

Public Opinion on Exagamglogene Autotemcel (Casvegy) for Sickle Cell Disease: A Qualitative Thematic Analysis Using Social Media Data in Cameroon

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Abstract

Background: On January 31, 2025, the UK's National Health Service (NHS) approved exagamglogene autotemcel (Casvegy), a gene-editing therapy for severe sickle cell disease (SCD), at a cost of £1.65 million (approximately 1.287 billion CFA francs) per patient. Given SCD's high prevalence in Cameroon, we aimed to explore public opinion in this context, identify common themes, and assess implications for healthcare equity. **Methods:** We conducted a qualitative thematic analysis of 712 comments from a single, highly engaged Facebook post identified using the search string "sickle cell Cameroon cure". Comments, primarily in Pidgin English, were systematically translated into English by bilingual researchers (EEC and MBR) and coded using NVivo 14 to derive themes and sentiments. Manual cross-checking ensured coding consistency and reduced linguistic bias. The study adhered to the 32-item COREQ checklist. **Results:** Seven themes emerged: enthusiasm and appreciation, scepticism about cost, accessibility issues, advocating for genotype testing, scepticism about practical use, hopes for subsidies, and personal stories. Sentiment shifted from optimism to frustration due to the treatment's cost, with many emphasizing prevention through genotype testing over an unaffordable cure. While the approval of Casvegy elicits hope, its cost renders it inaccessible for most Cameroonians, exacerbating health inequities. **Conclusion:** The cure elicits optimism but is overshadowed by its cost, exacerbating inequities and emphasizing prevention. Subsidized testing and treatment are critical to meeting community needs. This study highlights social media as a lens for public health insights, especially in low-resource settings like Cameroon.

Keywords

Sickle Cell Disease, Cameroon, Gene Therapy, Social Media, Thematic Analysis, Health Equity

1. Introduction

Sickle cell disease (SCD) affects approximately 25 million people worldwide, predominantly in Africa, which accounts for 78% of the 515,000 annual SCD births, with sub-Saharan Africa heavily impacted by severe sickle cell anaemia (HbSS), where under-five mortality ranges from 50% to 90% and nearly 90% of patients do not survive to age 18 [1]-[4]. In Cameroon, the birth incidence of SCD is estimated to range between 500 and <1000 newborns per 100,000 live births [5]. SCD causes severe chronic pain, organ damage, and reduced life expectancy and leads to stigma with derogatory terms like “sickler”, “ogbanje” (one who comes and goes), “sika besa” (money will finish), “ene mewu” (I can die today, I can die tomorrow), “vampire” (blood consumer), and “Efiewura” (hospital landlord), driven by frequent crises, hospitalizations, physical traits, and cultural misconceptions [6]. Despite this heavy burden, access to basic evidence-based therapies like hydroxyurea remains a challenge in Sub-Saharan Africa [7]-[9].

On January 31, 2025, the UK’s National Health Service (NHS) approved exagamglogene autotemcel (Casgevy), a CRISPR-based gene-editing therapy, as a “functional cure” for severe SCD, with clinical trials reporting a 96.6% efficacy rate [10]-[12]. Priced at £1.65 million (approximately 1.287 billion CFA francs) per patient, this therapy raises a critical question: how can someone afford the therapy in Cameroon, where 23% of the population lives on less than 2 dollars a day [12] [13]. Understanding public perspectives in high-prevalence regions like Cameroon is essential, as community insights can reveal barriers, priorities, and potential solutions for SCD management [6] [14] [15].

Qualitative approaches are particularly suited to this inquiry, as they allow for an in-depth exploration of complex social, cultural, and economic factors shaping perceptions of SCD and its treatments [16]. Unlike quantitative methods, which may prioritize numerical trends, qualitative research captures nuanced sentiments, personal experiences, and contextual influences, providing a richer understanding of how communities navigate hope and frustration in the face of medical advancements [17]. In Cameroon, where cultural and linguistic diversity influence health communication, qualitative methods can amplify marginalized voices and highlight community-driven solutions [18]. This study aims to examine public opinion in Cameroon on Casgevy’s approval, identify key themes in community responses, and evaluate implications for health policy and SCD care in resource-constrained settings.

2. Methods

This qualitative study employed thematic analysis to explore public opinion in

Cameroon on the approval of exagamglogene autotemcel (Casgevy) for sickle cell disease (SCD), adhering to the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist for rigor and transparency [19].

2.1. Research Team and Reflexivity

2.1.1. Personal Characteristics

The study was conducted by three researchers: EEC (MD, MMED paediatrics, PGD sickle cell disease), EML (MD, MRes Clinical research), and MBR (MD, MMED paediatrics). At the time of the study, EEC and MBR were faculty members at the Faculty of Medicine and Pharmaceutical Sciences, University of Douala, Cameroon, and specialized in paediatrics with a special interest in sickle cell diseases. EML was a clinical research expert at the Faculty of Health Sciences, University of Buea, Cameroon. EEC and MBR are female, and EML is male. Only EML had formal training in qualitative research methods through graduate coursework and workshops, with over seven years of combined experience in public health and medical research.

2.1.2. Relationship with Participants

No prior relationships were established with commenters, as data were collected from a public Facebook post. Commenters were unaware of the researchers' involvement, as the study used anonymized, publicly available data. The researchers' interest in SCD stemmed from its high prevalence in Cameroon and their professional commitment to addressing health inequities. Their familiarity with SCD's socioeconomic impact in Cameroon may have influenced theme interpretation toward equity and access issues, which was acknowledged and discussed during analysis to minimize bias.

2.2. Study Design

2.2.1. Theoretical Framework

The study employed a constructivist paradigm, which seeks to comprehend the complexity of the world by exploring individuals' perspectives and personal experiences, recognizing that public perceptions are shaped by social, economic, and cultural contexts [20]. Thematic analysis, following Braun and Clarke's six-phase approach (familiarization, coding, theme generation, review, definition, and reporting), was used to identify patterns in sentiments expressed on social media [21]. This methodological orientation allowed for an inductive exploration of public opinion without preconceived hypotheses.

2.2.2. Participant Selection

Participants were commenters on a single, highly engaged Facebook post identified on February 1, 2025, using the search string "sickle cell Cameroon cure". Purposeful sampling was employed to select this post based on its high engagement (712 comments, 1500 likes, 108 shares), ensuring a rich dataset reflecting diverse opinions. Commenters were approached indirectly through the public post, with no direct recruitment. The sample consisted of 712 comments, with no refusals or

dropouts, as participation was voluntary and unsolicited. Commenters were primarily Cameroonian, inferred from their use of Pidgin English and references to local contexts, though specific demographic data (e.g., age, occupation) were unavailable due to the anonymous nature of the data.

2.2.3. Setting

Data were collected from a public Facebook post, an online setting accessible globally. No non-participants were present, as the data were text-based comments. The sample reflected Cameroon's linguistic diversity, with most comments in Pidgin English, a widely used language in informal communication. The post's prominence suggested engagement from a broad cross-section of Cameroonian social media users, including patients, caregivers, and healthcare advocates.

2.2.4. Data Collection

No interview guide was used, as the data consisted of unsolicited comments. The post was identified and comments extracted over one week (February 1 - 7, 2025). No audio or visual recordings were involved, as the data were text-based. Field notes were maintained to document coding decisions, researcher reflections, and contextual observations about the post's tone and engagement. Data saturation was achieved after coding all 712 comments, with no new themes emerging. Transcripts were not returned to commenters for verification due to the anonymous, public nature of the data. Comments were imported into NVivo 14 for coding and analysis, ensuring systematic data management.

2.3. Data Analysis

Three researchers (EEC, EMMML, MBR) independently coded the comments inductively, generating initial codes (e.g., "cost concern", "genotype advocacy"). Codes were organized into a coding tree, with sub-themes (e.g., emotional responses within enthusiasm) grouped into seven main themes through iterative discussions. Themes were derived entirely from the data, with no predefined categories. Discrepancies in coding were resolved through consensus meetings, ensuring inter-coder reliability. NVivo 14 facilitated data organization, theme visualization, and frequency analysis.

Sentiment scoring was performed manually by two independent coders (EEC and EMMML) and cross-checked for consistency, with 95% inter-coder agreement. Sentiment analysis supplemented thematic findings, tracking shifts from hope to frustration. Participant checking was not feasible due to anonymity.

2.4. Ethical Considerations

For this study, formal ethical approval was not sought based on the premise of minimal-risk research utilizing publicly available social media data. This was supported by two central claims: First, that the processing of personal data complied with the GDPR's legitimate interests basis (Article 6 (1) (f)), following a mandatory balancing test that determined the research's goals did not override the data

subjects' fundamental rights [22]. Secondly, all necessary steps were taken to ensure privacy. Specifically, the data were treated as pseudonymized to mitigate the risk of re-identification. To uphold participant welfare, the study adhered to strict ethical guidelines for social media research: all quotes used were anonymized with identifiers (e.g., "Participant A") and either sufficiently paraphrased or intentionally short and generic enough to prevent them from being searchable and traced back to the original Facebook post, thereby protecting individual privacy and minimizing the potential for harm.

2.5. Reporting

Participant quotations are presented to illustrate themes, with each quote identified by a participant code. The findings are consistent with the raw data, ensuring transparency. Major themes are clearly defined, with minor themes (e.g., emotional nuances within scepticism) discussed when relevant to provide a comprehensive understanding of public sentiment.

3. Results

Analysis revealed seven major themes capturing public opinion in Cameroon on Casgevy for SCD. The comments, predominantly in Pidgin English, reflected perspectives from patients, caregivers, and community members. Sentiment shifted from initial excitement to frustration and pragmatism, with a focus on prevention.

3.1. Theme 1: Enthusiasm and Appreciation (22%, ~157 Comments)

This theme captured excitement and gratitude for Casgevy's approval. Commenters expressed joy and hope for a cure, often emphasizing the breakthrough's significance. Sub-themes included celebration of the discovery and spiritual gratitude. Many praised the scientific advance (e.g., "Wow! That's good news" [Participant A]; "This is the best news of the year. See me pouring tears of joy" [Participant B]). Others attributed the breakthrough to divine intervention (e.g., "God is great" [Participant C]; "To God be the glory" [Participant D]). Comments often conveyed emotional relief, with phrases like "Wooooooow" (Participant G) and "Amazing" (Participant H) appearing frequently, particularly in the first 20% of the comment thread.

3.2. Theme 2: Scepticism about the Cost (28%, ~200 Comments)

This theme focused on disbelief and confusion about the treatment's cost, emphasizing psychological shock at the figure. Sub-themes included psychological shock and requests for clarification. Commenters expressed shock at the 1.287 billion CFA francs price (e.g., "Fear amount" [Participant I]; "Na billion that I di see so or na my eye and brain get problem?" [Participant J]). Many requested the amount in words to confirm its magnitude (e.g., "One billion, two hundred and eighty-seven million, five hundred and two thousand, two hundred and nineteen francs"

[Participant K]; “Abeg write the money in words” [Participant L]). Others used hyperbolic language to convey incredulity (e.g., “That money na phone number?” [Participant M]; “Only figure for the treatment dey like phone number” [Participant N]). This theme dominated the middle 50% of comments, with terms like “heeee” and “chaiiii” reflecting emotional intensity.

3.3. Theme 3: Accessibility Issues (20%, ~142 Comments)

This theme highlighted concerns about the therapy’s inaccessibility due to its cost. Sub-themes included economic barriers and exclusion of the poor. Commenters noted the disconnect between the cure and Cameroon’s economic realities (e.g., “Good news but the poor will still die” [Participant O]; “How many families in Cameroon will be able to raise the sum requested?” [Participant P]). Many emphasized that only the wealthy could afford the treatment (e.g., “That money na for rich man only” [Participant Q]; “Only for the rich” [Participant R]). Others questioned affordability for average families (e.g., “How many average families can afford this amount?” [Participant S]; “That money no be for poor man” [Participant T]). This theme appeared consistently, often overlapping with cost scepticism, and underscored a sense of exclusion.

3.4. Theme 4: Advocating for Genotype Testing (18%, ~128 Comments)

Commenters strongly advocated for genotype testing to prevent SCD. Sub-themes included calls for testing and personal anecdotes about testing. Many urged testing before relationships or marriage (e.g., “Go do your genotype test” [Participant U]; “Please I Join My Voice To Say ‘Go Check Out Yours’” [Participant V]). Personal stories highlighted the impact of testing (e.g., “Knowing my genotype made me feel so happy coz imagine I didn’t know and I planted my seed in another AS” [Participant U]; “Thank God we both are AA & AA. I was so excited” [Participant W]). Others referenced affordable testing options, like free campaigns in Kumba or tests for 8 - 11 k CFA (e.g., “In the month of March we will be campaigning against sickle cell and the test will be completely free” [Participant X]; “We do it here in our hospital in Bda for 11 k” [Participant Y]). This theme gained prominence in the final 30% of comments.

3.5. Theme 5: Scepticism about Practical Use (15%, ~107 Comments)

This theme reflected doubts about Casgevy’s practical relevance in Cameroon, emphasizing the perceived futility of an unaffordable treatment. Sub-themes included perceived irrelevance and the emotional impact of cost. Commenters viewed the cure as unattainable (e.g., “No cure if people can’t afford” [Participant Z]; “The simple truth is that there is no cure yet because just to read that figure can cure your sickle cell and add you enough high blood” [Participant AA]). Others suggested the cost negated the breakthrough’s value (e.g., “News good but

money spoil news” [Participant BB]; “With the price, I think there is no difference when the medicine wasn’t discovered” [Participant CC]). Some expressed frustration that the price caused additional stress (e.g., “That money alone can kill the patient” [Participant DD]). This theme overlapped with accessibility concerns, emphasizing the cure’s impracticality.

3.6. Theme 6: Hopes for Potential Subsidy (10%, ~71 Comments)

Commenters expressed hope for external interventions to make Casgevy affordable. Sub-themes included calls for institutional support and future optimism. Many urged governments, NGOs, or the WHO to subsidize the treatment (e.g., “The WHO, gov’t, NGO should subsidise so that a common man can benefit from this discovery” [Participant EE]; “Please let the government look into this” [Participant FF]). Others hoped for future cost reductions, citing precedents like HIV drugs (e.g., “We pray that the WHO finds a way to reduce the cost of treatment” [Participant GG]; “Just like treatment for HIV/AIDS was costly but now it’s almost free” [Participant HH]). This theme reflected a desire for collective solutions, often appearing alongside accessibility concerns.

3.7. Theme 7: Personal Stories (7%, ~50 Comments)

This theme captured personal experiences with SCD, adding emotional depth. Sub-themes included patient experiences and caregiver perspectives. Patients shared their struggles (e.g., “Yours truly... 59 year-old warrior” [Participant II]; “And some AS genes have sickle cell symptoms. Like me that money plenty ooh” [Participant JJ]). Caregivers described financial and emotional burdens (e.g., “I have friends that suffer from this type of disease and unfortunately 2 have already passed away” [Participant KK]; “She spends not less than 30 k monthly to get drugs for the boy out of her 65 k salary” [Participant LL]). These stories highlighted SCD’s toll, often reinforcing prevention advocacy. These themes and sub-themes are summarised in [Table 1](#) and [Table 2](#) and [Figure 1](#) below.

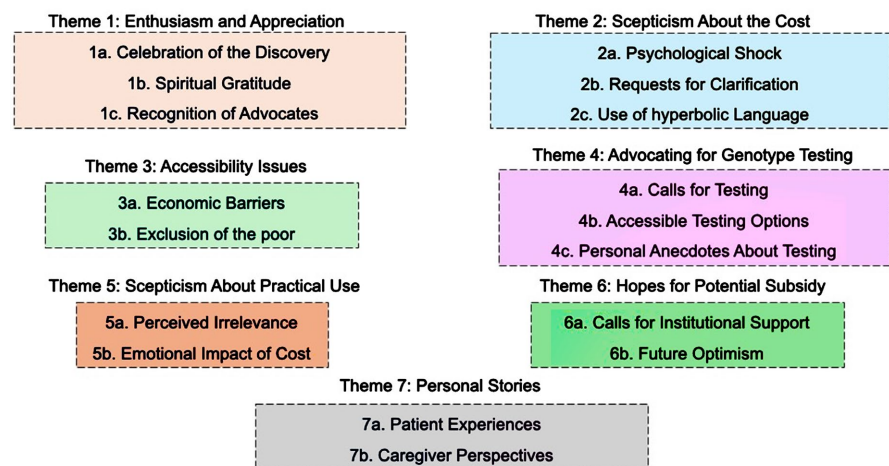


Figure 1. Themes and subthemes emerging from social media analysis of public opinion of Cameroonians on Casgevy.

Table 1. Themes generated, brief descriptions, and representative quotes.

Theme	Description	Representative Quotes (Pidgin English or English)
Enthusiasm and Appreciation	Commenters expressed excitement about Casgevy's approval, viewing it as a scientific milestone. This theme captured hope for improved outcomes for SCD patients, with some attributing the breakthrough to divine intervention.	<ul style="list-style-type: none"> • "Wow! That's good news." (Participant A) <p>"This is the best news of the year. See me pouring tears of joy" (Participant B)</p> <ul style="list-style-type: none"> • "God is great" (Participant C) • "Fear amount" (Participant I)
Skepticism About the Cost	The cost of 1.287 billion CFA francs dominated discussions, eliciting disbelief and confusion. Many requested that the amount be written in words, reflecting the psychological shock of the figure.	<p>"Na billion that I di see so, or na my eye and brain get problem?" (Participant J)</p> <ul style="list-style-type: none"> • "One billion, two hundred and eighty-seven million, five hundred and two thousand, two hundred and nineteen francs" (Participant K)
Accessibility Issues	Commenters highlighted that the cost renders Casgevy inaccessible. Exacerbating health inequities. This theme underscored the disconnect between medical advancements and practical access in a low-income context.	<ul style="list-style-type: none"> • "Good news, but the poor will still die" (Participant O) • "How many families in Cameroon will be able to raise the sum requested?" (Participant P)

Table 2. Themes generated, brief descriptions, and representative quotes (continued).

Advocating for Genotype Testing	A strong call for prevention emerged, with commenters urging genotype testing before relationships or marriage. Personal anecdotes reinforced the importance of testing to avoid incompatible partnerships.	<ul style="list-style-type: none"> • "Go do your genotype test" (Participant U) • "Please, I join my voice to say 'go check out yours'" (Participant V) • "Knowing my genotype made me feel so happy because imagine I didn't know and I planted my seed in another AS" (Participant U)
Skepticism About Practical Use	Many argued that the cure's cost makes it irrelevant for most Cameroonians, framing it as a theoretical rather than a practical solution.	<ul style="list-style-type: none"> • "No cure if people can't afford" (Participant Z) • "The simple truth is that there is no cure yet because just to read that figure can cure your sickle cell and add you enough high blood" (Participant AA)
Hopes for a Potential Subsidy	Commenters expressed hope that subsidies from governments, NGOs, or the WHO could improve access, reflecting reliance on external interventions to address affordability.	<ul style="list-style-type: none"> • "The WHO, gov't, and NGO should subsidise so that a common man can benefit from this discovery" (Participant EE) • "We pray that the WHO finds a way to reduce the cost of treatment" (Participant GG)
Personal Stories	Personal experiences with SCD added emotional depth, highlighting the disease's toll and the stakes of an inaccessible cure.	<ul style="list-style-type: none"> • "Yours truly... 59-year-old warrior" (Participant II) • "I have friends who suffer from this type of disease, and unfortunately, 2 have already passed away" (Participant KK)

3.8. Sentiment Analysis

Sentiment analysis showed a shift across the comment thread. The first 20% of comments were predominantly positive, with phrases like “Wow, great news” (Participant NN) and “Thank you Jesus” (Participant OO) reflecting excitement. The middle 50% shifted to frustration, driven by cost concerns (e.g., “That figure don spoil all the joy” [Participant PP]; “I was excited until I saw those figures, my mood changed” [Participant QQ]). The final 30% emphasized pragmatism, with 60% of comments focusing on prevention (e.g., “Better to avoid the sickness” [Participant RR]; “Check ya genotype abeg” [Participant SS]). This shift highlighted a progression from hope to disillusionment, culminating in actionable solutions.

4. Discussion

Analysis of 712 comments revealed seven themes reflecting public opinion in Cameroon on exagamglogene autotemcel (Casgevy) for SCD. Enthusiasm and appreciation captured excitement for the “functional cure” (e.g., “Wow! That’s good news”). Skepticism about the cost (1.287 billion CFA francs) elicited disbelief (e.g., “Fear amount”), while accessibility issues highlighted inequities (e.g., “Good news but the poor will still die”). Advocating for genotype testing emphasized prevention (e.g., “Go do your genotype test”). Skepticism about practical use framed Casgevy as irrelevant due to cost (e.g., “No cure if people can’t afford”). Hopes for potential subsidy reflected reliance on external support (e.g., “The WHO, gov’t, NGO should subsidise”). Personal stories underscored SCD’s toll (e.g., “Yours truly... 59 year-old warrior”). Sentiment shifted from optimism to frustration, with prevention prioritized over an unaffordable cure.

The findings align with studies on SCD and health equity. Enthusiasm for Casgevy echoes clinical trial data reporting 96.6% efficacy [12], but cost skepticism mirrors concerns about high-cost therapies in low-income settings [9]. Patel *et al.* (2025) note gene therapy costs exacerbate disparities, reflecting commenters’ accessibility concerns [23]. Advocacy for genotype testing aligns with Munung *et al.* (2024), who found support for genetic testing in Cameroon to reduce SCD incidence [16]. Hopes for subsidies align with Minja *et al.* (2020), who advocate global partnerships to improve SCD care access, including for basic therapies like hydroxyurea [24]. This study’s use of unsolicited discourse offers a novel perspective compared to traditional methods [25].

The themes reflect Cameroon’s socioeconomic and cultural context. Enthusiasm for Casgevy is driven by SCD’s high mortality (50 - 90% under-five) [1]-[4], but frustration stems from its cost, unaffordable for the average Cameroonian [13]. Genotype testing advocacy is a pragmatic response, supported by growing awareness of SCD’s hereditary nature [16]. Hopes for subsidies reflect reliance on external aid, given limited access to even hydroxyurea [7]-[9]. The sentiment shift highlights the psychological impact of an unattainable cure, prioritizing actionable solutions in a resource-constrained setting [26] [27].

Implications for Policy and Practice

Subsidized or free genotype testing programs could reduce SCD incidence, building on existing campaigns. Advocacy for subsidies or partnerships with global health organizations is critical to making Casgevy viable in Cameroon. Social media can be leveraged for SCD education, targeting rural and urban populations. Integrating genotype testing into routine health services (e.g., premarital or prenatal care) could institutionalize prevention.

Strengths and Limitations

Reliance on a single Facebook post may limit generalizability, anonymity prevented demographic analysis, and Pidgin English required nuanced interpretation. Selection bias toward highly engaged comments may overrepresent strong sentiments. Nonetheless, the major strength of this study is the use of social media, which provided authentic, unsolicited insights into public sentiment, and also the COREQ framework ensured methodological rigor.

5. Conclusions

The approval of exagamglogene autotemcel offers hope for SCD treatment but is overshadowed by its cost in Cameroon, where public sentiment reflects both optimism and frustration. The emphasis on genotype testing and calls for subsidies highlight the need for equitable solutions. Social media serves as a powerful tool for capturing public health perspectives, offering insights for policy and practice in low-resource settings.

What is known about the topic:

- Sickle cell disease (SCD) has a high prevalence in Cameroon, with significant mortality and stigma, yet access to basic treatments such as hydroxyurea remains limited.
- Exagamglogene autotemcel (Casgevy), a CRISPR-based gene-editing therapy approved by the UK's NHS in January 2025, offers a potential cure for severe SCD but is priced at £1.65 million (1.287 billion CFA francs), making it unaffordable in low-income settings.
- Public perceptions in high-prevalence regions like Cameroon are critical for understanding barriers to SCD treatment, with social media providing a platform for capturing community sentiment.

What this study adds:

- Seven key themes (enthusiasm, cost skepticism, accessibility issues, genotype testing advocacy, practical use skepticism, hopes for subsidies, and personal stories) were identified, reflecting Cameroonian public opinion on Casgevy, and highlighting a shift from optimism to frustration due to cost.
- This study also demonstrates the utility of social media (specifically, a Facebook post with 712 comments) as a tool for qualitative thematic analysis, capturing authentic, unsolicited public health insights in a low-resource setting.
- It emphasizes the community's focus on prevention through genotype testing and the need for subsidies, offering actionable policy recommendations to address health inequities in SCD care.

Acknowledgements

We thank all the commenters for publicly sharing their opinions on this topic of great interest.

Data availability statement

Anonymized thematic analysis data are available upon reasonable request to the corresponding author. Unanonymized data can be found on the Facebook post through the following link: <https://web.facebook.com/share/p/1NcMInd1B7/>.

Author Contributions

EEC and MMLE conceived and designed the study. MMLE, EEC, and MBR performed the qualitative analysis. MMLE and EEC wrote the initial manuscript draft. All authors revised the manuscript and agreed to publish the manuscript in its current form.

Conflicts of Interest

The authors declare no competing interests.

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