

Identifying Information Needs of Patients With IgA Nephropathy Using an Innovative Social Media–stepped Analytical Approach



Cristina Vasilica¹, Tom Oates^{2,3}, Christian Clausner¹, Paula Ormandy¹, Jonathan Barratt^{4,5} and Matthew Graham-Brown^{4,5}

¹School of Health and Society University of Salford, Salford, UK; ²Department of Nephrology, Royal London Hospital, Barts Health NHS Trust, London, UK; ³Department of General Medicine, Royal London Hospital, Barts Health NHS Trust, London, UK; ⁴John Walls Renal Unit, University Hospitals Leicester NHS Trust, Leicester, UK; and ⁵Department of Cardiovascular Sciences, University of Leicester, Leicester, UK

Introduction: The number of people with kidney disease using social media to search for medical information and peer support is increasing. IgA nephropathy (IgAN) predominantly affects young adults, demographically the biggest users of social media. This article presents an innovative analysis of social media interactions to identify unmet education and information needs of patients with IgAN.

Methods: Following ethical approval for the study, the IgAN Support UK Facebook group (<https://www.facebook.com/groups/915274415226674>) granted us permission to anonymously collect and analyze 1959 posts and comments from 498 group users. An initial patient focus group and quantitative word-frequency analysis created an initial categorization matrix that was iteratively refined after serial analyses of the social media database to generate a final categorization matrix of needs. We evaluated narrative data relating to each identified category to define patient narratives relating to each area.

Results: A large number of information gaps and unanswered questions were identified relating to the following: diet, symptoms, diagnosis, treatment, and patient comorbidities. Patient–clinician communication and the presentation of information were also drawn out as cross-cutting issues. These themes differed significantly from those identified from the traditional patient focus group, highlighting the value of this novel method for interrogating social media data to understand unmet patient needs.

Conclusion: Social media data are untapped and valuable resources that can be used to better understand patient information gaps, leading to the generation of targeted materials to address unmet educational needs. This innovative approach could be replicated across other health conditions.

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KEYWORDS: Facebook; IgA nephropathy; patient needs; social media

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See Commentary on Page 1205

Social networking sites have changed the nature of the Internet, with people now connected as never before. In 2019, there were 3.48 billion users of social media, an increase of 9% versus those in 2018.¹ In the United Kingdom, 86% of adults use the Internet, and the weekly length of time spent on the Internet has increased from 9.9 hours in 2005 to 22.9 hours in 2016.² Improvements in mobile technology mean that social networks, such as Facebook, Twitter, and Instagram, have become the preeminent way in which people

communicate and exchange information,³ including how patients search for information and support relating to medical conditions.⁴ Accessing appropriate, reliable information through social media and on the Internet remains a challenge for patients with long-term conditions.⁵

The ways we provide information for patients with chronic kidney disease (CKD) must improve, and we must be responsive to the ways people now search for and share information.^{6–8} Patients with CKD often express a desire for increased self-management and self-efficacy, with many acknowledging the value of other patients' opinions on their health as a way of learning from others' experiences.⁹ There are increasing data revealing that patients with chronic illnesses make use of social networking sites to search for information and seek peer support.^{10,11} For patients with a rare disease, social media

Correspondence: Matthew Graham-Brown, Department of Cardiovascular Sciences, University of Leicester, Leicester LE1 9HN, UK. E-mail: mgb23@le.ac.uk

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Table 1. Clarification of explained terms

Terms	Explanation
Mention	The occurrence of a keyword (including derivations) within a post. Multiple instances of a keyword still count as one mention for the respective post
Frequency analysis	Complete counts of all words or phrases used within the social media database
Posts	Comments and messages posted online
Scraping	Download of data from Facebook

allows patients to access disease-related information and connect with peer support from across the globe when neither of these resources is available locally.¹²

IgAN is a rare disease that tends to affect young patients who are demographically more likely to be active users of social media. Specific information needs of patients with IgAN relating to their health are unknown, and existing educational resources are limited. In this study, we used an innovative digital method to anonymously analyze the social media posts and interactions of patients with IgAN to identify and understand their unmet information needs. We compared the results of this method with those of a traditional patient focus group.

METHODS

In this study, we collected and anonymously analyzed the data obtained from the “closed” IgAN Support UK Facebook group (<https://www.facebook.com/groups/915274415226674>). After explicitly discussing with the group members, the administrators of the IgAN Support UK Facebook group approved the anonymous collection and analysis of posts within the group for the purposes of analysis in line with the study protocols¹³ and to the standards recommended by the Association of Internet Researchers.¹⁴ The study received ethical approval from the University of Salford (number HSR1617-127). The anonymity of the group members was protected throughout the study. No participant data were reported, and all analyses were conducted without any identifiable information. No direct quotations were used so as not to inadvertently identify participants. Terminology used throughout the methods and presentation of findings is clarified in [Table 1](#).

Data Collection and Preparation

Social media posts and associated comments were scraped (downloaded) using Facebook and Grytics (Facebook Groups Analytics & Management Tool), for a 2-year period (22 December, 2015–22 December, 2017). Data were merged into an anonymous database of posts and related comments. Duplicate posts and associated demographic information or data that could identify patients were removed.

Data Analysis

Data analysis was completed in the following 2 stages by the multiprofessional research team ([Figure 1](#)).

Creation of the Categorization Matrix

The database of Facebook posts and conversations was analyzed to define a matrix of existing needs, with the creation of serial categorization matrices that were iteratively updated in a structured and unstructured way (allowing for the identification of new categories) to systematically make sense of key information categories.¹⁵

- An initial thematic framework was developed using a face-to-face patient focus group convened to identify categories that patients felt were areas of unmet patient needs ([Table 2](#)). The focus group was transcribed, and thematic analysis was undertaken by a trained qualitative researcher to identify major themes. This was used to develop the initial categorization matrix ([Supplemental Table S1](#)), which was used for the first interrogation of the social media database and served as a reference to facilitate a comparison between the potential needs of patients with IgAN as defined by a patient focus group compared with analysis of social media data.
- The social media database was interrogated with a directed analysis using the predetermined categories outlined in categorization matrix 1. All posts within the database that contained words or phrases defined in categorization matrix 1 were reviewed and further classified with additional themes added to the matrix.
- A summative analysis of the social media data set was conducted to quantitatively define word/phrase frequency, generating complete counts of all words or phrases used in the social media database (uninformative words, such as “the,” “and,” “or,” were excluded).¹⁶ The categorization matrix was updated with this to create the second categorization matrix ([Supplemental Table S2](#)).
- The database was iteratively reanalyzed to develop and refine the categorization matrix in an inductive way based on additional categories and themes identified each time the data were reanalyzed. These steps were repeated until no new themes or categories were identified, and the final categorization matrix was defined ([Supplemental Table S3](#)).

Understanding the Narrative From Identified Categories

Once the final categorization matrix was created, all posts containing the words and phrases in the final categorization matrix and associated conversations

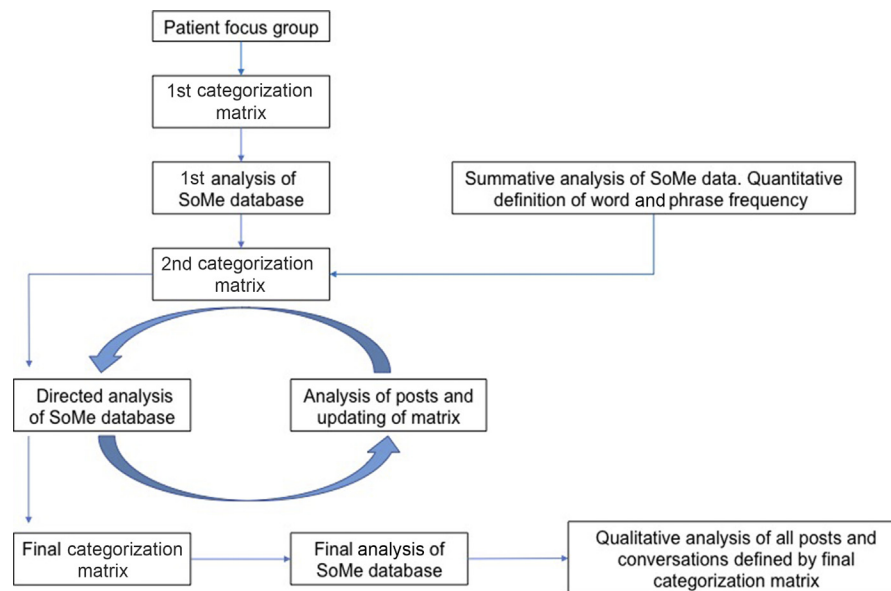


Figure 1. Data acquisition and analysis. SoMe, social media.

were read and reviewed by 2 researchers for content, meaning, and sense to distill the nature of the conversation and questions into narratives for each of the categories and subcategories.

The final summary findings were reviewed by a multiprofessional research team including patients, nurses, doctors, dietitians, pharmacists, and health care assistants to confirm the interpretation of the study findings and plan educational resources to inform the knowledge gaps identified.

Data Reliability and Privacy

To increase the reliability of the quantitative frequency and content analysis, data were interrogated by 2 researchers experienced in the techniques and checked for accuracy by a third independent researcher.

Table 2. Key themes of information identified from initial patient focus group

Categories	Information need
Diagnosis	Information on kidney biopsy Genetics and family testing Kidney scans Why some people get hematuria
Disease progression	Will my IgAN get worse? How can I stop my IgAN getting worse? Recurrence after transplantation
Diet	Potassium Phosphate Salt
Medications	Specific treatments for IgAN What do the medications I take do? Experimental trials
Information on disease staging	Staging of CKD The different ways IgAN can affect kidneys and what this means
Extra support available	Support relating to CKD IgAN support groups

CKD, chronic kidney disease; IgAN, IgA nephropathy.

Throughout the analysis sense-checking, face validity and trustworthiness of the data were confirmed through consensus review by the study team and patient representatives. The privacy of the members of the Facebook group was protected throughout the study in compliance with the General Data Protection Requirements (2018), study protocols, and ethical approval. No direct quotations from original data posts have been used. Quotations to illustrate study findings have been modified, so meaning can be inferred, but anonymity is protected.

RESULTS

A total of 1959 posts and comments were retrieved from the IgAN Support UK group from 498 different users, 113 of whom were active users (posted, and/or commented, and/or reacted to posts in the group during the period the data were acquired). The types of media included in the posts were as follows: text status update (80%); photo (11%); links to other sites (8%); and video (1%). A total of 96% of the posts were commented on or reacted to. Patients were the main users of the group, but family members and carers were also included as part of the community.

Major Themes of Unmet Patient Need

The final categories of major unmet need for patients with IgAN identified through the analysis of the social media database are shown in Figure 2. The subcategories relating to each of these themes and the corresponding number of posts are found in Table 3. The comparative categories of patient needs identified from the IgAN patient focus group are found in Table 2.

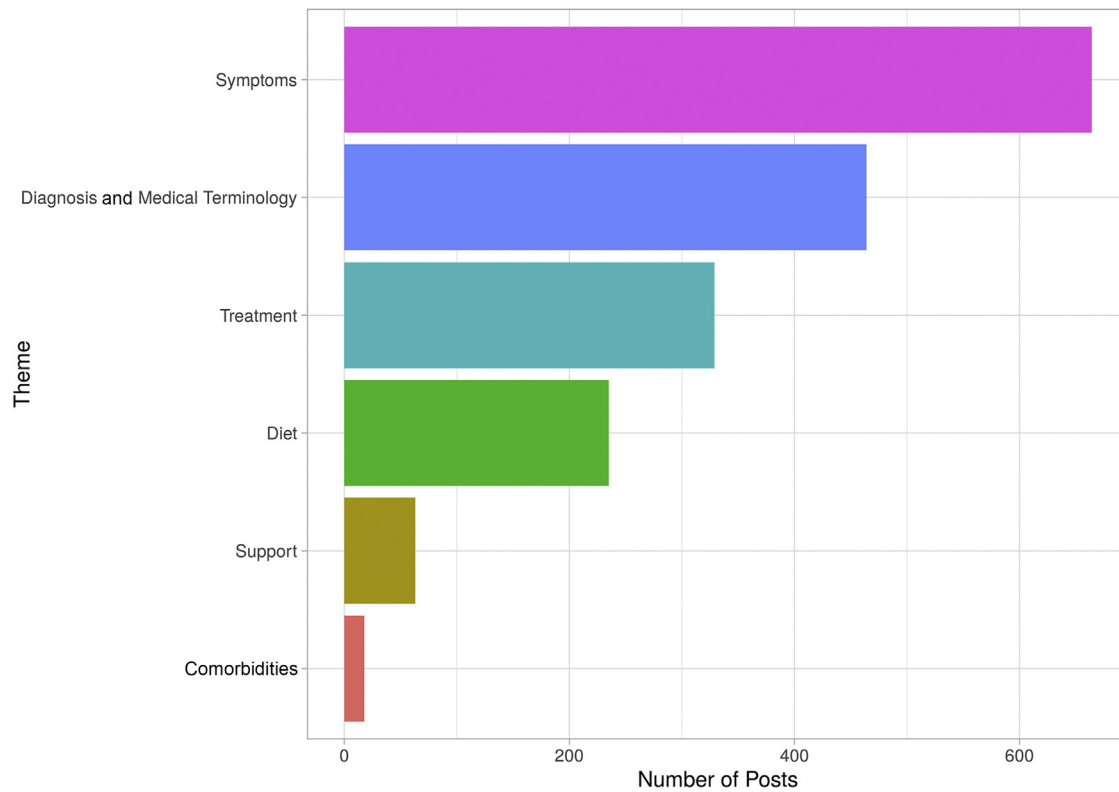


Figure 2. Key categories of unmet patient information needs identified through analysis of social media data.

Qualitative analysis of the final posts identified in the social media analysis identified the following 2 cross-cutting themes that were subcategorized and analyzed:

- Patient–clinician communication.
- Issues on presentation and trustworthiness of information.

Qualitative Analysis of Social Media Posts Relating to Specific Categories and Subcategories

Narratives related to the categories and subcategories are discussed subsequently.

Diet

There were 235 diet-related mentions in posts and comments. Many patients sought information on a healthy diet and wanted to know whether specific diets or dietary changes would help manage their disease and symptoms. Specific areas of diet-related discussion were as follows:

Protein (n = 81). There was confusion in the posts on dietary protein. Many patients stated that they had been explicitly told by medical staff to avoid high-protein diets, whereas others had been told the amount of protein intake did not make any difference to IgAN or progression of CKD.

Salt and Potassium (n = 35). Many posts were related to reducing salt intake. Peer-to-peer interactions

Table 3. Key themes of information need identified through analysis of social media data (final summative analysis)

Key categories	Information need
Symptom (n = 664)	Kidney pain (n = 11) Pain (n = 132) Fatigue/tiredness (n = 38) Blood pressure (n = 95) Blood (n = 160) Swelling (edema) (n = 35) Itchiness (n = 5) Headaches (n = 15) Poor sleep/sleep (n = 29) Others (n = 144)
Diagnosis and medical terminology (n = 464)	Kidney function (n = 48) Stage (n = 72) Biopsy (n = 77) GFR (n = 84) Diagnosis in general (n = 183)
Treatment (n = 329)	Medication/drugs (n = 105) Treatment (n = 57) Transplant (n = 142) Others (n = 25)
Diet (n = 235)	Salt and potassium (n = 35) Gluten and dairy (n = 20) Protein (n = 81) Fish oil (n = 6) Weight (n = 19) Others (n = 74)
Support (n = 63)	Support (n = 47) Insurance (n = 16)
Comorbidities (n = 18)	Diabetes (n = 9) Gout (n = 9)

GFR, glomerular filtration rate.

acknowledged the difficulties in maintaining a low-salt diet. Peers reinforced that it was important to adhere to low-salt diet as it helped the way medications (particularly blood pressure medications) worked. Specific advice was sought on low potassium foods.

Gluten and Dairy (n = 20). There were discussions on whether gluten or dairy-free diets were treatments for IgAN. Peers discussed possible links between gluten and autoimmune diseases. Some patients expressed feeling better on gluten-free and dairy-free diets and that symptoms improved with these diets. Several peers counseled that there was no evidence that these diets improved IgAN, but they were safe to follow.

Weight (n = 19). Patients acknowledged that weight loss was advisable if you were overweight and aiming for a “healthy weight.” Peers advised each other that not being overweight was important if a transplant was needed. Weight gain was frequently discussed as a side effect of steroid therapy, but no peer advice was found to help deal with this. Finally, weight loss was discussed as a possible way of improving kidney function, but no consensus was reached on whether weight loss was beneficial to preserve renal function for patients with IgAN.

Fish Oil (n = 6). There were discussions on whether fish oil was beneficial for patients with IgAN, particularly whether it reduced infections. Some patients were worried about the potential of fish oil to “thin their blood,” but others stated that whether it was beneficial for IgAN or not, eating oily fish was a way of reducing red meat intake.

Symptoms

There were 647 mentions in all posts related to symptoms from, or attributed to, IgAN. Newly diagnosed patients with IgAN asked for advice on what symptoms to expect and sought advice from more experienced patients on managing common symptoms.

Kidney Pain/Pain in General (n = 143). Kidney pain was described as a pervasive, unwanted symptom. Many patients suggested that it often followed a viral infection and wondered whether it was associated with a decline in kidney function. Some patients were interested to know whether pain was related to IgAN, but most wanted advice on controlling the pain as it was intrusive and unrelenting. Some suggested that dehydration and stress triggered their pain or made it worse. There was an overwhelming feeling that this symptom was dismissed by doctors, and many were told unequivocally that it was not related to their IgAN. Recurring advice in the peer support group was to avoid nonsteroidal anti-inflammatory drugs as these medications could “make kidney function worse.”

Table 4. Commonly asked questions around diagnosis and medical terminology

S. No.	Questions
1.	What “kidney function” meant?
2.	What protein spillage/leakage meant?
3.	How was creatinine different to eGFR?
4.	The relationship between urinalysis findings and IgAN?
5.	What are urine dipsticks for?
6.	What did doctors meant when they talked about “PCR?”
7.	How is blood pressure related to IgAN and what should it be?

eGFR, estimated glomerular filtration rate; IgAN, IgA nephropathy; PCR, polymerase chain reaction.

Fatigue/Tiredness (n = 38). Fatigue and tiredness were often-discussed symptoms, particularly their relationship with kidney function or phosphate levels. There were many pieces of peer advice on the importance of ensuring that hemoglobin and iron levels were well managed, and reminders were posted to ensure doctors tested for conditions unrelated to IgAN, such as thyroid problems. The impact of fatigue on daily life was clear, with many describing their being unable to undertake normal activities and lacking energy to exercise. There was acknowledgment from many that blood pressure medications often made tiredness worse.

Blood Pressure (n = 95). Blood pressure was discussed in the context of the importance of keeping it under control and managing its side effects (such as migraine/tiredness).

Swelling (edema) (n = 35). Patients discussed swelling as a side effect of medications and swelling relating to declining kidney function. Patients mentioned the “moon-face” associated with taking steroids and how it took time for steroid-related swelling to reduce and the importance of recording weight and taking “water tablets” as prescribed.

Itchiness (n = 5). Some patients described itchiness as a “sign” that their kidney function was dropping. Several patients noted that the itchiness changed into a “rash.” No solutions were offered by patients to manage this symptom.

Headaches (n = 15). Some patients experienced headaches on most days and questioned the relationship to IgAN. Salt intake was reported to worsen headaches. No consensus was reached in the discussions on the relationship between headaches and IgAN or CKD.

Poor Sleep/Sleep (n = 29). Many patients acknowledged not being able to sleep well and that sleeping tablets did not help. There was a suggestion that not drinking before bedtime might help.

Diagnosis and Medical Terminology

There were 464 posts from patients discussing issues on the diagnosis of IgAN and the implications of a diagnosis of IgAN. Some patients described anxiety before

their kidney biopsy and relief at getting a diagnosis. A number of posts were from patients who had received information on what a kidney biopsy entailed but who were searching for personal reassurance from peers about the process.

Table 4 summarizes the posts and questions from patients asking for explanations of medical terminology. These questions were well answered by the peers.

Treatment

Discussions regarding medications and treatments for IgAN were largely divided into the following 2 groups: first, patients searching for specific treatments for IgAN; and second, patients wanting help to deal with medication side effects.

There were 63 posts on specific treatments for IgAN and clinical trials. Most patients searching for details of clinical trials wanted to know if there were trials for which they might be eligible. A smaller numbers of patients were interested in understanding more about complementary therapies. Hyperbaric oxygen and naturopathic therapies were discussed, but most comments explained that there was no evidence of any complementary therapies slowing the disease or relieving symptoms. The use of painkillers was discussed, with peer advice that nonsteroidal anti-inflammatory drugs should be avoided in “kidney disease.” This advice was given regardless of estimated glomerular filtration rate of a patient (even when stated). Most patients were searching for advice on painkiller safety as much as efficacy.

Patients sought peer advice on specific medication side effects. The major side effects of blood pressure medications were dizziness, lack of energy, headaches, and migraines. Patients discussed if the time-of-day medications were taken would help reduce side effects. Peers reinforced the importance of taking blood pressure medications and discussing with doctors about changing medicines to alleviate symptoms rather than stopping them altogether. Patients also sought advice for dealing with side effects from steroids. Most often reported side effects included facial swelling, fluid retention, and weight gain. Importantly, most patients were not seeking answers for why side effects were common, but they were looking for reassurance that the side effects were “normal” and advice on how to manage them. A smaller number of patients made particular comments about hand tremors and excessive hair growth with tacrolimus therapy and gastrointestinal side effects from mycophenolate.

There were 230 mentions from patients seeking information about kidney transplantation and dialysis. These discussions and conversations were not unique to IgAN, and patients were looking for information on

the best time to start dialysis, the benefits of pre-emptive transplantation, and how to approach discussions with family and friends on donation. There were a small number of posts seeking information on exercise and whether this helped slow or improve IgAN.

Comorbidities

There were 113 posts from patients discussing conditions related to their IgAN, including diabetes, hypertension, and gout. Patients wanted to know if the conditions were related, and many mentioned that they had developed diabetes during a course of steroids. Others stated that they had developed diabetes alongside their IgAN. The knowledge on management of diabetes and gout was high, and patients mostly discussed the conditions as a common part of the patient experience.

Support

There were 63 posts related to the support of patients with IgAN. Many posts stated that they had joined the Facebook group to find support from people with similar experiences. Many reflected how helpful it was to share experiences with people who had experienced similar challenges. When appropriate, group members referred peers to other support groups, particularly with questions relating to CKD in general, rather than questions on IgAN. The inclusion of family and carers in the group was acknowledged as being important.

There were a smaller number of posts discussing health, holiday, and life insurance, with practical support and advice on these issues. Some patients also indicated that it was difficult to get support from employers who did not understand the implications of either CKD or a diagnosis of IgAN. Many patients felt that clinicians or patient support charities could write letters to acknowledge the needs and challenges of patients with CKD and IgAN and that training and information resources should be available for employers.

Cross-cutting Themes

There were 2 additional cross-cutting themes identified spanning the categories.

Patient–Clinician Communication. Peer conversations frequently highlighted that some of the “traditional advice” regarding immunosuppression in IgAN was now considered debatable and that it was hard to be sure of the current best evidence. There was frustration that many of the problems patients wanted to discuss (primarily relating to symptoms) were dismissed by clinicians, with a common feeling that doctors dismissed symptoms they did not know how to deal with them. Patients frequently stated that they did not mind if their doctors could not alleviate their symptoms but that they should acknowledge them. Many felt that

this was an issue of time and consultations being too short.

How to Present Material. A key theme that emerged was that information did not exist for the questions that people had, specifically about patients with IgAN. Many were concerned that often resources did not seem trustworthy or to be from a reputable source. The resources people found were often not presented in a format that was easy to digest, with the use of medical jargon widespread in the existing IgAN patient literature.

DISCUSSION

This study describes the unmet needs of patients with IgAN using a novel, digital approach to analysis of social media data. The categories identified through the analysis of social media were different from the categories identified in the patient focus group, emphasizing the importance of this digital method as a way of describing patient experience and needs. The needs identified were well defined, and we have created an open-access library of videos with patient partners to meet these needs (<https://www.youtube.com/channel/UCwZepd8YXUf9RkTYzgH4-cw/videos>).

The digital approach we describe differs from traditional methods for understanding patient needs, such as focus groups, questionnaires, and patient interviews. Selection and participation bias, ingroup bias, investigator bias, and limitations of the questions asked and the way/order they may be asked are all acknowledged limitations of these techniques.¹⁷ Although these limitations can be mitigated by inter-rater validation, individualized design of qualitative techniques, and triangulation of methods, they will remain in many cases. The digital method we describe may be free from some of these biases. The social media data we analyzed were created by users, free of any investigator agenda or bias, and as such can be considered an organic, uninfluenced data set of the conversations and discussions of patients with IgAN. Furthermore, because the group contained only patients, family members, and carers, patient posts and responses were not influenced or modified because of a preexisting relationship between the individual and their medical/research team. The database contained posts from nearly 500 participants, more than 20% of whom were active users. Focus groups contain a smaller number of individuals, and although questionnaires can be given to a large number of individuals, the responses are limited by the scope of the questionnaire. Patients who participate in focus groups for research are often more expert and confident about being involved in group discussions.¹⁸ This is

illustrated in this study by the differences between the information needs identified by the patient focus group and the final information needs defined by analysis of social media data. The information needs identified by the focus group tended to be more complex than those identified from social media analysis, perhaps reflecting a greater knowledge and expertise of those involved in the focus group. This also indicates that social media may provide a convenient space where patients with less knowledge and expertise feel comfortable asking questions. This is especially important for patients with a rare disease, for whom the opportunity to find local support groups is limited.

There were 2 categories of information needs were identified through this research: information on issues common to patients with CKD and information needs specific to patients with IgAN.

Questions on dietary potassium, phosphate, and salt would be expected of any patient with CKD, whereas questions on dietary fish oil are likely unique to patients with IgAN. Although both were found to be “information needs” for patients with IgAN, it is likely that information gaps relating to CKD would be common to all patients with CKD regardless of their primary disease. This also highlights the complexity for patients in the way health care professionals refer to and classify patients with both a primary disease (e.g., IgAN) and a syndrome to explain the manifestation of the disease (e.g., CKD/end-stage kidney disease/nephrotic syndrome). These definitions are largely for the convenience of health care professionals to help with risk stratification and appropriate management but may be confusing for patients. It is, therefore, unsurprising that CKD does not permeate public consciousness such as other chronic health conditions. Not only is CKD a largely invisible condition from the outside, but the terminology used to discuss it is opaque and confusing. This may explain the frustration patients expressed - that employers had limited understanding of the implications of a diagnosis of IgAN or CKD. This needs to be addressed by clinicians and policy makers with consistent public health messaging.

Many of the conversations related to symptoms attributed to IgAN or CKD are in keeping with the symptoms described in patients with CKD.^{19–21} Often, these posts expressed frustration that clinicians frequently dismissed symptoms as being unrelated to kidney disease or of minimal importance. The peer support offered in relation to symptom management was practical and suggested that clinicians did not address these issues as there are often no good therapies. Although this may be true, these data are a reminder to clinicians that acknowledgment of patient concerns is fundamental to their role. Most patients did

not expect a solution to their symptoms but did expect empathy in how clinicians responded to their concerns and a balanced psychosocial approach to their personal challenges.

Limitations

Although the method we describe protects patient anonymity, the lack of participant-level demographic data limits the generalizability of the findings; for example, to know how to correctly respond appropriately to questions about potassium. It also means that we cannot conduct analyses to identify whether certain questions were more likely for patients of different ages, sexes, ethnicities, kidney function, or those with other factors. This study was conducted in the United Kingdom, and the IgAN Support UK group was chosen for this reason. This, again, reduces the generalizability of the findings, as patient opinions and questions are invariably “framed” by interactions with clinicians. There was no mention of tonsillectomy for treatment of IgAN, for example. Had this study been conducted in a Japanese Facebook group, this would likely have been different. This highlights the value of completing similar studies in different countries and populations.

The digital method we have described allows analysis of organic, social media content at scale, but there are potential biases. Although the use of social media is widespread, there are patients who are not active Internet/social media users and their views may not be captured. It is also possible that the views expressed in groups are subject to ingroup bias, in which certain individuals lead and control the narrative. In this analysis, this was not the case as most discussions contained individuals expressing differing and sometimes opposing points of view suggesting group members were able to freely express different opinions and perspectives. Indeed, the way this approach identified discussions between patients is a strength of the study, highlighting areas where there is a lack of consensus. Importantly, this digital method is not a replacement for traditional qualitative study techniques, rather an additional and complementary method that is applicable to studying the needs of other patient groups, especially those with rare diseases.

CONCLUSION

This study describes a novel, digital method for the identification of the unmet needs of patients with IgAN using analysis of social media data. The findings highlight important knowledge gaps that can inform the creation of resources to satisfy these needs. This method can be applied to the study of patients with a variety of chronic illnesses.

DISCLOSURE

All the authors declared no competing interests.

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SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1. Categorization matrix 1.

Table S2. Categorization matrix 2.

Table S3. Final categorization matrix.

STROBE Statement (PDF).

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