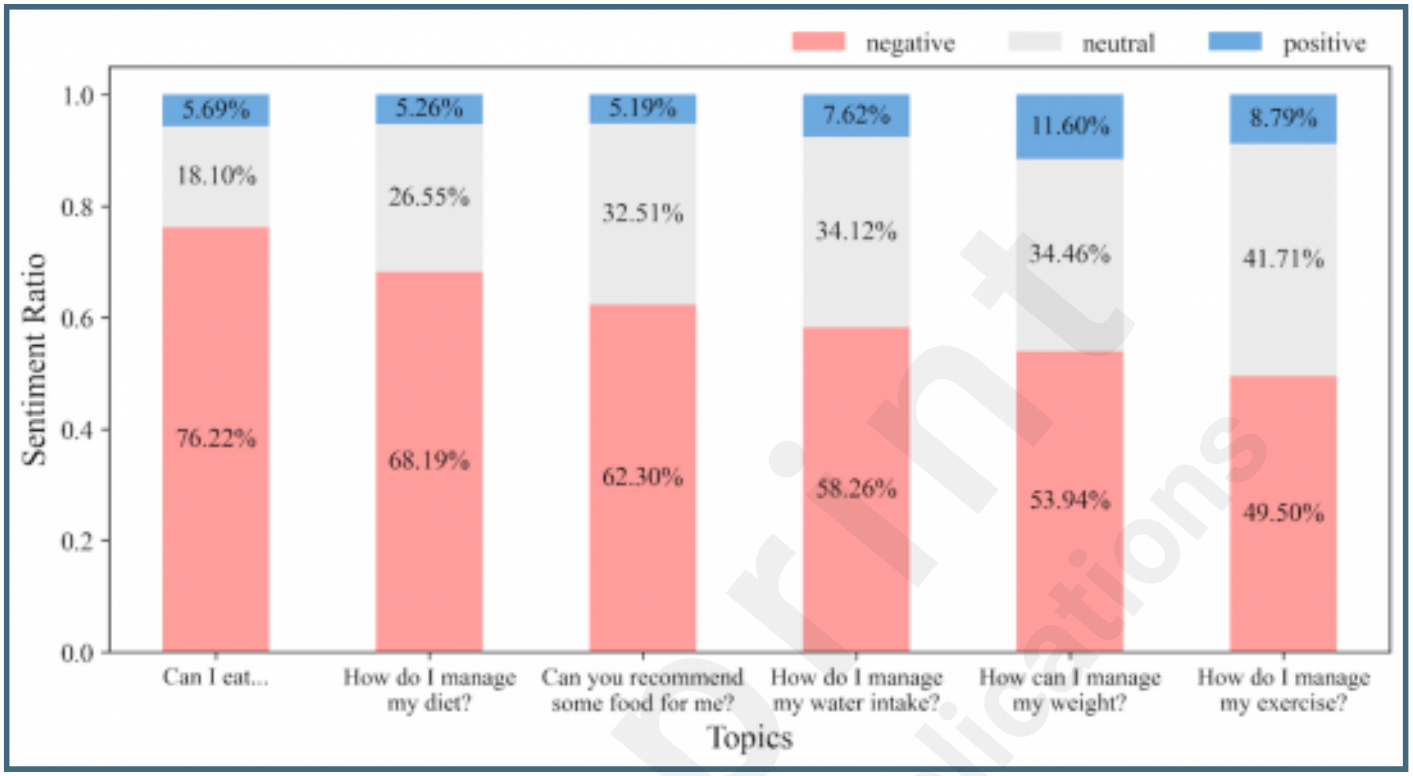
Sentiment analysis by topic. The distribution of positive, neutral, and negative sentiments across the six topics, demonstrating the varied emotional responses within the community discussions.



Subtopics in Disease Management.



Sentiment analysis by Disease Management topic. The distribution of positive, neutral, and negative sentiments across the six topics, demonstrating the varied emotional responses within the Disease Management topic.



Multimedia Appendixes

The coherence score for topic modeling using U_mass reaches its peak when 6 clusters are used.
URL: http://asset.jmir.pub/assets/3dfbff71d1f99f892b1d87d2cb668ade.docx