

Original Research

Challenges with accessing health care for young children presumed to have malaria in the rural district of Butaleja, Uganda: a qualitative study

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Abstract

Objective: A qualitative study was conducted to gain insight into challenges reported by Butaleja households during a previous household survey. Specifically, this paper discusses heads of households' and caregivers' perceptions of challenges they face when seeking care for their very young children with fever presumed to be malaria.

Methods: Eleven focus groups (FGs) were carried out with household members (five with heads of households and six with household caregivers) residing in five sub-counties located across the district. Purposive sampling was used to ensure the sample represented the religious diversity and geographical distance from the peri-urban center of the district. Each FG consisted of five to six participants. The FGs were conducted at a community centre by two pairs of researchers residing in the district and who were fluent in both English and the local dialect of Lunyole. The discussions were recorded, translated, and transcribed. Transcripts were reviewed and coded with the assistance of QDA Miner (version 4.0) qualitative data management software, and analyzed using thematic content analysis.

Results: The FG discussions identified four major areas of challenges when managing acute febrile illness in their child under the age of five with presumed malaria: (1) difficulties with getting to public health facilities due to long geographical distances and lack of affordable transportation; (2) poor service once at a public health facility, including denial of care, delay in treatment, and negative experiences with the staff; (3) difficulties with managing the child's illness at home, including challenges with keeping home-stock medicines and administering medicines as prescribed; and (4) constrained to use private outlets despite their shortcomings.

Conclusions: Future interventions may need to look beyond the public health system to improve case management of childhood malaria at the community level in rural districts such as Butaleja. Given the difficulties with accessing quality private health outlets, there is a need to partner with the private sector to explore feasible models of community-based health insurance programs and expand the role of informal private providers.

Keywords

Malaria; Child; Public Health; Health Services Accessibility; Delivery of Health Care; Health Facilities; Transportation; Attitude to Health; Focus Groups; Qualitative Research; Uganda

INTRODUCTION

Malaria persists as one of the most prevalent global health challenges.¹ While the number of annual malaria cases decreased from 239 million in 2010 to 217 million in 2016, recent data from the World Health Organization (WHO) suggests that progress may have stalled with the number of malaria cases rising to 219 million in 2017.¹ Children under the age of 5 years account for the majority of cases in sub-Saharan Africa, with malaria remaining the cause of up to 10% of all deaths within this age group, numbering at around 285,000 in 2018.¹⁻³ Furthermore, the WHO estimates suggest that over 40% of febrile children in sub-Saharan Africa received no medical attention whatsoever within the first 24 hours of initial symptoms in 2017.¹ The WHO African region accounts for 92% of all malaria cases, with Uganda accounting for 3.9% of the global total.⁴

Overall, Uganda ranks fifth on the list of countries with the highest malaria burden, close behind India (4.4%), Mozambique (4.6%), the Democratic Republic of Congo (11.4%) and Nigeria (24.5%).⁴ Malaria is endemic throughout Uganda, accounting for approximately 8–13 million episodes per year, 30–50% of outpatient visits, 35% of hospital admissions, and an estimated under-five mortality of 64 out of 1000 live births in 2016.^{5,6}

In young children, uncomplicated malaria typically mimic signs and symptoms of the common flu, such as: fever, fatigue, sweats, chills, lethargy, vomiting and poor feeding.^{1,7} While organ failure is rare in the early stage, and full recovery common if treatment is initiated within 24 hours of initial symptoms; in circumstances when treatment is delayed, malaria can rapidly progress to a serious and life-threatening illness.⁷ Frequently observed clinical sequelae of severe malaria include severe anemia, hypoglycemia, renal failure, respiratory distress, cerebral malaria with irreversible neurological deficits, and death.⁷⁻⁹ Given the severe consequences of malaria, timely caregiver action and effective health care provider response is critical in the early phase of the illness.

Uganda has initiated several strategies over the last decade in an effort to have 85% of children under five with suspected or confirmed malaria receive treatment with the first-line antimalarial treatment (Artemisinin-based

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combination therapy - ACTs) within 24-hours of initial symptoms by 2015 (and 90% by 2018).^{10,11} Some of the pivotal strategies include the Affordable Medicines Facility – Malaria (AMFm) program introduced in 2009-2011 to improve access to free ACTs from public facilities and subsidized ACTs from formal private drug outlets; the Integrated Community Case Management Program (iCCM) supported by trained community health workers (CHWs) in 2010, and the expansion of the iCCM model to include the formal private drug outlets in 2011 and 2012.¹²⁻¹⁶ The intent of the iCCM program has been to bring diagnostics and treatment closer to the communities.¹⁷ While these strategies have increased the availability and market share of ACTs, much of the reported benefits have been in regions where the iCCM model supported by CHWs and/or licensed drug outlets has been successfully implemented.^{12,15,18-20} The nation-wide scale up of CHW supported iCCM has been largely hindered due to high turnover rates combined with unreliable medical supplies, poor funding and insufficient supervision, training and monitoring, with successful implementation achieved in only 34 of the 112 districts.^{11,16,21,22} Similarly, the scale-up of the iCCM model supported by the formal private drug outlets has been restricted in rural areas where the formal drug sector is few and far between.^{15,23}

Despite national efforts, studies conducted in the rural and remote district of Butaleja demonstrate a substantial gap between Uganda's national malaria policy and malaria case management for children under 5 years of age. As part of a public health effort to improve the management of childhood malaria at the community and household level in Butaleja, a series of independent but integrated exploratory studies were conducted in 2011 to understand the extent of this gap, explore factors that might be contributing to this problem, and propose sustainable community and household-level strategies.²³⁻²⁸ This large scale exploratory research is the first and only such initiative to date in Butaleja District. Results from the district-wide household survey found that only 21% of children presumed to have malaria received a confirmatory blood test, a-third was treated with just the recommended anti-malarial medicine - ACT, over a-third received subordinate antimalarial medicines (such as quinine and chloroquine) either alone or alongside an ACT, and nearly a-third received no antimalarials.²³ Further analysis of the survey data and a subsequent case study identified multiple barriers to accessing appropriate case management, ranging from antimalarial stock-outs at public facilities to difficulty accessing health facilities and qualified health providers.²³⁻²⁵ In an attempt to mitigate the gaps identified in the household survey, the district partnered with a non-governmental organization - World Vision to implement the CHW lead iCCM program (H. Isogoli, verbal communication, Dec 2018). While anecdotal data suggests this measure improved malaria case management, as with other CHW programs, this initiative was unsustainable due to the lack of government funding and support. In Butaleja where there are no pharmacies, licensed private drug shops are scarce, the private clinics unaffordable, and a sustainable model of iCCM yet to be implemented, households continue to rely on the informal (unlicensed) private sector which makes up approximately

82% of the private-for-profit drug outlets.^{27,29-31} To-date, there is limited literature on key challenges and influencing factors at the community and household level in Butaleja to inform sustainable solutions that can translate health policies into practice.

This qualitative study was part of the large 2011 exploratory research in the district of Butaleja. The aim of the current study was to gain more insight into challenges reported by households during the district-wide survey. Specifically, this paper discusses the challenges experienced by heads of households' and caregivers' when seeking health care for their children five years and under with fever presumed to be malaria. Given the lack of any permanent solutions to-date to improve the status-quo of community-based health care delivery in Butaleja, households' account of their day-to-day challenges remain relevant.

METHODS

Study design

A qualitative study was conducted over a four-week period in July 2011 to explore challenges faced by families when seeking care for children five years and under presumed to have malaria in the rural and remote district of Butaleja, Uganda. Eleven focus groups (FGs) were conducted with household members (heads of households and caregivers) residing in five sub-counties located across the district. This study was guided by the Health Belief Model, a value-expectancy theory which posits that health behaviors are adopted based on assessments about benefits and barriers to action.³² Accordingly, public health interventions that successfully minimize perceived barriers and threats are more likely to increase self-efficacy to undertake a beneficial action.

Setting

The district of Butaleja is located in eastern Uganda. Its administrative structure consists of 10 sub-counties and two-town councils (Figure 1). The most recent National Population and Housing Census completed in 2017 estimates Butaleja's population at 269,900.³³ The major ethnic group is the Banyole tribe representing 85% of the population, the predominant spoken language is Lunyole, and the three largest religious groups include Protestants (53%), Muslims (30%), and Catholics (17%) (K. Mweru, MD, written communication, April 2011).³⁴ The majority of the population lives in poverty and relies on subsistence farming, with families growing food crops or raising livestock primarily to feed themselves, leaving little, if any, surplus for sale or trade.³⁵ As with the rest of Uganda, malaria is endemic throughout the region, affecting most of the population.³³ Health care (investigations and treatments) in Uganda is provided for free by government (public) health facilities. The public health facility infrastructure is stratified into four levels: level IV Health Centre (HC) - one main district hospital located in Busolwe town council; level III HCs located in eight sub-counties providing inpatient and out-patient care, and level II HCs providing outpatient care at the parish level.³³ While not yet implemented in Butaleja, some districts in Uganda have a network of level I HCs comprised of volunteer CHWs at

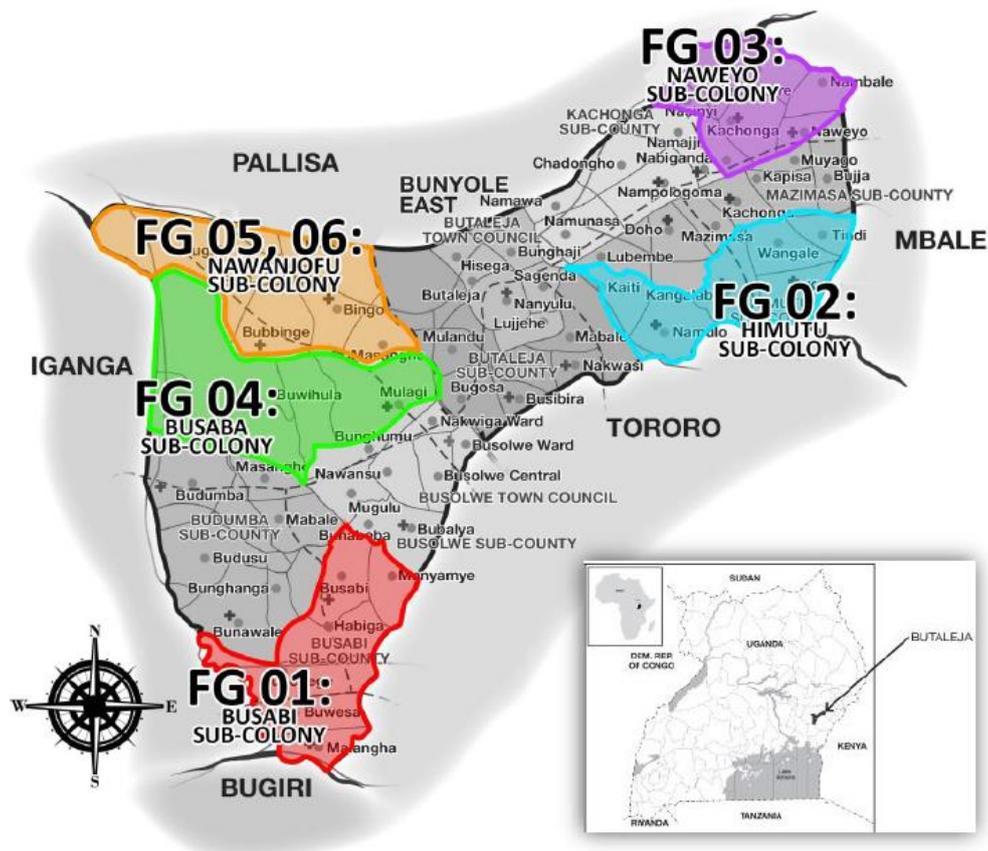


Figure 1. Butaleja District: Sub-counties where focus groups were held.

the village level trained to deliver integrated community case management (iccm) (K Mweru, MD, District Officer, personal communication, April 2011). With no pharmacies and a few licensed drug shops located mainly in town centers and market areas, many households are reliant on the predominant informal (unlicensed) drug outlets for health care and western medicines.^{23,25,27} For the purpose of this study, informal retail drug outlets are defined as mobile or stationary commercial settings, such as markets and shops, which sell antimalarials but are not registered with any government regulatory body and operate outside the purview of regulation, registration, or oversight by the government or other health or professional institutions.²⁸

Participants

A total of 11 separate FGs were carried out with residents of Butaleja Distict, five with heads of households (HH) and six with household caregivers (CG). The number of FGs were determined a-prior, based on the literature that suggests at least five FGs per demographic stratum (i.e., HH and CG) are needed to achieve approximately 90% data saturation.³⁶ Using purposive sampling, participants were recruited from across the district to ensure the sample represented the religious diversity and geographical distance from the peri-urban center of the district. Religious leaders and village elders facilitated recruitment by advertising the FGs at their respective congregations and villages through word of mouth. HHs and CGs who voiced an interest to the leaders/elders were referred to

the study coordinators, and the first six within each geographical setting to meet the following criteria were invited to participate: (1) they had at least one child five years or younger who had been febrile within the last two weeks, (2) they were the HH or the CG in the home, (HH defined as the person perceived to be responsible for major decisions in the home; CG defined as the person who provided the majority of the child's day-to-day care), (3) the HH and CG came from separate households and were not related, (4) they resided within the district, (5) they spoke the native dialect in which the FGs were conducted—Lunyole, (6) they agreed to participate, and (7) they willingly signed the consent form using thumb-print or written signature. On the day of each FG, five to six participants attended (refer to Table 1). Since the HHs are most often males and CGs most often females in Butaleja District, this was reflected in the sample population.

Data collection and analysis

FG discussions were carried out by two pairs of researchers residing within the district (a trained research assistant and an experienced research team member) and fluent in both English and the local dialect of Lunyole. FGs were carried out at a community centre and lasted approximately 90 minutes. Small refreshments were offered, and participants were reimbursed for transportation expenses. A set of open-ended questions were used to guide the discussions. This included two warm-up questions to get the groups thinking about malaria (How did you know if your child has

Focus Groups	N	Gender	Tribes	Age (years) mean (SD)	Religion (N)	Education (N)	Occupation (N)
Caregivers 01	5	Female	Banyole	29.8 (5.1)	Catholic (5)	Primary Incomplete (2) Primary Complete (1) Secondary Incomplete (2)	Subsistence Farmer (5)
Heads of Households 01	6	Male	Banyole	29.2 (3.7)	Catholic (6)	Primary Incomplete (3) Secondary Incomplete (3)	Subsistence Farmer (4) Petty Trader (2)
Caregivers 02	6	Female	Banyole	27.3 (4.5)	Protestant (6)	Primary Incomplete (4) Primary Complete (1) Secondary Incomplete (1)	Subsistence Farmer (6)
Heads of Households 02	5	Male	Banyole	26.6 (8.1)	Protestant (5)	Primary Incomplete (3) Primary Complete (1) Secondary Incomplete (1)	Subsistence Farmer (4) Unskilled Laborer (1)
Caregivers 03	5	Female	Banyole	22.8 (5.2)	Muslim (5)	None (1) Primary Incomplete (3) Primary Complete (1)	Subsistence Farmer (4) Unskilled Laborer (1)
Heads of Households 03	5	Male	Banyole	35.6 (5.4)	Muslim (5)	None (2) Primary Incomplete (2) Secondary Incomplete (1)	Subsistence Farmer (5)
Caregivers 04	5	Female	Banyole	23.8 (4.8)	Seventh Day Adventist (5)	Primary Incomplete (1) Primary Complete (1) Secondary Incomplete (3)	Subsistence Farmer (5)
Heads of Households 04	6	Male	Banyole	28.0 (4.5)	Seventh Day Adventist (6)	Primary Incomplete (5) Secondary Incomplete (1)	Subsistence Farmer (6)
Caregivers 05	5	Female	Banyole	41.8 (3.4)	Traditional African Religion (5)	None (1) Primary Incomplete (3) Secondary Incomplete (1)	Subsistence Farmer (5)
Heads of Households 05	6	Male	Banyole	35.8 (4.2)	Traditional African Religion (6)	None (4) Primary Incomplete (2)	Subsistence Farmer (5) Traditional Healer (1)
Caregivers 06	6	Female	Banyole	35.4 (13.4)	Catholic (3) Muslim (3)	None (3) Primary Incomplete (2) Primary Complete (1)	Subsistence Farmer (6)

malaria? What did you do when your child first shows these signs?); followed by questions centering on the research objective: Where do you first seek care (next) and why? Which treatment, traditional or western, do you commonly start with first (next) and why? Where do you obtain western anti-malarial medicine and why? What challenges do you face at home (at public health facilities, licensed and informal drug shops, and at private clinics)? Open-ended, conversational probes were used to encourage participants to expand on their thoughts and to clarify their responses (e.g., how accessible are public facilities and private outlets? Tell us about your experiences with the health providers? Tell us how you manage home-stock-medicines? Were there any challenges?). All discussions were conducted in Lunyole and, because Lunyole is not a written language, verbatim translated into English. Each pair was responsible for recording, translating and transcribing the discussions within 48 hours. This study followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ).³⁷

The analysis was built into the research methods and consisted of an iterative process of reviewing, reflecting, and revising. During the data collection phase, each transcription was examined by RK and RS immediately after being transcribed to ensure the topic guide/probes were congruent with the research objective and the sample size was adequate to reach saturation. At the end of the field study, all electronic transcripts were reviewed and coded with the assistance of QDA Miner (version 4.0) qualitative data management software, and subsequently analyzed (by RK, AR, and AMT) using thematic content analysis.³⁸ The post-field analysis began with first-level open coding. This

consisted of reading the transcripts line-by-line, dividing the text into meaningful units, labeling each unit for higher-level analysis, and creating a preliminary coding scheme. The research team (AR, RK, and AMT) reviewed the transcripts in parallel, coded the data, and identified the main themes. AR, RK, and AMT then discussed, reviewed, and revised the codes and the main themes, and re-categorized them based on differences and similarities. This process was repeated until an agreement was reached. Group discussions (with AR, RK, and AMT) and peer-checking (with RS) helped to reduce redundancy among the categories and to assure that the range and depth of the concepts from the data were captured in the themes. Finally, illustrative quotes were extracted to represent recurring or dominant themes. De-identified demographic information was entered into Microsoft Excel 2010 software to compile descriptive information about the sample.

Ethics approval

Ethics approval was obtained from the University of British Columbia Behavioral Research Ethics Board (certificate number H10-02909) and the Uganda National Council for Science and Technology (certificate number HS 906). Participants were informed of their voluntary participation, and consent (written or using thumb print) was obtained prior to conducting the focus groups.

RESULTS

The heads of households' (HHs') and caregivers' (CGs') demographic characteristics are summarized in Table 1. FG

participants ranged from 20 to 40 years of age, most were subsistence farmers, the majority had completed primary level education or less, and, collectively, they represented the major religious groups residing in Butaleja District. Four major themes related to challenges emerged from the data: (1) difficulties with getting to public health facilities within their sub-county; (2) poor service once at the public health facility, including denial of care, delay in treatment, and negative experiences with the staff; (3) difficulties with managing the child's illness at home, including challenges with keeping home-stock medicines and administering medicines as prescribed; and (4) constrained to use private outlets despite their shortcomings. With a few exceptions, the challenges experienced across the FGs were remarkably consistent. These are discussed below, together with select quotes from the FG transcripts.

Difficulties with getting to public health facilities within their sub-county

Several of the FGs (HH: 01, 03, 05; CG: 02, 04, 06) identified long geographical distances and the lack of affordable transportation to be major concerns, and viewed these as important barriers to accessing public health facilities II and III in a timely fashion when a child falls ill.

"So, at times you may not have transport means to get you there in time, let us say, that the fever has caught child in the evening hours ... [or] you may not have the money to get you to the health unit ... that is also a challenge." (HH FG3R4)

"Now, the problem is that health unit is too far. At times, you may fail to get means of transport and you move on your feet ... but since this health unit is too far, by the time you get there, the condition may have worsened. The health providers may try to treat the child but the temperature has risen high, what results is the child is affected and child dies." (CG FG4R2)

Poor service once at the public health facility

Having overcome the many obstacles to getting their child to a public health facility II or III (within their sub-county), all FGs expressed some level of frustration with the poor service they received from the receptionist to nurse's aides, nurses and doctors once they arrived.

Denial of care

Several of the FGs (HH: 01, 03; CG: 02, 04, 05) reported that they were routinely turned away and denied care if they forgot to bring with them the child's medical record (i.e. "book").

"At times you may go in haste [to the health facility] because of the child's condition. Then you start to panic because you realize that you have not packed the child's book. They [the health professionals] tell you, that, here, if you have no book, we shall not treat your child. So bring a book, then we can treat your child. And yet, at times, the child's condition is very bad or you have gone alone and there is no one you can send to the shop to buy you the book. The nearby shop is far and you

are failing to find someone to send for the book, so there, you are challenged in that way." (CG FG4R2)

A couple (HH: 01, 05) also raised the issue of bribery, stating that staff often threatened to withhold services from their family until the requested bribes were paid.

"At times, they tell you: my friend I am hungry, first give me tea [money] then we can proceed. That is the challenge that I face mainly. I may go there, not even with 100 UGX and child is very sick, I do not have money and they are asking for money, that is the challenge that I normally face at the government health unit." (HH FG1R5)

Delay in receiving care

Long-wait times due to staff shortages and/or absenteeism was raised as an important factor contributing to delay in care by all FGs, once they arrived at the public health facility.

"For me, the challenge that I usually find is that they do not normally attend to me very fast" (HH FG4R1)

The delay in care was further exacerbated in instances when there were stock-outs and families had to be referred to other public health facilities or private drug outlets to purchase the necessary medications/supplies. This often required families to secure additional funds to be able to pay-out-of-pocket for medications/supplies that they should have received at no cost from public health facilities.

"The challenges I find when I go to these public health facilities are two: (1) sometimes you reach there and the doctor is not around, and (2) sometimes you reach there and the health providers tell you there are no medicines. So this is a very big challenge since these medicines will require getting money before you can buy and I have to run to get money...." (HH FG5R6)

Negative experiences with public health facility staff

All FGs expressed some degree of discontent with staff at public health facilities (receptionist to nurse's aides, nurses and doctors). Most common reasons cited for dissatisfaction included cold reception, lack of compassion, and poor staff attitude.

"The illness strikes and I go [to the public health facility], and there are many people there before me. When its closing time, the health providers just chase me away ... without giving any treatment ... saying: Go back, you come back tomorrow. And yet my child is very sick." (HH FG2R2)

"So if you get to her [health provider] when she is tired, she tells you that: For me, I am going to eat. I am hungry ... she may take 1 ½ to 2 hours to finish her meal. For you, you have a sick child. When you tell her your child is dying, she says: Ah, for us, we have seen many dying'." (HH FG3R5)

In addition, a participant from one of the FGs (CG: 03) mentioned that she felt unsupported at the public health

facilities, as the providers never shared information about the child's condition and treatment with her.

"When you go there [at the public health facility], they only give PANADOL [paracetamol] and do not tell you what the illness is. They only give PANADOL [paracetamol] and tell you to go and give." (CG FG3R5)

While one of the FGs (CG: 05) agreed with the challenges mentioned by other groups, they were the only group to share positive experiences with public health facility staff.

"For me, I go for help at the health facility and I get a lot help from there. I leave home when the child's illness is beyond my control, but when I reach there I am helped. That is why I go there and that is what I get. They diagnose the child and if need be they also give a bed for the child.... I will explain to the health workers there and they attend to my problem without asking for money" (CG FG5R1)

Difficulties with managing the child's illness at home

Both CGs and HHs identified numerous challenges with managing the child's illness at home, with a large majority of the discussions centering on the use of home-stock medicines and adherence to medicines as prescribed. Home-stock medicines included western medicines kept in the home for future use in case their child got sick with fever and/or malaria. These medicines were commonly purchased from private outlets and/or obtained at a public health facility for a previous illness or to store for future use.

Challenges with home-stock medicines

All FGs acknowledged that many households within their village relied on traditional medicines, with one of the groups (CG: 04) indicating that the use of traditional medicines was a common first step to treat presumed malaria since they could not readily access transportation to get to the health center.

"Now like for me when I realize that my child has got malaria I get different herbs (mululusa, omgohegohe and mululusa) and I put them in water and boil and I cover the child to steam him. Then the child will sweat and I realize that he will feel better after." (CG FG5R4)

"At times, I have no means of transporting myself to health unit. That is why I use mululusa." (CG FG4R3)

With the exception of a couple of participants (HH: 02, 03) who voiced that they never kept any home-stock medicines, almost all others confirmed that they regularly kept western medications in their home in the event their child got sick with fever and/or malaria. The types of home-stock medicines kept by caregivers varied, and included one or more of the following: paracetamol, ACT, quinine, chloroquine, and Trimethoprim/sulfamethoxazole.

"As for me, I keep [medicines in the home] to use later. I keep PANADOL [paracetamol] and COARTEM [ACT]. Because the illness can attack the child at night and do not have transport to take

him there [public health facility] at that time, so can use them [home-stock medicines] to help as I wait for morning to go for further treatment." (CG FG1R1)

"Now for me, let me tell you, the illness can attack the child at night. I have Panadol [paracetamol] at home, that is what I give first. Then in the morning, when my mother comes to check on the sick child, she will say that this child has fallen with malaria, let us first give mulusa [traditional herbs]. Then if it gets to 1 PM and there is no improvement, we take child to health unit." (HH FG4R6)

Despite the high reliance on home-stock medicines, there was widespread worry among FGs (HH: 01, 02, 04, 05; CG: 01, 02, 04, 05, 06) regarding the quality and safety of home-stock medicines. Most common concerns were those associated with improper storage resulting in aeration and disintegration of medicines, possibly resulting in loss of potency and under or overdosing of medications.

"The problem I find with keeping medicines at home is that you may keep [store] the medicines in an improper place and you find the tablets broken [aerated] and on picking them up they turn into powder [disintegrate]. My wife could also give under or overdose to the children." (HH FG1R1)

Many were also apprehensive about unhygienic and insecure storage spaces in their home, citing that children were often given dirty medications and many had easy access to medicines putting them at a high risk of accidental poisonings.

"The challenge that I find when I keep these medicines [ACT and paracetamol] at home is sometimes ... the children have thrown them down and they get spoilt. I will not give the child because they are spoilt, so that is a challenge since they have thrown them down and there is no way I can pick them and give the child." (CG FG2R4)

"Now, the challenge is that, if you keep [store] your medicine badly and child discovers where those medicines are, child can swallow them ... and child can be affected." (HH FG2R1)

Since most medicines are not sold in their original containers with expiry dates, some FGs (HH: 01, 05; CG: 03, 05, 06) also feared giving expired medicines to their children.

"I get challenges [with keeping medicine at home]. Sometimes if you delay [keep them for too long], they can get expired". (CG FG3R5)

One of the FGs (CG: 06) shared that households within their village used home-stock medicines because they had little choice, as most could not afford to buy a fresh supply of medicines every time their child got sick.

"The expired ones do not work effectively. [But] you give anyways because of the situation of poverty that you are in, you may not be able to afford to buy [new] medicines." (CG FG6R2)

Another FG (CG: 03) noted that using home-stock medicines in many instances meant the child got less than the recommended dose of the medicine.

“I can keep [home-stock medicines] but the medicines are not curing very well... Because it is not a complete dose.” (FG3R1)

Challenges with adhering to medicines as prescribed

Difficulty adhering to prescribed medication regimen was an important emergent sub-theme that arose in just one of the FGs (HH: 04).

“Now, those medicines ... they are given to us. When the time to give the medicines to child comes ... [we forget] ... and the time for giving the medicine has already passed.” (HH FG4R3)

Constrained to use private outlets despite their shortcomings

Since informal drug shops are the most prevalent private drug outlet in the district, most of the discussions about drug shops centered on the informal sector.

Positive experiences

Several of the FGs (HH: 01, 02, 03; CG: 01, 02, 03, 04) cited that they often had to rely on private drug shops because of medication stock-outs at public health facilities, and they found them to be very accommodating.

“Now the good medicines, if you go to the government health unit these medicines are not there [and] they can refer you to the private shop. When at times my husband is not at home, I can talk to the health provider [at the shop] and request him to treat my child on credit so that later on I can bring the money.” (CG FG6R4)

A couple of the FGs (HH: 02, 03) went so far as to state a preference for the private shops because they felt they were more helpful than staff at public health facilities and offered higher quality and more efficient care.

“On my side, I see that they [drug shops] help me. If I have money, they treat my child and child becomes peaceful. And I thereby say that wow it is finished. I just buy because the government health unit is useless.” (HH FG3R3)

Negative experiences

Although the use of private outlets was prevalent, both the HH and CG FGs recognized that the private sector was not without challenges. All groups agreed that out-of-pocket expenses were a major limitation when seeking care at all private outlets (clinics, licensed and informal outlets), and most families did not have the money to pay for medicines upfront.

“Now you reach there with a child and the health provider [at the private outlet] touches the child, examines but he/she tells that your child needs treatment of 30,000 UGX and yet in pocket I have 13,000 UGX ... I want my child to cure so I have to go and look for the money.” (HH FG5R6)

There was also consensus among many FGs (HH: 02, 03, 04; CG: 01, 02, 04, 05) that most drug shop vendors lacked the necessary training to treat malaria.

“Sometimes they give you medicines that will just increase the illness in the child because they sell to you and yet they do not know the illness in the child. The illness may be severe and yet they will simply give tablets which may be strong and therefore make the illness worse. So those are the challenges with the medicines that are bought.” (CG FG5R1)

Several of the FGs (HH: 01, 04, 05; CG: 01, 02, 04) noted that drug shop vendors routinely recommended medications without examining the child's illness, they dispensed inadequate doses (CG: 01), and seldom provided appropriate instructions (HH: 03, 04; CG: 01)

“Now, the challenges that I find there [drug shops] is taking the child and the health provider does not examine the child and just gives treatment” (CG FG2R3)

“You go sometimes and the medicines are not enough and they give little coartem [ACT] and Panadol [paracetamol] and you come back.” (CG FG2R4)

“Now the challenge that we find [at drug shops] ... they have not given you any directions for the one month baby who is ill, and because you did not learn, you give over dose. So that is a challenge.” (CG FG1R2)

One of the FGs even alluded to unsafe injection practices at drug shops (CG: 03),

“Many have injected the child ... and the child becomes lame ... maybe the injection was not properly done.” (CG FG3R2)

And, several of the groups (HH: 02, 03; CG: 01, 02, 04, 05) alleged that some of the drug shops carried old and expired medicine stocks.

“The challenge, like for me, which I see is that if I go to such a clinic [drug shop] is that they can sell to me medicines that are expired” (CG FG4R2)

DISCUSSION

The current study provides greater insight into the specific challenges faced by households living in Butaleja District when trying to access care for their febrile child presumed to have malaria. Findings from this study identified four major challenge areas: (1) difficulty accessing public health facilities within their sub-counties; (2) poor service once at the public health facility; (3) difficulties with managing the child's illness at home; and (4) constrained to use private outlets despite their shortcomings.

Consistent with other research in Butaleja and rural districts of Uganda, this study identified travel distance and the lack of cost-effective transportation as a major concern to receiving timely care at public health facilities.^{23-25,39-45} The lack of adequate infrastructure in rural Uganda, such as

asphalted roads and affordable transport services, has been reported to be an important barrier to mobility.^{35,44,46}

A report published by the local government suggests that less than 10% of the roads in Butaleja District are motorable and accessible to local transportation services, such as mini buses (Matatu), pick-up trucks, motor bike taxi (Boda-boda), or bicycle taxi.³⁵ The case study by Kassam *et al.* (2016), found that it was not uncommon for caregivers in Butaleja to travel an average of 7 miles by foot on rough terrain with their sick child to the main road or directly to the public health facility.²⁵ As such, it was not surprising that FG participants residing furthest from the main road (and furthest from level III facilities) voiced the greatest concern with distance and their ability to find affordable transportation.

The second major concern expressed by FGs was the poor quality of care families received once they arrived at a public health facility. This ranged from denial of care to delay of care and negative experiences with staff. FG participants reported that children were often refused care if families were unable to pay the additional fees (“bribes”) demanded by staff or if they presented at the public health facility without the child’s medical book. Many expressed that it was an added burden to be responsible for the child’s medical book at a time when their priority was to get the sick child seen by a medical professional. There was a general consensus across FGs that it should be the public health facilities’ responsibility to replace these books free of charge in the event it was misplaced or forgotten. Similarly, FGs regarded the request for bribes as unjust. Despite the abandonment of formal user fees in 2001, informal fees cited in the literature as early as 1999 remains an on-going barrier in many parts of Uganda, with staff frequently withholding care until such payment is made.⁴⁷⁻⁵¹ The refusal of care was viewed as a lack of compassion and indifference on the part of the health providers, creating frustration, anger, and a feeling of helplessness, given most households did not have the resources to turn elsewhere.

Once at a public health facility, FGs noted that long wait times and the unavailability of staff routinely caused further delays, with the child’s illness often progressing from mild to severe as they waited. Many of the reasons shared, such as staff shortages, absenteeism, lack of compassion, and inattentiveness by health workers, have been cited by other researchers as key factors contributing to poor service delivery and quality of care across Uganda and other low to middle income countries.^{49,52-57} With respect to poor quality of care, the literature has linked it to inadequate wages, delayed or skipped payments, staff holding multiple jobs to make ends meet, inadequate training, and the lack of quality supervision and formal work schedules.^{49,52-57} The inadequate work environment also provides many staff with justification to set their own work hours and attend to personal matters instead of coming to work.⁵² On average, low level staff (such as nursing aids and orderlies) may report to work for as little as 18.5 hours a week, and high level staff (such as doctors, medical assistants and nurses) as little as 12.9 hours a week.^{49,52} Given the myriad of factors recognized to influence provider practices in Uganda, many have suggested that interventions far more complex than just

training, job aid, and new treatment guidelines are required to change behaviour.^{49,52,53}

The delay in care from long travel distances and wait times at public facilities was further exacerbated by stock-outs of medicines and supply at health facilities. In such circumstances, families often got the runaround, with health providers referring them to other public health facilities or private vendors to purchase supplies and medicines.^{25,41,42,53,58,59} When asked to explain reasons for stock-outs, some of the FG participants went as far as to suggest that theft and the resale of government supplied medicines by health workers for personal gain was the underlying problem for medication and supply stock-outs at public health facilities. The notion of embezzlement at public facilities is not new for Uganda, with the literature reporting that over two-thirds of medications meant for free distribution in the public sector are regularly lost due to theft or misappropriation.⁴⁹

A large majority of FG participants expressed that they could not afford care at formal private clinics. Consequently, when they are given the runaround at public health facilities, they have to secure additional funds and resort to using informal private shops where they can negotiate the price of the medicines. In some instances, many purchased only partial treatment regimens because this is all that they could afford. Consequently, in Butaleja District where the majority of informal outlets are managed by untrained vendors and have unreliable ACT stocks, case management routinely falls short of the national malaria treatment guidelines.^{5,25,27,50,60,61} Despite the government’s assurance of free access to diagnostics and medications at public facilities, this and other studies demonstrate that national policies in many such regions are not translated at the community level.^{5,23,25,43,47,53,62,63} Given the numerous challenges with accessing care at public facilities, this and other studies have reported that households commonly relied on home management for their initial action, seeking external care only if the child has not improved.^{23,25,50,64,65} In Butaleja, a household survey found over half of the caregivers had difficulties obtaining free ACTs and diagnostic testing.^{23,24} As a result, almost three-quarters of households used some form of home management as the first action to manage fever in their young children.²³ About a quarter reported using traditional herbs, just over a third used supportive care (e.g., bathing and sponging), and nearly two-thirds gave home-stock medicines.

This is the first qualitative study to investigate households’ challenges with seeking health care for their very young children in Butaleja District. Given the exploratory nature of this study, a few of the emerging themes could not be fully investigated. As such, this study raised a number of opportunities for future research, including the need to further investigate the different types of traditional medicines used, concerns raised about the quality of medicines available in their community and difficulty with medication adherence, and what was unique about CG FG 05 and their environment that enabled positive encounters at their respective public health facilities. Similarly, this research sought to explore health care challenges from the users’ perspective. Given health workers’ unprofessional conduct was a central concern in this study, a next step

might be to explore the root causes of such behaviors by engaging the health workers. There is a general acknowledgement in the literature that health workers should be held to higher standards for professional behavior than other professional groups, but there is little consensus on how best to effectively and efficiently achieve this outcome.^{49,52,53} Most, however, agree that factors influencing workers' behaviors are complex, interdependent and include political and economic instability, failed public policies, lack of educational opportunities, sociocultural traditions, competing opportunities, and inadequate wages, workload, organization leadership, and administrative practices. Consequently, comprehensive system-level approaches rather than simplistic solutions that just target performance and training are needed to change worker practices.^{49,52,53}

Future public health interventions

While policymakers, health authorities, administrators, and health system researchers tackle the broader long-term systemic-level issues, it is imperative to explore, examine, and confirm strategies beyond the public system that can offer more immediate results. At the household level, this may include public education to raise awareness on the importance of bringing the child's medical book to a public health facility, improve caregivers' knowledge about malaria, and enhance families' capacity to make informed decisions regarding diagnostic tests and choice of medicines. Given the low literacy rate, such initiatives will need to be disseminated using locally relevant and acceptable approaches. At the community level, options such as community-based health insurance (CBHI) need to be considered to enable households to access care outside the public sector. The CBHI is an emerging micro-health insurance concept for promoting health equity in low income countries where governments are not able to sustain universal health care coverage and households not able to pay out-of-pocket fees for quality care.^{66,67} Countries that have introduced CBHIs have seen an increase in both health care utilization and health outcomes for subscribers.⁶⁷ Since the scheme is a form of micro health insurance that is based on resource pooling using organized community structures and social groups, community initiatives are needed to help create such social networks. Similarly, restricted access to the formal private outlet is a major constraint, and efforts are needed to increase the prevalence of reliable private health care services in rural areas.^{22,68-70} In Butaleja where the informal private sector represents 82% of the private sector, future research needs to determine how best to engage this untapped resource in the delivery of care. Given the historical success of iCCM models using CHW, who are trained lay persons, similar outcomes may be possible with careful selection of vendors and appropriate training.⁷¹ The Department of Pharmacy at Makerere University can play a pivotal role in helping develop vendor competencies and facilitate training programs.

Limitations

As with any research, the findings from this study need to be considered in the context of potential limitations. First, as with any research that uses FGs, one must consider the

possibility of reporting and recall biases. However, given the participants' low endorsement of health providers and their acknowledgement that their children frequently did not receive optimal care, suggests that the influence of reporting bias was minimal in this study. Similarly, recall bias was likely reduced by asking participants to focus on the child who experienced fever within the last two weeks. Second, the researchers recognize that while the use of qualitative methods enabled us to obtain an in-depth understanding of the challenges faced by households, it does not allow the results to be generalized to a wider population. Still, our sampling strategy ensured the results reflected the views of the diverse population residing in Butaleja District. Third, given the interactive nature of focus groups, there is always the potential to discover new ideas which cannot be fully explored.⁷² Though the study methodology ensured sufficient rich data was gathered to explore and understand the majority of emergent issues related to the research objective (i.e., data saturation), given our a-priori sample size, a few emergent topics could not be fully examined. While a limitation, this can also be viewed as a strength, as the findings created opportunities for future research. Lastly, the authors recognize that since the inception of this study, it is plausible that households' experiences with childhood managements may have changed in Butaleja District. However, to-date, there is little empirical evidence to suggest any such change has occurred, and no evidence any pending sustainable solutions to improve households' experiences with managing childhood malaria. The current findings, therefore, contribute greatly to the scarce research in this district.

CONCLUSIONS

The current study provides an understanding of the everyday challenges faced by households when managing a febrile episode for their young child. The findings suggest that inadequate health care infrastructure combined with poor health provider behaviors and household practices are important elements limiting timely and effective care in young children. In addition to improving provider practice at public health facilities, future interventions need to identify community level solutions to expand existing social supports and promote household self-efficacy to seek out appropriate care. This includes exploring the feasibility of initiating CBHI and expanding the role of informal private providers to supplement the current public option.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interests. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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