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Care-seeking during fatal childhood illness in rural South Africa - a qualitative study

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ABSTRACT:

Objectives: This study aimed to better understand caregivers' care-seeking experiences, choice of treatment provider and barriers to accessing care during a child's final illness, and why children die at home despite seeking formal healthcare.

Design: This qualitative study included semi-structured in-depth interviews and focus group discussions with caregivers of deceased children. Data were thematically analysed, and key findings compared to the Pathways to Survival Framework - a model frequently used in the study of child mortality. An adapted model was developed.

Setting: Two rural health and demographic surveillance system (HDSS) sites in South Africa – the Agincourt HDSS and the Africa Health Research Institute.

Participants: Thirty-eight caregivers of children who died below the age of five years. Caregivers were purposively sampled to ensure maximum variation across place of death, child age at death, household socioeconomic status, maternal migration status and maternal HIV status.

Findings: Although caregivers faced barriers in providing care to children (including insufficient knowledge and poor transport), almost all did seek care from the formal health system. Negative experiences in health facilities did not deter care-seeking, but most respondents still received poor quality care and were not given adequate safety-netting advice. Traditional healers were only consulted as a last resort when other approaches had failed.

Conclusion: Barriers to accessing healthcare disrupt the workings of previously accepted care-seeking models. The adapted model presented in this paper more realistically reflects care-seeking experiences and decision-making during severe childhood illness in rural South Africa and helps explain both the persistence of home deaths despite seeking healthcare, and the impact of a child's death on care-seeking in future childhood illness. This model can be used as the basis for developing interventions to reduce under-5 mortality.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa.
- This study included a diverse sample of caregivers, including fathers and traditional healers whose view are seldom included in studies of child illness and care-seeking.
- Interviews and focus group discussions were conducted in participants' first language (isiZulu or Xitsonga), enabling inclusion of caregivers who did not speak English fluently. However, subtilties of meaning and tone may have been lost in the translation process.
- Interviews and focus group discussions took place at least one year after the child's death, which may have resulted in recall bias.

INTRODUCTION

Under-5 mortality remains a priority in low- and middle-income countries. Despite advances in the care of mothers, newborns and children in resource constrained settings, over 5.3 million children died in 2018 before their fifth birthday globally, 54% of those in sub-Saharan Africa (SSA) [1]. In SSA, over 50% of child deaths occur at home despite many children having contact with the formal healthcare system during their final illness [2–5]. Understanding the factors that contribute to home deaths is critical to designing interventions to reduce under-5 mortality, including those which occur beyond the remit of the formal healthcare sector.

However, investigating home deaths is not easy. It requires community-based approaches rather than facility-based research. The Pathways to Survival Framework [6] is a commonly-used conceptual model for analysing care-seeking processes and demonstrating the fluid interaction between healthcare provided within and outside the home. A large body of research across SSA has used this model to identify modifiable factors in under-5 deaths highlighting the different stages where children were lost from formal care pathways [2,7–9]. In South Africa specifically, research has highlighted that over 80% of children who died at home had sought formal healthcare during their final illness, of whom about a third sought care more than once [10,11]. Although caregivers' failure to recognise danger signs and lack of transport can explain delayed or no treatment-seeking, these factors do not explain why so many children die at home despite having sought care. One modifiable factor may be the low referral rate of children from primary level facilities to higher levels of care [10–13]

This study aims to better understand caregivers' care-seeking experiences, choice of treatment provider and barriers to accessing care during a child's final illness, and why children die at home despite seeking care.

METHODS

Study design, setting and participants

We conducted a qualitative study using semi-structured in-depth interviews and focus group discussions (FGDs) from July 2018 to January 2019 with caregivers of deceased children, usually the child's mother, however given high levels of temporary migration in the study communities, grandmothers and aunts were sometimes the appropriate respondent.

This research was conducted in two largely rural health and demographic surveillance system (HDSS) sites in South Africa (Agincourt and the Africa Health Research Institute (AHRI)). Together these include over 280 000 people in over 40 500 households, most of which fall into the lowest socioeconomic quintiles nationally. There are high levels of temporary labour migration (33-36%) with household members oscillating between their place of work and rural homes. Most households rely on income from government social grants (including the old age pension and child support grant). Both sites routinely conduct verbal autopsies on all deaths to determine probable biological cause of death [14,15]. These were used to identify potential participants.

Participants were recruited using purposive sampling to seek maximum variation. Consideration was given to place of death (at home or in a health facility), age of the child at death, socioeconomic status of the household, whether the child or mother was known to be HIV positive and whether the mother was a temporary migrant at the time of the child's deaths, all of which affect child mortality, place of death, and care-seeking during the final illness [10,16–18]. Sample size was determined by the point at which data saturation was reached [19,20].

Data collection

In-depth interviews were conducted to gather personal narratives describing the time around the child's death. FDGs produced communal narratives around childhood illness and were used to validate findings from in-depth interviews. All interviews and FGDs were conducted in the participant's first language (either isiZulu or Xitsonga), digitally audio-recorded, and subsequently transcribed and translated into English. All interviewers and FGD mediators were from the local communities. All were non-medical (i.e. they were not doctors, nurses nor community health workers) thereby minimising the effect of social desirability bias [21] which often leads to under-reporting of traditional medicine use, and may discourage participants from speaking freely about their experiences of the healthcare system (particularly negative experiences).

Data analysis

We undertook thematic analysis [22,23] to identify and analyse the main themes emerging from the interviews and FGDs. In developing the analysis, we adapted the Pathways to Survival Framework (figure 1) [6] – which considers care provision within the home and care-seeking outside the home when a child becomes unwell. We demonstrated the stages of the care-seeking process at which each major theme acted, and how caregivers' accounts of the processes of seeking and receiving healthcare in rural South African communities deviated from those outlined in the original model. We used NVivo 11 (QSR International, Australia) to assist in data management, coding of transcripts and organisation of codes into themes.

Figure 1 here

Ethics

This study was approved by the Oxford Tropical Research Ethics Committee (OxTREC ref: 509-18), the University of the Witwatersrand Human Research Ethics Committee (Medical) (M180102), the Mpumalanga Province Health Research Committee (MP_201804_006) and the University of KwaZulu-Natal Biomedical Ethics Research Committee (BE259/18). To protect confidentiality of participants, anonymised transcripts will only be made available on request.

Patient and public involvement

The community advisory boards at each HDSS site provided input into the study design and assisted with the distribution of findings back to the communities.

RESULTS

Participant characteristics

Respondent demographics and key case details are presented in Table 1 and Supplementary material S1. Of a total of 38 respondents, 29 were parents (27 mothers, two fathers), seven grandmothers and two aunts. Interviews and FGDs detailed events relating to a total of 38 deaths, comprising four neonatal deaths (0-27 days), 16 deaths of infants 1-11 months and 18 deaths of children 1-4 years. Nineteen children had died in health facilities, 16 at home and three on route to a health facility. Overall, 32 caregivers had sought formal healthcare for their child during the child's final illness. Eight caregivers used traditional or faith-based medicines and practices during the final illness, all of whom also sought formal healthcare. A further four indicated that traditional medicines and practices had been used in previous illness episodes for the child or other family members even if not used in the final illness. Three caregivers did not provide home care or seek any formal, traditional or faith-based care outside the home – all were sudden deaths.

Table 1: Summary of characteristics of respondents and their deceased children

Characteristic	**Total (N=38)**		**Agincourt (N=19)**		**AHRI (N=19)**	
	n	**%**	**N**	**%**	**n**	**%**
Age of the deceased child						
0-27 days (neonate)	4	11	2	11	2	11
1-11 months	16	42	9	47	7	37
12-59 months	18	47	8	42	10	53
Relationship of respondent to the deceased						
Mother	27	71	10	53	17	89
Father	2	5	2	11	0	0
Grandmother	7	18	5	26	2	11
Aunt	2	5	2	11	0	0
Place of death						
Home	16	42	6	32	10	53
Healthcare facility	19	50	12	63	7	37
On route	3	8	1	5	2	11
Cause of death						
Acute respiratory infection	11	29	8	42	3	16
Diarrhoeal disease	4	11	0	0	4	21

Meningitis/encephalitis	3	8	0	0	3	16
Neonatal conditions	3	8	2	11	1	5
Burns	2	5	2	11	0	0
Other	5	13	3	16	2	11
Unknown	10	26	4	21	6	32
Household socioeconomic quintile within HDSS						
1 (poorest)	8	21	7	37	1	5
2	9	24	5	26	4	21
3	7	18	4	21	3	16
4	7	18	1	5	6	32
5 (least poor)	7	18	2	11	5	26
Mother's HIV status						
Positive	8	21	3	16	5	26
Negative	23	61	14	74	9	47
Unknown/unreported	7	18	2	11	5	26
Mozambican descent	Not totalled		4	21	-	-
Sought formal healthcare outside the home	32	84	16	84	16	84
Used traditional medicine or consulted a traditional healer for child's final illness	6	16	1	5	5	26
Used traditional medicine or consulted a traditional healer for previous childhood illness	10	26	3	16	7	37

Themes

The main themes to emerge from the analysis relate to (i) caregiver knowledge and advice-seeking, (ii) the use of traditional medicines and practices, (iii) transport barriers, and (iv) experiences of care-seeking during the final illness.

Caregiver knowledge and advice-seeking

Some caregivers appear to have lacked understanding of their child's condition, failing to recognise or appreciate the severity of symptoms or comprehend why the child died. A young mother described her child having a seizure; *"during 01:00 am she had fits and was foaming at the mouth. We then called my in-laws, they took her here at home. They burnt incense for her and she was getting better. We left her, and I went to school in the morning." (*Participant 29). A mother whose infant died at home, expressed regret at not taking the child to the hospital sooner, but she just *"never thought that he [her child] cried because he was sick, (she) thought it was normal for all the babies."* (Participant 21).

When caregivers were uncertain about a child's illness, they sometimes turned to family members, as in the case above, and neighbours for advice in assessing the illness and whether to seek care outside the home. In general, mothers felt such consultations were not about seeking family members' permission to take a given action, but rather consulting them in an exercise of joint decision-making based on a joint assessment of the child's condition. The mother of a neonate who died in a health facility explained their household's usual processes of assessing child illness and whether further care is needed: *"we normally discuss [the child's condition] with whoever is around home" (*Participant 26). A grandmother explained that both she and the mother were uncertain about the child's illness: *"We were sharing ideas on what to do. Even my daughter's sister in-law was also here and she is the one who said that it is better to take the child to the clinic." (Participant 6).*

Traditional medicine and practices

Traditional medicine and practices in these settings operate within a complex set of belief systems. Most participants reported practicing cultural traditions or rituals related to African ancestral belief systems which underpin their worldview. However, our participants differentiated use of traditional healers and medicine from the much more common practice of cultural rituals and traditions. For example, one mother explained: *"Yes, [we practice] the burning of incense, also that we do slaughtering. In most times maybe we slaughter goats when we have something we will be doing…?".* But this participant also noted *"In our church we don't go for traditional healers nor faith healers."* (Participant 25).

The motivations participants described for using traditional medicines and traditional healers varied. Some caregivers admitted to administering enemas as part of the routine care they provide within the home to promote well-being or treat common symptoms of mild illness. One grandmother frequently administered enemas to her grandchildren: *"children here at home are being given enemas when the sun is too hot to release the gall. She used to enema them, not only my child but all the kids at home."* (Participant 30).

Other caregivers used traditional enemas despite being aware of advice against this, because they did not seem to know what to do instead and didn't want to do nothing: *"It's not easy. They say children should no longer be given enemas. [But] you are also trying to help." (Participant 35).*

Caregivers who consulted traditional healers during the child's final illness all did so as a last resort, out of desperation as they did not know what else to do to help their child. *"I thought I will go to someone [a traditional healer] to hear what is really happening for I've been to the clinic there were no help, I go to the doctor I get no help"* (participant 24, mother of young child who died at home despite seeking care). This reasoning was also echoed in FGDs in relation to the use of traditional healers in other illnesses (be that for adults or children): *"you can see that maybe you need pills or rubbing ointment and get them, but if it continues…what must you do? Go to a traditional healer to give you something that will relieve you"* (participant 37). In our study, caregivers did not express a strongly held belief that the illness that had resulted in their child's death had an underlying traditional cause. However, some caregivers indicated that in previous illnesses of their other children or family members, they believed that the cause of the illness was traditional and so sought traditional treatment first, believing it was the most appropriate means of healthcare.

Transport barriers

Caregivers consistently identified a lack of transport as a significant barrier to accessing healthcare. Transport costs could be prohibitive and *"there are people who end up not getting to clinic because they don't have money for transport."* (Participant 26). Participants noted that ambulances were slow or unavailable. Arranging a private car was difficult and often caused delays with disastrous consequences: *"I was not having a car by that time. Then we found my wife's father's car. While we were on our way to the hospital around [the village] the car just stopped. We waited for another car* *to come and assist us. The car came and when we arrived at [the hospital], we found that … I am not sure if the child died at the gate of the hospital or he died inside the hospital, I can't remember. We never got any assistance because he was dead already."* (Participant 9).

Many were ultimately able to overcome the transport barrier, borrowing money from family and neighbours to cover the costs of taxis or hire private cars, or by asking others to help with lifts to the health facilities. But a lack of transport frequently caused a delay in accessing healthcare and was an important consideration in deciding when and where to access healthcare. Participants from the FDGs added that transport barriers were exacerbated at night as *"there is no other option but to pay for someone's car and go to [the 24-hour clinic] as it is always open."* (Participant 36).

Experiences of care-seeking during the final illness

Table 2 summarises the specific features of care-seeking interactions during the final illness that caregivers associated with a positive or negative experience. Caregivers had more positive experiences if they perceived tangible interventions or treatments were being offered such as *"giving oxygen"* (participant 37) or giving medication in the form of syrups or injections, and if staff communicated well. Negative experiences were associated with poor communication, being shouted at or blamed for the death by healthcare workers. Caregivers had very low expectations of the healthcare system, so much so that positive experiences of care-seeking were often the result of an *absence* of poor care rather than the *presence* of good care practices. For example, participants were satisfied with a care-seeking interaction when nurses *"didn't blame me or say something that was out of line"* (participant 3), and when *"they didn't shout at me"* (participant 21). However, despite low expectations and negative experiences, caregivers continued to engage with formal health services.

Table 2: Care-seeking experiences

Negative care-seeking experiences	**Positive care-seeking experiences**
Poor communication - Healthcare workers shouting at caregiver - Blaming caregiver for death - Failing to take caregivers' opinions seriously - Not explaining what procedure is being performed or why it is being performed - Not explaining which treatment was being given or why it was being given - Not providing safety-netting advice - Not explaining the cause of death	Good communication - Respect for caregivers' opinion and knowledge of a change in the child's condition - Offering safety-netting advice - Not being shouted at
Inattentive staff - Distracted by mobile phones while seeing patients, or while patients are waiting to be seen - Taking lunch when still many patients to see - Not coming to review patient when caregiver alerts them to a change in the child's condition	Tangible sense of "being treated" - Receiving interventions (Drips, injections, tablets, oxygen, bandages) - Physical examination performed by the nurse or doctor

- Sense that nurses are not “passionate” about their jobs (particularly younger nurses).	
Delays or waiting: - Ambulance transport very delayed in arrival	Timings - Seen and treated immediately or urgently, skipping the queues - Ambulance arriving quickly

Communication clearly influenced caregivers’ experience of care. Features of good communication included demonstrating respect for the caregiver’s knowledge of their child, explaining what procedures or treatments were being administered and not shouting at or blaming caregivers. As one mother recalled: *“The nurses from [the hospital] communicate with you as the children’s parents, ask how the child is and what changes you see or that you don’t see change.” (Participant 22).* Unfortunately most caregivers experienced poor communication and reported that healthcare workers were hostile, rude and dismissive, shouted at caregivers for bringing children at the wrong time (either too late in the day, or at the weekend) and blamed caregivers for the child’s illness – especially if traditional medicine was used - saying they *“killed the child.”* (Participants 30 and 36).

In some cases, healthcare workers were dismissive of caregivers’ concerns, despite caregivers being sure that something was seriously wrong with their child. The mother of a child who died at home was worried: *“I woke up with him in that morning and he was not fine”*. She took her child to the clinic, but the nurses dismissed her *saying “they don’t work on nominals [meaning non-emergency patients] on Sunday.”* (Participant 25). Despite waiting many hours at the clinic, the staff refused to assess the child and eventually she left the facility *“bare handed”*. A father whose neonate was crying constantly, not eating or drinking, explained that *“we didn’t get any help from the clinic”* (participant 8) after he and his wife were dismissed by nurses.

Safety-nets were another important part of communication: one father recalled “(the GP) *told us that he is going to give us some medication that we need to go and give to the child. He also said to us as it is Monday today, if you don’t see any changes on Tuesday, please come back.*” (Participant 8). This experience stood out from the experiences of most other participants, who did not recall being given any advice about what danger signs to look out for and when to come back for review. This implies that many caregivers did not know what they should expect of the treatment or that the child might deteriorate despite receiving medication and need to return to the healthcare facility.

Poor communication also resulted in caregivers failing to understand why their child had died. This left caregivers feeling anxious, often doubting their own assessment of the child’s condition, and they lost confidence in their ability to assess and manage future child illness (even mild cases). Many caregivers said that, following their child’s death, they now relied fully on clinic staff to assess the severity of their other children’s illnesses and provide treatment guidance: *“I don’t do anything by myself. I take the child to the clinic. Even if it can be something that I know, I do take the child to the clinic… because of what happened to me last time, I think that something like that can happen again.”* (Participant 13).

Despite their negative experience of care-seeking, fear of further vindictive treatment discouraged caregivers from complaining about the quality of care or asking questions related to the diagnosis or management of their child, but did not seem to discourage them from seeking care. Caregivers felt they would *"regret"* asking questions (participant 35) and that *"it's better to shut up and when a nurse talks bad to you say no word in return. Because some of the time you will find that when you reply, he/she will not give your child a proper treatment"* (participant 25).

In summary, caregivers' knowledge of childhood illness varied – with some unable to identify severe illness in their child or appreciate the urgency of the need for healthcare. Traditional medicine was utilised by some caregivers, though rarely as a first port-of-call. When used as part of home care, caregivers suggested that they turned to traditional medicines as something familiar, even when they did not identify a traditional cause of their child's illness. Transport barriers remain significant: cost, limited minibus-taxi times and having to arrange to hire or borrow private cars caused delays in accessing healthcare. Finally, caregivers' low expectations of the healthcare system coloured their experiences of seeking healthcare during their child's final illness, often lending a positive lens to the experience where it merely exceeded the lowest of expectations. However, many still experienced the healthcare system negatively. Care-seeking interactions were often characterised by disrespectful and dismissive staff, even where caregivers clearly recognised that their child was ill, and a lack of explanation of the child's illness, treatments and safety-netting advice.

DISCUSSION

This study highlighted the multiple barriers faced by caregivers in providing care to children within the home, and seeking and receiving care outside the home including a lack of knowledge and limited transport. In spite of these, almost all did seek care from the formal health system: negative experiences in health facilities did not deter care-seeking. However, most respondents received poor quality of care and were not given adequate safety-netting advice. Traditional healers were only consulted as a last resort when other approaches had failed. As such, existing models of care-seeking must be adapted to reflect caregivers' realities.

Adapting the Pathways to Survival Framework

Figure 1 showed a simplified version of the Pathways to Survival Framework [6]. Many of the key issues identified by participants are overlaid on this model, demonstrating the stage and manner in which these issues act as barriers to accessing high quality healthcare. We found that transport delays are an important issue, in contrast to findings from standard quantitative verbal and social autopsies in this context (which likely reflects that the quantitative survey questions are framed too broadly) [2]. Given the barriers that caregivers in this study experienced at each stage of the care pathway, we believe that the care-seeking process in rural South Africa more closely resembles the model shown in figure 2.

Figure 2 here

Following this model, we start with a severely ill child (pathway indicated by black arrows). In some cases, caregivers lacking knowledge might not recognise the illness and so the child dies at home without care (indicated by arrow 1). However, in many cases the caregiver identifies signs of illness and appropriately seeks healthcare for the child (step 2). For a series of reasons, caregivers have a negative experience at the healthcare provider (step 3). When the child deteriorates (step 4) caregivers' responses may differ: some might re-seek care, though often going to a different provider (either to a different clinic, to a private GP or to a hospital) (step 5a). Some believe that the failure to improve having received allopathic treatment must indicate that this is a traditional problem and so seek out traditional healers (step 5b). Others are either unable to re-seek care, or believe that having seen a healthcare professional already, there is nothing more to be done (step 5c). Ultimately the child dies (whether at home or in a health facility) (steps 5c, 6).

In addition to more accurately describing the care pathway for fatal child illness in rural South Africa as experienced by caregivers, our proposed model is the first to offer insights into what follows a child's death in the context of poor caregiver knowledge of childhood illness, both in identifying signs of severe illness and in understanding why the child died (pathway indicated by orange dashed arrows). Following the death of their child, caregivers lose confidence in their ability to identify severe child illness (arrow A) and become reliant on healthcare workers to identify disease and guide treatment (arrow B). This is true even for very mild childhood illness which could be adequately managed at home. As a result, there is a growing burden on the health system, whereby mildly unwell children are also brought to the clinic, exacerbating the existing supply-side barriers to high quality care (staff shortages, resource limitations, poor management, long waiting times etc) (arrow C) and perpetuating negative experiences of care (arrow D).

The adapted model is similar to the scenario reported by Sharkey et al (2011), whereby repeated negative experiences of are results in care seeking from multiple service providers and use of traditional healers (though not as the first port of call) [24]. However, Sharkey et al suggest that this pattern demonstrated a distrust in the formal healthcare system; in contrast we did not find evidence to support a loss of trust in formal healthcare providers. This may reflect differences in the degree of community and caregiver empowerment, caregiver education, or differences in rural and urban communities (with urban caregivers in their study seeking care more frequently and from more providers than those from rural areas). Furthermore, their model does not describe care-seeking for future child illness, emphasising the value of this adapted model in understanding care-seeking behaviours in rural South African contexts.

Social exclusion

Amartya Sen's work on social exclusion [25] may help explain caregivers' response of growing (rather than declining) use of the formal healthcare system despite repeated negative experiences and low expectations of the quality of care they are likely to receive. Sen highlights the relational nature of poverty. He argues that impoverishment extends beyond the material and includes non-material elements (also called capabilities) which are critical to the freedom to access opportunities. Viewed through this lens, impoverishment is defined not merely as a lack of wealth or income but as a loss of the ability to claim essential services and to participate in social relationships [25].

When applied to the South African public healthcare context, the concept of social exclusion helps to explain caregivers' responses to seeking healthcare. Negative engagements with health professionals - be that in the form of disrespectful staff, lack of medications, long waiting times or poor communication - which occur in the context of disadvantage or poverty - undermine caregivers' ability to claim a minimum standard of healthcare by reinforcing perceptions of social exclusion which feed into the lived experience of poverty. This also helps explain the persistently low expectations of the healthcare system that were implicit in many of the respondents' comments.

The sense of capacity deprivation and social exclusion driven by the negative experiences of care-seeking and the death of their child contributes to an internalisation of self-doubt and blame for the child's death. One caregiver exemplified this, referring to their child's death as "*their mistake*", rather than recognising that there were multiple failures throughout the healthcare system that contributed to the child's death. Consequently, caregivers lose confidence in their assessment of illness severity. Instead of doubting the healthcare system, or even turning away from it, caregivers delegate more of their parental authority in the assessment and management of their children to health professionals.

This behaviour is described elsewhere in the South African healthcare system in relation to maternal care-seeking and institutional delivery. Verbal and physical abuse of labouring mothers by nursing staff is well documented across South Africa [26]. Yet mothers have come to normalise nurses' aggressive language as a means of coping with the situation, and as a result may no longer feel that it is unacceptable or offensive [27]. Such seemingly counter-intuitive behaviours reflect societal power dynamics of race, class and poverty that play out in healthcare interactions whereby healthcare staff feel the need to "control" patients, and this becomes an accepted and institutionalised modus operandi [27].

Policy Implications and priorities for further research

Our adapted care-seeking model highlights the urgent need to empower caregivers, building confidence in seeking and providing appropriate healthcare for their children both within and outside the home, and increasing expectations of the quality of care they receive. Policy implications therefore include improved communication strategies with specific emphasis on providing safety netting information at every consultation and encouraging caregivers to ask questions about their child's diagnosis and treatment. Behaviour change programmes targeting staff attitudes have been successful when trialled at individual facilities [28,29]. Strategies to provide such programmes at scale should be prioritised. Finally, community mobilisation programmes using Women's Groups and Care Groups have been shown to effectively improve neonatal and child health, improving caregiver knowledge and capability [30–33]. As investment in community health worker programmes is extended, consideration should be given to their role in mobilising such groups within the communities they serve.

Further research is needed to understand in which circumstances parents react to a child death by increasing their use of health services for every minor illness in subsequent children, or by not seeking treatment from formal health services until the illness becomes severe. Further qualitative research is also needed to understand why enemas are so commonly used for home treatment of childhood illnesses in South Africa, while they are not so commonplace elsewhere. This could help to inform the development of interventions to improve the use of home treatments and treatment-seeking behaviour for children in South Africa.

Strengths and limitations

This study had four important strengths, and corresponding limitations. First, all interviews and FGDs were conducted in participants' first language (isiZulu or Xitsonga). This encouraged participation of individuals who might otherwise have refused or been unable to participate in the study if all data collection had been in English. However, it is possible that some of the subtilties of the meaning and tone of the conversation were lost during translation of the interviews into English. Second, interviews were conducted at least one year after the death of the children in question, but in some cases two to three years after the child's death. Most caregivers had therefore grieved the loss of their child and the risk of the study causing significant emotional distress was lower. However, this time delay also introduced the potential for recall bias. We tried to reduce the impact of this by concentrating on caregiver's impressions of healthcare services and how they felt about their care-seeking experiences and less on precise timings or medications prescribed. Third, our sampling strategy allowed us to capture a diverse set of opinions and included fathers and traditional healers – both of whom are generally under-represented in research on childhood illness despite being important stakeholders, contributing to decision-making and caregiving, often holding positions of authority within the household and community and sometimes acting as gatekeepers to care. Fourth, caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa. This model contributes to the literature on theories of care-seeking and access to healthcare and can be used as a basis for further research on childhood illness and intervention development to reduce child mortality. However, the adapted model may be context-specific and would require further validation in other settings before it is more widely applied.

CONCLUSION

Repeated negative experiences of care-seeking in the context of poverty and social exclusion can disempower caregivers and limit their ability to claim a minimum standard of healthcare. This realisation is critical in refining our thinking around care-seeking. It explains why children die at home despite having sought formal healthcare during fatal childhood illness, and why healthcare services are overwhelmed with minor illnesses, and why traditional healers are consulted. Interventions designed to empower caregivers - including improved communication and safety netting, changing staff attitudes and community mobilisation - should be prioritised as part of a wider strategy to reduce child mortality.

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AUTHOR CONTRIBUTIONS

JP, LH, MW, KK and AH conceived and designed the study. VD, AK and PK conducted, transcribed and translated the interviews and FGDs. JP, MW and LH analysed the data with input from KK, JS, VD, AK and PK. JP and LH led the writing of the manuscript. All author contributed to, and critically revised it.

CONFLICTS OF INTEREST

The authors do not declare any conflicts of interest

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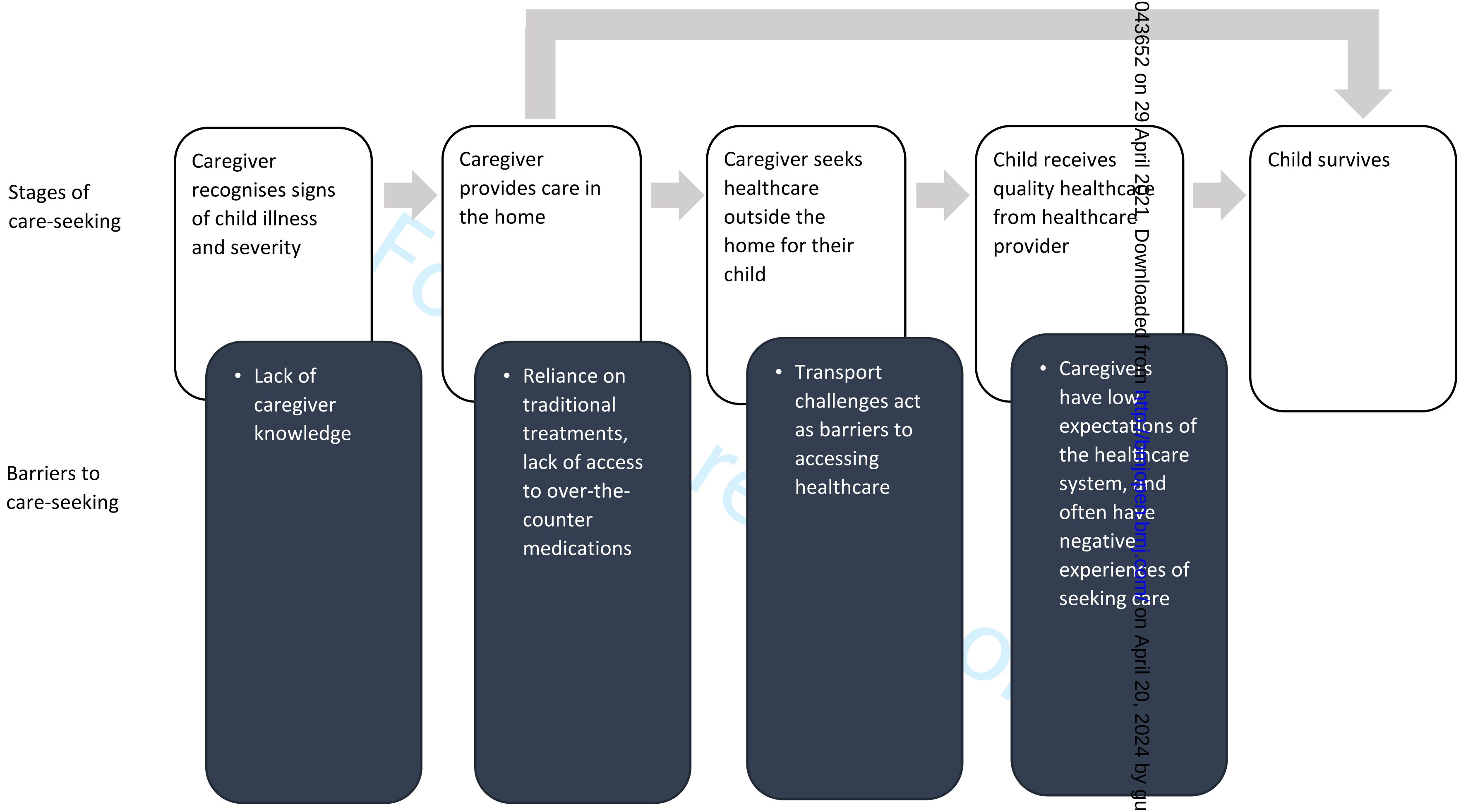

Figure 1: Simplified, linear representation of stages of seeking and providing care based on the CDC/BASICS Pathways to Survival framework (6), and key barriers to care identified at each stage of the care-seeking process.

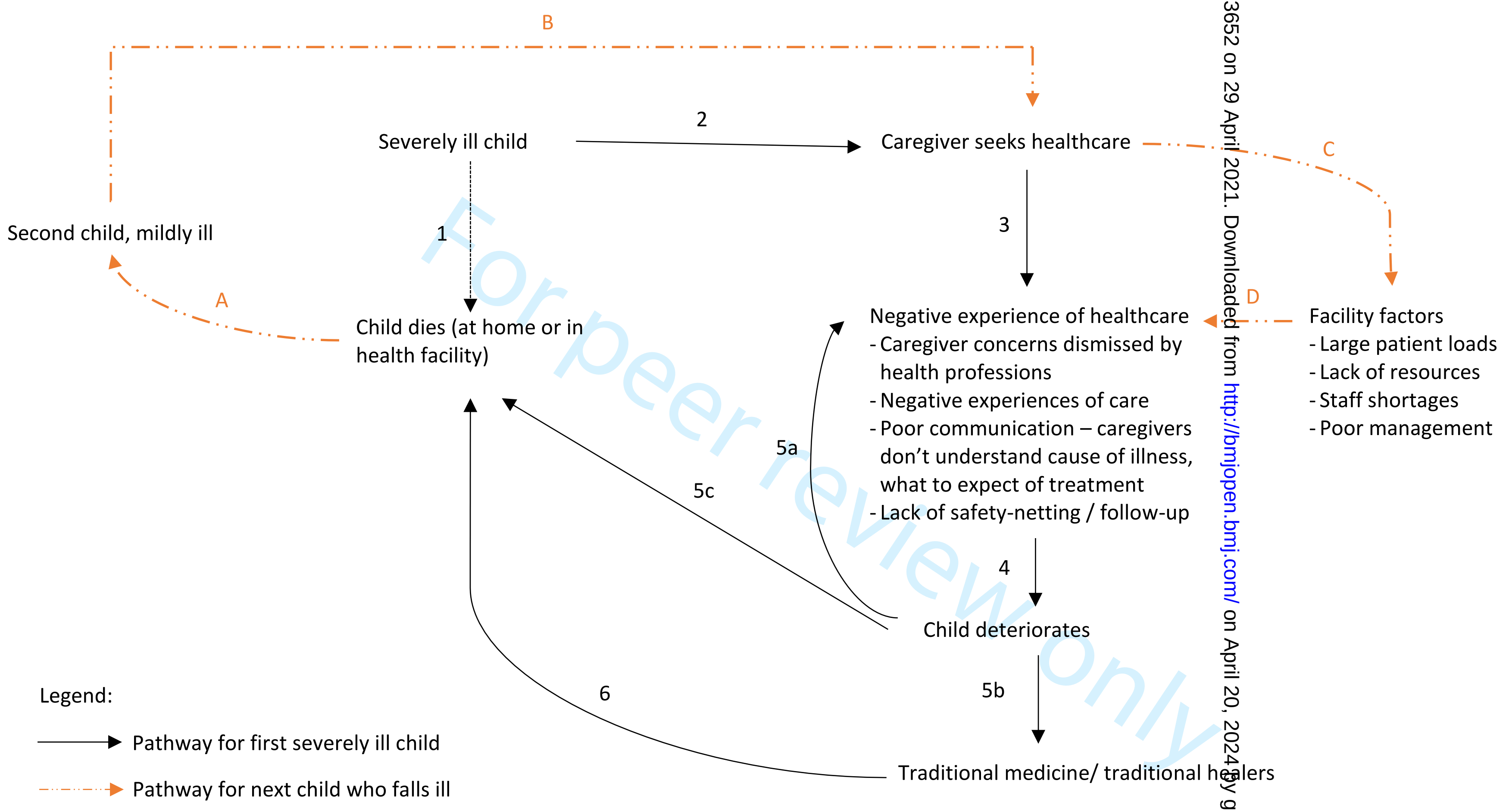

Figure 2: Modified model of the process of seeking and providing healthcare during childhood illness in rural South Africa

Supplementary material: Table S1: Individual participant characteristics

Participant ID	Method: IDI or FGD^Ŧ^	Age group of child who died	Respondent's relationship to deceased child	Place of death	Cause of death	Household socio-economic quintile (1=poorest, 5=least poor)	Sought healthcare outside the home	Used traditional medicine or consulted a traditional healer for child's final illness
1	IDI	1-11 months	Mother	Home	Acute respiratory infection	4	Yes	No
2	IDI	1-11 months	Mother	Home	Acute respiratory infection	3	No	No
3	IDI	1-4 years	Grandmother	Home	Unknown	5	Yes	No
4	IDI	1-4 years	Grandmother	Health facility	Other and unspecified external cause of death	5	Yes	No
5	IDI	1-11 months	Grandmother	Health facility	Acute respiratory infection	2	Yes	No
6	IDI	Neonatal	Grandmother	Health facility	Acute respiratory infection	1	Yes	No
7	IDI	1-4 years	Mother	Health facility	Acute abdomen	3	Yes	No
8**	IDI	Neonatal	Father	On route	Neonatal sepsis	1	Yes	Yes
9	IDI	1-11 months	Father	Health facility	Acute respiratory infection	3	Yes	No
10	IDI	1-4 years	Mother	Home	Burns	1	Yes	No
11	IDI	1-11 months	Mother	Home	Unknown	1	No	No
12	IDI	1-4 years	Aunt	Health facility	Unknown	1	Yes	No
13**	IDI	1-11 months	Mother	Home	Unknown	2	No	No
14	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	2	Yes	No
15	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	3	Yes	No
16	FGD	1-4 years	Grandmother	Health facility	Burns	2	Yes	No
17	FGD	1-4 years	Aunt	Health facility	Acute abdomen	1	Yes	No*
18	FGD	1-11 months	Mother	Health facility	Acute respiratory infection	1	Yes	No
19	FGD	Neonatal	Mother	Health facility	Birth Asphyxia	2	Yes	No
20	IDI	Neonatal	Mother	Health facility	Birth asphyxia	2	Yes	No
21	IDI	1-11 months	Mother	Home	Meningitis or Encephalitis	4	No	No
22	IDI	1-4 years	Mother	Health facility	Unknown	3	Yes	No
23	IDI	1-11 months	Mother	Health facility	Meningitis or Encephalitis	4	Yes	No
24	IDI	1-4 years	Mother	Home	Unknown	4	Yes	No
25	IDI	1-4 years	Mother	Home	Diarrhoeal disease	4	Yes	No
26	IDI	1-4 years	Mother	Home	Unknown	2	Yes	No
27	IDI	Neonatal	Mother	Health facility	Acute respiratory infection	4	Yes	No

Participant ID	**Method: IDI or FGD**Ŧ	**Age group of child who died**	**Respondent's relationship to deceased child**	**Place of death**	**Cause of death**	**Household socio-economic quintile (1=poorest, 5=least poor)**	**Sought healthcare outside the home**	**Used traditional medicine or consulted a traditional healer for child's final illness**
28	IDI	1-4 years	Mother	Home	Unknown	3	No	Yes
29	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	4	Yes	Yes
30	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	3	Yes	Yes
31	IDI	1-11 months	Mother	Home	Unknown	2	Yes	Yes
32	IDI	1-4 years	Mother	Home	HIV/AIDS related death	1	Yes	No
33	IDI	1-11 months	Mother	On route	Diarrhoeal disease	5	No	Yes
34	FGD	1-11 months	Grandmother	Home	Unknown	5	Yes	No
35	FGD	1-11 months	Mother	On route	Diarrhoeal disease	5	Yes	No
36	FGD	1-4 years	Grandmother	Health facility	Severe malnutrition	2	Yes	No
37	FGD	1-11 months	Mother	Home	Diarrhoeal disease	5	Yes	Yes
38	FGD	1-4 years	Mother	Home	Meningitis or encephalitis	5	Yes	No

*This participant did not use traditional medicines or consult a traditional healer, but went to consult "prophets" (considered faith-based healers)

** The respondent was a traditional healer

Ŧ IDI - In-depth Interview; FGD - focus group discussion

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
Purpose or research question - Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	3-4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	3-4
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5-6
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	4
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-9
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-9

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	9-11
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	13-14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

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Care-seeking during fatal childhood illness in rural South Africa - a qualitative study

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ABSTRACT:

Objectives: This study aimed to better understand caregivers' care-seeking experiences, choice of treatment provider and barriers to accessing care during a child's final illness, and why children in South Africa die at home despite seeking formal healthcare.

Design: This qualitative study included semi-structured in-depth interviews and focus group discussions with caregivers of deceased children. Data were thematically analysed, and key findings compared to the Pathways to Survival Framework - a model frequently used in the study of child mortality. An adapted model was developed.

Setting: Two rural health and demographic surveillance system (HDSS) sites in South Africa – the Agincourt HDSS and the Africa Health Research Institute.

Participants: Thirty-eight caregivers of children who died below the age of five years. Caregivers were purposively sampled to ensure maximum variation across place of death, child age at death, household socioeconomic status, maternal migration status and maternal HIV status.

Findings: Although caregivers faced barriers in providing care to children (including insufficient knowledge and poor transport), almost all did seek care from the formal health system. Negative experiences in health facilities did not deter care-seeking, but most respondents still received poor quality care and were not given adequate safety-netting advice. Traditional healers were only consulted as a last resort when other approaches had failed.

Conclusion: Barriers to accessing healthcare disrupt the workings of previously accepted care-seeking models. The adapted model presented in this paper more realistically reflects care-seeking experiences and decision-making during severe childhood illness in rural South Africa and helps explain both the persistence of home deaths despite seeking healthcare, and the impact of a child's death on care-seeking in future childhood illness. This model can be used as the basis for developing interventions to reduce under-5 mortality.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa.
- This study included a diverse sample of caregivers, including fathers and traditional healers whose view are seldom included in studies of child illness and care-seeking.
- Interviews and focus group discussions were conducted in participants' first language (isiZulu or Xitsonga), enabling inclusion of caregivers who did not speak English fluently. However, subtleties of meaning and tone may have been lost in the translation process.
- Interviews and focus group discussions took place at least one year after the child's death, which may have resulted in recall bias.

INTRODUCTION

Under-5 mortality remains a priority in low- and middle-income countries. Despite advances in the care of mothers, newborns and children in resource constrained settings, over 5.3 million children died in 2018 before their fifth birthday globally, 54% of those in sub-Saharan Africa (SSA) [1]. In SSA, over 50% of child deaths occur at home despite many children having contact with the formal healthcare system during their final illness [2–5]. Understanding the factors that contribute to home deaths is critical to designing interventions to reduce under-5 mortality, including those which occur beyond the remit of the formal healthcare sector.

However, investigating home deaths is not easy. It requires community-based approaches rather than facility-based research. The Pathways to Survival Framework [6] is a commonly-used conceptual model for analysing care-seeking processes and demonstrating the fluid interaction between healthcare provided within and outside the home. This model also recognises the use of informal healthcare providers – whether in parallel or in place of formal healthcare providers [6]. A large body of research across SSA has used this model to identify modifiable factors in under-5 deaths highlighting the different stages where children were lost from formal care pathways [2,7–9]. In South Africa specifically, research has highlighted that over 80% of children who died at home had sought formal healthcare during their final illness, of whom about a third sought care more than once [10,11]. Although caregivers' failure to recognise danger signs and lack of transport can explain delayed or lack of treatment-seeking, these factors do not explain why so many children die at home despite having sought care. One modifiable factor may be the low referral rate of children from primary level facilities to higher levels of care [10–13]. Use of informal providers may also contribute to home deaths [14], though the limited quantitative data from South Africa does not support this [10]; and qualitative studies have highlighted that the direction of any association is unclear (as informal providers are often used in conjunction with formal healthcare providers, or may be utilised where formal healthcare providers are difficult to access due to distance, transport or cost and so where other barriers exist that may increase the risk of home deaths, unrelated to the actual use of informal providers [15–18]).

There have been no previous qualitative studies in South Africa to explore reasons for children dying at home, despite having sought care from the formal health care system. Therefore, this paper reports on a qualitative study, that used interviews and focus group discussions to explore caregivers' care-seeking experiences, choice of treatment provider and barriers to accessing care during a child's final illness, and why children die at home despite seeking care.

METHODS

Study design, setting and participants

We conducted a qualitative study using semi-structured in-depth interviews and focus group discussions (FGDs) from July 2018 to January 2019 with caregivers of deceased children, usually the child's mother, however given high levels of temporary migration in the study communities, grandmothers and aunts were sometimes the appropriate respondent.

This research was conducted in two largely rural health and demographic surveillance system (HDSS) sites in South Africa (Agincourt and the Africa Health Research Institute (AHRI)) [19,20]. Together these include over 280 000 people in over 40 500 households, most of which fall into the lowest socioeconomic quintiles nationally. There are high levels of temporary labour migration (33-36%) with household members oscillating between their place of work and rural homes. Most households rely on income from government social grants (including the old age pension and child support grant). Public healthcare facilities comprise primary healthcare clinics (open from 7am to 4pm Monday-Sunday, staffed by nurses) community health centres (open 24 hours Monday-Sunday, staffed by nurses) and district hospitals (open 24 hours Monday-Sunday, staffed by doctors and nurses). Allopathic medical care is also accessible via consultation of private general practitioners in the area. Informal healthcare is provided by traditional and faith healers who operate in each village. These sites are considered representative of the dynamics found across rural South Africa. Both sites routinely conduct verbal autopsies on all deaths to determine probable biological cause of death [19,20]. These were used to identify potential participants.

Participants were recruited using purposive sampling to seek maximum variation. Consideration was given to place of death (at home or in a health facility), age of the child at death, socioeconomic status of the household, whether the child or mother was known to be HIV positive and whether the mother was a temporary migrant at the time of the child's deaths, all of which affect child mortality, place of death, and care-seeking during the final illness [10,21–23]. Sample size was determined by the point at which data saturation was reached [24,25].

Selected participants identified from verbal autopsies were directly approached at their place of residence to participate in this study.

Data collection

Twenty-nine in-depth interviews were conducted by three interviewers to gather personal narratives describing the time around the child's death. Two FGDs (including four participants in Agincourt and five participants in AHRI) produced communal narratives around childhood illness and were used to validate findings from in-depth interviews. The interviewers at each site also mediated each FGD. All interviews and FGDs were conducted between six and 24 months after the child's death, in the participant's first language (either isiZulu or Xitsonga), digitally audio-recorded, and subsequently transcribed and translated into English by the interviewer. A random selection of transcripts were reviewed to ensure accurate translation. All interviewers were from the local communities, trained in qualitative research and each received additional training from JP to work through the topic guide. All were non-medical (i.e. they were not doctors, nurses nor community health workers) thereby minimising the effect of social desirability bias [26] which often leads to under-reporting of traditional medicine use, and may discourage participants from speaking freely about their experiences of the healthcare system (particularly negative experiences).

Data analysis

We undertook thematic analysis [27,28] to identify and analyse the main themes emerging from the interviews and FGDs. The initial a coding scheme was based on the topic guide (deductive codes) (Supplementary material S1) and updated to reflect interview and focus group content (inductive codes) [29]. Related codes were grouped into themes. A sample of six interview transcripts were independently coded by JP and MW to confirm and expand the coding scheme. JP and LH – an experienced social scientist – met to develop the coding frame, whereafter a team meeting was held including JP, MW, LH, AH, JS and KK to agree on a coding framework, which was then used to code all 29 interviews and the focus group discussions. JP, JS and KK have over 30 years combined experience working with these communities and were able to provide context and sensitivity to interpretation of the data. We used the One Sheet of Paper (OSOP) method [27] to summarise each of the codes relating to a given theme, being careful to retain nuances across different accounts to represent both convergent and divergent experiences. Findings from the interviews were validated by presenting them to focus group discussions. We considered data saturation to be reached for the major themes after 10-12 interviews at each study site, and a further three to four interviews per site did not alter the understanding of the main themes.

In developing the analysis, we adapted the Pathways to Survival Framework (figure 1) [6] – which considers care provision within the home and care-seeking outside the home when a child becomes unwell. We demonstrated the stages of the care-seeking process at which each major theme acted, and how caregivers' accounts of the processes of seeking and receiving healthcare in rural South African communities deviated from those outlined in the original model.

We used NVivo 11 (QSR International, Australia) to assist in data management, coding of transcripts and organisation of codes into themes.

Figure 1 here

Ethics

This study was approved by the Oxford Tropical Research Ethics Committee (OxTREC ref: 509-18), the University of the Witwatersrand Human Research Ethics Committee (Medical) (M180102), the Mpumalanga Province Health Research Committee (MP_201804_006) and the University of

KwaZulu-Natal Biomedical Ethics Research Committee (BE259/18). Participants provided written consent to participate.

Data sharing:

To protect confidentiality of participants, anonymised transcripts will only be made available on request.

Patient and public involvement

The community advisory boards at each HDSS site provided input into the study design and assisted with the distribution of findings back to the communities.

RESULTS

Participant characteristics

Respondent demographics and key case details are presented in Table 1 and Supplementary material S2. Of a total of 38 respondents, 29 were parents (27 mothers, two fathers), seven grandmothers and two aunts. Interviews and FGDs detailed events relating to a total of 38 deaths, comprising four neonatal deaths (0-27 days), 16 deaths of infants 1-11 months and 18 deaths of children 1-4 years. Nineteen children had died in health facilities, 16 at home and three on route to a health facility. Overall, 32 caregivers had sought formal healthcare for their child during the child's final illness. Eight caregivers used traditional or faith-based medicines and practices during the final illness, all of whom also sought formal healthcare. A further four indicated that traditional medicines and practices had been used in previous illness episodes for the child or other family members even if not used in the final illness. Three caregivers did not provide home care or seek any formal, traditional or faith-based care outside the home – all were sudden deaths.

*Table 1: Summary of characteristics of respondents and their deceased children**

Characteristic	Total (N=38)		Agincourt (N=19)		AHRI (N=19)	
	n	%	N	%	n	%
Age of the deceased child						
0-27 days (neonate)	4	11	2	11	2	11
1-11 months	16	42	9	47	7	37
12-59 months	18	47	8	42	10	53
Sex of deceased child						
Male	21	55	11	58	10	53
Female	17	45	8	42	9	47
Relationship of respondent to the deceased						
Mother	27	71	10	53	17	89
Father	2	5	2	11	0	0
Grandmother	7	18	5	26	2	11
Aunt	2	5	2	11	0	0
Place of death						
Home	16	42	6	32	10	53
Healthcare facility	19	50	12	63	7	37

On route	3	8	1	5	2	11
Cause of death						
Acute respiratory infection	11	29	8	42	3	16
Diarrhoeal disease	4	11	0	0	4	21
Meningitis/encephalitis	3	8	0	0	3	16
Neonatal conditions	3	8	2	11	1	5
Burns	2	5	2	11	0	0
Other	5	13	3	16	2	11
Unknown	10	26	4	21	6	32
Household socioeconomic quintile within HDSS						
1 (poorest)	8	21	7	37	1	5
2	9	24	5	26	4	21
3	7	18	4	21	3	16
4	7	18	1	5	6	32
5 (least poor)	7	18	2	11	5	26
Mother's HIV status						
Positive	8	21	3	16	5	26
Negative	23	61	14	74	9	47
Unknown/unreported	7	18	2	11	5	26
Mozambican descent	Not totalled		4	21	-	-
Sought formal healthcare outside the home	32	84	16	84	16	84
Used traditional medicine or consulted a traditional healer for child's final illness	6	16	1	5	5	26
Used traditional medicine or consulted a traditional healer for previous childhood illness	10	26	3	16	7	37

* Data for Table 1 is drawn from data collected as part of the routine household survey conducted in each site, as well as data collected specifically as part of this study.

Themes

The main themes to emerge from the analysis relate to (i) caregiver knowledge and advice-seeking, (ii) the use of traditional medicines and practices, (iii) transport barriers, and (iv) experiences of care-seeking during the final illness.

Caregiver knowledge and advice-seeking

Some caregivers seemed not to appreciate the severity of their child's symptoms or comprehend why their child died. As noted by a mother whose child died at home:

> *"He urinated on yellow stuff but, I never thought that he cries because he was sick, I thought it was normal for all the babies."* (Participant 21, mother, child died at home from meningitis/encephalitis).

The same participant also noted:

> *"I can say that if I could have taken my child to the hospital early maybe he would have been fine, because maybe they would have help him; because I never thought, but I just thought it was a normal cry for most of the babies."* (Participant 21, mother, child died at home from meningitis/encephalitis)

When caregivers were uncertain about a child's illness, they sometimes turned to family members, as in the case above, and neighbours for advice in assessing the illness and whether to seek care outside the home. In general, mothers felt such consultations were not about seeking family members' permission to take a given action, but rather consulting them in an exercise of joint decision-making based on a joint assessment of the child's condition. The mother of a child who died at home explained their household's usual processes of assessing child illness and whether further care is needed:

> *"we normally discuss [the child's condition] with whoever is around home" (*Participant 26, mother, child died at home from an unknown cause).

A grandmother explained that both she and the mother were uncertain about the child's illness:

> *"We were sharing ideas on what to do. Even my daughter's sister in-law was also here and she is the one who said that it is better to take the child to the clinic." (Participant 6, grandmother, child died in a health facility from an acute respiratory infection).*

Traditional medicine and practices

Traditional medicine and practices in these settings operate within a complex set of belief systems [30,31]. Most participants reported practicing cultural traditions or rituals related to African ancestral belief systems which underpin their worldview. However, our participants differentiated use of traditional healers and medicine from the much more common practice of cultural rituals and traditions. For example, one mother explained:

> *"Yes, [we practice] the burning of incense, also that we do slaughtering. In most times maybe we slaughter goats when we have something we will be doing…?".*

But this participant also noted

> *"In our church we don't go for traditional healers nor faith healers."* (Participant 25, mother, child died at home from diarrhoeal disease).

The motivations participants described for using traditional medicines and traditional healers varied. Some caregivers admitted to administering traditional enemas as part of the routine care they provide within the home to promote well-being or treat common symptoms of mild illness. One grandmother frequently administered enemas to her grandchildren:

> *"children here at home are being given enemas when the sun is too hot to release the gall. She used to enema them, not only my child but all the kids at home."* (Participant 30, mother, child died in a health facility from an acute respiratory infection).

Other caregivers used traditional enemas despite being aware of advice against this, because they did not seem to know what to do instead and didn't want to do nothing:

> *"It's not easy. They say children should no longer be given enemas. [But] you are also trying to help."* (Participant 35, mother, child died on route to a health facility from diarrhoeal disease).

Caregivers who consulted traditional healers during the child's final illness all did so as a last resort, out of desperation as they did not know what else to do to help their child.

> *"I thought I will go to someone [a traditional healer] to hear what is really happening for I've been to the clinic there were no help, I go to the doctor I get no help"* (participant 24, mother of young child who died at home despite seeking care).

This reasoning was also echoed in FGDs in relation to the use of traditional healers in other illnesses (be that for adults or children):

> *"you can see that maybe you need pills or rubbing ointment and get them, but if it continues…what must you do? Go to a traditional healer to give you something that will relieve you"* (participant 37, mother, child died of diarrhoeal disease at home despite seeking care).

In our study, caregivers did not express a strongly held belief that the illness that had resulted in their child's death had an underlying traditional cause. However, some caregivers indicated that in previous illnesses of their other children or family members, they believed that the cause of the illness was traditional and so sought traditional treatment first, believing it was the most appropriate means of healthcare.

Transport barriers

Caregivers consistently identified a lack of transport as a significant barrier to accessing healthcare. Transport costs could be prohibitive and

> *"there are people who end up not getting to clinic because they don't have money for transport."* (Participant 26, mother, child died at home from an unknown cause).

Participants noted that ambulances were slow or unavailable. Arranging a private car was difficult and often caused delays with disastrous consequences:

> *"I was not having a car by that time. Then we found my wife's father's car. While we were on our way to the hospital around [the village] the car just stopped. We waited for another car to come and assist us. The car came and when we arrived at [the hospital], we found that … I am not sure if the child died at the gate of the hospital or he died inside the hospital, I can't remember. We never got any assistance because he was dead already."* (Participant 9, father, child died on arrival at a health facility from an acute respiratory infection).

Many were ultimately able to overcome the transport barrier, borrowing money from family and neighbours to cover the costs of taxis or hire private cars, or by asking others to help with lifts to the health facilities. But a lack of transport frequently caused a delay in accessing healthcare and was an important consideration in deciding when and where to access healthcare. Participants from the FDGs added that transport barriers were exacerbated at night as

> *"there is no other option but to pay for someone's car and go to [the 24-hour clinic] as it is always open."* (Participant 36, grandmother of child who died in a health facility from severe acute malnutrition).

Experiences of care-seeking during the final illness

Table 2 summarises the specific features of care-seeking interactions during the final illness that caregivers associated with a positive or negative experience. Caregivers had more positive experiences if they perceived tangible interventions or treatments were being offered such as *"giving oxygen"* (participant 37, child died from diarrhoeal disease at home despite seeking care) or giving medication in the form of syrups or injections, and if staff communicated well. Negative experiences were associated with poor communication, being shouted at or blamed for the death by healthcare workers. Caregivers had very low expectations of the healthcare system, so much so that positive experiences of care-seeking were often the result of an *absence* of poor care rather than the *presence* of good care practices. For example, participants were satisfied with a care-seeking interaction when nurses

> *"didn't blame me or say something that was out of line"* (participant 3, child died at home despite seeking care, of unknown cause), and when *"they didn't shout at me"* (participant 21, child died at home without seeking care from meningitis/encephalitis).

However, despite low expectations and negative experiences, caregivers continued to engage with formal health services.

Table 2: Care-seeking experiences

Negative care-seeking experiences	**Positive care-seeking experiences**
Poor communication - Healthcare workers shouting at caregiver - Blaming caregiver for death - Failing to take caregivers' opinions seriously - Not explaining what procedure is being performed or why it is being performed - Not explaining which treatment was being given or why it was being given - Not providing safety-netting advice - Not explaining the cause of death	Good communication - Respect for caregivers' opinion and knowledge of a change in the child's condition - Offering safety-netting advice - Not being shouted at
Inattentive staff - Distracted by mobile phones while seeing patients, or while patients are waiting to be seen - Taking lunch when still many patients to see - Not coming to review patient when caregiver alerts them to a change in the child's condition - Sense that nurses are not "passionate" about their jobs (particularly younger nurses).	Tangible sense of "being treated" - Receiving interventions (Drips, injections, tablets, oxygen, bandages) - Physical examination performed by the nurse or doctor
Delays or waiting: - Ambulance transport very delayed in arrival	Timings - Seen and treated immediately or urgently, skipping the queues - Ambulance arriving quickly

Communication clearly influenced caregivers' experience of care. Features of good communication included demonstrating respect for the caregiver's knowledge of their child, explaining what procedures or treatments were being administered and not shouting at or blaming caregivers. As one mother recalled:

> *"The nurses from [the hospital] communicate with you as the children's parents, ask how the child is and what changes you see or that you don't see change."* (Participant 22, grandmother, child died in a health facility of unknown cause*).*

Unfortunately most caregivers experienced poor communication and reported that healthcare workers were hostile, rude and dismissive, shouted at caregivers for bringing children at the wrong time (either too late in the day, or at the weekend) and blamed caregivers for the child's illness – especially if traditional medicine was used - saying they *"killed the child."* (Participants 30, mother, child died a health facility of an acute respiratory illness and participant 36, grandmother, child died in a health facility of severe acute malnutrition).

In some cases, healthcare workers were dismissive of caregivers' concerns, despite caregivers being sure that something was seriously wrong with their child. The mother of a child who died at home was worried:

> *"I woke up with him in that morning and he was not fine"*.

She took her child to the clinic, but the nurses dismissed her *saying*

> *"they don't work on nominals [meaning non-emergency patients] on Sunday."* (Participant 25, mother, child died from diarrhoeal disease at home despite seeking care).

Despite waiting many hours at the clinic, the staff refused to assess the child and eventually she left the facility *"bare handed"*. A father whose neonate was crying constantly, not eating or drinking, explained that *"we didn't get any help from the clinic"* (participant 8, father of neonate, died on route to heath facility from neonatal sepsis) after he and his wife were dismissed by nurses.

Safety-nets were another important part of communication: one father recalled

> "(the GP) *told us that he is going to give us some medication that we need to go and give to the child. He also said to us as it is Monday today, if you don't see any changes on Tuesday, please come back.*" (Participant 8, father of neonate, died on route to heath facility from neonatal sepsis).

This experience was in contrast to the experiences of most other participants, for whom poor communication was the norm and who did not recall being given any advice about what danger signs to look out for and when to come back for review. This implies that many caregivers did not know what they should expect of the treatment or that the child might deteriorate despite receiving medication and need to return to the healthcare facility.

Poor communication also resulted in caregivers failing to understand why their child had died. This left caregivers feeling anxious, often doubting their own assessment of the child's condition, and they lost confidence in their ability to assess and manage future child illness (even mild cases), and internalised blame for the child’s death. Many caregivers said that, following their child’s death, they now relied fully on clinic staff to assess the severity of their other children’s illnesses and provide treatment guidance:

> *“I don’t do anything by myself. I take the child to the clinic. Even if it can be something that I know, I do take the child to the clinic… because of what happened to me last time, I think that something like that can happen again.”* (Participant 13, mother and traditional healer, child died at home without seeking care of unknown cause).
>
> *“For me, I use the clinic a lot because I learnt a lesson with the one that died. When they have a little cough or diarrhoea, no-one tells me, I put one on my back and pull the other by the hand to the clinic, I no longer make a mistake.”* (Participant 37, mother of a child who died at home of diarrhoeal disease despite seeking care). “
>
> *“I encourage the clinic because I have buried other children”* (participant 36, grandmother, child died in a health facility from severe acute malnutrition)

Despite their negative experience of care-seeking, fear of further vindictive treatment discouraged caregivers from complaining about the quality of care or asking questions related to the diagnosis or management of their child, but did not seem to discourage them from seeking care. Caregivers felt they would *“regret”* asking questions (participant 35, mother, child died on route to a health facility from diarrhoeal disease) and that

> *“it’s better to shut up and when a nurse talks bad to you say no word in return. Because some of the time you will find that when you reply, he/she will not give your child a proper treatment”* (participant 25, mother, child died from diarrhoea disease at home despite seeking care).

In summary, caregivers’ knowledge of childhood illness varied – with some unable to identify severe illness in their child or appreciate the urgency of the need for healthcare. Traditional medicine was utilised by some caregivers, though rarely as a first port-of-call. When used as part of home care, caregivers suggested that they turned to traditional medicines as something familiar, even when they did not identify a traditional cause of their child’s illness. Transport barriers remain significant: cost, limited minibus-taxi times and having to arrange to hire or borrow private cars caused delays in accessing healthcare. Finally, caregivers’ low expectations of the healthcare system coloured their experiences of seeking healthcare during their child’s final illness, often lending a positive lens to the experience where it merely exceeded the lowest of expectations. However, many still experienced the healthcare system negatively. Care-seeking interactions were often characterised by disrespectful and dismissive staff, even where caregivers clearly recognised that their child was ill, and a lack of explanation of the child’s illness, treatments and safety-netting advice.

DISCUSSION

This study highlighted the multiple barriers faced by caregivers in providing care to children within the home, and seeking and receiving care outside the home including a lack of knowledge and limited transport. In spite of these, almost all did seek care from the formal health system, though most respondents reported negative experiences in health facilities and few were given adequate safety-netting advice. However, such experiences did not deter care-seeking. Traditional healers were only consulted as a last resort when other approaches had failed. As such, existing models of care-seeking must be adapted to reflect caregivers' realities.

Adapting the Pathways to Survival Framework

Figure 1 shows a the Pathways to Survival Framework [6]. Many of the key issues identified by participants are overlaid on this model, demonstrating the stage and manner in which these issues act as barriers to accessing high quality healthcare. We found that transport delays are an important issue, in contrast to findings from standard quantitative verbal and social autopsies in this context (which likely reflects that the quantitative survey questions are framed too broadly) [2]. Given the barriers that caregivers in this study experienced at each stage of the care pathway, we believe that the care-seeking process in rural South Africa more closely resembles the model shown in figure 2.

Figure 2 here

Following this model, we start with a severely ill child (pathway indicated by black arrows). In some cases, caregivers lacking knowledge might not recognise the illness, or the child dies suddenly before any care can be given and so the child dies at home without care (indicated by arrow 1). However, in many cases the caregiver identifies signs of illness, and provides care within the home (whether allopathic or traditional) (step 2). In severe illness, the caregiver also appropriately seeks healthcare for the child outside the home (step 3). For a series of reasons, caregivers have a negative experience at the healthcare provider (step 4). When the child deteriorates (step 5) caregivers' responses may differ: some might re-seek care, though often going to a different provider (either to a different clinic, to a private GP or to a hospital) (step 6a). Some believe that the failure to improve having received allopathic treatment must indicate that this is a traditional problem and so seek out traditional healers (step 6b). Others are either unable to re-seek care, or believe that having seen a healthcare professional already, there is nothing more to be done (step 6c). Ultimately the child dies (whether at home or in a health facility) (steps 6c, 7). Although depicted as a broadly linear model for ease of understanding, caregivers may simultaneously seek care from multiple providers (both formal and informal).

In addition to more accurately describing the care pathway for fatal child illness in rural South Africa as experienced by caregivers, our proposed model is the first to offer insights into what follows a child's death in the context of poor caregiver knowledge of childhood illness, both in identifying signs of severe illness and in understanding why the child died (pathway indicated by orange dashed arrows). Following the death of their child, caregivers lose confidence in their ability to identify severe child illness (arrow A) and become reliant on healthcare workers to identify disease and guide treatment (arrow B). This is true even for very mild childhood illness which could be adequately managed at home. As a result, there is a growing burden on the health system, whereby mildly unwell children are also brought to the clinic (as has been described in work by Horwood et al [32]), exacerbating the existing supply-side barriers to high quality care (staff shortages, resource limitations, poor management, long waiting times etc [33]) (arrow C) and perpetuating negative experiences of care (arrow D).

Our model also highlights the role of traditional healers and traditional medicine use in South Africa. While participants admitted to continued use of traditional medicines (traditional enemas in particular), their motivations largely reflect a familiarity with these treatment methods and a trust in their value based on a shared world view. Traditional treatments such as enemas (which may include herbal administrations, toothpaste, water and dishwashing liquid) are a common treatment in South Africa used in both preventative and curative traditional healthcare [34,35], and were part of a repertoire of home treatments upon which caregivers drew when their child was ill. Of note, traditional healers were typically not the first port of call when seeking care for fatal child illness, though were consulted if child was not improving after seeking formal medical care. This is in keeping with work elsewhere in Africa which shows that use of traditional healers as the first treatment provider is declining over time[36]. There was a sense of desperation in caregivers' desire to try all options to help their child. This understanding has significant implications for interventions: it is clearly not a question of blame – caregivers' intentions were to help the child, not to harm. Furthermore, in this study, caregivers did not clearly identify or name a specific traditional cause of disease that they were trying to treat, though other work in South Africa and sub-Saharan Africa found that many caregivers believe in alternate traditional explanations for specific disease symptoms - such as convulsions associated with cerebral malaria - and so preferentially seek traditional care when such illnesses are identified [37–39].

The adapted model is similar to the scenario reported by Sharkey et al (2011), whereby repeated negative experiences of care result in care seeking from multiple service providers and use of traditional healers (though not as the first port of call) [18]. However, Sharkey et al suggest that this pattern demonstrated a distrust in the formal healthcare system; in contrast we did not find evidence to support a loss of trust in formal healthcare providers. This may reflect differences in the degree of community and caregiver empowerment, caregiver education, or differences in rural and urban communities (with urban caregivers in their study seeking care more frequently and from more providers than those from rural areas). Furthermore, their model does not describe care-seeking for future child illness, emphasising the value of this adapted model in understanding care-seeking behaviours in rural South African contexts.

Social exclusion

Amartya Sen's work on social exclusion [40] may help explain caregivers' response of growing (rather than declining) use of the formal healthcare system despite repeated negative experiences and low expectations of the quality of care they are likely to receive. Sen argues that impoverishment extends beyond the material and includes non-material elements (also called capabilities) which are critical to the freedom to access opportunities [40].

In the South African public healthcare context, negative engagements with health professionals undermine caregivers' ability to claim a minimum standard of healthcare by reinforcing perceptions of social exclusion which feed into their lived experience of poverty. This also helps explain the persistently low expectations of the healthcare system that were implicit in many of the respondents' comments. This behaviour is described elsewhere in the South African healthcare system in relation to maternal care-seeking and institutional delivery. Verbal and physical abuse of labouring mothers by nursing staff is well documented across South Africa [41], however mothers have come to normalise nurses' aggressive language as a means of coping with the situation, and as a result may no longer feel that it is unacceptable or offensive [42].

In our study, one caregiver exemplified this, referring to their child's death as "*their mistake*", rather than recognising that there were multiple failures throughout the healthcare system that contributed to the child's death. The internalisation of self-doubt and self-blame for the child's death my be explained by capacity deprivation and social exclusion driven by the negative experiences of care-seeking. Consequently, caregivers lose confidence in their assessment of illness severity. Instead of doubting the healthcare system, or even turning away from it, caregivers delegate more of the assessment and management of their children to health professionals.

Policy Implications and priorities for further research

Our adapted care-seeking model highlights the urgent need to empower caregivers, building confidence in seeking and providing appropriate healthcare for their children both within and outside the home, and increasing expectations of the quality of care they receive. Policy implications therefore include improved communication strategies with specific emphasis on providing safety netting information at every consultation and encouraging caregivers to ask questions about their child's diagnosis and treatment. Behaviour change programmes targeting staff attitudes have been successful when trialled at individual facilities [43,44]. Strategies to provide such programmes at scale should be prioritised. Finally, community mobilisation programmes using Women's Groups and Care Groups have been shown to effectively improve neonatal and child health, improving caregiver knowledge and capability [45–48]. As investment in community health worker programmes is extended, consideration should be given to their role in mobilising such groups within the communities they serve.

Further research is needed to understand in which circumstances parents react to a child death by increasing their use of health services for minor illnesses in subsequent children, or by not seeking treatment from formal health services until the illness becomes severe. We would also recommend research to elucidate the care pathway for severely ill children who improve, as this may provide valuable insights into those factors which promote positive outcomes. Further qualitative research is also needed to understand why traditional enemas are so commonly used for home treatment of childhood illnesses in South Africa, while they are not so commonplace elsewhere. This could help to inform the development of interventions to improve the use of home treatments and treatment-seeking behaviour for children in South Africa.

Strengths and limitations

This study had four important strengths, and corresponding limitations. First, all interviews and FGDs were conducted in participants' first language (isiZulu or Xitsonga). This encouraged participation of individuals who might otherwise have refused or been unable to participate in the study if all data collection had been in English or via an interpreter. However, it is possible that some of the subtilties of the meaning and tone of the conversation were lost during translation of the interviews into English. Second, interviews were conducted at least one year after the death of the children in question, but in some cases two to three years after the child's death. Most caregivers had therefore grieved the loss of their child and the risk of the study causing significant emotional distress was lower. However, this time delay also introduced the potential for recall bias. We tried to reduce the impact of this by concentrating on caregiver's impressions of healthcare services and how they felt about their care-seeking experiences and less on precise timings or medications prescribed. Third, our sampling strategy allowed us to capture a diverse set of opinions and included fathers and traditional healers who were the primary caregivers of the child during their final illness – both of whom are generally under-represented in research on childhood illness [49,50]despite being important stakeholders, contributing to decision-making and caregiving, often holding positions of authority within the household and community and sometimes acting as gatekeepers to care. Fourth, caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa. This model contributes to the literature on theories of care-seeking and access to healthcare and can be used as a basis for further research on childhood illness and intervention development to reduce child mortality. However, the adapted model may be context-specific and would require further validation in other settings before it is more widely applied.

CONCLUSION

Repeated negative experiences of care-seeking in the context of poverty and social exclusion can disempower caregivers and limit their ability to claim a minimum standard of healthcare. This realisation is critical in refining our thinking around care-seeking. It helps to explain why children die at home despite having sought formal healthcare during fatal childhood illness, and why traditional healers are consulted even when caregivers do not identify a traditional cause of illness. Interventions designed to empower caregivers - including improved communication and safety netting, changing staff attitudes and community mobilisation - should be prioritised as part of a wider strategy to reduce child mortality.

FUNDING

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AUTHOR CONTRIBUTIONS

JP, LH, MW, KK and AH conceived and designed the study. VD, AK and PK conducted, transcribed and translated the interviews and FGDs. JP, MW and LH analysed the data with input from KK, JS, VD, AK and PK. JP and LH led the writing of the manuscript. All author contributed to, and critically revised it.

CONFLICTS OF INTEREST

The authors do not declare any conflicts of interest

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FIGURES AND CAPTIONS:

Figure 1: Adaptation of the Pathways to Survival Framework showing those modifiable factors identified by participants within and outside the home, and the stage of the pathway at which each factor acts.

Figure 2: Modified model of the process of seeking and providing healthcare during childhood illness in rural South Africa.

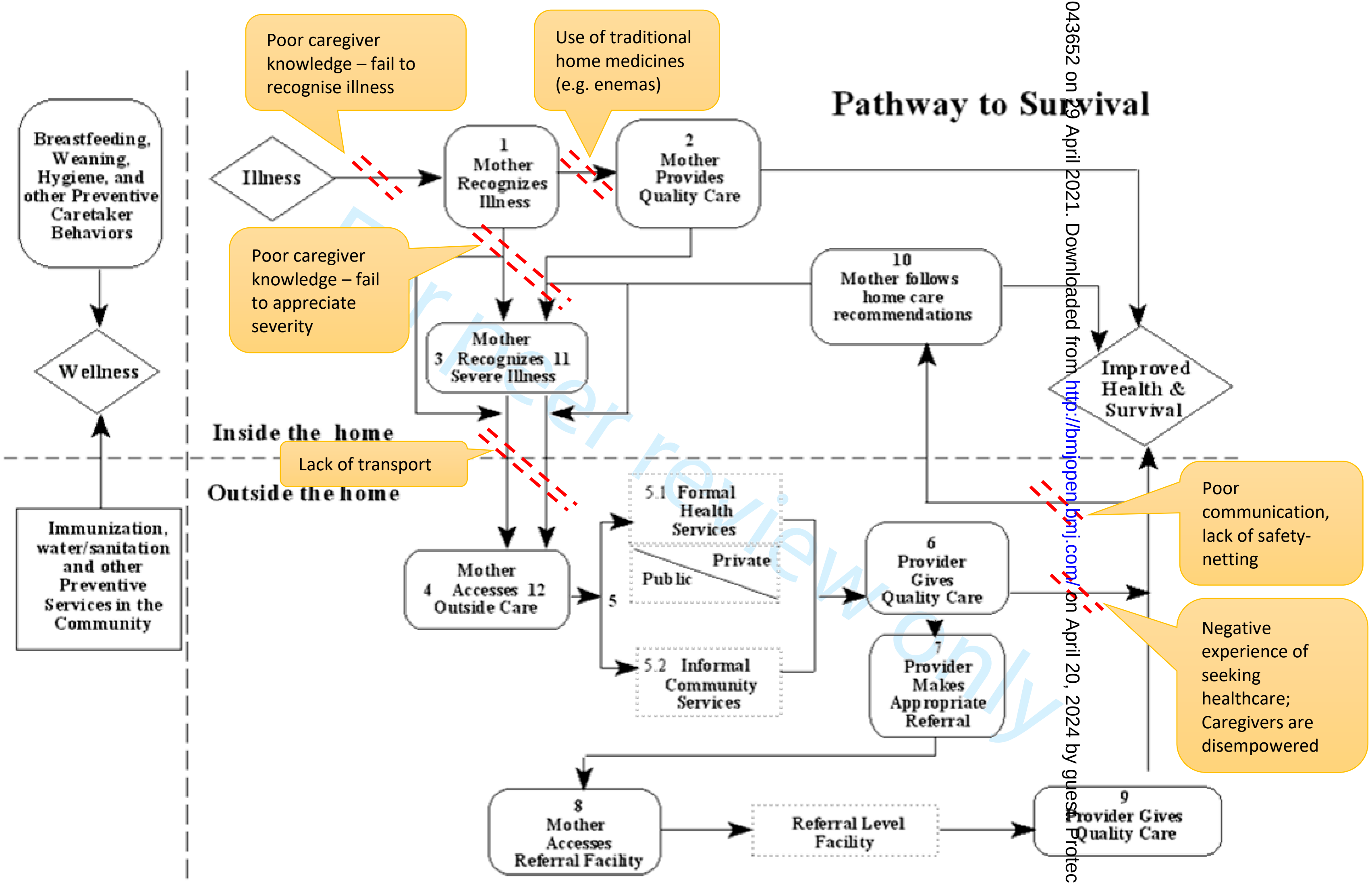

Figure 1: *Adaptation of the Pathways to Survival Framework showing those modifiable factors identified by participants within and outside the home, and the stage of the pathway at which each factor acts.*

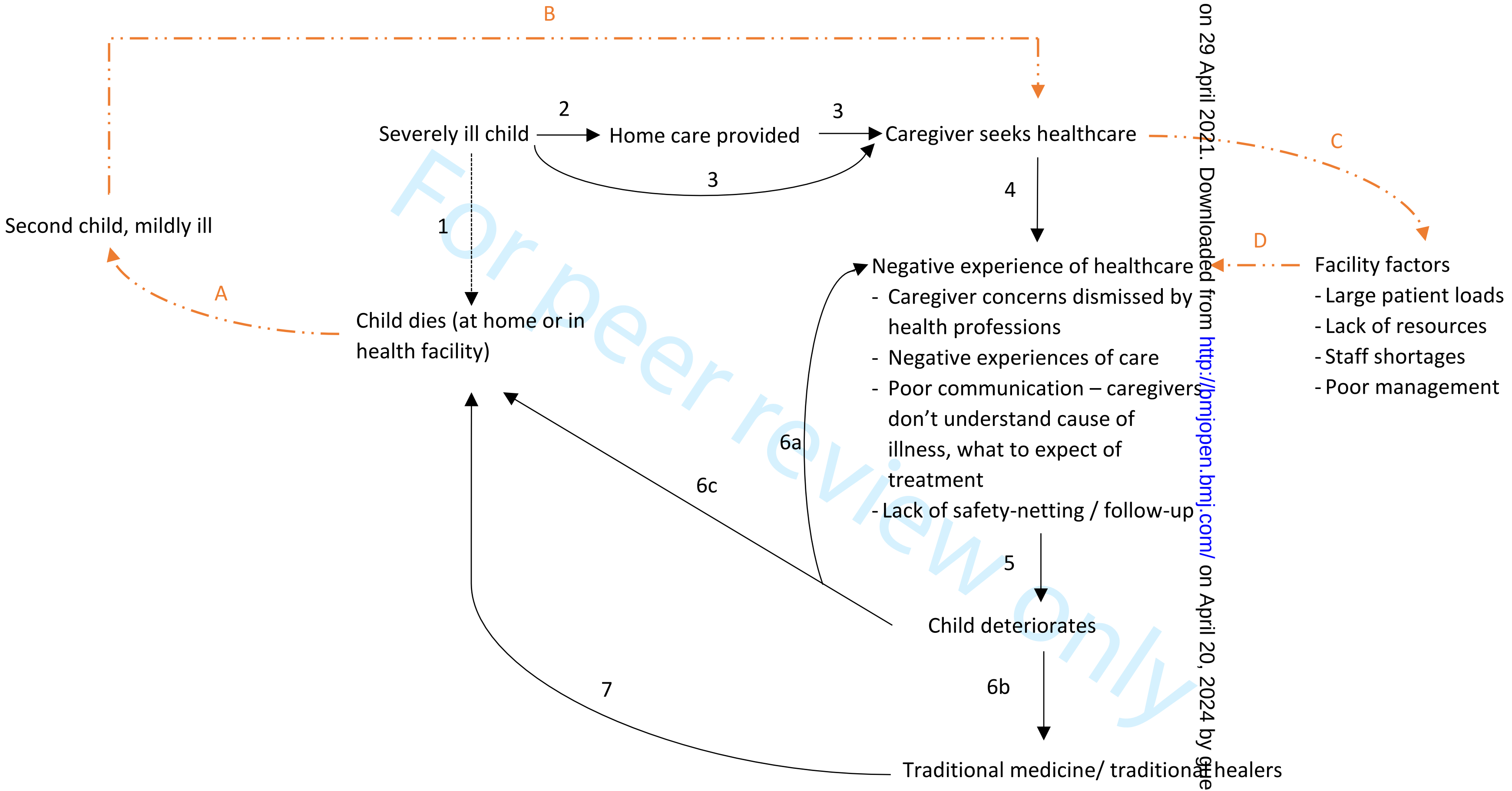

Figure 2: Modified model of the process of seeking and providing healthcare during childhood illness in rural South Africa.

Supplementary Material S1: Interview Guide

Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

****** *This interview guide was developed following extensive reading around the topic. discussions with experienced social scientists (LH and JS), as well as context experts (KK and JS), and population-based research conducted in the Agincourt and AHRI HDSS sites on under-5 mortality, including the completion of verbal and social autopsies for all under-5 deaths in the HDSS sites to better understand the circumstances of death and barriers to accessing healthcare during the final illness.*

Interview Guide (Key Informant Interviews):

*Note: Consent to be taken before starting the interview. Interviewer to then start by introducing themselves, reminding the participant they will be audio-recorded, they can refuse to answer any questions and/or pause the interview.

Possible introductions:

"I want to talk about your child's death but before we talk about that, I would like to ask a few general questions to understand more about your family and your daily life".

1) Respondent's relationship to the child
2) Family structure, how many members in the household, how many children, and how old are they, anyone working, any previous deaths in the household (esp child deaths).
3) Relationship to community, do they feel close to the community, are they well integrated?
4) Religion, and role of religion in daily life.
5) For Agincourt and if Mozambican: how do you think being Mozambican affects your daily life here? How does it affect your experience and access to health care?

"I have some questions about your child's death that I want to ask but I am really interested in hearing about your experience in your own words. I expect that some of my questions will be answered in your story, so I would like to hear from you first. "

1) Can you tell me about your child's final illness? About how it started, when you first started noticing symptoms, what you did etc. (allow participant to finish their story without interruption. If not supplied, then probe for symptoms recognised, what they did in response to those symptoms, where they sought care and when)

2) Can you tell me about your experience of seeking care?

   a. Explore where they went for care
   b. Why did they choose to go where they did?
   c. (if Mozambican: might probe with :do you think your experience of seeking care was in any way related to your being Mozambican?”

3) How did the staff treat you?

   (Probe for positive and negative experiences, how did the staff treat them, were they made to wait, were they allowed to stay with their children during any treatments/procedures – and did they like this or not?)

   *If they didn’t seek care, explore issues around why they didn’t access care.

   *any causes of major delays in seeking care

4) What treatment did you get from the provider? What advice did the provider give you? Were your referred somewhere else?

5) Explore whether they completed/complied with the treatment, why or why not, if referred did they take up the referral?

6) Traditional medicine used/visited traditional healer? - why?

7) Can you tell me about any challenges you faced in accessing healthcare? Is there anything that made is difficult to get healthcare?

8) Why did you go to your chosen healthcare facility or provider?

9) How did you overcome those difficulties?

10) Were you satisfied with the care you were offered? Is there anything that could have been done better?

11) Is there anything else you want to tell me?

Supplementary material: Table S2: Individual participant characteristics

Participant ID	Method: IDI or FGD[Ŧ]	Age group of child who died	Respondent's relationship to deceased child	Place of death	Cause of death	Household socio-economic quintile (1=poorest, 5=least poor)	Sought healthcare outside the home	Used traditional medicine or consulted a traditional healer for child's final illness
1	IDI	1-11 months	Mother	Home	Acute respiratory infection	4	Yes	No
2	IDI	1-11 months	Mother	Home	Acute respiratory infection	3	No	No
3	IDI	1-4 years	Grandmother	Home	Unknown	5	Yes	No
4	IDI	1-4 years	Grandmother	Health facility	Other and unspecified external cause of death	5	Yes	No
5	IDI	1-11 months	Grandmother	Health facility	Acute respiratory infection	2	Yes	No
6	IDI	Neonatal	Grandmother	Health facility	Acute respiratory infection	1	Yes	No
7	IDI	1-4 years	Mother	Health facility	Acute abdomen	3	Yes	No
8**	IDI	Neonatal	Father	On route	Neonatal sepsis	1	Yes	Yes
9	IDI	1-11 months	Father	Health facility	Acute respiratory infection	3	Yes	No
10	IDI	1-4 years	Mother	Home	Burns	1	Yes	No
11	IDI	1-11 months	Mother	Home	Unknown	1	No	No
12	IDI	1-4 years	Aunt	Health facility	Unknown	1	Yes	No
13**	IDI	1-11 months	Mother	Home	Unknown	2	No	No
14	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	2	Yes	No
15	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	3	Yes	No
16	FGD	1-4 years	Grandmother	Health facility	Burns	2	Yes	No
17	FGD	1-4 years	Aunt	Health facility	Acute abdomen	1	Yes	No*
18	FGD	1-11 months	Mother	Health facility	Acute respiratory infection	1	Yes	No
19	FGD	Neonatal	Mother	Health facility	Birth Asphyxia	2	Yes	No
20	IDI	Neonatal	Mother	Health facility	Birth asphyxia	2	Yes	No
21	IDI	1-11 months	Mother	Home	Meningitis or Encephalitis	4	No	No
22	IDI	1-4 years	Mother	Health facility	Unknown	3	Yes	No
23	IDI	1-11 months	Mother	Health facility	Meningitis or Encephalitis	4	Yes	No
24	IDI	1-4 years	Mother	Home	Unknown	4	Yes	No
25	IDI	1-4 years	Mother	Home	Diarrhoeal disease	4	Yes	No
26	IDI	1-4 years	Mother	Home	Unknown	2	Yes	No
27	IDI	Neonatal	Mother	Health facility	Acute respiratory infection	4	Yes	No

Participant ID	**Method: IDI or FGD**Ŧ	**Age group of child who died**	**Respondent's relationship to deceased child**	**Place of death**	**Cause of death**	**Household socio-economic quintile (1=poorest, 5=least poor)**	**Sought healthcare outside the home**	**Used traditional medicine or consulted a traditional healer for child's final illness**
28	IDI	1-4 years	Mother	Home	Unknown	3	No	Yes
29	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	4	Yes	Yes
30	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	3	Yes	Yes
31	IDI	1-11 months	Mother	Home	Unknown	2	Yes	Yes
32	IDI	1-4 years	Mother	Home	HIV/AIDS related death	1	Yes	No
33	IDI	1-11 months	Mother	On route	Diarrhoeal disease	5	No	Yes
34	FGD	1-11 months	Grandmother	Home	Unknown	5	Yes	No
35	FGD	1-11 months	Mother	On route	Diarrhoeal disease	5	Yes	No
36	FGD	1-4 years	Grandmother	Health facility	Severe malnutrition	2	Yes	No
37	FGD	1-11 months	Mother	Home	Diarrhoeal disease	5	Yes	Yes
38	FGD	1-4 years	Mother	Home	Meningitis or encephalitis	5	Yes	No

*This participant did not use traditional medicines or consult a traditional healer, but went to consult "prophets" (considered faith-based healers)

** The respondent was a traditional healer

Ŧ IDI - In-depth Interview; FGD - focus group discussion

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
Purpose or research question - Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	3-4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	3-4
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5-6
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	4
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-9
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-9

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	9-11
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	13-14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

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Care-seeking during fatal childhood illness in rural South Africa - a qualitative study

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ABSTRACT:

Objectives: This study aimed to better understand reasons why children in South Africa die at home, including caregivers' care-seeking experiences, decision-making, choice of treatment provider, and barriers to accessing care during a child's final illness.

Design: This qualitative study included semi-structured in-depth interviews and focus group discussions with caregivers of children who died below the age of five years. Data were thematically analysed, and key findings compared to the Pathways to Survival Framework - a model frequently used in the study of child mortality. An adapted model was developed.

Setting: Two rural health and demographic surveillance system (HDSS) sites in South Africa – the Agincourt HDSS and the Africa Health Research Institute.

Participants: Thirty-eight caregivers of deceased children (29 participated in in-depth interviews and nine were participants in two focus group discussions). Caregivers were purposively sampled to ensure maximum variation across place of death, child age at death, household socioeconomic status, maternal migration status, and maternal HIV status.

Findings: Although caregivers faced barriers in providing care to children (including insufficient knowledge and poor transport), almost all did seek care from the formal health system. Negative experiences in health facilities did not deter care-seeking, but most respondents still received poor quality care and were not given adequate safety-netting advice. Traditional healers were only consulted as a last resort when other approaches had failed.

Conclusion: Barriers to accessing healthcare disrupt the workings of previously accepted care-seeking models. The adapted model presented in this paper more realistically reflects care-seeking experiences and decision-making during severe childhood illness in rural South Africa and helps explain both the persistence of home deaths despite seeking healthcare, and the impact of a child's death on care-seeking in future childhood illness. This model can be used as the basis for developing interventions to reduce under-5 mortality.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for fatal childhood illness in rural South Africa.
- This study included a diverse sample of caregivers, including fathers and traditional healers whose views are seldom included in studies of child illness and care-seeking.
- Interviews and focus group discussions were conducted in participants' first language (isiZulu or Xitsonga), enabling inclusion of caregivers who did not speak English fluently. However, subtleties of meaning and tone may have been lost in the translation process.
- Interviews and focus group discussions took place at least one year after the child's death, which may have resulted in recall bias.

INTRODUCTION

Under-5 mortality remains a priority in low- and middle-income countries. Despite advances in the care of mothers, newborns and children in resource constrained settings, over 5.3 million children died in 2018 before their fifth birthday globally, 54% of those in sub-Saharan Africa (SSA) [1]. Moreover, in SSA, over 50% of child deaths occur at home despite many children having contact with the formal healthcare system during their final illness [2–5]. Understanding the factors that contribute to home deaths is critical to designing interventions to reduce under-5 mortality in SSA, including those which occur beyond the remit of the formal healthcare sector.

A large body of research across SSA has drawn on the Pathways to Survival Framework [6] in an attempt to analyse under-5 deaths [2,7–9]. This approach has a number of advantages; it demonstrates the fluid interaction between healthcare provided within and beyond the home, recognising too the role of informal healthcare providers, whether alongside or in place of formal providers. The model has been used to highlight the different stages at which children were lost from formal care pathways [2,7–9]. In South Africa specifically research has highlighted that over 80% of the carers of children who died at home had sought formal healthcare during the child's final illness, of whom about a third sought care more than once [10,11]. One modifiable factor may be the low referral rate of children from primary level facilities to higher levels of care [10–13]. Use of informal providers including traditional healers may also contribute to home deaths [14], though the limited quantitative data from South Africa does not support this [10]; and qualitative studies have highlighted that the direction of any association is unclear (as informal providers are often used in conjunction with formal healthcare providers, or may be utilised where formal healthcare providers are difficult to access due to distance, transport or cost and so where other barriers exist that may increase the risk of home deaths, unrelated to the actual use of informal providers [15–18]).

There have been no previous qualitative studies in South Africa to explore reasons for children dying at home. This paper reports on one such study, using the findings to adapt the Pathways to Survival Framework, which helps to identify key sites of intervention in tackling the problem of child death at home.

METHODS

Study design and setting

We conducted a qualitative study using semi-structured in-depth interviews and focus group discussions (FGDs), from July 2018 to January 2019, with caregivers of children who died under the age of five years.

This research was conducted in two largely rural health and demographic surveillance system (HDSS) sites in South Africa (Agincourt in Mpumalanga province and the Africa Health Research Institute (AHRI) in KwaZulu-Natal) [19,20]. These sites are considered broadly representative of the dynamics found across rural South Africa. Together these sites include over 280 000 people in over 40 500 households, most of which fall into the lowest socioeconomic quintiles nationally. In Agincourt, most residents speak Xitsonga, while in AHRI isiZulu is predominant. Routine household surveys are conducted every 4 months (in AHRI) and annually (in Agincourt) to update household rosters, record births, deaths, pregnancy outcomes, migrations, education level of each household member, household assets, income sources and employment status. There are high levels of temporary labour migration (33-36%) with household members oscillating between their place of work and rural homes. Most households rely on income from government social grants (including the old age pension currently valued at R1860 per month ($180) and child support grant (R450/$30 per month)). Public healthcare facilities comprise primary healthcare clinics (open from 7am to 4pm Monday-Sunday, staffed by nurses) community health centres (open 24 hours Monday-Sunday, staffed by nurses) and district hospitals (open 24 hours Monday-Sunday, staffed by doctors and nurses). Allopathic medical care is also accessible from private general practitioners in the area. Informal healthcare is provided by traditional and faith healers who operate in each village. Both sites routinely conduct verbal autopsies (VAs) on all deaths to determine probable biological cause of death [19,20].

Sampling

All under-5 deaths where a VA was completed in 2017, were eligible for inclusion in this study. Participants were recruited using purposive sampling to seek maximum variation, based on relevant demographic details from the completed VA and household survey. Consideration was given to place of death (at home or in a health facility), age of the child at death, socio-economic status of the household, whether the child or mother was known to be HIV-positive and whether the mother was a temporary migrant at the time of the child's deaths, all of which affect child mortality, place of death, and care-seeking during the final illness [10,21–23]. Sample size was determined by the point at which data saturation was reached [24,25].

Selected participants were directly approached at their place of residence to participate in this study. The most appropriate respondent was usually the child's mother. However, given high levels of temporary migration in the study communities, grandmothers and aunts were sometimes more appropriate.

Data collection

In-depth interviews were conducted by three interviewers to gather personal narratives describing the time around the child's death. FGDs (facilitated by the same interviewers) produced communal narratives around childhood illness and were used to validate findings from in-depth interviews. All interviews and FGDs were conducted between six and 24 months after the child's death, in the participant's first language (either isiZulu or Xitsonga), digitally audio-recorded, and subsequently transcribed and translated into English by the interviewer. A random selection of transcripts were reviewed to ensure accurate translation. All interviewers were from the local communities, trained in qualitative research, and each received additional training from JP to work through the topic guide. All were non-medical (i.e. they were not doctors, nurses or community health workers) thereby minimising the effect of social desirability bias [26] which often leads to under-reporting of traditional medicine use, and may have discouraged participants from speaking freely about their experiences of the healthcare system (particularly negative experiences).

Data analysis

We undertook thematic analysis [27,28] to identify and analyse the main themes emerging from the interviews and FGDs. The initial coding scheme was based on the topic guide (deductive codes) (Supplementary material S1) and updated to reflect interview and focus group content (inductive codes) [29]. Related codes were grouped into themes. A sample of six interview transcripts were independently coded by JP and MW to confirm and expand the coding scheme. JP and LH – an experienced social scientist – met to develop the coding frame, whereafter a team meeting was held including JP, MW, LH, AH, JS and KK to agree on a coding framework, which was then used to code all 29 interviews and the focus group discussions. JP, JS and KK have over 30 years combined experience working with these communities and were able to provide context and sensitivity to interpretation of the data. We used the One Sheet of Paper (OSOP) method [27] to summarise each of the codes relating to a given theme, being careful to retain nuances across different accounts to represent both convergent and divergent experiences. Findings from the interviews were validated by presenting them to focus group discussions. We considered data saturation to be reached for the major themes after 10-12 interviews at each study site, and a further three to four interviews per site did not alter the understanding of the main themes.

In developing the analysis, we adapted the Pathways to Survival Framework (figure 1) [6] – which considers care provision within the home and care-seeking outside the home when a child becomes unwell. We demonstrated the stages of the care-seeking process at which each major theme acted, and how caregivers' accounts of the processes of seeking and receiving healthcare in rural South African communities deviated from those outlined in the original model.

We used NVivo 11 (QSR International, Australia) to assist in data management, coding of transcripts and organisation of codes into themes.

Figure 1 here

Ethics

This study was approved by the Oxford Tropical Research Ethics Committee (OxTREC ref: 509-18), the University of the Witwatersrand Human Research Ethics Committee (Medical) (M180102), the Mpumalanga Province Health Research Committee (MP_201804_006) and the University of KwaZulu-Natal Biomedical Ethics Research Committee (BE259/18). Participants provided written consent to participate.

Data sharing:

To protect confidentiality of participants, anonymised transcripts will only be made available on request.

Patient and public involvement

The community advisory boards at each HDSS site provided input into the study design and assisted with the distribution of findings back to the communities.

RESULTS

Participant characteristics

We conducted 29 in-depth interviews and two FDG's (including four participants in Agincourt and five participants in AHRI). Respondent demographics and key case details are presented in Table 1 and Supplementary material S2. Of a total of 38 respondents, 29 were parents (27 mothers, two fathers), seven grandmothers and two aunts. Interviews and FGDs detailed events relating to a total of 38 deaths, comprising four neonatal deaths (0-27 days), 16 deaths of infants 1-11 months and 18 deaths of children 1-4 years. Nineteen children had died in health facilities, 16 at home and three on route to a health facility. Overall, 32 caregivers had sought formal healthcare for their child during the child's final illness. Eight caregivers used traditional or faith-based medicines and practices during the final illness, all of whom also sought formal healthcare. A further four indicated that traditional medicines and practices had been used in previous illness episodes for the child or other family members even if not used in the final illness. Three caregivers neither provided home care nor sought any formal, traditional or faith-based care outside the home – all three children died within 24 hours of caregivers recognising signs of illness.

*Table 1: Summary of characteristics of respondents and their deceased children**

Characteristic	Total (N=38)		Agincourt (N=19)		AHRI (N=19)	
	n	%	N	%	n	%
Age of the deceased child						
0-27 days (neonate)	4	11	2	11	2	11
1-11 months	16	42	9	47	7	37
12-59 months	18	47	8	42	10	53
Sex of deceased child						
Male	21	55	11	58	10	53
Female	17	45	8	42	9	47
Relationship of respondent to the deceased						
Mother	27	71	10	53	17	89

Father	2	5	2	11	0	0
Grandmother	7	18	5	26	2	11
Aunt	2	5	2	11	0	0
Place of death						
Home	16	42	6	32	10	53
Healthcare facility	19	50	12	63	7	37
On route	3	8	1	5	2	11
Cause of death						
Acute respiratory infection	11	29	8	42	3	16
Diarrhoeal disease	4	11	0	0	4	21
Meningitis/encephalitis	3	8	0	0	3	16
Neonatal conditions	3	8	2	11	1	5
Burns	2	5	2	11	0	0
Other	5	13	3	16	2	11
Unknown	10	26	4	21	6	32
Household socioeconomic quintile within HDSS						
1 (poorest)	8	21	7	37	1	5
2	9	24	5	26	4	21
3	7	18	4	21	3	16
4	7	18	1	5	6	32
5 (least poor)	7	18	2	11	5	26
Mother's HIV status						
Positive	8	21	3	16	5	26
Negative	23	61	14	74	9	47
Unknown/unreported	7	18	2	11	5	26
Mozambican descent	Not totalled		4	21	-	-
Sought formal healthcare outside the home	32	84	16	84	16	84
Used traditional medicine or consulted a traditional healer for child's final illness	6	16	1	5	5	26
Used traditional medicine or consulted a traditional healer for previous childhood illness	10	26	3	16	7	37

* Data for Table 1 is drawn from data collected as part of the routine household survey conducted in each site, as well as data collected specifically as part of this study.

Themes

The main themes to emerge from the analysis relate to (i) caregiver knowledge and advice-seeking, (ii) the use of traditional medicines and practices, (iii) transport barriers, (iv) experiences of care-seeking during the final illness and v) communication.

Caregiver knowledge and advice-seeking

Some caregivers seemed not to appreciate the severity of their child's symptoms or comprehend why their child died. As noted by a mother whose child died at home:

> *"I can say that if I could have taken my child to the hospital early maybe he would have been fine, because maybe they would have help him; because I never thought, but I just thought it was a normal cry for most of the babies."* (Participant 21, mother, child died at home from meningitis/encephalitis)

When caregivers were uncertain about a child's illness, they sometimes turned to family members and neighbours for advice in assessing the illness and whether to seek care outside the home. In general, mothers felt such consultations were not about seeking family members' permission to take a given action, but rather consulting them in an exercise of joint decision-making based on a joint assessment of the child's condition. The mother of a child who died at home explained their household's usual processes of assessing child illness and whether further care was needed:

> *"we normally discuss [the child's condition] with whoever is around home" (*Participant 26, mother, child died at home from an unknown cause).

However, such processes of advice seeking did not necessarily improve the capacity to assess the situation accurately. One grandmother explained that both she and the mother were uncertain about the child's illness:

> *"We were sharing ideas on what to do. Even my daughter's sister in-law was also here and she is the one who said that it is better to take the child to the clinic." (Participant 6, grandmother, child died in a health facility from an acute respiratory infection).*

Traditional medicine and practices

Traditional medicine and practices in these settings operate within a complex set of belief systems [30,31]. Most participants reported practicing cultural traditions or rituals related to African ancestral belief systems which underpin their worldview. However, our participants differentiated use of traditional healers and medicine from the much more common practice of cultural rituals and traditions. For example, one mother explained:

> *"Yes, [we practice] the burning of incense, also we do slaughtering. In most times maybe we slaughter goats when we have something we will be doing…"* (Participant 25, mother, child died at home from diarrhoeal disease).

But this participant also noted:

> *"In our church we don't go for traditional healers nor faith healers."* (Participant 25, mother, child died at home from diarrhoeal disease).

The motivations participants described for using traditional medicines and traditional healers varied. Some caregivers admitted to administering traditional enemas as part of the routine care they provide within the home to promote well-being or treat common symptoms of mild illness. One grandmother frequently administered enemas to her grandchildren:

> *"children here at home are being given enemas when the sun is too hot to release the gall. She used to enema them, not only my child but all the kids at home."* (Participant 30, mother, child died in a health facility from an acute respiratory infection).

Other caregivers used traditional enemas despite being aware of advice against this, because they did not seem to know what to do instead and didn't want to do nothing:

> *"It's not easy. They say children should no longer be given enemas. [But] you are also trying to help."* (Participant 35, mother, child died on route to a health facility from diarrhoeal disease).

Caregivers who consulted traditional healers during the child's final illness all did so as a last resort, having experienced formal providers as unhelpful.

> *"I thought I will go to someone [a traditional healer] to hear what is really happening for I've been to the clinic, there was no help, I go to the doctor I get no help"* (participant 24, mother, child died at home of an unknown cause).

In our study, caregivers who consulted traditional healers did not express a strongly held belief that the illness that had resulted in their child's death had an underlying traditional cause. In fact, some caregivers distinguished their recourse to traditional healers in these cases, from others in which they went directly to a traditional healer in the belief that the cause of the illness was traditional and therefore traditional treatment was the most appropriate means of healthcare.

Transport barriers

A lack of affordable transport frequently caused a delay in accessing healthcare and was an important consideration in deciding when and where to access healthcare.

> *"there are people who end up not getting to clinic because they don't have money for transport."* (Participant 26, mother, child died at home from an unknown cause).

Participants noted that ambulances were slow or unavailable. Arranging a private car was difficult and often caused delays with disastrous consequences:

> *"I was not having a car by that time. Then we found my wife's father's car. While we were on our way to the hospital around [the village] the car just stopped. We waited for another car to come and assist us. The car came and when we arrived at [the hospital], we found that … I am not sure if the child died at the gate of the hospital or he died inside the hospital, I can't remember. We never got any assistance because he was dead already."* (Participant 9, father, child died on arrival at a health facility from an acute respiratory infection).

Many were ultimately able to overcome the transport barrier, borrowing money from family and neighbours to cover the costs of taxis or hire private cars, or by asking others to help with lifts to the health facilities. But a lack of transport frequently caused a delay in accessing healthcare and was an important consideration in deciding when and where to access healthcare. Participants from the FDGs added that transport barriers were exacerbated at night as

> *"there is no other option but to pay for someone's car and go to [the 24-hour clinic] as it is always open."* (Participant 36, grandmother, child died in a health facility from severe acute malnutrition).

Experiences of care-seeking during the final illness

For many of the caregivers, a negative experience at the hands of nurses or doctors was not unusual; yet this did not deter them from seeking care for their sick children at formal healthcare facilities. Unfortunately, many of the children who died at home were sent home on the strength of inadequate diagnoses or treatment, and/or little information as to what to look out for and when to seek further care (i.e. poor safety netting advice).

Table 2 summarises the specific features of care-seeking interactions during the final illness that caregivers associated with a positive or negative experience. Of note, most caregivers had very low expectations of the healthcare system, so much so that positive experiences of care-seeking were often the result of an *absence* of poor care rather than the *presence* of good care practices. For example, participants were satisfied with a care-seeking interaction when nurses

> *"didn't blame me or say something that was out of line"* (participant 3, grandmother, child died at home of unknown cause), and when *"they didn't shout at me"* (participant 21, mother, child died at home from meningitis/encephalitis).

However, many caregivers continued to engage with formal health services despite negative experiences of seeking care - and so these are not sufficient to explain the phenomenon of home deaths.

Table 2: Care-seeking experiences

Negative care-seeking experiences	**Positive care-seeking experiences**
Poor communication - Healthcare workers shouting at caregiver - Blaming caregiver for death - Failing to take caregivers' opinions seriously - Not explaining what procedure is being performed or why it is being performed - Not explaining which treatment was being given or why it was being given - Not providing safety-netting advice - Not explaining the cause of death	Good communication - Respect for caregivers' opinion and knowledge of a change in the child's condition - Offering safety-netting advice - Not being shouted at
Inattentive staff - Distracted by mobile phones while seeing patients, or while patients are waiting to be seen - Taking lunch when still many patients to see - Not coming to review patient when caregiver alerts them to a change in the child's condition - Sense that nurses are not "passionate" about their jobs (particularly younger nurses).	Tangible sense of "being treated" - Receiving interventions (Drips, injections, tablets, oxygen, bandages) - Physical examination performed by the nurse or doctor
Delays or waiting: - Ambulance transport very delayed in arrival	Timings - Seen and treated immediately or urgently, skipping the queues - Ambulance arriving quickly

Communication

Communication clearly influenced caregivers' overall experience of care but also more directly linked to their subsequent care-seeking behaviour. Features of good communication included demonstrating respect for the caregiver's knowledge of their child, explaining what procedures or treatments were being administered and not shouting at or blaming caregivers. As one mother recalled:

> *"The nurses from [the hospital] communicate with you as the children's parents, ask how the child is and what changes you see or that you don't see change."* (Participant 22, grandmother, child died in a health facility of unknown cause*).*

Unfortunately, most caregivers experienced poor communication when seeking care during the child's final illness and reported that healthcare workers were hostile, rude and dismissive, shouted at caregivers for bringing children at the wrong time (either too late in the day, or at the weekend) and blamed caregivers for the child's illness – especially if traditional medicine was used - saying they *"killed the child."* (Participants 30, mother, child died a health facility of an acute respiratory illness and participant 36, grandmother, child died in a health facility of severe acute malnutrition).

In some cases, healthcare workers were dismissive of caregivers' concerns, despite caregivers being sure that something was seriously wrong with their child. The mother of a child who died at home was worried:

> *"I woke up with him in that morning and he was not fine"*. (Participant 25, mother, child died at home from diarrhoeal disease).

She took her child to the clinic, but the nurses dismissed her, saying

> *"they don't work on nominals [non-emergency patients] on Sunday."* (Participant 25, mother, child died at home from diarrhoeal disease).

Despite waiting many hours at the clinic, the staff refused to assess the child and eventually she left the facility without receiving help. A father whose neonate was crying constantly, not eating or drinking, explained that *"we didn't get any help from the clinic"* (participant 8, father, child died on route to heath facility from neonatal sepsis) after he and his wife were dismissed by nurses.

Safety-netting was another important part of communication: one father who had taken his child to a GP during the final illness recalled

> "(the GP) *told us that he is going to give us some medication that we need to go and give to the child. He also said to us as it is Monday today, if you don't see any changes on Tuesday, please come back.*" (Participant 8, father, child died on route to heath facility from neonatal sepsis).

This experience was in contrast to the experiences of most other participants, for whom poor communication was the norm and who did not recall being given any advice about what danger signs to look out for and when to come back for review. This implies that many caregivers did not know what they should expect of the treatment or that the child might deteriorate despite receiving medication and need to return to the healthcare facility.

Poor communication also resulted in caregivers failing to understand why their child had died. This left caregivers feeling anxious, often doubting their own assessment of the child's condition. They lost confidence in their ability to assess and manage future child illness (even mild cases), and internalised blame for the child's death. Many caregivers said that, following their child's death, they now relied fully on clinic staff to assess the severity of their other children's illnesses and provide treatment guidance:

> *"I don't do anything by myself. I take the child to the clinic. Even if it can be something that I know, I do take the child to the clinic… because of what happened to me last time, I think that something like that can happen again."* (Participant 13, mother, child died at home of unknown cause).
>
> *"For me, I use the clinic a lot because I learnt a lesson with the one that died. When they have a little cough or diarrhoea, no-one tells me, I put one on my back and pull the other by the hand to the clinic, I no longer make a mistake."* (Participant 37, mother, child died at home of diarrhoeal disease). "
>
> *"I encourage the clinic because I have buried other children"* (participant 36, grandmother, child died in a health facility from severe acute malnutrition)

DISCUSSION

This study highlighted the multiple barriers faced by caregivers in providing care to children within the home, and seeking and receiving care outside the home. Caregivers' knowledge of childhood illness varied – with some unable to identify severe illness in their child or appreciate the urgency of the need for healthcare. Traditional medicine was utilised by some caregivers, though rarely as a first port-of-call. When used as part of home care, caregivers suggested that they turned to traditional medicines as something familiar, particularly when they felt desperate, even when they did not identify a traditional cause of their child's illness. Transport barriers remain significant: cost, limited minibus-taxi times and having to arrange to hire or borrow private cars caused delays in accessing healthcare. Finally, caregivers continued to engage formal healthcare services despite many reporting negative care-seeking experiences; poor communication both exacerbated negative experiences and contributed to failures to re-seek care appropriately. Furthermore, failure to explain the cause of death of the child led to a greater a sense of dependency on formal healthcare services in future child illness. As such, existing models of care-seeking must be adapted to reflect caregivers' realities.

Adapting the Pathways to Survival Framework

Figure 1 shows the Pathways to Survival Framework [6]. Many of the key issues identified by participants are overlaid on this model, demonstrating the stage and manner in which they act as barriers to accessing high quality healthcare. We found that transport delays are an important issue, in contrast to findings from standard quantitative verbal and social autopsies (VASAs) in this context (probably because the VASA questions are framed too broadly) [2]. In Figure 2, we summarise the care-seeking process in rural South Africa, based on barriers reported by caregivers in this study.

Figure 2 here

The pathway for a severely ill child is indicated by black arrows. While the initial pathway remains similar to the standard model, differences arise following negative experiences of seeking care outside the home (step 4), and so when the child deteriorates (step 5) caregivers' responses may differ: some might re-seek care, though often going to a different provider (either to a different clinic, to a private GP or to a hospital) (step 6a). Some believe that the failure to improve having received allopathic treatment must indicate that this is a traditional problem and so seek out traditional healers (step 6b). Others are either unable to re-seek care, or believe that having seen a healthcare professional already, there is nothing more to be done (step 6c). Ultimately the child dies (whether at home or in a health facility) (steps 6c, 7). Although depicted as a broadly linear model for ease of understanding, caregivers may simultaneously seek care from multiple providers (both formal and informal).

In addition to more accurately describing the care pathway for fatal child illness in rural South Africa as experienced by caregivers, our proposed model is the first to offer insights into the effects on care-seeking in future childhood illness in the context of poor caregiver knowledge both in identifying signs of severe illness and in understanding why the first child died (pathway indicated by orange dashed arrows). Following the death of their child, caregivers lose confidence in their ability to identify severe child illness (arrow A) and become reliant on healthcare workers to identify disease and guide treatment (arrow B). This is true even for very mild childhood illness which could be adequately managed at home. As a result, there is a growing burden on the health system, whereby mildly unwell children are also brought to the clinic (as has been described in work by Horwood et al [32]), exacerbating the existing supply-side barriers to high quality care (staff shortages, resource limitations, poor management, long waiting times etc [33]) (arrow C) and perpetuating negative experiences of care (arrow D).

Our model also highlights the role of traditional healers and traditional medicine use in South Africa. While participants admitted to continued use of traditional medicines (traditional enemas in particular), their motivations largely reflect a familiarity with these treatment methods and a trust in their value based on a shared world view. Traditional treatments such as enemas (which may include herbal administrations, toothpaste, water and dishwashing liquid) are common home treatments in South Africa used in both preventative and curative traditional healthcare [34,35]. Traditional healers were not typically the first port of call for fatal child illnesses, though were consulted if a child was not improving after formal medical care. Work elsewhere in Africa also shows that use of traditional healers as the first treatment provider is declining [36]. Caregivers did not clearly identify a specific traditional cause of disease that they were trying to treat, though other work in sub-Saharan Africa found that many caregivers believe in traditional explanations and so preferentially seek traditional care for specific disease symptoms - such as convulsions associated with cerebral malaria[37–39].

Sharkey et al (2011) report that repeated negative experiences of care result in care-seeking from multiple service providers and use of traditional healers (though not as the first port of call) [18], but they suggest that this pattern demonstrated a distrust in the formal healthcare system. In contrast we did not find evidence to support a loss of trust in formal healthcare providers. This may reflect differences in the degree of community and caregiver empowerment, caregiver education, or between rural and urban communities (with urban caregivers seeking care more frequently and from more providers). Furthermore, their model does not describe care-seeking for future child illness.

Social exclusion

Amartya Sen's work on social exclusion [40] may help explain caregivers' response of increasing (rather than reducing) use of the formal healthcare system despite repeated negative experiences and low expectations of the quality of care they are likely to receive. Sen argues that impoverishment extends beyond the material and includes non-material elements ("capabilities") which are critical to the freedom to access opportunities [40].

In the South African public healthcare context, negative engagements with health professionals undermine caregivers' ability to claim a minimum standard of healthcare by reinforcing perceptions of social exclusion which feed into their lived experience of poverty. This also helps explain the persistently low expectations of the healthcare system that were implicit in many of the respondents' comments. This behaviour is described elsewhere in the South African healthcare system in relation to maternal care-seeking and institutional delivery. Verbal and physical abuse of labouring mothers by nursing staff is well documented across South Africa [41], however mothers have come to normalise nurses' aggressive language as a means of coping with the situation, and as a result may no longer feel that it is unacceptable or offensive [42].

In our study, one caregiver exemplified this, referring to their child's death as "*their mistake*", rather than recognising that there were multiple failures throughout the healthcare system that contributed to the child's death. The internalisation of self-doubt and self-blame for the child's death may be explained by capacity deprivation and social exclusion driven by the negative experiences of care-seeking. Consequently, caregivers lose confidence in their assessment of illness severity. Instead of doubting the healthcare system, or even turning away from it, caregivers delegate more of the assessment and management of their children to health professionals.

Policy Implications and priorities for further research

Our adapted care-seeking model highlights the urgent need to empower caregivers, building confidence in seeking and providing appropriate healthcare for their children both within and outside the home, and increasing expectations of the quality of care they receive. Policy implications therefore include improved communication strategies with specific emphasis on providing safety netting information at every consultation and encouraging caregivers to ask questions about their child's diagnosis and treatment. Behaviour change programmes targeting staff attitudes have been successful when trialled at individual facilities [43,44]. Strategies to provide such programmes at scale should be prioritised. Finally, community mobilisation programmes using women's groups and care groups have been shown to effectively improve neonatal and child health, improving caregiver knowledge and capability [45–48]. As investment in community health worker programmes is extended, consideration should be given to their role in mobilising such groups within the communities they serve.

Further research is needed to understand in which circumstances parents react to a child death by increasing their use of health services for minor illnesses in subsequent children, or by not seeking treatment from formal health services until the illness becomes severe. Validating the model in a larger sample or with mixed-methods research may also help identify differences in the pathways for children who died at home or en route to a facility compared to those who die in a facility. We would also recommend research to elucidate the care pathway for severely ill children who improve, as this may provide valuable insights into those factors which promote positive outcomes. Further qualitative research is also needed to understand why traditional enemas are so commonly used for home treatment of childhood illnesses in South Africa, while they are not so commonplace elsewhere. This could help to inform the development of interventions to improve the use of home treatments and treatment-seeking behaviour for children in South Africa.

Strengths and limitations

This study had four important strengths, and corresponding limitations. First, all interviews and FGDs were conducted in participants' first language (isiZulu or Xitsonga). This encouraged participation of individuals who might otherwise have refused or been unable to participate in the study if all data collection had been in English or via an interpreter. However, it is possible that some of the subtleties of the meaning and tone of the conversation were lost during translation of the interviews into English. Second, interviews were conducted at least one year after the death of the children in question, but in some cases two to three years after the child's death. Most caregivers had therefore grieved the loss of their child and the risk of the study causing significant emotional distress was lower. However, this time delay also introduced the potential for recall bias. We tried to reduce the impact of this by concentrating on caregiver's impressions of healthcare services and how they felt about their care-seeking experiences and less on precise timings or medications prescribed. Third, our sampling strategy allowed us to capture a diverse set of opinions and included fathers and traditional healers who were the primary caregivers of the child during their final illness – both of whom are generally under-represented in research on childhood illness [49,50] despite being important stakeholders, contributing to decision-making and caregiving, often holding positions of authority within the household and community and sometimes acting as gatekeepers to care. Fourth, caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa. This model contributes to the literature on theories of care-seeking and access to healthcare and can be used as a basis for further research on childhood illness and intervention development to reduce child mortality. However, the adapted model may be context-specific and would require further validation in other settings before it is more widely applied.

CONCLUSION

Understanding factors that contribute to home deaths in rural South Africa is critical in designing effective policies to reduce child mortality. Failure to recognise signs of severe illness, lack of access to transport, poor communication and a lack of safety-netting advice from healthcare providers all contribute to home deaths of children under-5. Furthermore, repeated negative experiences of care-seeking in the context of poverty and social exclusion may disempower caregivers, limiting their ability to claim a minimum standard of healthcare. This realisation is critical in refining our thinking around care-seeking. Interventions designed to empower caregivers - including improved communication and safety netting, changing staff attitudes and community mobilisation - should be prioritised as part of a wider strategy to reduce child mortality.

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AUTHOR CONTRIBUTIONS

JP, LH, MW, KK and AH conceived and designed the study. VD, AK and PK conducted, transcribed and translated the interviews and FGDs. JP, MW and LH analysed the data with input from KK, JS, VD, AK and PK. JP and LH led the writing of the manuscript. All author contributed to, and critically revised it.

CONFLICTS OF INTEREST

The authors do not declare any conflicts of interest

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FIGURES AND CAPTIONS:

Figure 1: Adaptation of the Pathways to Survival Framework showing those modifiable factors identified by participants within and outside the home, and the stage of the pathway at which each factor acts.

Figure 2: Modified model of the process of seeking and providing healthcare during fatal childhood illness in rural South Africa.

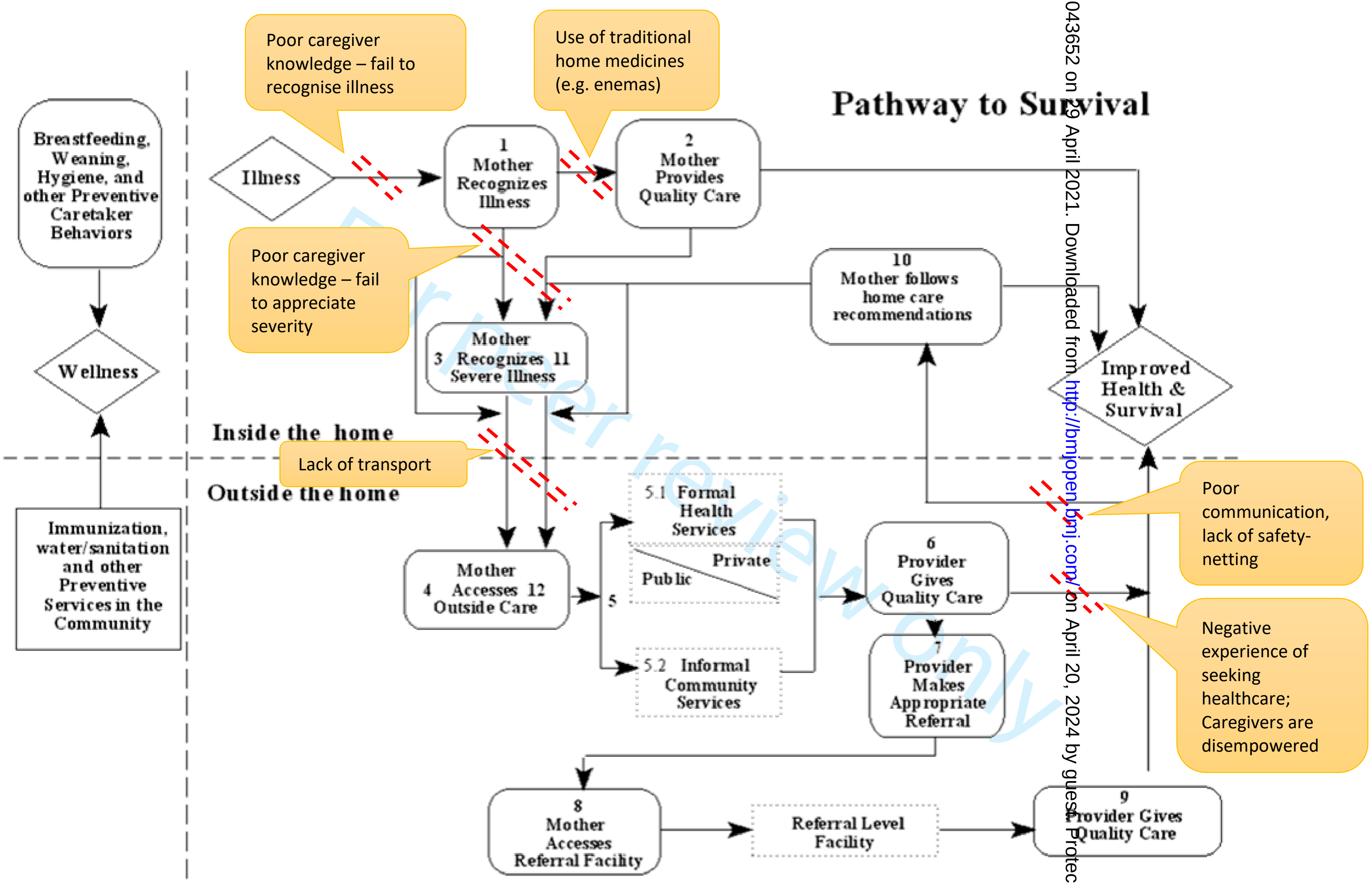

Figure 1: *Adaptation of the Pathways to Survival Framework showing those modifiable factors identified by participants within and outside the home, and the stage of the pathway at which each factor acts.*

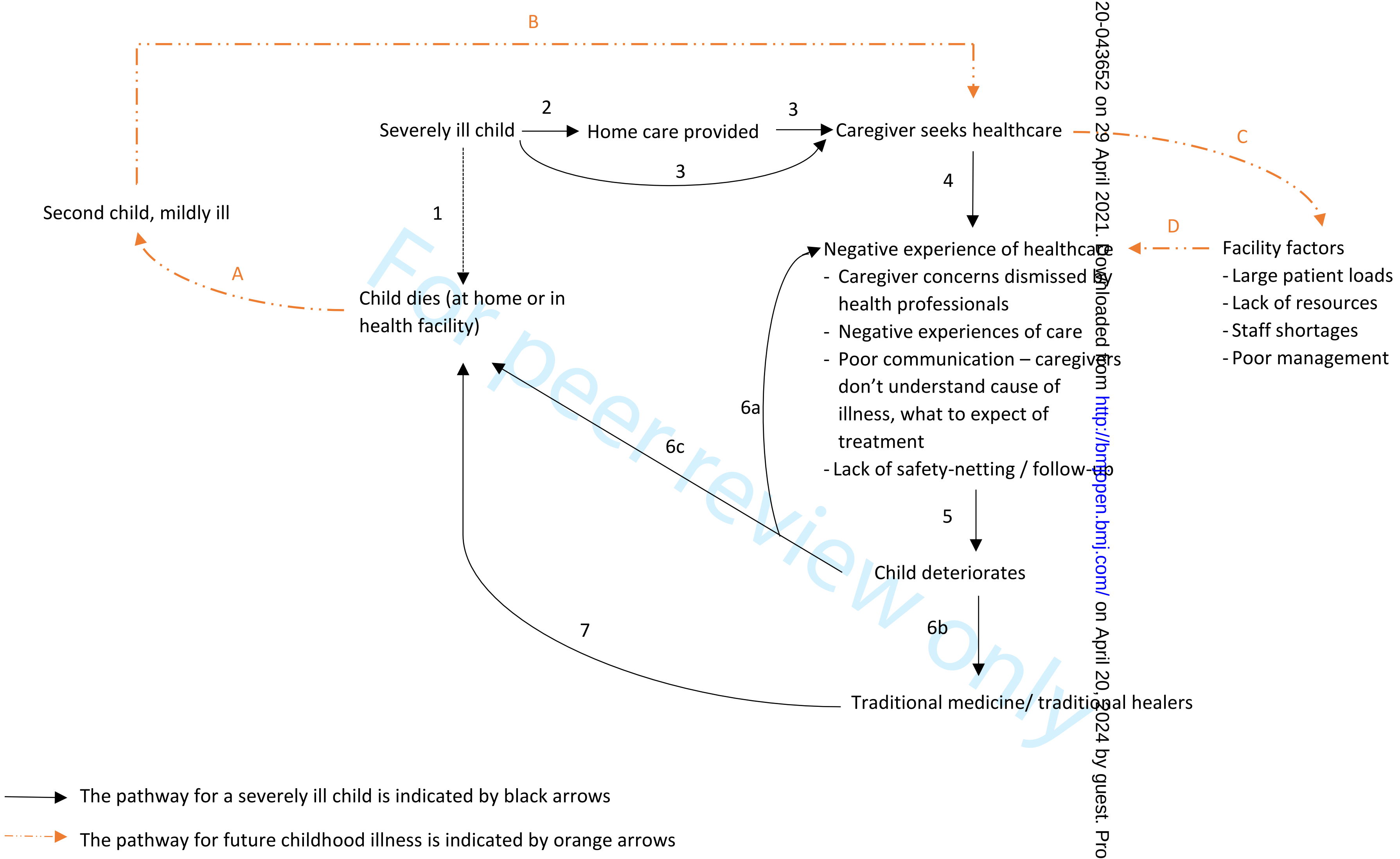

Figure 2: Modified model of the process of seeking and providing healthcare during fatal childhood illness in rural South Africa.

Supplementary Material S1: Interview Guide

Study Title: Caregivers’ experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

****** *This interview guide was developed following extensive reading around the topic. discussions with experienced social scientists (LH and JS), as well as context experts (KK and JS), and population-based research conducted in the Agincourt and AHRI HDSS sites on under-5 mortality, including the completion of verbal and social autopsies for all under-5 deaths in the HDSS sites to better understand the circumstances of death and barriers to accessing healthcare during the final illness.*

<u>Interview Guide (Key Informant Interviews):</u>

*Note: Consent to be taken before starting the interview. Interviewer to then start by introducing themselves, reminding the participant they will be audio-recorded, they can refuse to answer any questions and/or pause the interview.

Possible introductions:

“I want to talk about your child’s death but before we talk about that, I would like to ask a few general questions to understand more about your family and your daily life”.

1) Respondent’s relationship to the child
2) Family structure, how many members in the household, how many children, and how old are they, anyone working, any previous deaths in the household (esp child deaths).
3) Relationship to community, do they feel close to the community, are they well integrated?
4) Religion, and role of religion in daily life.
5) For Agincourt and if Mozambican: how do you think being Mozambican affects your daily life here? How does it affect your experience and access to health care?

“I have some questions about your child’s death that I want to ask but I am really interested in hearing about your experience in your own words. I expect that some of my questions will be answered in your story, so I would like to hear from you first. “

1) Can you tell me about your child’s final illness? About how it started, when you first started noticing symptoms, what you did etc. (allow participant to finish their story without interruption. If not supplied, then probe for symptoms recognised, what they did in response to those symptoms, where they sought care and when)

2) Can you tell me about your experience of seeking care?

  a. Explore where they went for care
  b. Why did they choose to go where they did?
  c. (if Mozambican: might probe with :do you think your experience of seeking care was in any way related to your being Mozambican?”

3) How did the staff treat you?

(Probe for positive and negative experiences, how did the staff treat them, were they made to wait, were they allowed to stay with their children during any treatments/procedures – and did they like this or not?)

*If they didn’t seek care, explore issues around why they didn’t access care.

*any causes of major delays in seeking care

4) What treatment did you get from the provider? What advice did the provider give you? Were your referred somewhere else?

5) Explore whether they completed/complied with the treatment, why or why not, if referred did they take up the referral?

6) Traditional medicine used/visited traditional healer? - why?

7) Can you tell me about any challenges you faced in accessing healthcare? Is there anything that made is difficult to get healthcare?

8) Why did you go to your chosen healthcare facility or provider?

9) How did you overcome those difficulties?

10) Were you satisfied with the care you were offered? Is there anything that could have been done better?

11) Is there anything else you want to tell me?

Supplementary material: Table S2: Individual participant characteristics

Participant ID	**Method: IDI or FGD[Ŧ]**	**Age group of child who died**	**Respondent's relationship to deceased child**	**Place of death**	**Cause of death**	**Household socio-economic quintile (1=poorest, 5=least poor)**	**Sought healthcare outside the home**	**Used traditional medicine or consulted a traditional healer for child's final illness**
1	IDI	1-11 months	Mother	Home	Acute respiratory infection	4	Yes	No
2	IDI	1-11 months	Mother	Home	Acute respiratory infection	3	No	No
3	IDI	1-4 years	Grandmother	Home	Unknown	5	Yes	No
4	IDI	1-4 years	Grandmother	Health facility	Other and unspecified external cause of death	5	Yes	No
5	IDI	1-11 months	Grandmother	Health facility	Acute respiratory infection	2	Yes	No
6	IDI	Neonatal	Grandmother	Health facility	Acute respiratory infection	1	Yes	No
7	IDI	1-4 years	Mother	Health facility	Acute abdomen	3	Yes	No
8**	IDI	Neonatal	Father	On route	Neonatal sepsis	1	Yes	Yes
9	IDI	1-11 months	Father	Health facility	Acute respiratory infection	3	Yes	No
10	IDI	1-4 years	Mother	Home	Burns	1	Yes	No
11	IDI	1-11 months	Mother	Home	Unknown	1	No	No
12	IDI	1-4 years	Aunt	Health facility	Unknown	1	Yes	No
13**	IDI	1-11 months	Mother	Home	Unknown	2	No	No
14	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	2	Yes	No
15	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	3	Yes	No
16	FGD	1-4 years	Grandmother	Health facility	Burns	2	Yes	No
17	FGD	1-4 years	Aunt	Health facility	Acute abdomen	1	Yes	No*
18	FGD	1-11 months	Mother	Health facility	Acute respiratory infection	1	Yes	No
19	FGD	Neonatal	Mother	Health facility	Birth Asphyxia	2	Yes	No
20	IDI	Neonatal	Mother	Health facility	Birth asphyxia	2	Yes	No
21	IDI	1-11 months	Mother	Home	Meningitis or Encephalitis	4	No	No
22	IDI	1-4 years	Mother	Health facility	Unknown	3	Yes	No
23	IDI	1-11 months	Mother	Health facility	Meningitis or Encephalitis	4	Yes	No
24	IDI	1-4 years	Mother	Home	Unknown	4	Yes	No
25	IDI	1-4 years	Mother	Home	Diarrhoeal disease	4	Yes	No
26	IDI	1-4 years	Mother	Home	Unknown	2	Yes	No
27	IDI	Neonatal	Mother	Health facility	Acute respiratory infection	4	Yes	No

Participant ID	**Method: IDI or FGD**Ŧ	**Age group of child who died**	**Respondent's relationship to deceased child**	**Place of death**	**Cause of death**	**Household socio-economic quintile (1=poorest, 5=least poor)**	**Sought healthcare outside the home**	**Used traditional medicine or consulted a traditional healer for child's final illness**
28	IDI	1-4 years	Mother	Home	Unknown	3	No	Yes
29	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	4	Yes	Yes
30	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	3	Yes	Yes
31	IDI	1-11 months	Mother	Home	Unknown	2	Yes	Yes
32	IDI	1-4 years	Mother	Home	HIV/AIDS related death	1	Yes	No
33	IDI	1-11 months	Mother	On route	Diarrhoeal disease	5	No	Yes
34	FGD	1-11 months	Grandmother	Home	Unknown	5	Yes	No
35	FGD	1-11 months	Mother	On route	Diarrhoeal disease	5	Yes	No
36	FGD	1-4 years	Grandmother	Health facility	Severe malnutrition	2	Yes	No
37	FGD	1-11 months	Mother	Home	Diarrhoeal disease	5	Yes	Yes
38	FGD	1-4 years	Mother	Home	Meningitis or encephalitis	5	Yes	No

*This participant did not use traditional medicines or consult a traditional healer, but went to consult "prophets" (considered faith-based healers)

** The respondent was a traditional healer

Ŧ IDI - In-depth Interview; FGD - focus group discussion

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
Purpose or research question - Purpose of the study and specific objectives or questions	3

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	3-4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	3-4
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5-6
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	4
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-9
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-9

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	9-11
Limitations - Trustworthiness and limitations of findings	12

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	13-14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388