

RESEARCH ARTICLE

# REVISED Health care-seeking behavior for childhood illnesses in western Kenya: Qualitative findings from the Child Health and Mortality Prevention Surveillance (CHAMPS) Study [version 3; peer review: 3 approved]

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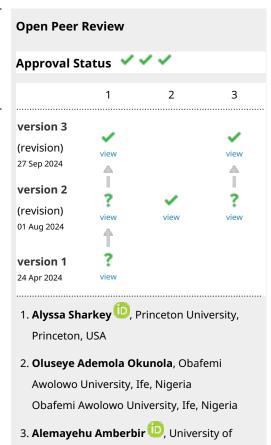
## **Abstract**

## **Background**

Child mortality in Kenya is 41 per 1,000 live births, despite extensive investment in maternal, newborn, and child health interventions. Caregivers' health-seeking for childhood illness is an important determinant of child survival, and delayed healthcare is associated with high child mortality. We explore determinants of health-seeking decisions for childhood illnesses among caregivers in western Kenya.

## Methods

We conducted a qualitative study of 88 community members between April 2017 and February 2018 using purposive sampling in an informal urban settlement in Kisumu County, and in rural Siaya County. Key informant interviews, semi-structured interviews and focus group discussions were performed. We adopted the Partners for Applied



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Social Sciences model focusing on factors that influence the decision-making process to seek healthcare for sick infants and children. The discussions were audio-recorded and transcribed. Data management was completed on *Nvivo®* software. Iterative analysis process was utilized and themes were identified and collated.

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Any reports and responses or comments on the article can be found at the end of the article.

#### **Results**

Our findings reveal four thematic areas: Illness interpretation, the role of social relationship on illness recognition and response, medical pluralism and healthcare access. Participants reported some illnesses are caused by supernatural powers and some by biological factors, and that the illness etiology would determine the health-seeking pathway. It was common to seek consensus from respected community members on the diagnosis and therefore presumed cause and necessary treatment for a child's illness. Medical pluralism was commonly practiced and caregivers would alternate between biomedicine and traditional medicine. Accessibility of healthcare may determine the health seeking pathway. Caregivers unable to afford biomedical care may choose traditional medicine as a cheaper alternative.

#### Conclusion

Health seeking behavior was driven by illness interpretation, financial cost associated with healthcare and advice from extended family and community. These findings enrich the perspectives of health education programs to develop health messages that address factors that hinder prompt health care seeking.

## **Keywords**

Health-seeking behavior, childhood illness, under-5 mortality, qualitative research, traditional medicine

## Gates Open Research

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#### **REVISED** Amendments from Version 2

We have made minor changes to the results and discussion section.

Any further responses from the reviewers can be found at the end of the article

## **Background**

Globally, under-five mortality rates (U5MR) have declined; however sub-Saharan Africa on average has 74 deaths per 1,000 live births, compared to the global rate of 38 deaths per 1,000 live births in 2020¹. In Kenya, U5MR has reduced from 101 to 41 per 1000 live births since 1990², but achieving the 2030 Sustainable Development Goal of 25 deaths per 1,000 live³.⁴, will require a deeper understanding of how decision-making is made by the family before formal healthcare is sought. A large proportion of children still die due to delays in seeking appropriate care attributed by caregivers choosing to first use over-the-counter (OTC) medication and/or traditional medicine⁵.⁻¹.

Health seeking behavior is defined as a complex process guided by a decision-making process that is governed by socio-cultural, structural and economic factors7-11. Belief systems ingrained by cultural beliefs define causes of illness under two broad categories: Those caused by supernatural etiology and those caused by biological pathogens. The category determined to cause an illness provides the basis for health-care seeking decision making 12,13. Studies conducted in Tanzania, report that the determination of a natural or supernatural cause of illness is made by the caregiver's perception of severity and etiology<sup>14,15</sup>. Previous studies indicate that lack of knowledge and delay in recognition of the severity of an illness are reasons for delayed health care seeking<sup>16,17</sup>. Lack of awareness of severity informs health care decisions that are not favorable to the child's health such as use of OTC medications and engagement of traditional healers rather than formal health care<sup>17–19</sup>.

Community based information is needed regarding drivers to health care decision making. Understanding what governs caregivers' health seeking decisions for childhood illnesses is essential to understanding the health seeking behavior. This is important in formulating policies and strategies that optimize response to illness. Using the constructs of the Partners for Applied Social Sciences (PASS) model, we explored how cultural, social and economic factors drove health care decision making.

## **Methods**

#### **Ethics**

This study was part of Child Health and Mortality Surveillance (CHAMPS) Kenya study which was approved by the KEMRI Ethics Review Committee (KEMRI Protocol # 3313). Each participant provided verbal informed consent. We used codes to name audio recordings, stored them in an offline

device, and deleted them from the audio recorders. All study staff involved in data collection and transcription were trained in the handling of confidential information. All laptops with data were password-protected; the storage device was kept in lockable cabinet and was only accessed by the authorized staff. No personal identifiers were used in reporting or publication.

## Study setting and design

For this analysis, we collected data among community members of Manyatta (urban informal settlement) and Karemo (rural) Health and Demographic Surveillance System (HDSS) sites located in Kisumu and Siaya counties respectively between April 2017 and February 2018. A descriptive cross-sectional study was conducted during the formative phase of the Socio-Behavioral Science (SBS) study of Child Health and Mortality Prevention (CHAMPS) Network; these methods have been published elsewhere<sup>20-22</sup>. The SBS aim was to evaluate the feasibility (i.e. acceptability, practicality and implementation) and ethical considerations of child mortality surveillance. We employed a qualitative design using a combination of ethnography and phenomenological approaches. The data collection methods involved for the current analysis included key informant in-depth interviews (KIIs), focus group discussions (FGDs) and semi-structured interviews (SSIs). Interview guides were developed in English and translated into Swahili and Dholuo. The multi-approach method was used to triangulate findings across all data sources.

### Study participants

Participants were purposively selected from a predetermined sampling frame outlined in the CHAMPS socio-behavioral protocol<sup>20</sup>. Participant categories included: Community representatives and religious leaders (Christian and Muslim representatives); community leaders (opinion leaders, chiefs, assistant chiefs and village elders) and other community members; Healthcare providers in the formal healthcare system, traditional birth attendant midwives (TBA); and traditional healers.

### Theoretical framework

The study drew on the Partners for Applied Social Sciences (PASS) model - developed within the PASS International organization to explore contextual factors that drive health care seeking decisions. The PASS model has four categories which independently or interdependently determine the health care choice to use biomedical, traditional medicine or a combination of both. These include: i) illness perception; ii) social values and stigma; iii) social pressure and support; iv) access to care and resource seeking<sup>12</sup>. The availability of health care resources within an area, accessibility to these resources by the population, and accommodation between the health services and people's needs are the basic determinants for access to healthcare and ultimately healthcare behavior. From the perspective of the PASS model, illness is not only an individual matter but a social matter where health care decisions can be determined by the community.

## Data management and analysis

All interviews and focus group discussions were audio recorded, transcribed verbatim, and then translated from Dholuo or Swahili to English. A code book was developed and an iterative analysis process was performed. Nvivo® software was used to organize and manage data and code themes from transcribed discussion. We applied deductive coding based on constructs of the PASS framework. Then we assigned codes to segments of the transcribed texts and searched for themes from the coded texts. The lead author interpreted the themes and summarized them. Quotes were selected based on their clear representation of themes.

#### Ethical considerations

This study was part of Child Health and Mortality Surveillance (CHAMPS) Kenya study which was approved by the KEMRI Ethics Review Committee (KEMRI Protocol # 3313). Each participant provided a verbal informed consent. We used codes

to name audio recordings, stored them in an offline device, and deleted them from the audio recorders. All study staff involved in data collection and transcription were trained in the handling of confidential information. All laptops with data were password-protected; the storage device was kept in a lockable cabinet and was only accessed by the authorized staff. No personal identifiers were used in reporting or publication.

### **Results**

A total of 88 participants were interviewed in 29 IDIs, 5 FGDs and 11 SSIs, of whom fifty-one (58%) were female. Thirty-eight (43%) had at least secondary education or higher, and most 80/88 (91%) were Christian (Table 1).

## **Thematic findings**

We identified four main themes: illness interpretation (theme 1), social relationships and illness response (theme 2), medical pluralism (theme 3) and healthcare access (theme 4). Table 2

Table 1. Socio-demographic characteristics of study participants.

|                   | Caregivers | Health<br>workers | Religious<br>leaders | ТВА | Traditional<br>healer | Community leaders | Total     |
|-------------------|------------|-------------------|----------------------|-----|-----------------------|-------------------|-----------|
| Gender            |            |                   |                      |     |                       |                   |           |
| Female            | 33         | 9                 | 1                    | 3   | 1                     | 4                 | 51(57.9%) |
| Male              | 20         | 4                 | 6                    | 0   | 0                     | 7                 | 37(42%)   |
| Age               |            |                   |                      |     |                       |                   |           |
| <30               | 26         | 3                 | 0                    | 0   | 1                     | 0                 | 30(34%)   |
| 31–49             | 19         | 8                 | 3                    | 0   | 0                     | 4                 | 34(38.6%) |
| 50+               | 8          | 2                 | 4                    | 3   | 0                     | 7                 | 24(27%)   |
| Highest education |            |                   |                      |     |                       |                   |           |
| None              | 1          | 0                 | 0                    | 0   | 0                     | 0                 | 1(0.0%)   |
| Upper Primary     | 18         | 0                 | 5                    | 1   | 0                     | 4                 | 28(31.8%) |
| Lower Primary     | 5          | 0                 | 0                    | 1   | 0                     | 0                 | 6(6.8%)   |
| Some Secondary    | 14         | 0                 | 1                    | 0   | 0                     | 0                 | 15(17%)   |
| Secondary         | 7          | 0                 | 0                    | 1   | 1                     | 3                 | 12(13.6%) |
| College and above | 8          | 13                | 1                    | 0   | 0                     | 4                 | 26(29.6)  |
| Source of income  |            |                   |                      |     |                       |                   |           |
| Formal employment | 1          | 13                | 4                    | 0   | 0                     | 3                 | 21(23.9%) |
| Self-employment   | 32         | 0                 | 3                    | 3   | 1                     | 4                 | 43(48.9%) |
| Other             | 20         | 0                 | 0                    | 0   | 0                     | 4                 | 24(27.2%) |
| Religion          |            |                   |                      |     |                       |                   |           |
| Christian         | 48         | 12                | 6                    | 3   | 1                     | 10                | 80(90.9%) |
| Muslim            | 3          | 0                 | 1                    | 0   | 0                     | 0                 | 4(4.6%)   |
| Other             | 2          | 1                 | 0                    | 0   | 0                     | 1                 | 4(4.6%)   |

Table 2. Summary of emerging themes.

| PASS Model<br>Constructs                  | Themes  | Summary of findings   |  |  |  |  |
|---|---|---|--|--|--|--|
| Illness perception                        | Illness interpretation as naturally- or supernaturally-caused | Illness was divided into 2 major categories: supernatural etiology and biomedical etiology. The interpretation of symptoms and treatment determination is based on cultural beliefs.  |  |  |  |  |
| Social values and stigma                  | Social relationships and illness response                     | The community and family are consulted when a child falls ill. They give advice on the best treatment course depending on their understanding of the illness. Fathers tend not to be included in the child healthcare decision making process.  |  |  |  |  |
| Social pressure and support               | Social support and pressure in healthcare seeking             | Community and family members often offer advice to caregivers on appropriate treatment, caregivers usually oblige. In a show of support, caregivers are sometimes escorted to see traditional healers.  |  |  |  |  |
| Access to care<br>and resource<br>seeking | Healthcare access   | Financial difficulty was revealed to be a barrier to health care access for children. Though sick children were referred to higher level facilities there was reluctance to take them to the referral hospital or they did not have financial capability to heed the call to take a child to a referral facility. |  |  |  |  |

summarizes the thematic areas as well as the major findings for each area.

### Illness interpretation

Most respondents reported that there are different kinds of illness, those caused by supernatural powers and those caused by biological factors. Respondents report symptoms appraisals based on illness interpretation which is arrived at from symptoms exhibited or events preceding the illness. Depending on the perceived etiology of the illness, the caregiver would seek appropriate care for the illness.

"I'd say it depends on the sickness that you are seeking treatment for. Let's say for children you'll look at the type of sickness they have. It could be measles; most people always go for traditional remedies. You make the child sniff bhang [marijuana] and it [measles] goes away and if it is malaria you will either rush to Russia [Jaramogi Oginga Odinga Teaching and Referral Hospital] or District [Kisumu County Referral Hospital]."

(Male, Kisumu FGD1)

Some respondents described how some illnesses require traditional medicine depending on what kind of illness it is, and if conventional medicine is sought instead, then dire consequences such as death may occur:

"Our community has a disease called the small disease [locals refer to measles by a term that loosely translates as 'the small disease']. They believe that if a child who has contracted the disease is injected [as they would usually do in hospitals], then the child will not recover; they don't recover. So they believe that they must be given 'medicine of the pot' [herbal medicine prepared by boiling in a pot]."

(Female, Siaya FGD2)

According to the respondents, the community attributes illness to events. For example, an ill child may become sick because

of something the mother did that's considered a taboo by the community.

"There are illnesses that can ail a child that is called 'Chira' [illness caused to punish wrongdoing]. The child can get it from the mother if she does something wrong[(taboo] then they would look for 'manyasi' [herbal concoction that remedies the effects of doing something against cultural norms]"

(Male, Siaya FGD3)

Symptoms are interpreted into a diagnosis, and then the appropriate treatment is sought:

"There is one called "okul bat". This disease makes the child congested and the body becomes feverish. You just massage the child using Rob [a mentholated ointment] and OMO [handwashing powder] then he/she sweats a bit, sleeps and then they are cured."

(Male, Kisumu FGD1)

Most of the respondent's report that there is a common belief among community members who believe that any illness that does not fit a medical diagnosis is caused by witchcraft:

"...I have an experience. My child was sick and when you looked at the child you could see that he was truly unwell. When I went to Russia I was told that there was no disease so when I came back I was told that it was witchcraft."

(Female, Kisumu FGD2)

# Role of social relationship on illness recognition and response

The respondents reported a communal approach to treatment of child illness: Whenever a child is ill, family, friends and neighbors are consulted about the illness. Due to longstanding cultural beliefs, community diagnosis is common and every so often appropriate course of action is derived. Mostly, traditional medicine is sought for cases believed to have a supernatural etiology:

"When I gave birth to my first born, my child had symptoms such as fever and sweating. I took him to the hospital and when he was tested he was found not to be having malaria. When I came back with him I was not seeing any changes and a neighbor told me that "your child might have been flushed" [bewitched] and she took me to someone. When we went to that person he told me that my child had been bewitched even before I could say what had taken me there. There is something he did and he removed some things from the child and from there the child was alright."

#### (Female, Kisumu FGD1)

The respondent report that consultations among community members may result into switching from one medicine to the other depending on how the people consulted understand the illness thus causing confusion to the caregiver:

"So you have two medicines, the traditional one and the one from the doctor. So when I go back home, you find you are being advised by the neighbor to first administer the traditional one. So you have two different medicines and when you give them to the child, they end up not working on the body of the child and you end up losing the child."

#### (Female, Kisumu FGD1)

A few respondents agree that treatment in their community is communal:

"...The child was treated with herbal medicine because the people from Ugenya are knowledgeable in traditional medicine. They tried all traditional medicine on my child until my child became a zombie [non-responsive]. Now we were just waiting for him to die and be buried. My mum then asked me to come back to Kisumu and take the child to the hospital... my child was admitted and she took almost one month but when I was discharged the child had improved a lot. The child is alive to date..."

## (Female, FGD1 Kisumu)

However, a few respondents explained that in some cases the father can be left out in the decision making process of care seeking for the child:

"...you may find that a woman has taken a child to hospital and she may be referred to Siaya [county referral hospital]. This matter it is only her who knows it in her heart...When she goes back home those drugs that she was given to use are what she will use. Instead of even telling the father [husband] that she was told to take the

child to Siaya [referral], she will only try to give the child those drugs she had been given but she knows very well that she was told to go there [hospital she was referred to]

#### (Male, Siaya FGD2)

## Social pressure and support in healthcare seeking

Caregivers report receiving advice from relatives and community members regarding the appropriate treatment for illnesses. Their advice typically reflects the practice of medical pluralism, where both biomedical or traditional treatment are used, depending on the interpretation of the illness. While the advice given may be perceived as social support, it can also manifest as social pressure where caregivers maybe compelled to follow the advice, even if it is not in line with their preference or judgement.

Respondents reported using either biomedicine or traditional medicine primarily due to advice from their family or community members. This advice to opt for traditional medicine stemmed from deeply ingrained health beliefs regarding various illnesses. It was uncommon for people outside the family to advise mothers on the best course of action. Most often, caregivers complied with these suggestions.

"When I gave birth to my first born, my child had symptoms such as fever and sweating. I took him to the hospital and when he was tested he was found not to be having malaria. When I came back with him I was not seeing any changes and a neighbor told me that "your child might have been flushed" (bewitched) and she took me to someone. When we went to that person (witchdoctor) he told me that my child had been bewitched even before I could say what had taken me there. There is something he did and he removed some things from the child and from there the child was alright."

## (Female, KII Kisumu)

When caregivers were living away from extended family, neighbors often advised caregivers on treatment options. This external influence further reinforced the reliance on traditional practices, contributing to the decisions made by caregivers in managing health issues. These pieces of advice can sometimes be confusing to caregivers.

"So you have two medicines, the traditional one and the one from the doctor. So when I go back home, you find you are being advised by the neighbor to first administer the traditional one. So you have two different medicines and when you give them to the child, they end up not working on the body of the child and you end up losing the child."

#### (Female, KII Kisumu)

Respondents reveal that the advice can be fatal, as seen in the case of a caregiver in the quote below.

He was sick for a while; malaria was in his blood for long. He had gone with the mother to visit her paternal home when the child became sick but they thought it was 'sihoho' [folk illness]. They tried to treat it with local herbs but it was not 'sihoho'. Eventually my child was brought home and died in the doctor's hands at the dispensary here.

## (Male, Siaya FGD3)

The respondents reported that it is common for caregivers to alternate between biomedicine and traditional medicine depending on their own or family's interpretation of the disease and severity of symptoms they see in their child through the communal support to make decisions, caregivers would start treatment at the hospital and switch to traditional medicine when biomedicine is 'slow' or illness is not improving:

"There are some people who say that they go to hospital to seek treatment but they find that the treatment isn't helpful. So they or their family may have alternative thoughts, then they decide to go to faith healers or they go to traditional herbalists."

#### (Male, KII Kisumu)

#### Healthcare access

The respondents explained that a patient may be unable to seek prescribed care because they cannot afford services at the health facilities from the formal healthcare system. Although they started seeking healthcare services at the health facility, they may choose to go to traditional healers who are perceived to be more affordable:

"Maybe when a person comes to the hospital and you refer her/him and then he/she thinks that she will not be able to afford to pay at the county referral, he will choose to stay and seek herbal treatment."

## (Female, FGD3 Siaya)

A few respondents believe that health services at the government facility is free of charge:

...the government health centers that we have are free then apart from being free we can't afford the private ones because of lack of income. That's what makes most of us not go to the private ones.

#### (Female, Siaya FGD2)

During the discussions, the respondents state that frequent strikes in government health facilities and healthcare workers' frequent strikes has made the community look for health care elsewhere. When healthcare workers in public health facilities are on strike, caregivers have to seek alternative healthcare seeking:

"Manyatta community, nowadays they don't trust the government hospital because of strikes every now and then, Strike! Strike! Strike! So they prefer these private hospitals and these pharmacies. Some just go and buy drugs from the pharmacies, yes."

#### (Female, SSI Kisumu)

#### Discussion

This study revealed that caregivers' interpretation of childhood illness is reflected in the treatment-seeking behavior for child illness in western Kenyan communities. Illnesses were believed to have two broad etiologies, supernatural and biological. Interpretation is made based on signs and symptoms of a particular illness and presumed cause of illness23. Often illnesses with supernatural etiology such as those that follow breaching a taboo or caused by witchcraft are first treated using traditional medicine, a finding which is congruent with previous studies<sup>24–26</sup>. Measles was one such disease, with severe consequences to be expected if biomedicine was chosen instead. Similarly, in Tanzania, degedege, a folk illness with symptoms of malaria, was given mystical etiology and treatment with traditional medicine prioritized to avoid death<sup>23,27</sup>. Beliefs about the cause of the illness results in customs and practices that can adversely affect illness outcome<sup>28</sup>. Our findings report that malaria was recognized as a biologically-caused illness, and this shows caregivers' awareness of malaria symptoms. These findings are similar to other studies which report that malaria symptoms were easily recognized and treated at the hospital<sup>29,30</sup>.

The respondents report a communal approach to finding treatment for childhood illness where a caregiver with a sick child would be advised on appropriate care for the child. PASS framework posit that health-seeking behavior is founded on social values whereby a particular behavior is expected12. Seeking and receiving advice was socially expected from caregivers of young children in this context. Therefore, social relationship is important in illness recognition and response and is derived from social values. Consultation with neighbors, mother in law and spouse is common in our setting, similar to other studies findings<sup>6,17</sup>. In urban areas, where caregivers lived far from their extended family, neighbors stepped in to provide caregivers with care-seeking advice. This was noted to contribute to delays in seeking healthcare<sup>6,26,30</sup>. Some studies have established the importance of fathers' financial support and participation in childhood illness31-33, however, our findings show that fathers were not involved in a child's treatment because mothers concealed doctor's advice about child's treatment. Concealing doctors' advice may hinder father's involvement or participation in decision making and this may deny a child clinical management that they need to restore health. Therefore, there is a need to understand why mothers are not involving fathers in health seeking for children.

Consistent with previous reports, medical pluralism was common among caregivers<sup>34,35</sup>. The treatment course varies with some starting treatment at the health facility then switching to a traditional medicine when the illness gets worse. These decisions are often consultative as is socially expected which can pressurize caregivers to oblige to advice on appropriate treatment. Price's study conducted in South Africa among

caregivers seeking care during a fatal childhood illness report that traditional medicine was used as a last resort when caregivers were feeling desperate or when the illness gets worse<sup>36</sup>. Hooft, et al. also reported that most caregivers sequentially seek multiple healthcare providers and treatment modalities until there is a perceived benefit<sup>17</sup>. Our findings reveal gaps in communication between the medical practitioner and caregiver, as the medical practitioner fails to inform caregiver of treatment and progress with the caregiver, the caregiver isn't aware of what to expect. This shows a need for counseling for caregivers with critically ill children who may get desperate when they don't notice immediate improvement. Our findings also reveal that treatment with traditional medicine first caused delays in definitive care leading to severe illness and death. Previous research has also documented the importance of prompt clinical management to avert severe morbidity34. These findings show a nonlinear health care seeking pathway as described by the PASS model where health care seeking behavior is made and reevaluated depending on the patient's response to treatment<sup>10,15</sup>.

The 2030 Sustainable Development Goals emphasize having all people receive quality care without financial hardship3. Community members find healthcare unaffordable in private facilities during public health worker's strikes. During these periods, caregivers consult local pharmacies which they perceive to be affordable, a finding consistent with a study conducted in Kilifi county in Eastern Kenya<sup>37</sup>. Referral to higher levels of care is an important component of child survival, but caregivers report not being able to afford to take their children to referral facilities. This leads them to seek alternative treatment which are perceived to be more affordable and still effective. This shows a gap in the implementation of the integrated management of childhood illness (IMCI) strategy which aims at strengthening referral pathways to improve health outcomes<sup>38</sup>. The decision not to take a child to the referred facility is still not clearly understood given the fact that Free Health Care Initiative (FHCI) and Universal Health care was instituted to protect vulnerable populations from catastrophic expenditures and to promote equity in health care provision<sup>37</sup>. The full cost to a family of a very sick child's care needs to be better understood in order to improve healthcare

access in our setting, particularly as other studies in the region have also reported that poverty can be a major deterrent to 'appropriate' health care seeking behavior.

This study has four main limitations. First, we asked caregivers about hypothetical situations, and did not describe the caregivers' actual behavior and rationale for actions. Second, we did not explore perceptions about health services, which can influence health seeking behavior. Finally, it is possible that participants expressed what they perceived to be appropriate or socially desirable responses.

## Conclusion

Health-seeking decisions are driven by both intrinsic and extrinsic factors, and understanding community drivers to health-seeking behavior is important in formulating policies and interventions that improve health outcomes. Our findings indicate that a strong health education program at community level could improve caregivers' ability to interpret signs and symptoms of common childhood diseases, understand danger signs that require immediate clinical intervention, and involve fathers in decision-making around healthcare for their children. We recommend involving caregivers in the development of educational program interventions ensures that the messages are tailored to the audience's needs. This collaboration helps create more effective and relevant health promotion strategies.

## **Data availability**

The data provided cannot be made available due to ethical constraints from the Kenya Medical Research Institute- Scientific Ethics Review Unit (KEMRI-SERU), as participants have not provided consent for their data to be stored in a public repository. KEMRI-SERU state that anonymized data can be shared under specific requests via the corresponding author.

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## **Open Peer Review**

**Current Peer Review Status:** 







## Version 3

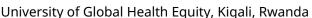
Reviewer Report 06 November 2024

https://doi.org/10.21956/gatesopenres.17687.r38168

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## Alemayehu Amberbir 🗓



No further comments.

Competing Interests: No competing interests were disclosed.

**Reviewer Expertise:** Global health epidemiologist, health system research in Africa, implementation research, non-communicable diseases

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 18 October 2024

https://doi.org/10.21956/gatesopenres.17687.r38169

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## Alyssa Sharkey 🗓

Princeton University, Princeton, New Jersey, USA

I have read through the authors' responses to my earlier queries and am satisfied with their responses. I approve this article.

**Competing Interests:** No competing interests were disclosed.

Reviewer Expertise: Qualitative research, global health, maternal, newborn and child health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

## Version 2

Reviewer Report 19 September 2024

https://doi.org/10.21956/gatesopenres.17662.r37756

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## ? Alemayehu Amberbir 🗓

University of Global Health Equity, Kigali, Rwanda

This study qualitatively investigates the healthcare-seeking behaviors of both the community and providers regarding childhood illnesses in Kenya. It offers valuable contextual insights into the factors influencing these behaviors and suggests potential interventions aimed at reducing child mortality in these settings.

However, a significant limitation is that the research was conducted seven years ago, raising concerns about the relevance of the findings in today's context. This time gap makes it challenging for general readers to assess how applicable the results are in the current healthcare landscape. The background section should be updated to reflect the latest developments in this area.

Additionally, given that the study was conducted prior to the COVID-19 pandemic, it is worth considering whether any of the findings may have changed in light of the pandemic's impact on healthcare-seeking behaviors.

Furthermore, the application of the PASS theoretical framework is not clearly articulated. It is important to clarify whether this framework was applied to both providers and caregivers in the analysis.

## Minor Comment:

1. The Methods section contains a repeated ethics approval statement on pages 4 and 5. Please review and amend accordingly.

Is the work clearly and accurately presented and does it cite the current literature? Yes

Is the study design appropriate and is the work technically sound? Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

Yes

If applicable, is the statistical analysis and its interpretation appropriate? Yes

Are all the source data underlying the results available to ensure full reproducibility? Partly

Are the conclusions drawn adequately supported by the results?

Competing Interests: No competing interests were disclosed.

**Reviewer Expertise:** Global health epidemiologist, health system research in Africa, implementation research, non-communicable diseases

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 25 Sep 2024

## Sarah Ngere

The authors would like to thank the reviewer for reviewing and providing comments. We have addressed all the comments below.

## **Reviewer Comment:**

This study qualitatively investigates the healthcare-seeking behaviors of both the community and providers regarding childhood illnesses in Kenya. It offers valuable contextual insights into the factors influencing these behaviors and suggests potential interventions aimed at reducing child mortality in these settings.

However, a significant limitation is that the research was conducted seven years ago, raising concerns about the relevance of the findings in today's context. This time gap makes it challenging for general readers to assess how applicable the results are in the current healthcare landscape. The background section should be updated to reflect the latest developments in this area.

**Author Response:** Thank you for the comment. The authors appreciate the concern of the time taken to publish these results. The authors included more recent papers in the areas in the introduction section.

## **Reviewer Comment:**

Additionally, given that the study was conducted prior to the COVID-19 pandemic, it is worth considering whether any of the findings may have changed in light of the pandemic's impact on healthcare-seeking behaviors.

**Author Response:** Thank you for your comment. The authors acknowledge the difference in pre and post COVID-19 pandemic in regards to care-seeking. However, the study was

conducted pre-COVID and therefore we cannot provide any findings at this time. We will take this as a recommendation.

## **Reviewer Comment:**

Furthermore, the application of the PASS theoretical framework is not clearly articulated. It is important to clarify whether this framework was applied to both providers and caregivers in the analysis.

**Author Response:** Thank you for the comment. The study had a wide range of participants. We used the PASS framework to understand motivations to their health seeking behavior. The constructs of the PASS frame-work directly address individual motivations which in this case are the caregivers and not the healthcare workers.

### **Reviewer Comment:**

Minor Comment:

The Methods section contains a repeated ethics approval statement on pages 4 and 5. Please review and amend accordingly.

**Author Response:** Thank you for the comment. One ethical approval statement has been removed.

**Competing Interests:** No competing interests were disclosed.

Reviewer Report 19 August 2024

https://doi.org/10.21956/gatesopenres.17662.r37626

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Princeton University, Princeton, New Jersey, USA

## Response to reviewer

The authors would like to thank the reviewer for the comments and insights provided during the review.

We acknowledge that education and religion can influence perceptions. However, we found no difference in perception among participants across various socio-demographic characteristics. This is likely because the participants' perceptions and responses were more influenced by their shared culture, which was similar among all participants.

**New response:** I might need to clarify my concern regarding this point which was that it would is not possible to determine whether or not there is a difference in perceptions among participants by the socio-demographic characteristics of education and religion because your sample has very few individuals from these groups that I mentioned. So this should be included as a limitation of the study unless there are very few individuals of Muslim or "Other" religions among populations in Western Kenya, and if almost all caregivers have an education. That seems unlikely to me, so I

am suggesting that this may be a limitation.

The constructs within the PASS model need more clarification. It is not immediately clear what the difference is between 'social values and stigma' and 'social pressure and support' – specifically, why wouldn't medical pluralism also represent social values?

Thank you for your observation. The authors acknowledge that the constructs within the PASS model was not immediately clear to readers. Therefore, the section has been rewritten. Medical pluralism as a title and results was not brought out clearly to showcase social pressure and support which the authors initially implied. The authors have reworked this section to bring out clearly the construct social pressure and support. Under the new theme, social support, the results show that caregivers receive support through advice from community and friends on the best course of action when a child is ill. The title and results have been reworked for clarity. Grammar and typo: Thank you for the comment. We have checked the whole document for grammatical errors and typos.

<u>New response:</u> The Theoretical Framework section of the paper still only lists the 4 constructs without clarifying the differences. I could not find where these are described and differentiated within the paper.

## **Conclusion**

The conclusion places too much emphasis on the need to better educate local caregivers, when the study clearly highlights the range of barriers that need to be addressed. The conclusion should also emphasize that any solutions developed to address the identified barriers should incorporate the inputs of the local community (e.g., to ensure a human-centered design approach).

Thank you for the comment. We have included a recommendation to involve caregivers in the process of message/intervention development.

<u>New response:</u> Recommendations should be made relating to all the themes (including the financial barriers theme). While it looks like you have included this within the Discussion, this should also be added to the Conclusions.

## **New reviewer comments**

**Background:** "Using the constructs of the Partners for Applied Social Sciences (PASS) model, we explored how cultural and social factors drove health care decision making." I would say you also explore economic factors (i.e., in the healthcare access theme)

**Results**: The four stated constructs of the PASS framework are i) illness perception; ii) social values and stigma; iii) social pressure and support; iv) access to care and resource seeking. However, now the four themes listed within the Results section are: illness interpretation, social relationships and illness response, medical pluralism and healthcare access.

Given how different the emerging themes are from the PASS constructs (particularly themes 2 and 3), it is not clear why the PASS is still included as the theoretical framework. At least there should be a discussion (in the Discussion section) about how the two new themes arose in spite of the guiding framework.

The first two examples included under the heading "Role of social relationship on illness recognition and response" seem to overlap significantly with the examples included under "Illness interpretation." For example, compare the text of the last quote under "Illness interpretation" (which ends with "...when I came back I was told that it was witchcraft") with these first two quotes (which also indicate that someone else telling the caregiver what the illness cause was). It is still not completely clear how the authors are trying to distinguish these two themes.

Similarly, there is overlap with what is still included under the heading "Social support in healthcare seeking." In fact, the quote that begins, "When I gave birth to my first born...." has been used in both sections. This is also true of the quote that begins, ""So you have two medicines..." This makes the Results section confusing. Perhaps these two themes need to be combined, and then all duplicate quotes should be dropped.

**Discussion**: I think you can drop the following sentence: "First, our findings are contextual and may not be generalizable to the wider country context." Generalizability is not an aim of qualitative methods (as opposed to in-depth, contextually specific analysis) and therefore should not be considered a limitation.

Is the work clearly and accurately presented and does it cite the current literature? Yes

Is the study design appropriate and is the work technically sound? Yes

Are sufficient details of methods and analysis provided to allow replication by others? Yes

If applicable, is the statistical analysis and its interpretation appropriate? Yes

Are all the source data underlying the results available to ensure full reproducibility? Yes

Are the conclusions drawn adequately supported by the results? Yes

**Competing Interests:** No competing interests were disclosed.

Reviewer Expertise: Qualitative research, global health, maternal, newborn and child health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 25 Sep 2024

## Sarah Ngere

## **Response to comments**

The authors would like to thank you for reviewing the manuscript and providing comments which the authors have found very useful. We have carefully addressed all the comments below.

## **New reviewer comments**

Background: "Using the constructs of the Partners for Applied Social Sciences (PASS)

model, we explored how cultural and social factors drove health care decision making." I would say you also explore economic factors (i.e., in the healthcare access theme).

**Author Response:** Thank you the comment. We have added economic factors to the statement.

#### **Reviewer Comments:**

**Results:** The four stated constructs of the PASS framework are i) illness perception; ii) social values and stigma; iii) social pressure and support; iv) access to care and resource seeking. However, now the four themes listed within the Results section are: illness interpretation, social relationships and illness response, medical pluralism and healthcare access. Given how different the emerging themes are from the PASS constructs (particularly themes 2 and 3), it is not clear why the PASS is still included as the theoretical framework. At least there should be a discussion (in the Discussion section) about how the two new themes arose in spite of the guiding framework.

**Author Response:** Thank you for the comment. The authors have included an explanation of theme 2; the role of social relationships and illness response in the discussion section on paragraph 2. We have maintained the original PASS framework theme; social pressure and support and provided clarity in the result section.

#### **Reviewer Comments:**

The first two examples included under the heading "Role of social relationship on illness recognition and response" seem to overlap significantly with the examples included under "Illness interpretation." For example, compare the text of the last quote under "Illness interpretation" (which ends with "...when I came back I was told that it was witchcraft") with these first two quotes (which also indicate that someone else telling the caregiver what the illness cause was). It is still not completely clear how the authors are trying to distinguish these two themes.

Similarly, there is overlap with what is still included under the heading "Social support in healthcare seeking." In fact, the quote that begins, "When I gave birth to my first born...." has been used in both sections. This is also true of the quote that begins, ""So you have two medicines..."

**Author Response:** Thank you for the comment. The authors would like to keep the repeated quote in the 2 different themes because it portrays both the role of social relationship on illness recognition and response and social pressure and support in healthcare seeking which are explained below.

## **Reviewer Comments:**

This makes the Results section confusing. Perhaps these two themes need to be combined, and then all duplicate quotes should be dropped.

**Author Response:** Thank you for the observation and comment. The issues you have mentioned here are pertinent and the authors have explained the difference between the 3 themes below -

**Illness interpretation:** According to our findings illness was categorized into having biomedical and supernatural etiology. Authors explain how the different ways of interpreting illness influence health seeking behavior. Illness interpretation therefore influences the kind of treatment a caregiver would give her/his child for the particular

#### illness.

**Role of social relationship on illness recognition and response:** The findings indicate how social relationship influence health seeking behavior by recognizing the illness. Our data reveal that cultural beliefs held by others would greatly influence the course of action for caregiving.

**Social pressure and support in healthcare seeking:** The authors agree that there was an overlap between theme number 2 and 3 which was confusing and therefore wish to give the 3<sup>rd</sup> theme more clarity. The PASS framework 3<sup>rd</sup> construct is social pressure and social support which the authors would want to maintain. We have therefore made theme clearer by explaining the overlap between social support and pressure in the context of health seeking. Community members may feel pressurized to take up support during sickness which can be offered as advise or practical care-seeking (taking them for treatment) depending on the illness.

### **Reviewer Comments:**

Discussion: I think you can drop the following sentence: "First, our findings are contextual and may not be generalizable to the wider country context."

Generalizability is not an aim of qualitative methods (as opposed to in-depth, contextually specific analysis) and therefore should not be considered a limitation.

Author Response: Thank you for the suggestion the statement has been dropped in the revised version.

**Competing Interests:** No competing interests were disclosed.

Reviewer Report 16 August 2024

https://doi.org/10.21956/gatesopenres.17662.r37635

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## Oluseye Ademola Okunola

- <sup>1</sup> Obafemi Awolowo University, Ife, Osun, Nigeria
- <sup>2</sup> Sociology and Anthropology / Medical and Health Services, Obafemi Awolowo University, Ife, Osun, Nigeria

The study offers useful insights into caregivers' experiences and perceptions, emphasizing the intricacies of healthcare-seeking behavior.

The application of qualitative approaches generates rich, contextualized data.

The study's focus on western Kenya fills a significant gap in understanding healthcare-seeking behavior in the region. However, the study's small sample size and geographic coverage may restrict generalization, and the lack of quantitative data and healthcare practitioner opinions may result in an incomplete picture.

In conclusion, this article provides important qualitative insights into healthcare-seeking behavior for pediatric diseases in western Kenya. Despite several limitations, the study's findings have significant implications for improving healthcare access and outcomes in this region. Future study could build on these findings, combining quantitative data and viewpoints from healthcare providers to produce a more comprehensive understanding.

Is the work clearly and accurately presented and does it cite the current literature? Yes

Is the study design appropriate and is the work technically sound?

Are sufficient details of methods and analysis provided to allow replication by others? Partly

If applicable, is the statistical analysis and its interpretation appropriate? Yes

Are all the source data underlying the results available to ensure full reproducibility? Yes

Are the conclusions drawn adequately supported by the results? Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** My Research areas include, health systems services and health behavior research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 25 Sep 2024

#### Sarah Ngere

The authors would like to thank you for reviewing the article and providing feedback.

**Competing Interests:** No competing interests were disclosed.

## **Version 1**

Reviewer Report 19 July 2024

https://doi.org/10.21956/gatesopenres.16194.r37169

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## ? Alyssa Sharkey 🗓

Princeton University, Princeton, New Jersey, USA

This study focuses on an important topic that has been widely studied but also requires qualitative analysis within local settings to understand the specific barriers and solutions that might contribute to improved care-seeking among families with young children. This study focuses on Western Kenya which is an important and disadvantaged part of the country. It is unfortunate that the data were collected over 6 years ago and are only being published now as the key factors influencing care-seeking behaviors may have changed since that time. However, the study likely has yielded many findings that continue to have relevance today. I also note that only one caregiver without an education was included within the sample. It is possible that this sub-group might face different or additional to barriers to care-seeking so was perhaps not adequately represented within the study. Similarly, there are few respondents included in Table 2 who stated that they were Muslim or "Other" religions – this may be another limitation of the sample.

The constructs within the PASS model need more clarification. It is not immediately clear what the difference is between 'social values and stigma' and 'social pressure and support' – specifically, why wouldn't medical pluralism also represent social values?

## <u>Results</u>

In table 2, the text under "summary of findings" for 'social values and stigma' has typos: "The community and family are consulted when a child <u>falls</u> ill. They give advice on the best treatment course depending on their understanding of the illness. Fathers tend not to be included <u>in the</u> child healthcare decision making process."

I was surprised that previous experiences with health services were not found to be a determinant of care-seeking although it seems this is not even considered within the PASS framework so was not explored. This is a limitation and might explain not just medical pluralism but rejection of conventional health services.

## Discussion

Were there important differences between the urban and rural areas that could be reported? <u>Conclusion</u>

The conclusion places too much emphasis on the need to better educate local caregivers, when the study clearly highlights the range of barriers that need to be addressed. The conclusion should also emphasize that any solutions developed to address the identified barriers should incorporate the inputs of the local community (e.g., to ensure a human-centered design approach).

## <u>Overall</u>

There are a few areas in the paper where grammatical correction needed. Please see the attached PDF where I have marked some of these. I have also included some specific comments within the PDF.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound? Yes

Are sufficient details of methods and analysis provided to allow replication by others? Partly

If applicable, is the statistical analysis and its interpretation appropriate? Not applicable

Are all the source data underlying the results available to ensure full reproducibility?  $\ensuremath{\text{No}}$ 

Are the conclusions drawn adequately supported by the results?  $\label{eq:partly} \mbox{\sc Partly}$ 

**Competing Interests:** No competing interests were disclosed.

Reviewer Expertise: Qualitative research, global health, maternal, newborn and child health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 02 Aug 2024

## Sarah Ngere

## Response to reviewer

The authors would like to thank the reviewer for the comments and insights provided during the review.

We acknowledge that education and religion can influence perceptions. However, we found no difference in perception among participants across various socio-demographic characteristics. This is likely because the participants' perceptions and responses were more influenced by their shared culture, which was similar among all participants.

The constructs within the PASS model need more clarification. It is not immediately clear what the difference is between 'social values and stigma' and 'social pressure and support' – specifically, why wouldn't medical pluralism also represent social values?

Thank you for your observation. The authors acknowledge that the constructs within the PASS model was not immediately clear to readers. Therefore, the section has been rewritten. Medical pluralism as a title and results was not brought out clearly to showcase social pressure and support which the authors initially implied. The authors have reworked this section to bring out clearly the construct social pressure and support. Under the new theme, social support, the results show that caregivers receive support through advice from community and friends on the best course of action when a child is ill. The title and results have been reworked for clarity.

Grammar and typo: Thank you for the comment. We have checked the whole document for

grammatical errors and typos.

I was surprised that previous experiences with health services were not found to be a determinant of care-seeking although it seems this is not even considered within the PASS framework so was not explored. This is a limitation and might explain not just medical pluralism but rejection of conventional health services.

Thank you for the observation. The authors agree that previous experiences with health services were not explored. We have included the limitation in the limitation section. Discussion

# Were there important differences between the urban and rural areas that could be reported?

Thank you for the comment. Consultation with family within the rural area was observed however, in urban areas caregivers received care-seeking report receiving support from neighbors. No other difference was observed.

## Conclusion

The conclusion places too much emphasis on the need to better educate local caregivers, when the study clearly highlights the range of barriers that need to be addressed. The conclusion should also emphasize that any solutions developed to address the identified barriers should incorporate the inputs of the local community (e.g., to ensure a human-centered design approach).

Thank you for the comment. We have included a recommendation to involve caregivers in the process of message/intervention development.

## Overall

There are a few areas in the paper where grammatical correction needed. Please see the attached PDF where I have marked some of these. I have also included some specific comments within the PDF.

We were unable to locate the PDF however, we have gone through the entire document and corrected all grammatical errors.

Competing Interests: None