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“When selling anything to an audience, visible publicity is key:” experiences, barriers, and enablers to participate in a COVID-19 study in Malawi

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Abstract

Background Many studies in infectious diseases struggle to recruit participants. The SARS-CoV-2 infection, transmission dynamics, and household impact in Malawi (SCATHIM) study reported a refusal rate of 57.2%. Adequate publicity can lead to more people participating in studies. This study explored the reasons for participating in the SCATHIM study.

Methods A descriptive qualitative study informed by the theory of reasoned action was conducted in Blantyre between January 2022 and March 2022 to assess factors that influence participation in a COVID-19 study among 10 index cases, 10 caregivers, 10 study decliners, and 5 research staff. The data were collected via in-depth interview guides, audio recorded, transcribed, managed via NVIVO and analysed via a thematic approach.

Results The factors that motivated participation in the study included one’s knowledge of COVID-19; potential access to medical services, including free COVID-19 tests for members of the household; financial reimbursements; and the ability to contribute scientific knowledge. The barriers to participation included minimal publicity of the study amidst a novel condition, perceived stigma and discrimination, perceived invasion of privacy, discomfort with the testing procedures, and suboptimal financial reimbursements.

Conclusion Effective publicity and outreach strategies have the potential to decrease refusal rates in study participation, especially if a condition is novel. Studies on infectious diseases should address stigma and discrimination to promote participation and ensure participant safety.

Keywords Study participation, Research publicity, Stigma and discrimination, Financial reimbursements, COVID-19

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Background

The coronavirus SARS-CoV-2 (COVID-19) is a highly infectious and fatal disease that evokes fear among communities. As of December 3, 2022, Malawi alone recorded a total of 88,086 confirmed cases of infection and 2,685 deaths [1].

Since then, Malawi has implemented various pandemic-related studies. Through Kamuzu University of Health Sciences, a study was undertaken to understand SARS-CoV-2 infection, transmission dynamics, and household impact in Malawi (SCATHIM). The key goal was to understand the secondary attack rate of the COVID-19 virus from an index case in a household setting. However, during the implementation of the study, investigators noted a refusal rate of 57.2% among the eligible potential participants [2]. A key determinant of a successful study is to efficiently recruit and retain an adequate number of study participants [3]. However, worldwide, medical studies face pressure and several challenges concerning the recruitment and retention of participants. Studies regarding highly infectious diseases tend to face even more challenges with the recruitment of participants [4].

Several factors influence participation in studies. The provision of financial incentives in a COVID-19 study in South Korea was a catalyst for increasing the voluntary participation and testing of individuals, with the potential to limit the rapid spread of the infection at a lower cost [5]. Previous studies further suggest that access to better treatment [6] and approval and support by family and friends aid people in participating in a research study [7]. The factors that impede participation in clinical studies include a lack of approval by friends and family [8]; a lack of study benefits at the individual or community level; limited knowledge and understanding of the research process, which is more prevalent among participants living in rural areas; and perceptions of flawed recruitment measures that lack community engagement [9]. Understanding the recruitment process implies that research participants can comprehend the information provided and appreciate its relevance to their situations [9]. A study conducted in Blantyre suggested seeking consent from the chief or community leaders before a sensitization meeting in the targeted community as a strategy for recruiting participants into a study because it creates a sense of security and safety among the community members [9].

In the SCATHIM study, individuals who tested positive for COVID-19 for the first time were called and notified of their results by the Blantyre district health office team. They were further notified that a KuHES team was interested in contacting them to explain the COVID-19 study that they were conducting. Those who accepted the invitation were called by the study team for more discussions on the matter. Those who agreed were visited at their homes and consented to participate in the study, i.e., the index case and their household contacts. The qualitative component of the study included caregiver and index cases, where a caregiver was defined as "one providing most of the care to the patient." Participants in the SCATHIM study undertook several responsibilities, including permitting weekly visitations by the study team to monitor their clinical status, collecting nasal and throat swabs for retesting for COVID-19, and collecting blood samples for immunological tests.

The study managed to enrol 581 participants, representing 21% of the total population contacted. A total of 153 (95%) index cases and 344 (84%) contacts continued in the study until day 28 (study exit day). It is not known what motivated a smaller proportion of eligible people to enroll and remain in this study, as well as the factors associated with nonparticipation in studies of highly infectious diseases such as COVID-19. This study explored the experiences and factors associated with participating in a COVID-19 study among index cases, caregivers, and research staff. Exploring the participants' experiences as well as learning their enablers and barriers to study participation is one way to help in finding solutions in study recruitment and retaining participants.

Conceptual framework

This study used the theory of reasoned action (TRA), which is a behavioural theory that assumes that human beings are rational and make systematic use of the information available to them. People consider the implications of their actions before they decide whether to engage in certain behaviours. The TRA was an ideal framework for this research because it enhanced the exploration of motivational influences on the basis of one's attitudes, intent, and subjective norms on whether to participate in a study of a highly infectious disease.

Methods

Study design

This descriptive qualitative research was nested within the SCATHIM study (mother study) (Fig. 1). SCATHIM is a prospective cohort study that was undertaken by Kamuzu University of Health Sciences researchers to determine the infection transmission dynamics and household socioeconomic impact of SARS-CoV-2 infection in Malawian settings. In the present study, in-depth interviews were conducted with index cases (first laboratory-confirmed cases of COVID-19 in the household), their caregivers, those who refused to participate in the mother study, and SCATHIM research staff.

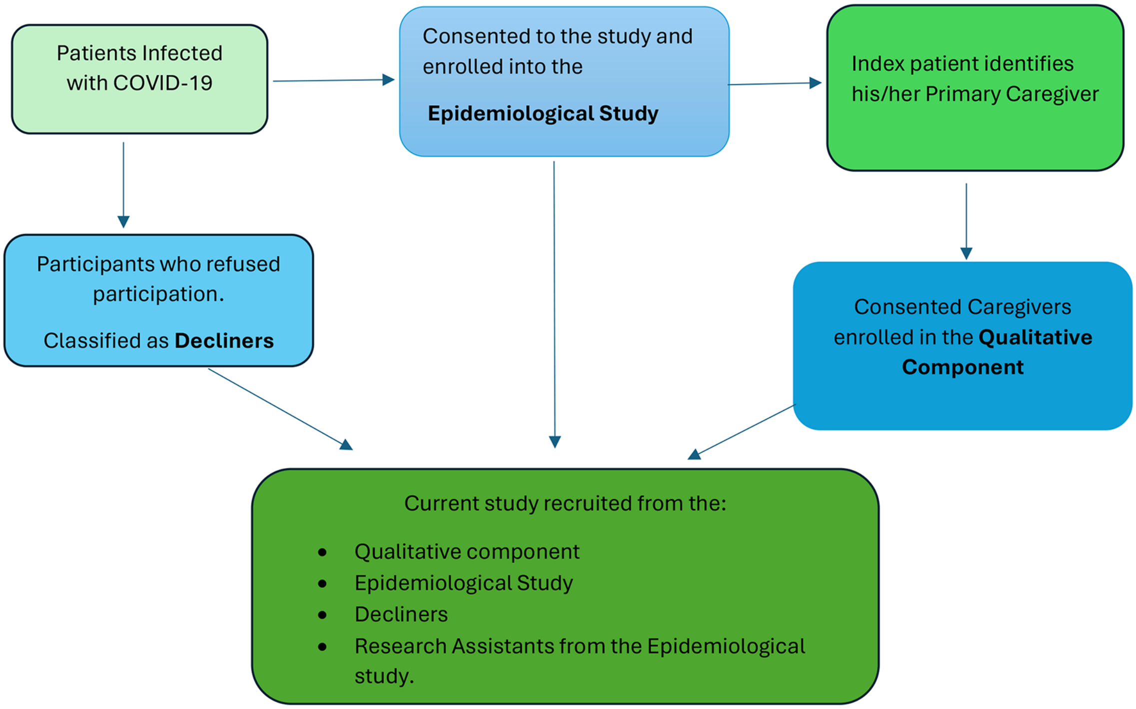

Fig. 1 Illustration of the flow of the SCATHIM study indicating sections where participants were drawn from

Study setting

The study replicated the same setting as the mother study, which was conducted in communities located in Blantyre, a district located in southern Malawi with a population of 1.25 million as per the 2018 Malawi Population and Housing Census Report, of whom 64% reside in urban areas [10]. Like the mother study, the study sought participants from rural, urban low-density, and urban high-density areas, hence providing good representation. The study location was selected to include views of people living in various social and economic statuses to broaden the scope of the responses.

Sample size

A purposive sampling method was used to select 35 study participants while applying maximum variation. In this case, the area of residence was the variable that determined the maximum variation of the sample. We selected index cases that were willing to share their experiences after they participated in the SCATHIM study. Caregivers were included to understand the reasons why their patient (the index case) chose to participate, whereas study decliners were selected to understand the reasons that made them refuse participation. We further included research staff to explore their experiences while conducting the study, as they had direct encounters with index cases, caregivers, and refusals.

Data collection

Data were collected via telephone by the primary researcher via a semistructured tool (Supplementary File 1) from January to March 2022. At the time of data collection, the researcher was studying for a master's degree in public health and had a degree in media and communication. The researcher is female, has received training in qualitative research, and was working under the mentorship of her supervisor, who is a seasoned qualitative researcher. The researcher introduced herself as a student who was pursuing her studies at Kamuzu University of Health Sciences and had no prior relationship with the participants. We opted for telephone interviews because they ensured convenience and ease of data collection, as the qualitative data in the mother study utilized the same approach, and a database of contact details was readily available to the researcher. Additionally, in January 2022, when the researcher started collecting data, there was a surge in COVID-19 cases; hence, interviews were conducted over the phone. The data tools were pretested on one research staff member and one caregiver to determine their ability to collect reliable and valid data before data collection. After the pretest, the tools were revised to include more open-ended questions and probes to ensure that all nuances were explored. None of the participants refused to participate in the study, and they were all audio-recorded.

The interviews were conducted in English as well as Chichewa as per the participant's preference and lasted for 30 min on average. Field notes were captured to note any aspects that were not within the data collection tools. There were no repeat interviews. Data were collected until no new ideas emerged from the participants. We maximized the trustworthiness and rigor of the study by summarizing the key points that were discussed in an interview at the end of each interview as a form of member checking [11]. Credibility was established by increasing the visibility of the researcher's involvement by sharing their number for further questions or comments, creating enough time to chat with the participants, which showed prolonged engagement with the participants. Transferability was attained by providing sufficient contextual information about the data collection sites to enable the reader to make such a transfer [11]. Furthermore, the presentation of quotes supporting the findings increased the confirmability of the findings [11]. Our results were reported according to COREQ guidelines (Supplementary File 2).

Data management and analysis

All the data were kept on a computer with a passcode known only to the investigator. The researcher transcribed the interviews verbatim in Chichewa and English. Audios in Chichewa were translated into English for coding. Data were managed by NVivo 12 software (QSR International, Melbourne, Australia). A coding guide was developed by VM and ALN-M by independently coding three transcripts [12]. Codes were inductively realized from the data and deductively from the framework of the study [13]. Once the three transcripts were coded, VM and ALN-M discussed the codebook to develop a codebook that was used by VM to code the rest of the transcripts [Supplementary File 3 Code Book]. VM and ALN-M held multiple meetings to discuss the coding process, review the coded data, and appraise the new codes being added to the codebook. The researcher allocated preliminary codes to the data to describe the content following the codebook, which simplified and reduced the dataset into meaningful small chunks [14, 15]. The data were analysed via a thematic approach, as suggested by Braun and Clarke [16]. The researchers familiarized themselves with the dataset by reading and rereading the transcripts when developing the codebook. Similar codes were grouped under the overarching themes of experiences in participating in a COVID-19 study, enabling enrolment in a COVID-19 study, and barriers to enrolment in a COVID-19 study. The data were reviewed under each theme to ensure congruence between the theme and the data under it and to further classify the data into subthemes. For example, the data under enablers were classified according to the type of enabler, such as financial reimbursements or access to medical services. The themes were examined for sufficiency and accurate data representation, and they were cross-referenced with the audio to ensure that the results were not misrepresented. To ensure that the themes and subthemes remained distinct from one another and did not overlap, the subthemes with limited data were blended with others that were comparable or related. To achieve clarity in the data presentation, the subthemes were discussed iteratively among the researchers.

Table 1 Characteristics of the study participants

Characteristic	Index cases $n = 10$	Caregivers $n = 10$	Decliners $n = 10$	Research staff $n = 5$
Sex				
Male	7	6	7	1
Female	3	4	3	4
Age	25–44	25–25	22–45	25–44
Education Level				
College	**5**	**6**	**4**	**5**
Secondary	**4**	**4**	**4**	
Primary	**0**	**0**	**2**	
No Education	**1**			

Ethics considerations

Ethical approval was obtained from the College of Medicine Research Ethics Committee (COMREC) (P. 10/21/3445) before any study procedures were performed. COMREC is based in Blantyre, Malawi, and is an institutional review board for Kamuzu University of Health Sciences, which is in Blantyre, Malawi. All participants provided verbal informed consent prior to study participation, and this was approved by the Institution Review Board. The consent form was read to them, and it provided the rationale and selection process of individuals for participation and stated that they were free to withdraw at any point, which was captured through the recording of the conversation. If some were illiterate, the presence of an impartial witness was not possible considering the nature of the consent process. All participants provided consent prior to study participation. The interviews were conducted in a private space so that there was no overhearing of the conversations. All participants were given an identification number, and no names were recorded on transcripts or used in final reports. The data were stored on a password-protected laptop belonging to the researcher.

Results

The characteristics of the study participants are displayed in Table 1. The majority of the participants were males. Six of the caregivers were married. Five caregivers were employed, three ran businesses, and two were students. Of the 10 decliners, eight were employed, whereas two were not employed.

Experiences in participating in a COVID-19 study

The experiences that the participants shared centered on knowledge of COVID-19, medical studies, the SCATHIM study, and the recruitment approach.

Knowledge of COVID-19, medical studies, and the SCATHIM study

When the participants were asked for their understanding of COVID-19, most participants linked COVID-19 to their definitions of a virus, elaborated on the transmission process, and described the signs and symptoms.

> *"It is a virus that attacks one's respiratory system, and with it, various complications arise, such as loss of breath, sweating…no, rather fever, loss of appetite. It was a disease that emanated from China in 2019, and it is now a world pandemic. That is what I can say." [Participant 1, Index Case, Chilomoni].*

> *"Alright, COVID-19 is a respiratory disease—a virus rather. It attacks the respiratory system and, with it, results in signs and symptoms such as loss of breath, body pain, etc. It is easily transmitted from person to person, especially when social distance is not observed. It can be deadly if not well managed. I think that's what I know about COVID-19." [Participant 22, Caregiver, Chilomoni].*

When asked about their understanding of medical studies, index cases and caregivers stated that medical studies entail research to discover something that needs further exploration in medicine.

> *"Well, a medical study is when scientists conduct research in a particular area to discover something. It's what you are doing here." [Participant 3, Index case, Chileka-Chatha].*

> *"A medical study is an area of research where those in the medical field are researching to understand a particular area of interest to understand or find a solution for that particular gap. I hope I make sense." [Participant 4, Caregiver, Namiwawa].*

Index cases and caregivers reported having some knowledge of what the SCATHIM study was, and they related it to COVID-19. They stated that the study was interested in following those who had tested positive for COVID-19.

> *"Well, from what I remember, I know that this was a COVID-19-related study that was being conducted by the College of Medicine. They told us that they had taken our records from the DHO's office and that they were interested in us participating, as we had tested positive for COVID-19. Therefore, the plan was that they would be coming to our homes to test and take samples of not just me but the entire household. I think they said their interest was the transmission aspect, if I am not mistaken. That's what I can recall for now." [Participant 7, Index case, Namiwawa].*

On the other hand, other participants did not know about the SCATHIM study altogether; they stated that they were only seeking help and wanted support from hospital officials when they were approached to enroll.

> *"As a caregiver, I noted that the main reason was for them [the index case] to be assisted and recover; about the study, they didn't know much or what its aim was."[Participant 5, Caregiver, Chilomoni].*

> *"I will be honest with you; I don't recall what exactly they shared with me about the study. I just remember that it involved researching COVID-19. I just wanted to be helped." [Participant 6, Index case, Chileka-Chatha].*

Recruitment approaches

The index cases and caregivers were able to share how they heard about the SCATHIM study and how they were approached to be part of the study. The participants explained that they received phone calls that explained to them about the study and why they were being approached; others heard it from their family members who had been approached, and others were given consent forms that explained the study and the recruitment process itself.

> *"The recruitment approach was quite detailed. I think at that time, it was quite detailed. I remember she telling us that as part of the study, there will be several tests that will be occurring after some period." [Participant 8, Index case, Chilomoni].*

> *"How did I get to learn about it? Okay my wife at her workplace was referred to the College of Medicine for a test. Therefore, in the midst of her going there for a test after getting the results, I think that's when she was approached and introduced to the whole study, and that's how the whole household was recruited for the study." [Participant 9, Caregiver, Chilomoni].*

Enabling enrollment in a COVID-19 study

The factors that facilitated enrollment in the SCATHIM study included knowledge of COVID-19, medical services, access to medical services, financial reimbursements, and the need to contribute to the findings of the study.

Knowledge level of COVID-19

Research staff indicated that the level of knowledge of the pandemic was an enabler for those who mostly chose to participate. The participants who lived in urban areas, especially low-density urban areas, were more knowledgeable and exposed to the pandemic and rarely refused to participate.

> *"Therefore, most of the time, it was very hard, but those who were participating were mostly motivated due to their knowledge level on the subject. They were able to understand the motive behind what we wanted to achieve at the end of the day." [Participant 33, Research Staff].*

Medical services

The subthemes under this theme include a quest to understand the COVID-19 status of other household members and access to medical services.

A quest to determine the COVID-19 status of other household members

Some index cases indicated that their main interest in participating in the study was that they could know the status of their households as a measure of controlling transmission. They viewed this as a convenient way to access a test as opposed to accessing it at a health facility, where they may have had to queue for a long time. This approach also guaranteed frequent tests until a household was rated as an infection-free zone.

> *"Okay, aah, I wanted to know whether the people I am staying with within my household are safe because they told me that I was found with COVID-19. Therefore, I also wanted them to check because, it would have been an opportunity for me to get tested each time. Therefore, to me, I saw it as a good thing because they were following us home to monitor how we were doing. It was an easy thing for me. Because when you go to the hospital, you do stay on the line. Because at the hospital, getting t tested for COVID-19 wasn't easy." [Participant 5, Index Case, Chilomoni].*

Access to medical care

Most of the research staff shared that index cases and caregivers attributed the opportunity to access medical services so easily as their main motivation to participate in the study. With respect to the information they were given regarding the study, they knew that they had the opportunity to call health workers if they were not feeling well.

> *"And then most of them chose to participate because they had a serious illness, so they thought once they participated in our study, that meant they were going to receive good treatment. That was the main motivation." [Participant 31, Research Staff].*

> *"They [index cases] thought their quality of health and life would easily improve because we were visiting them weekly. Therefore, some felt comfortable that our things would work; we wouldn't be going to the hospital; people would be visiting us. Therefore, they were feeling good, and some were asking questions through their phones anytime they wanted. As a result, it was a good thing." [Participant 35, Research Staff].*

Financial reimbursements

Some caregivers and index cases stated that receiving money while participating in the study was a motivation to stay in the study, considering the economic hardships that the pandemic had caused.

> *"Of course, there was another motivating factor, which was that at the end of the day, we will be paying you some amount, it was quite motivating to the other guys in the household." [Participant 9, Caregiver, Chilomoni].*

Need to contribute to the response to the pandemic

Very few participants shared the view that their participation was intended purely to help find answers to the study being carried out in response to the pandemic. They said that their participation in the study would help give the researchers answers for a greater reason in trying to understand the area of interest they want to know and that they would have helped in finding solutions for the greater good.

> *"Well, the pandemic is something that affects everyone. Therefore, I thought it was quite important that we take part as well so that whatever can be done to combat the pandemic should be done." [Participant 8, Index Case, Chilomoni].*

Barriers to enrolment in a COVID-19 study

The commonly cited barriers included minimal study publicity and stigma/discrimination. The other barriers were suboptimal financial reimbursements, invasion of privacy, and testing procedures.

Minimal study publicity

In most index cases, the research staff as well as the study decliners indicated that the study lacked adequate publicity, as they were not aware of the study before being approached by the research staff. They stated that publicity on various media platforms would have helped give them confidence in its legitimacy and existence beforehand, considering that the study occurred at a time when the occurrence of COVID-19 was marred with skepticism.

> *"When selling anything to an audience, visible publicity is key. I feel the study would have gotten the necessary attention it needed had they been communicating about it, noting that it was happening during a time when everyone was scared and facilities did not have adequate testing kits. So imagine the number of people who would appreciate having medical personnel follow and test you for free." [Participant 26, Caregiver, Chileka-Chatha].*

Research staff acknowledged that there was limited publicity about the study and attributed that as a factor in nonenrollment in the study.

> *"We didn't do much publicity. There was no sensitizing community, moving around, or using fliers, radio, television, or any radio station. Maybe had it been that we did a lot of sensitization around the communities, people would have known that this was happening.". [Participant 35, Research Staff]*

Other participants suggested that community leaders, such as chiefs and pastors, could have been utilized through their churches to help engage, which would have helped the study gain substantial participants.

> *"We need to know. Use the media to publicize your study, churches, mosques, chiefs, or any other influential figures in our communities to engage us; it makes it easier to trust you when you call for us to enroll in studies." [Participant 8, Index case, Chilomoni].*

Stigma/discrimination

Discussions with the SCATHIM research staff indicated that potential participants declined to participate in the study because most people feared stigma from society. This was mainly a result of the limited knowledge of COVID-19 by those surrounding them. They said that participants feared that the moment those surrounding them saw the health workers in their protective wear and arriving in an ambulance to conduct study procedures, it would lead to more stigma.

> *"The major one is stigma; that one was a blow because most people saw that the moment we visit them, it's an alarm to the community around, and people are refusing to go to their homes… People were afraid that since the car was supposed to visit them every week, it would be an alarm to their community, hence leading to stigma [participant 34, Research staff].*

On their part, some decliners felt that they had inadequate time to process the possibility of joining a study, especially when they factored in the stigma associated with being infected with COVID-19. The participants also weighed the effects of their participation on their families.

> *"Well, basically, I wasn't emotionally ready to be in a study. By that, I mean, I just didn't feel the need to expose my family to the stigma that was coming in with the pandemic in those earlier days. Don't get me wrong, the thought of getting first-hand support from a medical team was tempting, but I was uncertain how my family would also feel about it. I didn't want it to feel as if they were imposed on it." [Participant 25, Decliner, Chileka-Chatha].*

Financial reimbursements

Some participants who refused to participate in the study attributed it to the financial reimbursement that was proposed. They mostly stated that the money offered was small.

> *"The money that you said you would give us was so little, so aah, that's when I just decided not to proceed." [participant 28, Decliner, Chileka-Chatha].*
>
> *"When I heard that we would be given some sort of money for the time spared to participate, I did get tempted to participate, but when I learned of the amount, I immediately lost interest. I was expecting thousands of Kwachas (laughs). Yeah, but they can do better." [Participant 24, Decliner, Chilomoni].*

Invasion of one's privacy

Some participants chose not to take part in the study because they felt that their privacy was being invaded and feared the possibility of their health issues being publicized through social media for others to see.

> *"First, I just wasn't interested; I believe issues to do with my health are private and should remain that way." Pparticipant 30, Decliner, Namiwawa].*

> *"It's just my belief that my health is something that should remain a private matter, so I will be honest with you; I don't think I would ever be part of a study." [Participant 23, Decliner, Chileka-Chatha].*

Researchers corroborated the participants' views and reported that some participants who refused participation in the study were mainly concerned with their privacy and the likelihood that it would predispose them to stigma and discrimination related to COVID-19.

> *"Some people were denying to participate not because they are illiterate but because they would like to safeguard their privacy." [Participant 32, Research Staff].*

> *"They feared for their privacy. They also felt that there was going to be stigma from the neighbours but also that they had doubts about us (health care workers). They feared that we might take their information and tell other people. You know issues to do with social media. They were afraid that maybe they would wake up one morning and find their names written somewhere that they have COVID-19 or whatever." [Participant 34, Research Staff].*

Testing procedures

Index cases and caregivers, as well as research staff, expressed concern with the testing procedure. They reported that the process of inserting the swab into the nose resulted in discomfort. The feeling of discomfort in their nose that lasted for a considerable amount of time made them very uneasy with the procedure.

> *"For starters, I think they need to find friendlier modes of testing participants than the nasal swab. I will be honest with you, even as a grown man, I can never get used to that process; it is so uncomfortable. Therefore, imagine testing an entire household that consists of children as well for a certain period … I don't think anyone would easily volunteer for that." [Participant 1, Index case, Chilomoni].*

> *"Testing for COVID-19 can be improved. The oral one is also painful, but the number one is nasal. The children mostly dreaded the test because it was painful. Yes, there should be another way." [Participant 4, Caregiver, Namiwawa].*

Healthcare workers supported the caregivers and index case experiences with the testing by sharing their experience in conducting the tests. They stated that a lot of fear came from the thought that the procedure would be done repeatedly throughout the study.

> *"Others would say the procedure is so painful, so with our explanation that the samples will be collected twice or three times, we faced a lot of fear from them." [Participant 31, Research staff].*

Discussion

Our study revealed that the index cases and caregivers' perceptions of participating in a COVID-19 study demonstrated an adequate understanding of what COVID-19 is and what medical studies are, as well as an understanding of the recruitment procedure. The enablers of participation included access to medical services, the level of COVID-19 knowledge, financial reimbursements, and advances in the science of COVID-19. The barriers to participation included suboptimal financial reimbursements, invasion of privacy, and testing procedures, and the commonly cited barriers were discrimination and stigma and minimal study publicity.

Perceptions of medical studies and recruitment approaches

The findings from the study demonstrate that the participants had an overall understanding of what COVID-19 was, as well as what medical studies entail. A good level of knowledge about a disease is a key factor in causing individuals to become infected and helps them understand their study needs when they are approached [17]. In our study, most of the index cases and caregivers understood what COVID-19 was, which accelerated their willingness to participate in the study. This heightened level of understanding could be explained by the higher literacy level of the participants who were recruited for this study.

Participation in research must be voluntary [18] and in a manner that offers participants adequate time and the ability to freely consider whether they wish to take part. Undue pressure because of the timing of the request, who makes the request, the method of request, or the offering of undue inducements should be avoided [18]. Our findings show that the index cases and caregivers were properly recruited by the SCATHIM research staff, who gave them adequate information and presented them with consent forms. An earlier European study revealed that a well-conversed research team is key to the recruitment team, as it will be able to share the right information with the participants [19]. This means that the researchers were well trained on recruitment procedures and provided adequate information to potential participants before recruitment.

Enablers of participation in a COVID-19 study

Our findings revealed that caregivers indicated that their patients (index cases) chose to participate largely because they wanted to access better treatment. Similarly, another study in Brazil reported that many study participants enroll in clinical studies because they believe that they will have improved access to health care and a better quality of care [20]. The participants believe that they will be better able to check their health and avoid the time that they would spend in the public health sector. Moreover, the ability to call a study physician at any time is attractive to most patients [20], which was also a shared feeling among our respondents. The need for easy access to medical services could have been largely influenced by the increase in cases and deaths due to COVID-19 at the time the study of mothers was conducted. The COVID-19 variant beta wave identified in South Africa was attributed to the second wave in Malawi, which was also the time when the SCATHIM study was being conducted. The increase in the number of cases during this wave resulted in hospitals being overwhelmed, further resulting in substandard services offered to COVID-19 patients [21]. This has been reported before in an earlier Malawian study where participants reiterated that their main motivator to participate in a study was the guarantee of better medical treatment [9]. The respondents in a Malawian study characterized normal health care in health centres as inadequate with limited diagnostic capabilities, which compromises the treatment one receives, which is further compromised by the lack of supplies such as medications [9]. Hence, studies that are perceived to provide additional care to participants in an infectious disease setting are more likely to attract easy participation.

Our findings showed that the quest to understand the COVID-19 status of other household members as a way of controlling transmission among their households was another factor that motivated their enrolment in the SCATHIM study. This finding is consistent with the results of a multicentre study conducted in Egypt, Saudi Arabia, and Jordan, which revealed that approximately 50% of the study participants had positive attitudes towards participation in COVID-19 trials, and the main factor that influenced public willingness was the desire to protect family members from COVID-19, accelerating the return of life to normal [22]. This finding further agrees with the TRA's element of belief, which states that a person's attitude towards performing some behavior is a function of the beliefs that one holds regarding the behavior [23]. In this case, the participants believed that their choice to participate in the study was the solution to protecting their families.

Our study revealed that most participants had a good understanding of COVID-19 and medical studies, which was a factor in their willingness to participate and could also be further based on the participants' demographics. Similarly, a study in India focused on the awareness and understanding of the COVID-19 virus among rural and urban populations.

According to an Indian study, rural residents require considerably more information and awareness about COVID-19 for infection prevention and control than do urban residents. Rural residents are less aware of the virus than urban residents [24]. It may be that those in urban areas are likely to be educated and therefore knowledgeable and concerned about their health and well-being through access to more information sources and become more engaged in life events that could impact them [24], such as COVID-19. The above finding is also consistent with the theory of reasoned action (TRA), which assumes that human beings are rational and make systematic use of the information available to them [25]. The belief that people hold about a behavior follows reasonably well from the information and knowledge that people possess about the behavior under consideration. These beliefs originate from a variety of sources, such as personal experience, formal education, radio, newspapers, TV, the internet, and other media, as well as interactions with family [25].

Financial incentives, as reported in our study, have been suggested as catalysts to increase the voluntary participation and testing of individuals and can play a vital role in limiting the rapid spread of the infection at a lower cost if monetary rewards are given [5]. In Ghana, as in Malawi, the IRBs have set the allowable amount for a token or incentive as a way of minimizing coercion because of what participants stand to gain if they participate in the study [26, 27]. Participants in a Vietnamese study indicated that they did not join studies merely for financial reimbursements alone but had other interests that were different from what the healthcare workers stated [28]. Financial reimbursements have the risk of being coercive, especially in areas of low socioeconomic status [28]. Furthermore, a study conducted among the African-American community cautioned that individuals are less willing or able to consider the risks of participation when monetary reimbursement is involved and described payment for research participation as just one part of the “informal economy” in poor communities [29]. Nonetheless, it is important to note that the amount that the main study provided as reimbursement, which was 2 USD, was not high enough to coerce someone to join the study, and that is why others were able to opt out solely of this financial incentive basis if the other factors, in their opinion, were not strong enough to persuade them to join the study.

Another reason given by others for their decision to take part in the study was their desire to further the body of knowledge regarding the management of COVID-19. In a similar vein, an investigation into the reasons for community study participation found that research participants valued studies that went beyond the specific study environment by helping advance basic science by understanding novel concepts [30]. According to the study, one of the things that drives people to participate in research is the desire to provide knowledge that would benefit medicine or the medical field [30]. Hence, researchers could utilize this approach by ensuring that the informed consent form and process highlight how participation in the study contributes to understanding the disease and how the results will be used.

Barriers to participation in a COVID-19 study

The respondents in our study emphasized a lack of adequate publicity as a barrier to adequate participant recruitment. The SCATHIM study did not adequately sensitize the communities to the study because of the COVID-19 preventive measures that were reinforced at the time. The measures eliminated community gatherings where information about an upcoming event could have been shared. Instead, potential participants learned about the study when they presented at a health facility for a COVID-19 test. Although our sample was adequate, the reluctance of the others who were approached to join the study could be due to a lack of awareness of the study. Public awareness and engagement are among the main prerequisites of successful research [31]. The implementation of these principles requires concerted efforts from all stakeholders, including the public [31]. The literature suggests that effective outreach to potential research participants, especially those who are difficult to access, requires a partnership approach with community-based influencers, media, and other relevant stakeholders [32]. Engaging community members in research activities is crucial for meeting recruitment and enrollment goals and resolving key barriers [33]. Using community leaders as champions and recruiters is a successful recruitment approach, as they create trust among participants [33]. Additionally, a study on chemical exposure in pregnant women revealed that online advertising, radio, TV, posters, and flyers at hospitals and clinics were the most successful recruitment strategies [34]. Our findings and those of a previous study on public awareness and perceptions of clinical research in India indicate that creating public awareness changes attitudes towards, enrolment in, and the benefits of participation [35]. There is a need to increase public awareness and understanding of research to ensure its success while being compliant with all ethical considerations. In the main study, COVID-19 was associated with stigma and community reproduction. Hence, to balance privacy and ensure that many people hear about the study, the approach of contacting people directly was employed.

Our study revealed that some people were scared of being stigmatized by their communities if their sickness was disclosed to the public for some reason. The fear of being stigmatized by being in the study area may lead to being labeled as having spread COVID-19. Research has shown that stigmatized people are often associated with nondisclosure of their disease status [36], avoidance of medical care, and nonadherence to treatment to avoid discrimination [37]. This may severely disrupt efforts to manage any infectious disease outbreak [37, 38]. Similar findings regarding the impact of disease-related stigma on research efforts have been reported in other research fields, including HIV and mental health research. One study on HIV conducted in South Africa revealed that 80% of the 400 patients with HIV who participated in the study did not feel comfortable disclosing their status due to fear of stigma [39]. While studies related to social stigma among individuals with COVID-19 are limited, the SCATHIM decliners’ experience could be similar to that of persons affected by other infectious diseases, such as HIV/AIDS and tuberculosis [40], where a large proportion of eligible patients refused to participate in a study because of high levels of stigma from society [40]. These findings are consistent with the TRA’s tenet on subjective norms as an influencer of one’s intent toward a behavior. Subjective norms involve individuals’ beliefs about the extent to which other people surrounding them think they should or should not perform behaviours [25]. Subjective norms could explain the high refusal rates experienced during recruitment in the SCATHIM study because most of the decliners made their decisions on the basis of what others would or said. However, for those who choose to participate in the SCATHIM study, the theory also points out that sometimes, even if others prescribe a certain behavior, one may still not be motivated to comply. The concerns raised by regulatory bodies in South Africa are similarly illustrated by our findings, which indicate that greater incentive value may have led to increased participation in the study [41]. For example, the South African Medical Council advocated the introduction of flat rates that compensate participants only for their time, inconvenience, and expenses [41]. The assertion by the medical council was not favourably received by the community members, as it translated into reduced reimbursements [41]. Additionally, in a study in Kenya where reimbursement amounts were discussed, zero payments were deemed unfair, and high reimbursements evoked suspicion among the prospective participants [42]. However, participants in a study conducted in America viewed substantial financial incentives as a benefit and did not perceive them as coercive or suspicious but rather as compensation for their time [25]. The variation in perceptions between participants in our study and those from the USA could be secondary to the different socioeconomic statuses of the different settings, with those in the USA being less needy. The importance of considering substantial financial incentives as a strategy to retain participants in longitudinal studies was similarly acknowledged by the participants in our study, showing that participants will be motivated to enroll in a study when an incentive is brought into the picture. Building trusting relationships between researchers and participants is essential in research. This can therefore contribute to the authenticity of the study [37]. Although this was done in the SCATHIM study by presenting the participants with consent forms highlighting the privacy obligations of the researchers on whatever was to be shared with research staff, the study findings still indicated that the decliners felt that their health issues were not for others to know, leading to their denial of participation. In relation to this finding, a study on perspectives regarding privacy in clinical research revealed that when potential research participants are directly contacted by the research team after having accessed their medical records to determine which patients meet study criteria, the researchers' access to these records violates informational privacy, hence leading to prospective participants not being interested in participating in their research [43]. Furthermore, findings from a clinical study on barriers to the recruitment of HIV-infected people further revealed that the need for privacy in one's status was a more potent barrier to recruitment than having others learn of other habits, such as substance use disorders. Prospective study participants were concerned about their status being exposed and family and community members discovering their HIV status because they had participated in the clinical trials [44]. This further means that low enrollment rates in studies can be attributed to the fear of personal information being exposed to a wider audience, as indicated by the findings.

The fear of an invasion of privacy can be linked to attitude, another element of TRA, as a reason not to participate. According to the theory, attitude formation is the process by which a large set of specific beliefs, which have been associated with behavior over time, informs an overall sense of favourableness toward the behavior [25]. Attitude is a multiplicative combination of behavioral beliefs, which are perceptions of the likelihood that performing a particular behavior will have certain consequences [25]. In this case, the idea that participating in the SCATHIM study would lead to their health status being known by others led to the belief that participation would breach their privacy.

The COVID-19 nasal swab testing procedure used in the study was a barrier to participation. Similarly, participants in a study carried out to identify perceived barriers to COVID-19 testing in the USA described their perceptions that the nasopharyngeal swab method was too painful, echoing what has been reported by the media [45]. Even those who had not been tested were deterred from doing so because of their fear of the pain associated with the nasopharyngeal swab. The study further revealed that among all sources of samples tested, those obtained from the lower respiratory tract and nasopharyngeal area are viewed to have the highest sensitivity compared with saliva, sputum, blood, and feces [45].

Our theoretical framework, however, indicates that behavioral intention is the most immediate determinant of behavior. It is defined as people's readiness to perform a behavior [25]. This intention comes from the belief that performing the behaviour will lead to a specific outcome. This can also be attributed to the fact that the decision by the index cases and caregivers to participate was determined by one's intention to want to participate, disregarding the discomfort that accompanies the process.

Strengths and limitations

This study collected data from SCATHIM research staff through in-depth interviews, which provided a better understanding of the subject from key stakeholders who interacted with index cases, caregivers, and decliners, as well as sharing their own experiences in the study, which was deemed a strength of the study. However, the study faced limitations due to misconceptions about the study being coercive, particularly among SCATHIM decliners who had previously declined to participate in the mother study. Furthermore, telephone interviews did not allow for observations of the participants' reactions, which could have limited the amount of nonexpressed information captured as well as the personal interaction that is beneficial in face-to-face interviews. Again, by only including participants could be reached via telephone introduced a bias in that we left out those who we could not contact via telephone and these may have had other insights into the topic. We conducted the study after some time had passed since the mother study was performed, which could have resulted in recall bias among the participants in this study. However, we probed more to ensure that the recollection was detailed. Future studies should aim at including participants that had no telephone access to ensure a representative sample. In countries like Malawi where telephonic interviews are not common among community members, there is a need on establishing how this approach can be made effective through dialogues between researchers and study participants.

Conclusion

The participants in the SCATHIM study had sufficient knowledge and understanding of COVID-19 and medical studies and were familiar with the recruitment process. Decisions to participate in a study are influenced by perceived risks and benefits, which may not always be scientifically based. Publicity through various means is necessary to achieve optimal recruitment rates and dispel rumours surrounding new studies. Studies on infectious diseases should address stigma and discrimination to promote participation and ensure participant safety.

Abbreviations

SCATHIM	SARS-CoV-2 infection, transmission dynamics and household impact in Malawi
TRA	Theory of Reasoned Action
COMREC	Research Ethics Committee of the College of Medicine
COVID-19	Coronavirus disease

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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Author contributions

VM conceptualized, developed, conducted the study, analyzed the data and drafted the initial manuscript. DB and VM offered a critical review of the article. SM offered a critical review of the article and the provision of necessary data from the SCATHIM study. ALNM provision of step-by-step guidance throughout the whole research study. ALNM, SM, DB, VM all gave a final approval of the version to be published.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the College of Medicine Research Ethics Committee (COMREC)-P. 10/21/3445 before any study procedures were performed. COMREC is based in Blantyre, Malawi, and is an institutional review board for Kamuzu University of Health Sciences, which is in Blantyre, Malawi. All participants provided informed verbal consent prior to study participation, and this was approved by COMREC, the Institution Review Board that assessed the study. The consent form was read to them, and it provided the rationale and selection process of individuals for participation and stated that they were free to withdraw at any point, which was captured through the recording of the conversation. If there were some who were illiterate, the presence of an impartial witness was not possible considering the nature of the consent process. All participants provided consent prior to study participation. The interviews were conducted in a private space so that there was no overhearing of the conversations. All participants were given an identification number, and no names were recorded on transcripts or used in final reports. The data were stored on a password-protected laptop belonging to the researcher.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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