Social Media Content Analysis of Public and Private Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency Facebook Groups

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ABSTRACT

Background. As social media continue to grow as popular and convenient tools for acquiring and disseminating health information, the need to investigate its utilization by laypersons encountering common medical issues becomes increasingly essential.

Objectives. This study aimed to analyze the content posted in Facebook groups for Glucose-6-Phosphate Dehydrogenase (G6PD) deficiency and how these engage the members of the group.

Methods. This study employed an inductive content analysis of user-posted content in both public and private Facebook groups catering specifically to G6PD deficiency. The G6PD Facebook groups with 10 or more posts within the past 12 months were selected for this study. Data were harvested from posts and comments using ExportComment.

Results. A total of 46 G6PD-related Facebook groups were identified. Of which, 19 were public and 27 were private groups, with an average membership of 5000-6000 accounts. After eligibility based on criteria and authorization for private groups, 3 public and 3 private groups were included, with the majority of these groups focused on sharing information. Five main themes of posted content were identified: diagnosis, management, beliefs, psychosocial factors, and medical requirements. "Diagnosis"-related posts referred to conversations about the causes and symptoms of G6PD, "management" referred to medication or diet, "beliefs" involved traditional or lay perceptions, "psychosocial factors" referred to posts that disclosed how psychosocial factors influenced G6PD deficiency practices, and "medical requirements" referred to documentation regarding the condition. The bulk of these posts used three strategies for communication: information-requesting, self-disclosure, and promotion of products/services. Information requests were the most common.

Conclusion. The results of the study showed opportunities and challenges in health education on G6PD, especially in evaluating the credibility and accuracy of the information given and received. Looking at the content and manner of communicating information noted, the newborn screening program may improve its advocacy and education campaign, and may develop targeted educational materials and effective dissemination strategies that could clarify, explain, or refute information and beliefs mostly shared on these platforms.

Keywords: G6PD deficiency, support groups, Facebook group, online communities

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INTRODUCTION

Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the most common enzyme deficiency in the world with around 400 million people affected. G6PD is an enzyme in the pentose phosphate pathway responsible for the prevention of cellular damage during oxidative stress caused by reactive oxygen species.[1] It converts nicotinamide adenine dinucleotide phosphate (NADP+) to its reduced form, nicotinamide adenine dinucleotide phosphate (NADPH). NADPH is needed to maintain glutathione in its reduced state. Reduced glutathione acts as a scavenger for oxidative metabolites and converts hydrogen peroxide into water, thus preventing damage to cells. Red blood cells are particularly vulnerable in G6PD deficiency because NADPH in the pentose phosphate pathway is their only source of protection, coupled with their limited ability for repair once they mature. G6PD deficient patients then exhibit hemolysis when exposed to stressors like infection, fava beans or medications with numerous oxidative substances.[2] Fava beans and antimalarial drugs specifically primaquine and tafenoquine are well-known examples of agents causing hemolytic crises. Hemolysis can cause back pain, abdominal pain, jaundice, transient splenomegaly, hemoglobinuria, and scleral icterus. In severe cases, newborns with G6PD deficiency are complicated with kernicterus or bilirubin encephalopathy caused by neonatal jaundice from the ongoing hemolysis.[3]

G6PD deficiency is particularly most prevalent in Africa, Western, and Southeast Asia, which includes the Philippines – geographically correlated areas inhabited by populations exposed to endemic malaria.[4,5] It was included in the Philippine newborn screening program, which was made into law in 2004 under Republic Act No. 9288 or better known as the "Newborn Screening Act of 2004". With the implementation of this law, every newborn baby has the chance to be screened for conditions with the goal of early intervention to prevent life-threatening complications.[6,7] In 2006, the fee for the NBS panel which includes G6PD deficiency is included in the Newborn Care Package of the national health insurance.[8] Data from the Newborn Screening Reference Center has shown that as of December 2021, G6PD deficiency has a prevalence of 1:63, making it the most common condition included in the expanded newborn screening panel.[9]

This condition requires consistent care and compliance with the newborn screening procedures. After a positive screen for G6PD deficiency, parents were given a brochure by the Newborn Screening Centers about the condition and were advised to do confirmatory testing. Once confirmed, education primarily is given by the primary physicians who at times refer them for genetic counseling. Despite newborn screening being implemented for more than 20 years in the country, parents still need and seek information concerning the diagnosed conditions of their children. The information given to them initially is limited. The level of public awareness and knowledge differs from communities ranging from poor to good. However, even in countries where there's a good level of awareness and knowledge, there are still existing misconceptions and confusion in the management and on the patterns of inheritance.[10-12] In a local study, midwives who were among the primary information resources for parents of infants with G6PD deficiency in the Philippines were assessed to have sufficient knowledge about the medical management and follow-up but inadequate knowledge of the underlying genetic cause of G6PD deficiency.[13] Additional information needs to be supplemented by the primary physicians. Increasingly, parents may rely on and access possible sources of information and other types of support through social media platforms.[14-16]

The internet has become a powerful tool for providing health information. A survey done by Ayantunde and colleagues in 2007 showed that 42% of their respondents have used the internet to seek medical information, while 7.2% of the participants who had no access to the internet still asked someone else to check the internet for health information. The survey also showed that 95% responded that the information they found was average to excellent.[17] In the Philippines, the Social Weather Stations (SWS) conducted a survey on the internet usage of Filipinos before the COVID-19 pandemic. They found that 45% of Filipinos had access to the internet. There has been an upward trend in the use of the internet since 2006 across all demographics such as gender, age, educational background, and financial stature. Metro Manila had the highest number of internet users at 65% followed by the rest of Luzon at 49%, then Visayas at 39%, and Mindanao at 32%. Facebook was found to be the most popular social media application followed by YouTube, then Instagram, Snapchat, Twitter, and Viber.[18]

Facebook, the most popular social media platform, has been used by 90.1 million Filipinos as of 2021.[19] Created in 2004 as a social networking site, its basic function is to make it easy for people to connect and share posts with other people. Over the years, Facebook has evolved from a platform that connects people to an alternative way of watching news and entertainment and as a means of receiving social support.[20,21] According to the survey done by the SWS, 15.7 million adult Filipinos read the daily news on Facebook.[18] In a local study conducted in Iloilo, Philippines among college students, Facebook was identified as the most believable (41.7%) source of health information among social media platforms.[22] In another study, the use of image and text-based slide-decks on Facebook pages to communicate health information on the needs of persons with diabetes yielded high engagement.[23] Different social and interest groups have also emerged on Facebook, such as political groups, e-commerce groups, and health-related groups. Likewise, as the number of active users continues to increase, the data generated by Facebook users also increases – making the platform a rich source of quantitative and qualitative data. For this reason, a vast number of studies have utilized the platform as a data source, such as psychopathology studies and chronic illnesses. The

textual data, images, photos, exchanges, and reactions provide substantial opportunities for researchers.[20]

In terms of health-related research, social media use has been examined in relation to access to information and other forms of support, particularly for patients and their families. For instance, Iyer et al. found that SMA (spinal muscular atrophy) patients and their families utilized social media to find and disseminate information related to new treatment while also assessing the veracity of such information.[16] The study also demonstrates that Facebook groups may serve as "modern-day disease advocacy communities, assuming some roles of more traditional advocacy organizations, i.e., information dissemination, fact-checking, emotional support, and advocacy around treatment access," especially for patients of rare genetic conditions and their families as the platform facilitates the connection and interactions of previously unconnected actors in a convenient and cost-effective manner.[16] Barton et al. echoed the same findings in their study on the experiences and attitudes of the parents of children who underwent clinical genetic testing concerning their internet and social media use.[14] Apart from the accessing informational needs for different phases of clinical genetic testing, the article also points to the importance of social media platforms in providing emotional support to mitigate the feelings of anxiety and distress amidst uncertainties and possible social isolation being experienced by these parents.[14] To harness the effectiveness of internet and social media platforms to provide reliable information and resources, the authors suggest that health care providers could engage the parents with regard to these platforms and recommend sites and groups that could provide such kinds of resources and support.

However, while these studies demonstrate the significance and potential of social media use in terms of health education and expanding access to trustworthy health information, such studies primarily rely on qualitative interviews to explore the accounts of patients and their families. As previously mentioned, other forms of data can be generated from social media platforms that could allow researchers to examine various facets of social media use and enrich our understanding of how social media platforms are being utilized for health-related reasons. This study analyzed the posts and exchanges in public and private G6PD Facebook groups not only to find out the contents of such posts and discussions but also to understand how information is being sought, communicated, evaluated, and shared. Since numerous G6PD deficiency Facebook groups have emerged, possibly being used by patients and families as a tool for information or as a source of social support, it is prudent to investigate the purpose and usage of these Facebook groups especially since no studies have yet been made about its utilization by the members of the G6PD Facebook groups. Having a closer look at the content of these Facebook groups may help health workers in addressing patient education concerns like misinformation and identify gaps in information dissemination.

METHODS

The study utilized a conventional qualitative content analysis through an inductive approach. The study population included public and private G6PD deficiency Facebook groups all around the world with English, Filipino or *Taglish* (combined Tagalog-English) as the primary language used. Private groups were defined as groups requiring approval from the administrator or current member to join before group content can be reviewed. Another criterion for inclusion was groups with ten or more posts for the past 12 months upon the start of data collection (July 2022). Not included in the study were private groups with no approval from the administrator or current members, groups using languages not specified from the above-mentioned languages, and groups with less than 10 posts for the past 12 months.

The posts reviewed in each group included the top 10 posts with the most engagement in the past 12 months. The data from the posts and comments were harvested using the ExportComment software, while the coding and thematic analyses were done with the MAXQDA software. Simple quantitative and descriptive analyses were done to summarize the characteristics of the posts and to support the themes that were derived from the qualitative content analysis.

The study was done using the computers in the Newborn Screening Reference Center, National Institutes of Health, University of the Philippines Manila. The project staff also utilized their own password-protected laptops and computers in data collection and analysis.

The researchers gathered data through a search procedure on Facebook of the different G6PD deficiency groups. The steps of the search procedure were listed below.

Search Procedure

The search procedure ensued by entering the keywords "G6PD deficiency" and "glucose-6-phosphate dehydrogenase deficiency" on the Facebook search engine. The searches were limited to Facebook groups operated in English as their primary language; groups with Filipino or *Taglish* were also included. Both public and private groups were considered. The following data were extracted from the groups: (1) name of Facebook group, (2) number of members, and (3) website URL (Uniform Resource Learning).

The public and private G6PD deficiency groups who fulfilled the inclusion criteria were identified and selected. The following data and characteristics were extracted and recorded: (1) name of Facebook group, (2) number of members, (3) type of group (i.e., awareness group/information sharing, support group/community building, non-profit fundraising, promotional, etc.) (4) number of posts in the past 30 days, (5) months in operation, (6) country of origin, and (7) website URL. After the initial group characteristics have been recorded, a more in-depth review of the content was done and the data gathered were used for content analysis.

Data Extraction

Data extraction was done using the Export Comments software (https://exportcomments.com/). The top 10 posts in the past year per group with the most engagements, defined as the posts with the most number of comments and reactions, were extracted. The nested comments under the posts were also harvested using the software and had been placed in an Excel file. Private group comments were extracted using the private export feature of Export Comments software.

Two of the co-investigators were assigned as the first coder and second coder. The coders decided which Facebook groups should be included and which posts should be harvested. In case of disagreement, the two other investigators and the primary investigator resolved it. The information collected were recorded in collection sheets using an Excel file and were kept under lock and key for three years. No identifiers were included; only tallied numbers corresponding to the variables of interest were encoded. The information was then stored in a hard drive that is password-protected and owned by the principal investigator. The hard drive would be maintained for a maximum of three years and would be deleted afterward. The transfer of information to other hard drives was also password-protected. All documents collected were under the safekeeping of the principal investigator.

Content Analysis

An inductive approach for the content analysis was employed. There were two coders for the content analysis. The first coder and second coder recorded and categorized the raw data and made codes out of them using the MAXQDA Academia Pro software (Lockeren, Belgium). Similar to the data extraction procedure, the two coders reviewed and agreed on the codes of the raw data. In case of disagreement, the two other investigators and the primary investigator resolved it and came up with the agreed coded data.

The extracted posts and comments in the past 12 months were reviewed for content analysis. The posts were read and selected thoroughly and the following characteristics of the posts were recorded: (1) media modality (i.e., text included in the post, video, audio, external website link), (2) communication patterns (i.e., personal experiences on G6PD deficiency, questions about the symptoms), (3) educational content (i.e., medical management of G6PD deficiency), (4) engagement (i.e., likes, shares, and comments).

Both coders organized the content of the posts and arranged them into themes. Illustrative quotes for each theme were also listed. Both coders discussed the content of the posts that differed in category or theme until a consensus was met. The interrelationship of the themes was discussed and its consistency with the literature.

A frequency count of the number of likes, shares, and comments per category and theme was done. These frequency counts were calculated into percentages rounded to whole numbers. Descriptive statistics and frequency distribution were calculated to summarize the results. MAXQDA Analytics Pro is a software that was used for qualitative data analysis.

Ethical Approval

This study (UPMREB 2021-436-EX) was submitted for ethics approval to the University of the Philippines Manila Research Ethics Board (UPMREB) and was processed for exemption from ethical review. This study protocol was qualified for exemption based on the criteria for exemption, since the study neither involve human participants nor identifiable human tissue, biological samples, and data.

RESULTS

G6PD Deficiency Facebook Groups

As shown in Figure 1, a total of 46 Facebook groups were identified during the data collection phase: 19 (41.30%) public and 27 (58.70%) private. After screening, only 13 (13/46, 28.26%) of the original list met the inclusion criteria, of which most (10/13, 76.92%) were in private and few (3/13, 23.08%) were in public privacy settings. The groups were further filtered based on the consent given by the three private group administrators. The final list was then classified into three public and three private groups (Table 1).

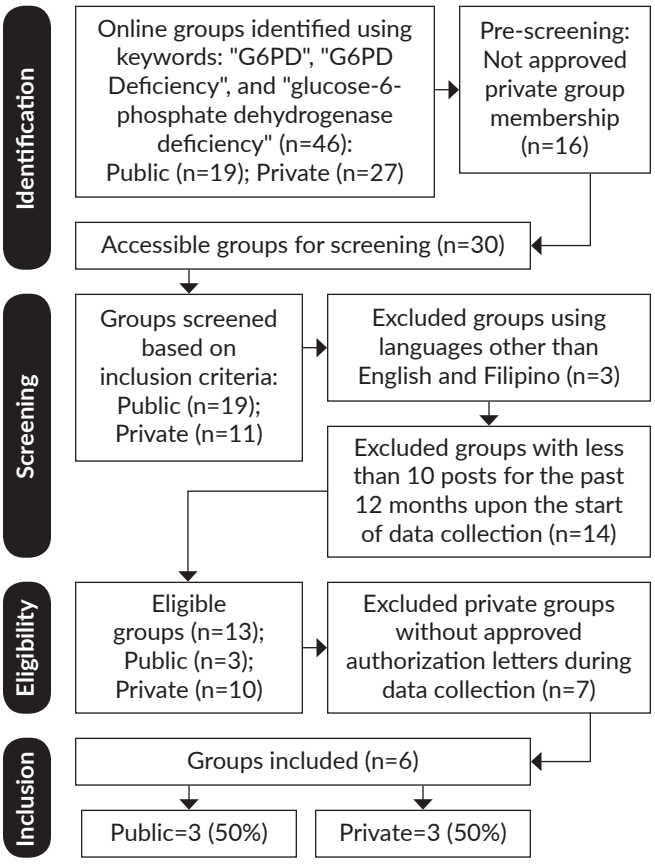

Figure 1. G6PD deficiency Facebook groups identification diagrammatic workflow.

Table 1. General Characteristics of the Included Public and Private G6PD Deficiency Groups as of September 2022

Group Name	# of Members	Privacy Setting	Type of group	# of posts in the past 30 days	Months in operation	Country of origin
G6PDD COMMUNITY PH	3,162	Public	Awareness group/ Information sharing	15	36	Philippines
G6PDD Awareness Campaign Ph	26,155	Public	Awareness group/ Information sharing	253	99	Philippines
G6Pd	3,344	Public	Awareness group/ Information sharing	7	169	Not specified
G6PD Awareness Group Philippines	1,305	Private	Awareness group/ Information sharing	29	16	Philippines
G6PD Deficiency Awareness for Parents	8,276	Private	Awareness group/ Information sharing	138	66	Philippines
G6PD Awareness Group	8,969	Private	Support group/ community-building	755	37	Not specified

Most of these groups (5/6, 83.33%) were created with the primary purpose of providing awareness or information sharing, while a particular group (1/6, 16.67%) was intended for support or community building. For public groups, the group purpose was identified through a content analysis of the group page name, descriptions, and top posts in which the group purpose is overtly indicated. For the private groups, the primary purpose was verified by directly contacting the administrators of the Facebook groups.

In terms of group size, private groups recorded a higher average number of active group members with 6,011 compared to the public with 5,666 average members. Private groups were also observed to be more active compared to the public groups, as gauged from the number of posts in the past 30 days. Private groups recorded an average of 145 posts, while the public groups only had an average of 46 posts in the past 30 days. Public groups also had lower page posts despite the fact that these were generally 'older' than private groups, with a median of approximately 64 and 37 months in operation, respectively.

More than half of the included groups (4/6, 66.67%) were created in the Philippines, while the other 2 groups (2/6, 33.33%) did not specify their countries of origin. Some of the excluded groups had provincial names from the Philippines in their group names; for example, *G6PD Deficiency La Union*, *G6PD Deficiency Davao, G6PD DEFICIENCY BATAAN,* and *G6PD Awareness Group Bukidnon*. Similarly, excluded groups originating from different countries were identifiable by indicating the name of the country; for instance, *G6PD Deficiency HK Awareness, G6pd deficiency United Kingdom, and G6PD Deficiency living in Oman.* As previously mentioned, all included groups displayed posts using English and Filipino as the main languages.

Facebook group content and the topic discussed

This study generated diverse and substantive points of discussion about the G6PD deficiency from the analyzed Facebook groups. A total of 5 main themes were identified: *diagnosis, management, beliefs* as the top three, and *psychological factors, and medical requirements* as the last two. (Table 2).

The first theme concerns *diagnosis* with 138 observations. It covered the topics of etiology, pathophysiology, diagnostics, signs and symptoms, and prognosis. While this theme tackled objective discussions on G6PD deficiency, the contents posted were mostly based on personal observations since little to no citations were provided for scientific claims. As an example, the illustrative quotes for the code *Etiology* discussed hemolysis and the possible origin of the deficiency without citing the source.

The second theme was about *health management* with 131 observations. For this study, management was associated with Facebook group content about diet, medicine, and medical procedures related to G6PD deficiency. The codes supporting this were topical medicine, which referred to creams, ointment, lotions, and other remedies for rash and skin concerns; nutrition, which was about diet, milk formula, and vitamins; and blood transfusion, from the name itself, specifically tackled the medical procedure of transferring blood from a donor to assist with the production of blood or replace lost blood components.

Health beliefs based on 119 observations was the third salient theme. This refers to context- and culture-specific beliefs surrounding the management practices for G6PD deficiency. Included in this theme was the concept of *hiyang.* Early researchers explained this concept as a traditional assessment method to learn the food, company, and, or medicines' perceived or adverse effects on individuals (Hardon 1992).[36] In this study, however, it was observed that a medicine or ways of managing G6PD deficiency was considered *hiyang* if it had no negative effect on the patient (i.e., compatible or suited). Following *health beliefs* was the theme of *moderation.* This theme examined how some caregivers take risks and allow the consumption of food items that are included in the G6PD deficiency list of foods to avoid due to the belief that they are safe in moderation and do not cause adverse effects. The third code for this theme was *medical myths*, which pertained to posts and comments

regarding traditional beliefs that group members applied in the management of G6PD deficiency, but which have not yet been scientifically proven, approved, or recommended by professionals.

There were 57 observations for the fourth theme, *psychosocial factors*. Group members shared how psychological, geographical, and financial factors could influence G6PD deficiency care practices and diagnosis processes through comments and feed posts. Contents falling under this theme usually utilized self-disclosure as the communication strategy.

The last theme was focused on the discussion about *administrative and bureaucratic processes*, particularly obtaining required medical documents, which gained 19 observations. The two main medical requirements were *medical clearance*

Table 2. Themes of the Topic Discussed, Definition, and Code Source

Themes	Code	Illustrative Quotes
Diagnosis (n=138). Refers to any conversations about the origin, causes, symptoms, and long-term projected effect of the G6PD deficiency.	Etiology (n=11)	There is no medicine for this yet because this is a genetic issue. Genes are unrepairable, they cannot be altered. [...] Please note that infection can also trigger hemolysis, which is why it is important to not undermine a child's sickness (Public Group 2, Post 8).
	Pathophysiology (n=18)	G6PD is in every single cell of our bodies. When cells are formed without G6PD, they are built wrong. [...] G6PD is responsible for so much more than hemolysis, please avoid all legumes, naphthalene, synthetic colors, fragrances, preservatives, and flavors. Benzene and Quinolines are also a huge problem. (Public Group 3, Post 4).
	Diagnostics (n=27)	I already lost the confirmatory result of my child. It's been a while, but the result is low. However, it is not the same result (Public Group 3, Post 3).
	Signs and symptoms (n=56)	Some red spots came out … allergy (Private Group 1, Post 2)
	Prognosis (n=26)	They will gain weight eventually, just like other kids. Two of my kids have G6PD, one gets weight easily (*tabain*), and [one] eats hard but does not gain weight (Public Group 2, Post 6).
Management (n=131). Mentions of medications, dietary considerations for milk formula, meals, vitamins, and medical treatment such as blood transfusion.	Topical Medicine (n=47)	[...] What is the cream that can be applied to my baby with G6PD? I have tried Calmoseptine cream, but it was not suited for them (*hiyang)* (Private Group 2, Post 10)
	Nutrition (n=72)	[...] What milk formula is safe for a G6PD baby? (Private Group 1, Post 6)
	Blood transfusion (n=12)	My son, a 21-year-old, also has G6PD and has required transfusions since he was 9 days old (Public Group 3, Post 4)
Beliefs (n=119). Involves topics about traditional and lay beliefs on G6PD deficiency that inform management practices.	*"Hiyang"* (n=56)	There is nothing wrong with trying. At least we know which food is suited for them (*hiyang)* and not (Private Group 3, Post 9).
	Moderation (n=32)	[...] Then we gradually introduced food tagged as "prohibited". If it's just a "mild" G6PD, it's ok to eat, [just with] moderation. (Public Group 3, Post 3)
	Medical myths (n=31)	Ma'am, so that there will be no harmful effect, try using cornstarch. Just pat it on the part with a rash (*bungang araw)* (Private Group 1, Post 10) Try using breastmilk in cotton and put on the rashes on the baby's face. Soak it [breast milk] quickly before bathing the baby. This is the advice of our parents [...]. I did not believe it at first, but I tried it, and it worked. (Private Group 2, Post 3)
Psychosocial factors (n=57). Discussions of challenges and limitations posed by social and psychological factors.	Psychological (n=42)	Thank you for your tips, I feel like I am going insane (*napapraning*) (Public Group 3, Post 3) [...] I am so stressed. I do not know what to do already! I hope someone could help? (Public Group 2, Post 3)
	Financial (n=14)	I have not got a confirmatory (test) because we do not have money, but (my kid) is positive according to the Newborn Screening [...] (Private Group 1, Post 2)
	Geographical (n=1)	I have not got my confirmatory test yet for my youngest child because the hospital is too far from our place. It was also pandemic, so I just applied the routine from my eldest (Private Group 1, Post 2)
Administrative and bureaucratic processes (n=19). Pertains to the discussion of documents and institutional requirements for children with G6PD including ID, medical certificates, and clearance.	Medical certificate and clearance (n=16)	I have a nine-year-old son with G6PD (deficiency). According to the vaccination site, he needs a medical certificate. I would like to ask: can I just ask the doctor for a medical certificate? [...] (Public Group 2, Post 1)
	G6PD Deficiency ID (n=3)	Hello, where can I get a G6PD ID for school? (Public Group 3, Post 5)

and *G6PD deficiency identification cards*. Table 2 presents the summary of the main themes of the topics being discussed in the posts analyzed from both the public and private Facebook groups, together with the code source and quotes as illustrations.

Distinctions with regard to topics posted in public and private G6PD deficiency groups were evident. Most of the posts on public groups were focused on queries about nutrition, institutional documents, and management strategies, which were posted repetitively despite being addressed through past posts. Private groups also had recurring posts on milk formula, rash management, and diet, but with less frequency than that in public groups. It was observed that topics in private groups were more varied in contrast to public groups. Topics ranged from vaccines, fruits, baby's bodily movements, social concerns, and newborn screening processes. Sensitive and graphic content such as photos of rash, injury, their babies' excrement, and the like were also prevalent in private groups. Photos of babies were present in both private and public groups posted with a reason to: *"flex"* or show off their kids, supplement their queries with pictures, or ask for likes since they were participating in a *Baby Photo-liking contest* but were seen more in private groups.

Communication and engagement strategies

Apart from the contents of the posts in both public and private groups, we also analyzed how such contents were communicated and which strategies were commonly adopted by members who posted in such groups. For the main posts, the three most common communication strategies include information-requesting, self-disclosure, and product/service promotion (Table 3). More than two-thirds were categorized as information-requesting or information seeking. This was followed by self-disclosure or sharing one's experiences at 20%, product/service promotion at 6.67%, and information-providing at 5%. The most common engagement strategy for all communication strategies except information-providing was through comments. For information-providing posts, the most common engagement strategy was through shares.

Reactions comprised the second most common engagement strategies across all communication strategies. Of which, like and love were the two most common reactions to the posts (Table 4). For self-disclosure posts, another significant reaction was using the sad emoji.

Testimonials, suggestions, and *credibility building* emerged as the top three most comment strategies (Table 5). Other categories noted include comments that are *inquiring, sympathizing, encouraging,* and *deriding.*

Media Modality

The use of photos, videos, links, and graphics along with the texts in posts, also referred to as the varying media modalities, were also observed. All 60 posts used text, in which the majority (n=39) were supplemented with photo/s (n=26), video (n=1), and graphics (n=12). Text with graphics refers to posts that used illustrations, elements, colors, and text backgrounds afforded by Facebook News Feed feature. The other 20 posts simply used text to communicate their content, and only one used an external web link (Table 6).

Post Categories

Posts with information-requesting as the primary communication strategy were more likely to combine texts with photos, videos, and graphics to attract attention and, possibly, answer their inquiries. Visual representation of their questions helped detail the concern to get a more specific remedy. Similarly, posts that were categorized as self-disclosure and information-providing used photos

Table 3. Facebook Group Communication and Engagement Strategies

Communication Strategies (n=60)	Engagement Strategies		
	Reactions, n (%)	Comments, n (%)	Shares, n (%)
Information-requesting (n=41, 68.33%)	698 (35.45%)	1973 (55.41%)	5 (1.97%)
Self-disclosure (n=12, 20%)	418 (21.23%)	836 (24.73%)	13 (5.05%)
Product/service promotion (n=4, 6.67%)	97 (04.93%)	381 (11.27%)	-
Information-providing (n=3, 5%)	756 (38.40%)	290 (8.58%)	236 (92.91%)
Total	1969	3480	254

Table 4. Frequency Distribution of Reactions per Group Post Categories

Group Post Categories/ Communication Strategies (n=60)	Reactions (n=1,961)						
	Like	Love	Sad	Angry	Laugh	Surprise	Care
Information-requesting	553	68	38	-	15	10	14
Self-disclosure	206	101	100	-	-	-	11
Product/service promotion	63	32	-	-	-	1	1
Information providing	475	278	-	-	-	-	3
Total	1297	479	138	0	15	11	29

Table 5. Comment Categories and Illustrative Quotes

Comment Categories	Illustrative Quotes
Testimonial (n=166). Mentions of personal experiences and testimonials.	I am using homemade coconut oil, especially when there are diaper rashes, they are healing (Private Group 1, Post 6, Comment 6-12)
Suggestions (n=106). Mentions of the words "try" and "try this" and providing instructions for fellow group members.	Try Calmoseptine cream. It's good. I also tried Cetaphil, and it is okay as well. (Private Group 1, Post 10, Comment 1-3)
Credibility building (n=73). Mentions of information sources. (e.g. Pedia, research, vlogs, etc.)	Use this. It is effective. This is prescribed by my baby's Pedia (Private Group 1, Post 3, Comment 1-8) I watched a vlog from a doctor, who said that any milk is allowed except Soy milk (Private Group 2, Post 2, Comment 12-1) ALL legumes are contraindicated for G6PD deficiency according to the more recent research (Public Group 3, Post 5, Comment 5-6)
Inquiring (n=66). Mentions of questions, clarifications, and concerns about G6PD deficiency.	Is that really the effect of chocolate on G6PD? They become hyper, or chocolates can really make someone hyper? (Private Group 2, Post 2, Comment 22-3)
Sympathizing (n=51). Showing sympathy or agreeing with the OG (Main poster) or fellow commenter.	Same here. Paranoid mom before, but after a year, I gradually introduced food to be avoided. So far, kids are fine (Public Group 3, Post 3, Comment 5-5)
Encouraging (n=10). Sharing words of encouragement as a response to a post about their kid's confirmatory test or COVID-19 vaccine.	To all parents, let's not be afraid of the COVID vaccine. Let's keep our loved ones safe and protected ❤ (Public Group 2, Post 2, Comment 5-2)
Deriding (n=7). Teasing or mocking the person they are referring to – can be their kids – but not in a harmful or negative way.	I don't know what to say to you, but I would like to hit you (*batukan).* Do not give your child food to be avoided. You might regret this later. Poor baby (Private Group 2, Post 2, Comment 8-1)

Table 6. Frequency of Media Mode Used in Posts per Facebook Group Post Categories

	Post Categories			
	Information requesting (n=41)	Self-disclosure (n=12)	Product/service promotion (n=4)	Information providing (n=3)
Mixed (n=39)	29	7	1	2
Text with Photo (n=26)	17	7	1	1
Text with Video (n=1)	0	0	0	1
Text with Graphics (n=12)	12	0	0	0
Text only (n=20)	12	5	2	1
External Weblink (n=1)	0	0	1	0

to supplement the content posted. The second most used media, which was observed on 20 posts, was pure text without weblink and visualizations. The closest attempt to use visualization to communicate the text's messages was emojis. Self-disclosure posts that used text solely tend to be long and detailed to clearly depict their experience and current situation. Product and service promotions using text are similar to information-requesting: direct and short. Lastly, the only post that used external weblink was categorized as product/service promotion. As seen from the case in point, the external weblink content was still accompanied by a series of photos of the product being promoted.

DISCUSSION

Facebook is one of the largest networking sites, mainly used by people to forge and maintain ties with friends. However, in recent years, Facebook has been utilized by a considerable number of online health communities for dissemination and exchange of health information. Given the extent of reach and breadth of Facebook with reported 2.41 billion monthly active users in the second quarter of 2019 alone, it has the potential of linking people with shared health-related interests and needs irrespective of geographic location.[24] Also, due to the capacity of Facebook as a communication platform to host a vast number of users and networks, "chances are presumably high that another person affected by the same condition also uses Facebook and would be eligible to form a support group." [24]

For G6PD deficiency, Facebook is being used by at least 46 groups. Although all of these groups emerged for G6PD deficiency-related discussion, each Facebook group has their unique target audience, purpose, and specific topic of interest regarding G6PD deficiency. As seen from the titles, there are certain groups in which membership is limited to a province or country. This Facebook group segmentation per location is practiced online, especially for medical groups, as a consideration of the peculiarity of the health management

strategies for different communities. Some groups are exclusive to parents and caregivers while other groups were created specifically for awareness and fact-checking.

For the groups included in the present study, there were about 5000 to 6000 members per group, with private groups having a higher average of membership. This is similar to the findings of other studies which revealed that patients and families of patients with newly described or rare genetic findings felt discomfort and uneasiness in imparting information in public groups.[24,25] Notwithstanding the privacy group setting which supposedly ensures confidentiality and privacy, members of private Facebook groups are still divulging and disclosing personal stories and information, especially about children and children's health condition to strangers on an online platform. This can be referred to as what Meier and Krämer call a 'privacy calculus' by which health-related Facebook group members weigh the perceived privacy risks and potential benefits (i.e., obtain information and disseminate information about G6PD deficiency) before revealing any information to other people especially in an online setting.[26] This study also showed that not only were there more private Facebook groups than public Facebook groups on G6PD deficiency but the former were also more 'active' in terms of having a greater number of posts, averaging three times the average number of posts in public groups. Such is a foreseeable result as private groups are deemed to "create a more secure environment for participants to disclose personal information" and to share personal feelings and stories. The majority of the closed groups in this study utilized Facebook for information seeking, information sharing, and raising awareness about G6PD deficiency.[20]

Private Facebook groups whose main function is to provide information, knowledge, and materials about a particular health condition such as G6PD deficiency through social networking sites eventually create a support group intended for both informational and emotional support. While some existing literature revealed that there are online groups which provide more instrumental and reciprocal emotional support to parents and families of patients with diseases such as diabetes.[27] In another study of parents of children who are to undergo clinical genetic testing, parents described Facebook as an important site where families are able to identify with others with similar experiences and obtain support for interactive education, support and guidance.[14] The present study slightly departs from these findings on other conditions by demonstrating that online support groups for a genetic condition like G6PD deficiency are more focused on information sharing and information acquisition. However, this finding can be further nuanced by locating it within the discussion of social support broadly defined as "provided by other people and arises within the context of interpersonal relationships" and can be classified into four types – informational, emotional, instrumental, and appraisal support.[28,29] In this case, these interpersonal relationships emerged from an interaction between members of Facebook groups with shared needs, experiences, and insights about G6PD deficiency. Through interpersonal relationships albeit virtually and with (relative) strangers, informational support tends to be the foremost social support shared in the form of advice, suggestions, and knowledge to cope with G6PD deficiency. However, this does not imply that the informational support is disjointed and detached from the other types of social support such as emotional support (expressions of sympathy and encouragement, listening, and concern) as illustrated in the communicative strategies employed to interact with each other. Informational support was also related to appraisal support by "providing comparison, affirmation, feedback, and self-evaluation" about how the patients and families of the patients with G6PD deficiency are faring and coping with difficulties.[29,30]

Using 60 analyzed posts and more than 3000 comments, this study posits that the informational support that was provided in the Facebook groups investigated in the study played out in providing information about *diagnosis*, *disease management*, and *beliefs* about health and coping with the condition.

Sharing 'diagnosis' of G6PD deficiency

A diagnosis is often associated with the medical experts who "designate a specific condition [they] consider pathological, and the process, or deliberate judgment, by which such a label is applied."[31] It is also vital to the medical field and the medical system as it "organized illness [by] identifying treatment options, predicting outcomes, and providing an explanatory framework." In short, a diagnosis or the capacity to produce and diagnose a medical condition stem from a medical practitioner identifying an illness from "a complaint and physical or biological condition" which implies that the said medical practitioner has "greater knowledge and status" than lay people and other professionals.[31] Against the backdrop of the ubiquitous use of the Internet and social networking services, however, medical diagnoses have also been transformed in such a way that information about diseases and illnesses can now be easily sought and obtained from online sources hence "people can now bypass medical professionals entirely and find information, advice, support, and even treatment (e.g., pharmaceuticals and herbal remedies) on the Internet." Traditionally, medical experts are the 'official' and 'formal' sources of health-related information, and they do "held and filter health information for the public."[32] These days, sources of medical and health information can be found in large online repositories for health information such as WebMD and Medline, online health communities, blogs/vlogs as personal websites, discussion boards, and support groups. For the support groups and online communities such as the G6PD deficiency support groups on Facebook, medical diagnoses that members obtained from their doctors are shared with other members of the Facebook group as a response to those who are seeking new information about G6PD deficiency and/or obtaining appraisal support in

terms of feedback and comparison of diagnosis, symptoms, and outcomes. The discussion about medical diagnosis of G6PD deficiency included its formal origin, signs, symptoms, confirmatory test, newborn screening, and long-term effects.

Informational support on how to manage G6PD deficiency

Management for people with G6PD deficiency pertains to overseeing food, diet, medical procedures, and medication that may trigger the medical condition. Due to the long-term demand of managing the patients' diet and medication, families of patients with G6PD deficiency utilize social networking sites to elicit immediate and evidence-based health information based on the testimonials of other patients and families of the patients, interactions and engagements with other members of the Facebook groups.[33] Social networking sites such as Facebook are free, user-friendly and highly accessible hence these online platforms "provide the basis for performing relevant self-management work that can improve an individual's illness experience, tackling aspects of self-management that are particularly difficult to meet offline" due to lack of physical access to support groups, 'invisibility' of the community associated with G6PD deficiency or the inaccessibility of formal health care.[34]

For the management of G6PD deficiency, members of the Facebook groups studied had included topical medicine (creams, ointment, lotions, and other medications for rashes and skin problems), nutrition (milk formula, diet, and vitamins) and blood transfusion. Informational support by sharing information on how to manage G6PD deficiency is often linked to self-disclosure as a communicative strategy of engaging with other members of the Facebook groups. This is in part related to appraisal support being provided within these support groups. While presenting advice, suggestions and information on medication, nutrition, diet, and medical procedures, members of the Facebook groups were also disclosing personal stories and testimonials in the form of feedback, comparison, and self-evaluation whether the recommended diet or medication was effective or not. This is in agreement with the work of Apperson and colleagues on Facebook groups on Chronic Obstructive Pulmonary Disease (COPD) which suggested that "personal self-disclosures about the COPD experience and requests for information were more likely to be used as communication strategies in self-management posts (e.g., medication management, hospitalizations/doctor's visits)." Apperson et al. continued by attributing the gap between the number of members in private and public groups to the high reliance on personal self-disclosures because informational, emotional and appraisal support often entails sharing sensitive information.[33]

Beliefs and perceptions about G6PD deficiency

Together with the formal medical diagnoses on G6PD deficiency, families of patients with this condition also rely on lay perceptions and 'beliefs' based on experiences and to a large extent, 'trial-and-error' method until the 'best fit' or *hiyang*, the local approach to healing comes along or obtained.[35] This does not mean though that the 'trial-and-error' approach may be risky or may cause harm to the patient as it is often incorporated into management. What could be the best fit for diet, nutrition, medication, and medical procedures are based on the experiences of other people and the patients themselves.

Facebook groups originating from the Philippines or whose members are mostly Filipinos tend to integrate the concept of *hiyang* into the discussion of *management*. Aligned with the early operationalization of the concept of *hiyang*, G6PD deficiency Facebook group members determined if certain care practices, diets, or medicines are *'fit' or 'suitable' (hiyang)* to the patients if these have less adverse effects on the individual, and they minimize the appearance of symptoms.[36]

In this study, informational support has been provided in three ways - sharing of 'diagnosis' of G6PD deficiency, imparting the various management practices, and sharing of beliefs and perceptions about G6PD and how to cope with it. Using Facebook as a platform, information about G6PD has been obtained through various communication strategies and shared through various engagements/interactions among the members of the Facebook group.

Effectiveness of communication strategies and use of various media modalities

The main category of Facebook posts or communication strategy was information-requesting. It also has the highest number of engagements through comments. This is consistent with the results of the study by Kubb and Foran in 2020.[37] Worldwide, it was shown that parents are heavy online users of health-related information for their children across highly diverse circumstances. This was followed by self-disclosure with or without information-requesting, which is also second with the greatest number of comments. Product/service promotion came in third, but compared to the rest of the categories, had the most number of reactions and shares. Another category was information-providing, which group administrators or leaders mainly posted. For healthcare providers, this reinforces the need to regularly educate patients during follow-up. However, the importance of these groups in providing the needed information to patients and families cannot be overemphasized. As these groups may not necessarily be guided by healthcare providers, there is value in looking into these groups to be able to identify concerns on G6PD deficiency where clarification and additional information might be needed. In the study by Miller et al., it is important to examine if people are actually receiving credible information rather than misinformation and ensure that beneficial health information is accessible to families when they need it.[38]

In terms of media modality, posts combined with visuals were deemed effective in communicating essential concerns on G6PD deficiency, as this has been used more frequently

by group members. Houts and colleagues asserted in their study on health communications that compared to mere texts, content supplemented with photos could evoke recall, strike attention, and improve comprehension using photos and related visuals is especially relevant on urgent information-requesting posts to promptly invite answers.[39]

CONCLUSION AND RECOMMENDATIONS

While previous research relies on interview data to explore the support that patients and families alike can access through the internet and social media platforms, this present study contributes to further understanding not only the expressed needs and accessed support but also the types of topics that are most salient as well as the types of communication strategies that are most effective. By examining posts and exchanges in public and private G6PD Facebook groups, we can ascertain the kind of information that are most sought and needed by parents and caregivers through the number of posts about such topics as well as the reactions and ensuing interactions to such posts (e.g., number of likes, comments, and shares). By paying attention to the content and manner of communicating information on these platforms, the newborn screening program may improve its advocacy and education campaign and will be able to develop targeted educational materials and effective dissemination strategies that could clarify, explain, or refute information and beliefs mostly shared on these platforms.

Indeed, Facebook groups have become a popular tool for awareness, seeking information, and support for community-building, especially in the Philippines. Given Facebook's wide reach and popularity in the country, further research is needed to understand the motivations, implications, and risks of online communication among caregivers and patients with G6PD deficiency. As G6PD deficiency groups were mainly used for information-seeking, attending physicians should always emphasize key medical concepts of G6PD deficiency. Echoing the recommendation of Barton et al., the program support unit of the newborn screening program may create Facebook groups that contain accessible and vetted medical information as well as other forms of support and resources.[14]

This study has several limitations. Qualitative data was collected for this study; it may not be designed for formal hypothesis testing. The study also focused on Facebook groups of caregivers and patients with G6PD deficiency. Thus, it may not be representative of other groups with medical conditions. Other social networking sites such as Twitter, Instagram, and YouTube were not analyzed. The inclusion of other social networking sites may yield alternative results. The characteristics of the administrators of the groups and posters were not analyzed, and this may provide additional insights into the results of the study. In the article of Thoren et al., it was revealed that the majority of the administrators and posters are women; it was hypothesized that fathers are secondary role-takers in the parenting of preterm infants.[40]

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All authors certified fulfillment of ICMJE authorship criteria.

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