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Bridging the Gap: The Role of Social Media Support Groups in Diabetes Care and Management

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ABSTRACT

Background: With the growing prevalence of diabetes in Kenya and the complex challenges of managing the disease, individuals with diabetes increasingly turn to social media (SM) support groups. This study explores how these individuals engage with SM support groups and how they verify the information shared within these platforms.
Methods: A qualitative study was conducted from June-August 2022. Participants (n=15) were purposively recruited from Facebook and WhatsApp social support groups exclusively for those with diabetes. Participants included adults diagnosed with diabetes and were active members of the SM support group. Data was collected virtually through in-depth, semi-structured interviews conducted via Zoom. Data was transcribed, coded, and analyzed using content analysis.
Results: Five themes were constructed: 1) SM support groups provide accessible and affordable health information, 2) Participants leverage support groups as an alternative to formal professional healthcare engagement, 3) Participants leverage SM support groups to learn from peer-driven experiences and strategies to enhance diabetes self-care 4) Participants value community empathy and peer support in SM support groups 5) Participants strategies of authenticating and verifying information from SM support groups.
Conclusion: The study highlights the multifaceted role of SM groups in diabetes care in Kenya, suggesting the need for healthcare professionals to collaborate with these online communities. It emphasizes the necessity for accurate information verification and points to the future integration of SM groups into formal healthcare strategies.

Keywords: Diabetes, social media, support groups, diabetes self-care, diabetes management

INTRODUCTION

Diabetes, a concerning noncommunicable disease, impacts more than 422 million individuals worldwide, leading to over 1.6 million reported deaths each year (1). In Kenya, diabetes prevalence ranges from 3.5-5% in rural regions, with urban areas seeing rates as high as 12% (2). With the rise of diabetes globally and in Kenya, there is an overwhelming need to help those who live with it to manage and prevent the progression of the disease and the associated complications. Diabetes is a chronic and lifelong metabolic disease, which, if unmanaged, leads to microvascular and macrovascular complications with a substantial risk of mortality (3). Through scientific evidence, the best practices for people with diabetes include behavior adjustments such as dietary management, increased physical activity, and lifestyle changes, including reducing alcohol intake and smoking cessation (4,5) Additionally, the disease requires regular blood testing,

medical evaluations, and pharmacotherapy, all to meet glycemic targets (5). These rigorous and lifelong strategies increase the risk of psychological comorbidities, such as depression and anxiety disorders, for those with the disease (6).

For individuals with diabetes, a beneficial correlation exists between participation in social support groups and reduced emotional distress (7). Additionally, social support has been found to help patients with diabetes cope and adhere to treatment guidelines (7). Traditionally, social support groups were face-to-face. However, technology has helped transition them to SM, where those in need can connect with others, share acquired and experiential knowledge, offer support and connectivity, and raise collective awareness of the disease (8).

Kenya is considered a technology hub in Sub-Saharan Africa, where 45.7 million out of a population of 50 million people subscribe to an internet connection (9). The majority of Kenyans access the internet over their mobile devices, with Facebook (88.5%) and WhatsApp (88.6%) being the most used SM apps (9). In developing countries like Kenya, where health resources are often deficient and there is limited access to healthcare, there are few to no opportunities for continuous diabetes education. Many people with diabetes may be using these SM platforms to help them with diabetes management. As such, this study aims to explore how individuals with diabetes seek, utilize, and engage in SM support groups and to investigate the methods employed by these users to authenticate and verify the information shared within the groups.

MATERIALS & METHODS

Study Design

We conducted a qualitative study using in-depth and semi-structured interviews with participants from Kenya in June-August 2022. A semi-structured interview guide was developed to facilitate the interviews based on a review of previous literature on motivating factors driving individuals with diabetes to seek and participate in SM groups and their interactions with the information provided within these groups (10,11).

Study Setting and study population.

This study was conducted in an online setting via the Zoom platform. The study population consisted of individuals who were actively engaged in online social media (SM) support groups on Facebook and WhatsApp, dedicated to diabetes in Kenya. Members of these SM support groups had been drawn together by a shared interest in diabetes and a desire to connect with others facing similar challenges. There are multiple ways that individuals can join the SM support groups on Facebook. Typically, individuals will type relevant keywords or phrases related to their interests. For example, someone can type "diabetes support groups" in the search bar, and relevant groups will appear in the search results. Facebook may also suggest groups to users based on their interests or activities. Alternatively, they might be referred to these groups by friends, family, or clinicians who may be part of the group and recognize the value of such peer support communities. Membership in these groups is open to anyone who meets their criteria, and any member has the opportunity to actively participate by posting and engaging in discussions, as long as they adhere to the group's rules and community guidelines. On WhatsApp, membership is primarily by referral to the group.

Inclusion and Exclusion Criteria

To be eligible to participate in this study, participants had to be 18 years or older, able to communicate in English, diagnosed with diabetes and had to have been in the group for 2 years or more. Healthcare specialists, friends, or family members of those with diabetes who were members of the groups but who did not have diabetes were excluded from the study.

Sampling Strategy

The sampling strategy for this study involved a two-step procedure, first sampling of groups, followed by the sampling of participants. In the first step, a purposive sampling approach was employed to identify relevant social media (SM) support groups dedicated to diabetes. A systematic search on Facebook, employing key search terms such as 'diabetes support Kenya', 'diabetes peer support Kenya', 'diabetes management Kenya', and 'Kenya diabetes support group', was conducted to identify relevant groups. For WhatsApp, a contact well-versed with the diabetic community on WhatsApp introduced our team to two specific groups. We were added to these groups through this key person's assistance.

To ensure the inclusion of stable and active groups, only those SM groups that had been in existence for more than 2 years and exhibited regular member interaction were considered. The assessment of group stability was conducted using publicly available metadata for Facebook groups, including post frequency, member count, and join date, while for WhatsApp, this information was obtained from the group description section and from the group administrators.

After identifying suitable groups, group administrators were approached and briefed on our research objectives. While we initially approached five eligible groups, only two groups (one on Facebook and one on WhatsApp) granted us access to their members for participation in the study. The groups that declined our request did so mainly due to internal guidelines or community guidelines/policies that restricted external engagements, particularly those involving sharing member details or recounting their experiences. Notably, the participating Facebook group had a membership of 8100 individuals, and the WhatsApp group had 275 members, who were either individuals with diabetes or other support networks, including family, friends, and clinicians.

In the second step, recruitment efforts included the sharing of recruitment fliers in the two SM groups. Individuals interested in participating in the study would click on a link provided on the flier, which directed them to an eligibility form where they could complete the eligibility form and submit their contact information. Of the 772 who clicked the link, 132 completed the screening, 26 were eligible, and 15 were consented and interviewed.

Data Collection

Two research team members trained in qualitative methods conducted the virtual Zoom interviews. One researcher was the lead moderator (PG) who facilitated discussions, while the other (MKG) served as a co-moderator, ensuring a detailed account of the interviews was captured. The interviews were recorded and lasted approximately 45 minutes each. All interviews were recorded on zoom and the transcriptions were generated using Zoom's transcription feature.

Data Analysis

The transcripts were subjected to a clean verbatim process, and thereafter they were imported into NVivo (QSR Version 12) to assist with analysis. The researchers began the data analysis process by drafting an a-priori codebook based on the interview guide. Content analysis and a team-based coding approach were applied, and each researcher was assigned one transcript to conduct line-by-line coding using the codebook. The researchers created categories based on a review of the excerpts assigned to it. They then discussed the code summaries, built consensus on emerging concepts, and made changes to the codebook to reflect consensus-building and emerging concepts. data saturation was achieved when no new information or concepts emerged from the interviews. This indicated that the 15 interviews had comprehensively covered the range of perspectives and experiences related to the study's focus on motivating factors driving

individuals with diabetes to seek and participate in SM groups. After reaching this point, the research team members met to identify the most prevalent concepts and to extract and discuss high-level themes and sub-themes from the code summaries.

RESULT

Participant characteristics

From the 2 SM groups, we interviewed 15 participants (9 Facebook and 6 WhatsApp). The participants were 60% female and 40% male, ranging from 18 to 66 years. Participants had diabetes diagnoses ranging from 2 -12 years (Table 1).

Table 1: Demographic characteristics of participants

Demographic Characteristic	Facebook Group (n=9)	WhatsApp Group (n=6)	Total (n=15)
Gender			
- Female	5 (56%)	4 (67%)	9 (60%)
- Male	4 (44%)	2 (33%)	6 (40%)
Age Range (years)			
18-29	1 (11%)	1 (17%)	2 (13%)
30-44	4 (44%)	2 (33%)	6 (40%)
45-59	3 (33%)	2 (33%)	5 (33%)
60+	1 (11%)	1 (17%)	2 (13%)
Years with Diabetes			
2-5 years	3 (33%)	2 (33%)	5 (33%)
6-8 years	2 (22%)	2 (33%)	4 (27%)
9-12 years	4 (44%)	2 (33%)	6 (40%)
Residential Area			
Urban	6 (67%)	3 (50%)	9 (60%)
Peri-Urban	2 (22%)	2 (33%)	4 (27%)
Rural	1 (11%)	1 (17%)	2 (13%)

Various themes were constructed on why adults with diabetes seek, utilize, and engage in SM support groups. 1) SM support groups provide accessible and affordable health information, 2) Participants leverage support groups as an alternative to formal professional healthcare engagement, 3) Participants leverage SM support groups to learn from peer-driven experiences and strategies to enhance diabetes self-care 4) Participants value community empathy and peer support in SM support groups 5) Participants strategies for authenticating and verifying information from SM support groups.

Theme 1: Social media support groups provide accessible and affordable health information.

Participants reported they were in the SM groups to learn more about affordable places to purchase medications and helpful medical information on their day-to-day disease management. For instance, as indicated by the two respondents, P01 and P02.

"I could not afford medication after losing my job due to COVID. I got frustrated and wrote a post on Facebook asking people in the group for their advice. I was recommended to a wholesale chemist on River Road that sells insulin affordably." (P01)

"I cannot afford the strips for checking my blood sugar because it is too expensive for me to afford. However, someone in the group mentioned that I can buy single strips and not the entire container." (P02)

These respondents, P01 and P02, show that SM support groups are avenues for emotional support and empathy. Members use these groups to express frustration, seek guidance, and find solidarity with others facing similar challenges. In *this case, the SM group is a place where advice is given and guidance on where to purchase affordable medication and to tell stories about job loss or circumstances that individual patients are in.*

Participants also used the groups to get medical advice that complements information from their healthcare providers. While acknowledging the importance of consulting doctors for an overall understanding of their disease or in cases of

acute complications, participants reported that continuous visits to healthcare professionals were neither practical nor affordable. Participant P04 explained how advice from the group helped alleviate medication side effects:

"I experienced some side effects after changing my medication brand, and I consulted if anyone in the group had had a negative reaction to that medicine. I was advised to reduce the dosage from 1000mg to 500mg, and that's when the stomach upsets reduced."

The participants' responses reveal that knowledge sharing on SM constitutes an important aspect of their healthcare experience. SM groups offer platforms for individuals to share personal experiences with treatments, seek alternatives, and even access expertise from healthcare professionals within the community. The groups serve as supplementary resources, especially when regular doctor visits are perceived as costly or unnecessary.

Theme 2: Participants leverage support groups as an alternative to formal professional healthcare engagement.

The pattern of selective engagement with healthcare professionals, with an inclination towards self-management and peer support, was further elucidated by several other participants. Participant P07 mentioned consulting a doctor only when facing a specific medical problem, while Participant P02 emphasized the decreased need for medical visits after initial instruction:

"I thank God for the resourcefulness of this group. I now only consult the doctor when things are not good, and I am facing extreme medical problems." (P07)

"After seeing the doctor at the hospital and attending the [initial] diabetes classes. I have never gone back because I am taking my medicine and eating well. The group helps me by seeing what others are doing compared to what I'm doing" (P03)

Participants P03 and P09's responses highlight a pragmatic approach, where medical consultation is sought if self-management does not yield the expected results:

"I have a small wound on my leg, and I am taking herbal treatment recommended by many for immunity building [purchased from a group member]. I will see the doctor if it does not heal well." (P03)

"I like it when people go live in the group and talk about their experiences and what's worked to control their blood sugar. I haven't gone live myself, but I like how people are sharing and open. I apply what I hear, and it's worked so far. Besides, I already know which medicine to buy. I buy my supplies weekly from the Chemist and don't go to the hospital unless I have a persistent medical problem." (P09)

Theme 3: Participants leverage SM support groups to learn from peer-driven experiences and strategies to enhance diabetes self-care.

Most participants mentioned using diabetes SM groups to enhance their understanding of diabetes self-care, lifestyle and behavior changes, and overall disease management. The groups serve as platforms for mutual encouragement, education, and support, as illustrated by the experiences of participant P11.

"People take pictures of their food and exercises and share tips that help them keep on track in areas they need most help." (P11)

The groups also provided innovative ways to motivate adherence to medication and healthy living practices. Participant E05 detailed the positive impact of group challenges, describing a biannual, one-month-long challenge:

"Initially, I used to take my medicines irregularly even though my blood sugar levels were not good. This was until I started participating in adherence week. Every 6 months, the group will host a one-month challenge to help people get back on track with eating well and exercising. I participated in the last challenge, which has helped me be more careful about my medication and diet." (P05)

Newly diagnosed individuals also found support within the groups. Participant P10 shared how peer insights helped them manage symptoms better:

"I just got diagnosed a few months ago, and I often feel tired, hungry, and have extreme sweating. I tried to follow all the tips the doctor gave me, but I was struggling with this until I saw someone in the group saying that this was a sign that their blood sugar levels were very low, and they would quickly eat something and feel better. I started tracking when these episodes would happen, and I noticed that mine would be worse if I missed a meal and allowed myself to get too hungry." (P10)

Theme 4: Participants value community empathy and peer support in SM support groups.

Participants indicated they used the SM groups to seek and offer support or encouragement to other individuals with diabetes or to share personal experiences. Many participants reported that while families and friends were supportive, they did not fully understand the effects of having diabetes and could, therefore, not relate to them sometimes. Some participants who had reached saturation and were no longer benefiting from information offered in the group stated that they chose to remain members to give back and support new members with less diabetes experience.

"Look, I have had this thing for over ten years, and I know a thing or two about it. The power is in your mind. You have to be mentally strong! I am always sharing this with the group, especially those who are just starting the journey and are feeling overwhelmed." (P06)

The participants expressed that diabetes SM groups have been instrumental in providing emotional support, empathy, and a sense of belonging that they sometimes found lacking in their interactions with family and friends. This support was not confined to exchanging medical information but extended to mutual encouragement and understanding. For instance, many participants shared that the group offered a space where they felt seen and understood by others facing similar challenges. Participant P12 shared:

"No one in my family has diabetes, and many times, they do not understand what it feels like to constantly have to deal with this. I am constantly shaky, tired, or in pain, and the people in my group understand me better than my family members and friends." (P12)

The power of community encouragement and resilience was also emphasized. Participant P15 reflected:

"Look, I have had this thing for more than ten years, and I know a thing or two about it. The power is in your mind. You have to be mentally strong! I always share this with the group, especially those just starting the journey and feeling overwhelmed."

Some participants described how the groups had provided tangible support in times of personal loss and crisis, as noted by Participant P08:

When my dad died from diabetes, and I posted on the group, they consoled me and supported me emotionally and financially." (P08)

The sense of giving back was also a recurring theme. One participant who felt they had gained control and managed their blood sugar over the years chose to remain active within the groups to support newcomers. Participant P13's experience illustrates this commitment to peer support:

"I have lived with this disease for a long time now, years, and I have learned what to eat and which medications work for me. I'm not as active in the group now as I was in the beginning, but I occasionally chime in and share what has worked for me."

Theme 5: Participants' strategies for authenticating and verifying information from SM support groups.

The participants reported employing various methods to determine the accuracy of information received within the SM groups. Some relied on intuitive judgment, using their "gut feeling" to gauge the legitimacy of

information. One participant explained, *"Often, you come across advice that doesn't feel right. I trust my instincts and gut feelings when I read something that seems too good to be true or contradicts what I've learned from credible sources. It's important to combine what you know with what you feel; it's guided me well in filtering out potentially harmful suggestions." (P02)*

Others utilized a consensus-in-numbers approach, trusting information that many members in the group corroborated. For example, *"There was a big debate in the group on whether diabetes can be cured. Most people agreed that it can be cured and go into remission just like cancer, but then it can re-occur." (P14)*

Endorsements by familiar brands, famous people, or SM influencers also played a crucial role in information verification. Participants expressed trust in information if they recognized a brand, person, or influencer whom they've followed over time. One participant (P04) said, "*I like to share videos by [name withheld] because he has diabetes himself and often shares tips and products. I trust his recommendations since they've worked for me."* Another (P06) added, *"I trust information more when it comes from a known pharmaceutical company or a celebrity open about their diabetes journey. Their reputation is on the line, so they're less likely to mislead."*

A few participants did fact-checking and cross-referencing with online sources or from trusted sources. P03 noted, *"Some advocate for extreme dieting that seems wrong. I like to google everything before trying."* P05 shared, *"When I come across something new, I look for opinions from my daughter. She is a doctor."*

Lastly, personal experience and testimonies were valued as verification methods. P08 mentioned, *"Many people take herbal medication in the group. They vow that it works, and I've begun taking them; it's been helping me."* P01 also stated, *"I learned from the group that Coke Zero has no sugar and would be safe to take. My doctor said no soda, but my internet research showed I should take it."*

DISCUSSION

We found that SM groups were instrumental in facilitating access to affordable healthcare options and providing supplementary medical advice, especially in the context of financial constraints for those with diabetes. Participants selectively engaged with healthcare professionals, leaning towards self-management and peer support. Furthermore, the SM diabetes support groups functioned as platforms for knowledge exchange, emotional support, and community building. Various strategies were employed to assess the credibility of information, ranging from intuitive judgment to cross-referencing with authoritative sources.

Arguably, because of their usability, lack of direct costs, and attractiveness across multiple audiences, SM can promote health equity among underserved populations such as low-income individuals, seniors, and those living in rural or remote areas (12). As noted in our findings, participants were diverse in age, gender and culture. Platforms like Facebook and WhatsApp afford their users the social ability to share in a group, eliminating geographical and psychological barriers such as age, distance, or cultural taboos on subjects that are difficult to communicate (12). The study participants commonly found SM groups to be a viable platform for information and resource-sharing, and this supports the findings by Alhusseini et al., indicating different forms of social support, including emotional, tangible, informational, and companionship, may drive the use of SM groups for those with chronic disease management (13). However, studies of online health groups have reported pitfalls, including a lack of regulation and misinformation (14). Health misinformation is a continuous concern in SM groups and though many of these groups are moderated, administrators are often voluntary and untrained, leading to concerns with boundaries,

mis/disinformation and confidence in the shared information. (15).

This study underscores the critical role of SM support groups in addressing the healthcare affordability challenges faced by individuals with diabetes. Participants of this study commonly found SM groups to be a viable platform for information and resource-sharing. This is consistent with existing literature highlighting peer support's significance in chronic disease management (16). The ability to navigate the economic barriers related to medication purchase and healthcare consultations via community-based solutions demonstrates the essential function that SM groups have in these individuals' healthcare journeys. However, the trend of self-diagnosis and self-prescription, such as reducing medication dosage without professional medical oversight, also flags potential risks and underlines the need for careful facilitation and moderation within these groups. The pattern of selective engagement with healthcare professionals, as revealed by the participants, offers both promise and caution. On the one hand, empowerment in self-management and increased reliance on peer support may foster a sense of autonomy and control over the disease. On the other hand, it may also present hazards if unqualified advice leads to inappropriate self-management.

Themes around knowledge sharing, experience sharing, emotional support, and a sense of belonging were strong among participants. The innovative ways SM support groups engaged members in adherence to medication, healthy living practices, and emotional resilience were evident. This reflects broader research findings on the role of online communities in enhancing self-efficacy and emotional well-being among chronic disease patients (17). For instance, in one study (10), participants reported using SM support groups to increase knowledge on diabetes, help in increasing physical activity, reduce consumption of high-calorie foods and boost self-esteem and confidence, among others. Online communities are pivotal in promoting emotional well-being and tangible self-management behaviors among individuals with chronic illnesses. Moulaei et al. underscores these findings by highlighting the tangible ways participants used SM groups (10). Their emphasis on increased physical activity, dietary changes, and boosts in self-esteem and confidence complement our results. Together, these insights suggest that while SM groups provide the necessary information and knowledge, emotional support and shared experiences may act as catalysts, motivating individuals to apply this knowledge in their daily lives. Furthermore, in our study, the support system that transcends beyond seeking medical information into personal encouragement and financial support reflects a powerful community dynamic that is unique to these groups.

Participants used various methods to verify the information within SM groups. While some strategies were robust, such as cross-referencing with authoritative sources (18), others relied on intuitive judgment or endorsement by influencers. This study thus uncovers a landscape where misinformation could be disseminated, and harmful practices might be endorsed. This emphasizes the necessity for a more systematic approach to information verification and a possible collaboration with healthcare professionals to ensure that the guidance provided within these SM support groups is scientifically accurate.

This study, while offering significant insights into the role of SM support groups in diabetes care and management, is not without limitations. For instance, the sample size may be small; however, it is important to note that thematic saturation was achieved and ascertained during the analysis. This was ensured by continually analyzing the data until no new themes or patterns emerged, indicating that further interviews were unlikely to provide additional unique insights. A noteworthy limitation is that only two SM platforms were included in the study. The focus on

specific platforms like Facebook and WhatsApp may exclude insights from other relevant and widely used platforms, potentially affecting the comprehensiveness and applicability of the findings.

Furthermore, examining how information was verified within the groups might not fully capture the complexity of misinformation dynamics. The process might be influenced by many subtle factors not explored in the study, emphasizing the necessity for a more systematic approach to information verification. These limitations do not diminish the study's value but highlight areas where caution must be exercised in interpreting the results and suggest avenues for future research to expand our understanding of the complex role that SM support groups play in chronic disease management.

CONCLUSION

The findings reveal that SM support groups are not merely platforms for information exchange; they are vibrant ecosystems that foster community building, emotional support, and innovative solutions to healthcare access challenges, particularly among underserved populations. They break down geographical, financial, and cultural barriers, contributing to health equity, yet also pose complex challenges related to misinformation, unqualified advice, and lack of regulation. Given the pivotal role these platforms play in the lives of many, it is imperative for policymakers to recognize and integrate SM support groups into broader healthcare strategies. This may involve establishing guidelines for accurate information dissemination or encouraging partnerships between these groups and certified healthcare providers. Additionally, addressing the issues of misinformation and unverified advice necessitates a multi-pronged approach, including digital health literacy campaigns and closer monitoring of these platforms.

Additionally, addressing the issues of misinformation and unverified advice necessitates a multi-pronged approach, including digital health literacy campaigns and closer monitoring of these platforms. In clinical practice, Clinicians should be aware of the increasing role of SM support groups in their patients' healthcare journey. Recognizing the benefits these platforms offer, such as peer support and innovative self-care strategies, can allow healthcare professionals to guide their patients on utilizing these groups best. It can also help them proactively address potential misconceptions or misinformation that patients might encounter while promoting adherence to recommended treatments.

Declaration by Authors

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