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RESEARCH ARTICLE

REVISED Care-seeking patterns amongst suspected paediatric pneumonia deaths in rural Malawi [version 2; peer review: 2 approved]

A mixed methods study

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Abstract

Background: Pneumonia remains a leading cause of paediatric deaths. To understand contextual challenges in care pathways, we explored patterns in care-seeking amongst children who died of pneumonia in Malawi.

Methods: We conducted a mixed-methods analysis of verbal autopsies (VA) amongst deaths in children aged 1-59 months from 10/2011 to 06/2016 in Mchinji district, Malawi. Suspected pneumonia deaths were defined as: 1. caregiver reported cough and fast breathing in the 2-weeks prior to death; or, 2. the caregiver specifically stated the child died of pneumonia; or 3. cause of death assigned as 'acute respiratory infection' using InterVA-4. Data were extracted from free-text narratives based on domains in the 'Pathways to Survival' framework, and described using proportions. Qualitative analysis used a framework approach, with pre-specified themes.

Results: We analysed 171 suspected pneumonia deaths. In total, 86% of children were taken to a healthcare facility during their final illness episode, and 44% sought care more than once. Of children who went to hospital (n=119), 70% were admitted, and 25% received oxygen. Half of the children died within a healthcare setting (43% hospital, 5%

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health centre and 2% private clinics), 64 (37%) at home, and 22 (13%) in transit. Challenges in delayed care, transport and quality of care (including oxygen), were reported.

Conclusions: Healthcare was frequently sought for children who died of suspected pneumonia, however several missed opportunities for care were seen. Sustained investment in timely appropriate care seeking, quick transportation to hospital and improved case management at all levels of the system is needed.

Keywords
mortality, pneumonia, child, sub-Saharan Africa, pathways to survival

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REVISED **Amendments from Version 1**

We made minor edits to the main text, as follows:

1. Methods, Data Collection: clarification of the reason for randomising interviews to conduct an open narrative, and the interview sequence;

2. Methods, Quantitative Analysis: included a sentence to explain the indicators not extracted from the Pathways to Survival framework;

3. Results, Quantitative: we included the proportion of children with a pre-existing condition reported;

4. Discussion: we added a sentence to explain that we did not explore caregiver motivations in care-seeking;

5. We replaced the term 'attended' with 'visited' throughout the text;

6. In Table 2, we changed the category names for the pneumonia classification approach so they more closely matched the text explanation.

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

Introduction

Annually approximately 800,000 children aged under five years die from pneumonia. While the absolute number of deaths declined by 65% between 1990 and 2017, pneumonia remains the leading cause of infectious paediatric deaths[1]. Globally, pneumonia incidence is higher amongst male children, while mortality is higher amongst female children; however, this is not consistent across regions and the mechanisms for this trend are poorly understood[2]. Addressing paediatric pneumonia deaths will be crucial to achieving Sustainable Development Goal 3.2 in an equitable way[3].

Wide-spread adoption of standardised integrated community case management (iCCM) and Integrated Management of Childhood Illnesses (IMCI) protocols, alongside routine childhood vaccination, have led to significant reductions in paediatric pneumonia mortality[1,4]. These approaches aim to screen children at community and primary care levels, and refer those with severe illnesses to higher levels of care. However, there is evidence of poor-quality implementation for pneumonia assessment and management[5–8].

For these approaches to be optimised, caregivers at home must recognise signs of pneumonia, decide to seek, and be able to seek, care. A 2018 study estimated 60% of preventable deaths occur from poor-quality care, rather than issues in accessing care[9]. However, there is conflicting evidence around whether care is sought in time or too late during acute childhood illnesses, including pneumonia, and considerable evidence gaps remain[10,11].

Several frameworks have been developed to understand processes and barriers that contribute to mortality across the continuum from community to referral facility. The Three Delays model, developed for maternal mortality, breaks down challenges into delays in deciding to seek care, delays in reaching care, and delays in receiving appropriate care[12]. More specifically for childhood illnesses, the Pathways to Survival model was developed to support IMCI implementation, and arranges steps for communities and healthcare systems to take to promote survival[13].

To prevent paediatric pneumonia deaths, context specific understanding of caregiver, community and health system barriers to quality care are needed. We aimed to describe caregiver recognition of illness, care-seeking decisions and quality of care issues amongst families with a child pneumonia death in Malawi, and explore whether these patterns differed by sex or age.

Methods

We conducted a mixed-methods analysis of verbal autopsy (VA) data from a prospective community-based birth cohort in Mchinji District, central Malawi, amongst deaths in children aged 1 to 59 months from October 2011 to June 2016[14].

Setting

At the time of data collection Mchinji district had an approximate population of 450,000, with 85% living as rural subsistence farmers. The under-five mortality rate was 63/1000 livebirths in the 2015–2016 Malawi Demographic and Health Survey. Healthcare was provided for free by 354 community healthcare workers (known locally as Health Surveillance Assistants), 11 government primary healthcare centres, and one referral district hospital, and for a small fee in four rural hospitals.

Data collection

Full details of the community surveillance system have been published previously[14]. Briefly, deaths were recorded and reported monthly by 1059 village-level key informants. Deaths were also identified at household visits conducted for all children born in the district at four months and one year of age. Data were submitted to the office for cleaning. A list of all community reported deaths amongst 0–59 months olds in Mchinji district was generated monthly for VA interviews. VAs were conducted by nine senior fieldworkers, all with previous experience of conducting VAs. They received one week's training, including: translating the data collection tool, conducting mock interviews and using smart phones for data collection.

VAs interviews were randomised to conduct an open narrative or not, as part of a separate research question on the role of narratives in data quality, rapport and interview procedures[15]. This was done at the point of interview using a random number generator within the Open Data Kit (ODK) Collect application, version 1.4, used to collect data[16]. The open narrative was unstructured, conducted at the start of the VA and was either audio recorded then transcribed or captured using paper notes. Data collectors could record the information in the format they preferred, in English or Chichewa. Open narratives in Chichewa were later translated by the data collectors and data entry clerks. We used the standardized World Health Organization (WHO) 2012 VA questionnaire[17].

Pneumonia death definition

Suspected pneumonia deaths were identified in three ways: 1. the caregiver responded yes to both the child having a cough and fast breathing in the two weeks prior to death, according to the WHO 2012 VA questionnaire; 2. the caregiver explicitly stated that the child had died of pneumonia during the VA; or 3. the cause of death was classified as 'acute respiratory infection' by InterVA-4. We excluded deaths occurring in the neonatal period (aged 0–28 days).

Quantitative analysis

We extracted data from the open narratives using a custom-designed tool in Excel, based on the 'Pathways to Survival' framework (Table 1)[13,18]. We did not consider indicators relating to

Table 1. List of indicator definitions extracted from open narratives.

Indicator	Definition	Categories
Recognised illness	The respondent mentions any clinical sign of infection, diagnosis or acute illness. We did not include witchcraft or curses.	Yes, No, Don't know
Recognised pneumonia	The respondent mentions cough, difficulty or fast breathing, noisy breathing, chest indrawing, or states the child had pneumonia or an acute respiratory infection.	Yes, No, Don't know
Time taken to first seek care*	The approximate time from first recognising the child was sick to seeking care outside of the home.	<24 hours 24–72 hours >72 hours Don't know
Home care given	The respondent described providing any form of home-based treatment, such as medication or feeding, outside of healthcare advice (i.e. giving antibiotics at home as prescribed by a healthcare provider was not coded).	Yes, No, Don't know
Location of care-seeking	The location where the respondent stated they went to seek care, if care was sought outside of the home.	None sought Traditional medicine Community health worker Health centre Hospital Private clinic Don't know
Quality of care issue	There is mention of any aspect of poor quality of care, including: lack of staff, equipment, medication, transport, delays and negative staff attitude.	Text description
Action on care-seeking	The action that was taken or advised by a healthcare worker, while seeking care at a facility or provider. If a child was referred but never arrived at the facility, this was recorded as being referred.	Sent home Admitted Referred to another facility Don't know
Total duration of illness	The approximate time from first recognising the child was sick to the child dying.	Number of days
Location of death	The location where the child died was explicitly stated or could be determined from the narrative (e.g. 'after they died we were discharged').	Home In transit Health centre Hospital Private clinic Don't know
Oxygen given	The respondent stated that the child was given oxygen treatment, including terms such as 'breathing tube'.	Yes No Don't know
Other illness	The respondent described a long-term or chronic illness (e.g. asthma), malnutrition, a birth defect, or either being premature or low-birthweight.	Text description.

* We interpreted several as 3 days and couple 2 days

wellness inside the home (e.g. breastfeeding, hygiene) or outside the home (e.g. imminisation, water and sanitation), or indicators of quality of care inside the home. The tool was developed by TC and CK using three randomly selected narratives to define fields and categories. Data were then double coded from a random set of ten narratives. Disagreements between coding were discussed and the data extraction tool updated; a further 10 narratives were double coded to check for consistency. The remaining narratives were coded by CK. Data were described using proportions and means, and compared with chi^2 and t-tests. We stratified patterns of care-seeking by sex and age groups.

Qualitative analysis

Narratives were analysed using a framework approach[19]. Themes were pre-defined, based on the Pathway to Survival framework[18], as: wellness, illness recognition, care-seeking decisions, referral procedures, and quality of care. Concepts were inductively coded within these themes by CK, and a random sub-set of ten narratives were double coded by TC. The interpretation of the data was discussed with two of the data collectors who conducted VAs to check for context-appropriate interpretation. Disagreements in interpretation were discussed until consensus was reached.

Ethics

The data used were collected as part of the VacSurv Study, which was approved by the National Health Sciences Research Ethics Committee in Malawi (reference: 837), London School of Hygiene and Tropical Medicine (reference: 6047) and Centers for Disease Control and Prevention (reference: 6268). Verbal informed consent was taken from all respondents, and confirmed in the electronic data form; written consent was not sought due to literacy rates.

Patient and Public Involvement

Before starting any data collection, the study protocol was presented to the District Executive Committee and District Health Management teams in Mchinji for input and approval. Extensive community engagement was conducted through village development committees and traditional leaders. Community consent was sought from traditional authorities during study introduction, who also assisted in informing communities of verbal autopsies.

Results

Cohort description

During the cohort period, 4,855 death events were reported (Figure 1). Of the 1673 confirmed post-neonatal under-five deaths, 395 (24%) were classified as suspected pneumonia, representing a post-neonatal pneumonia mortality rate of 8.2 per 1000 livebirths. A total of 178 (45%) were randomised to open narrative, with balance between the two arms in terms of key demographics and care-seeking proxies (Table 2). Overall 171 suspected pneumonia deaths with complete data were included in analysis. Of these 37% (n=64/171) were completed in Chichewa and translated to English. The majority of deaths were classified as suspected pneumonia by InterVA (153/171, 89%).

Quantitative analysis

Overall, 86% (n=146/171) of children were taken to a public or private healthcare facility during their final illness episode. 44% (n=76/171) of caregivers sought care more than once in the final illness episode, with the most reported attendances being six over a 35-day period, visiting a health centre twice and hospital four times (Table 3). A sole visit to hospital occurred in (n = 50/171) 29%, and a single visit to a health centre in (n=17/171) 10%. Care-seeking at pharmacy shops was not explicitly reported. Of those where information on time to care-seeking could be extracted, 44% (n=36/81) of caregivers sought care within 24 hours of illness recognition. The median time from illness recognition to death was three days (IQR: 1 - 5). In 48 narratives (28%), the caregiver stated the child has a pre-existing condition or risk factor, such a birth defect or being born prematurely.

A total of 119/171 (68%) children ever visited a hospital, among whom 70% (n=83/119) were admitted. Amongst those admitted, caregivers specifically reported the child was given oxygen in 25% (n=21/83) of cases. Oxygen was more frequently reported amongst infants aged 1–11 months than those aged 12–59 months (32% vs 11%, p-value = 0.058), with no difference observed by sex (26% male vs 25% female). Pneumonia symptoms were recognised by caregivers less frequently in older children, but they were taken to hospital more frequently. Female children were taken to hospital more often than male children (74% vs 64%), but admitted less often than male children (68% vs 75%) – neither difference was statistically significant (Table 4).

Half of the children died within a healthcare setting (43% hospital, 5% health centre and 2% private clinics). Of the 64 (37%) children who died at home, 42% (n=27/64) had visited a hospital and 17% (n=11/64) had been admitted; we were unable to extract time from discharge to death. The remaining 13% of children died in transit, either from their home to seek care, or during referral from primary to secondary care (Figure 2). The majority of children aged 12–59 months died within a healthcare facility, while infants more often died at home (p-value = 0.028, Table 4).

Qualitative analysis

Wellness. Wellness includes prevent and protect indicators within households, with the sub-themes of: breastfeeding as a barometer of health; the role of a normal delivery; and sickly children.

Breastfeeding was frequently used to express the overall health of the child. A child who was able to breastfeed, and a caregiver who was able to breastfeed their child from birth, were presented as being healthy. While the converse was presented both as a cause of illness in the child or a sign of severe illness.

"the baby was ok, she was able to suck breastmilk" (2 months, female)

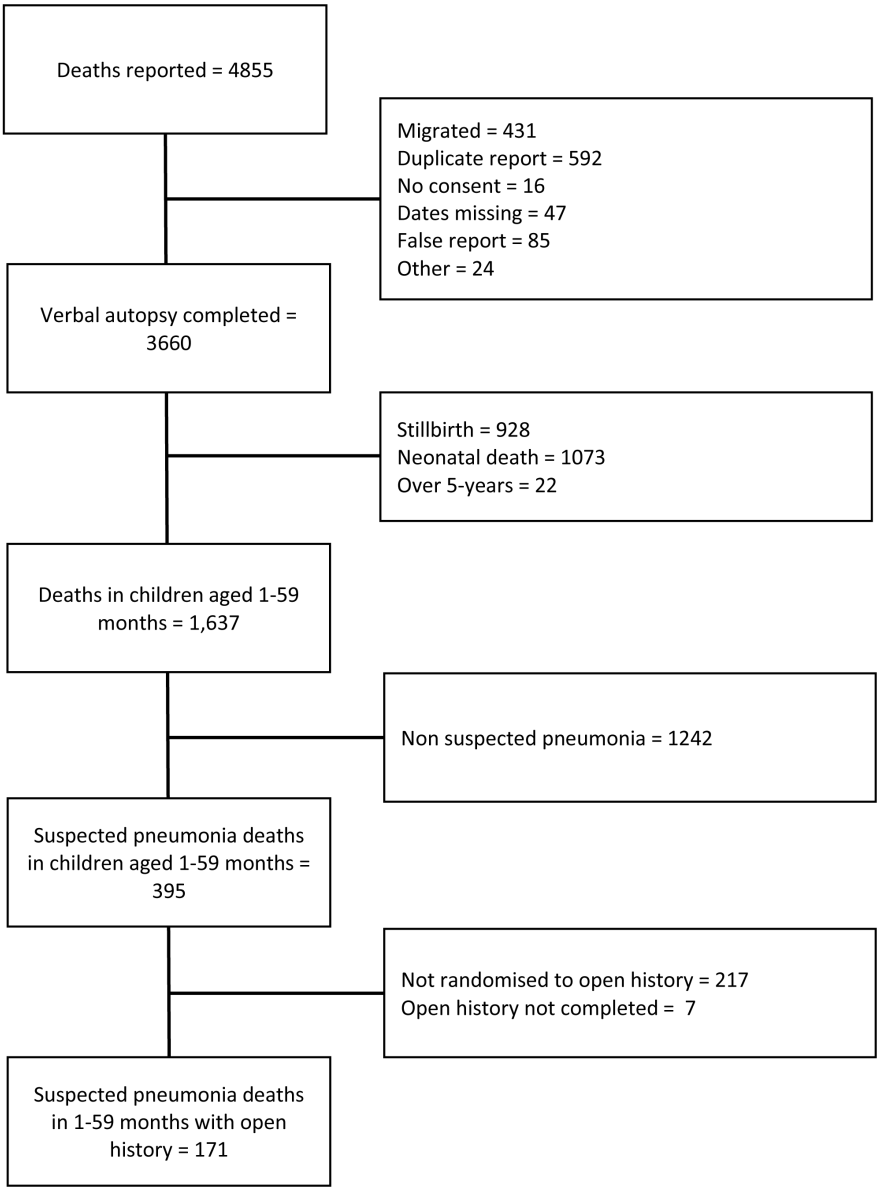

Figure 1. Participant inclusion flow-chart.

"He was not breastfeeding properly, because [I was] not producing milk. Then the child died" (13 months, male)

Like the mother's ability to breastfeed, the health of the child was linked to the mother having a 'normal' pregnancy and delivery. Narratives often started with the woman's pregnancy, highlighting whether they had attended antenatal care or had an uncomplicated delivery. In several narratives, the respondents indicated that the child had been born prematurely.

In a sub-group of narratives, caregivers described children who were repeatedly sick from recurrent and concurrent episodes of pneumonia, malaria, diarrhoea, and anaemia. In these cases, caregivers reported multiple episodes of care-seeking and described other comorbidities as explanations for their recurrent infections (e.g. prematurity, asthma, and congenital malformations). Misconceptions of asthma were apparent.

"This baby has been ill on and off since she was born. We were not surprised because the baby was born with asthma, and another problem was that the baby was born with a large chest." (10 months, female.)

Conversely, there were narratives where respondents expressed surprise that their child was ill, referring to them having been vaccinated and growing strongly.

Table 2. Description of suspected-pneumonia deaths, according to narrative allocation.

		Open Narrative* N = 171	No Narrative N = 217
Variable		**N (%)**	**N (%)**
Age	1–11 months 12–59 months	124 (73%) 47 (27%)	151 (70%) 66 (30%)
Sex	Male Female Missing	74 (43%) 96 (56%) 1 (1%)	103 (47%) 113 (52%) 1 (<1%)
Sought formal care prior to death**	Yes No Don't know	147 (86%) 23 (14%) 1 (<1%)	187 (86%) 29 (13%) 1 (<1%)
Location of death	Home Healthcare facility In transit Other*** Missing	64 (37%) 82 (48%) 22 (13%) 3 (2%) -	72 (33%) 97 (45%) 19 (9%) 18 (8%) 11 (5%)
Season of death	Rainy Dry	94 (55%) 77 (45%)	124 (57%) 93 (43%)
Pneumonia classification	InterVA only WHO VA signs only Caregiver reported only InterVA + WHO VA signs WHO VA signs + caregiver InterVA + caregiver InterVA + WHO VA signs + caregiver	106 (62%) 10 (6%) 7 (4%) 31 (18%) 1 (1%) 13 (8%) 3 (2%)	135 (62%) 21 (10%) 8 (4%) 36 (17%) 2 (1%) 10 (5%) 5 (2%)

*Only the open narrative records are included in the analysis

**Question from the WHO 2012 VA tool – "In the final days before death, did (s)he travel to a hospital or health centre"

***'Other' includes private clinics and outside of the household (e.g. with a neighbour or in the field).

Illness recognition. Illness recognition includes: pneumonia-specific signs and symptoms; overlap between pneumonia and asthma, and signs of severe illness.

Caregivers reported a range of clinical presentations for pneumonia, including; cough, difficulty breathing, noisy breathing, chest indrawing and fast breathing - in line with the IMCI chart booklet for diagnosing pneumonia. Caregivers differentiated between the severity of these different signs, with a cough often reported as the first sign of illness, which wasn't necessarily treated, followed by the more serious sign of difficulty breathing. Fever was frequently reported, and was almost exclusively associated with malaria.

"after some hours had passed the coughing started, and after a day or two passed the baby started having difficulties in breathing, so we went to the hospital." (5 months, female.)

Several caregivers stated that their children were 'born with asthma' and that asthma triggered them to seek care, or their child died of a sudden asthma attack. However, it was often unclear from the narratives whether the child had asthma, pneumonia, or both. It should be noted that in the Chichewa transcripts, distinct terms are used for pneumonia (*zibayo*) and asthma (*mphumo*), and field staff reflected that they were not used interchangeably.

"the child developed the problem of suffering from asthma - he had been admitted several times because of these attacks and during those times he was given medications like amoxicillin, Bactrim [cotrimoxazole], prednisone, Panadol and salbutamol." (24 months, male.)

Danger signs that triggered the caregiver to consider the illness severe included fainting and convulsions. A commonly used

Table 3. Description of location of care-seeking.

	First (n = 162)*	Second (n = 76)	Third (n=29)	Fourth (n=10)	Fifth (n=4)	Sixth (n=1)
No care sought	14 (9%)					
Traditional care	6 (4%)	7 (9%)	2 (7%)	1 (10%)	-	-
Community	5 (3%)	1 (1%)	-	-	-	-
Health centre	51 (31%)	14 (18%)	4 (14%)	3 (30%)	-	-
Hospital	81 (50%)	48 (63%)	21 (72%)	5 (50%)	4 (100%)	1 (100%)
Private	5 (3%)	6 (8%)	2 (7%)	1 (10%)	-	-

*In nine cases, we could not determine from the information provided in the open narrative if any care was sought

Table 4. Description of care-seeking behaviour, according to age and sex.

		Child's sex*			Child's age		
		Male (n=74)	Female (n=96)	p	1-11 months (n=124)	12-59 months (n=47)	p
Caregiver recognised pneumonia	No	33 (45%)	40 (42%)	0.639	44 (39%)	25 (53%)	0.087
	Yes	41 (55%)	56 (58%)		76 (61%)	22 (47%)	
Location of first seeking care	None	7 (9%)	7 (7%)	0.986^	14 (11%)	-	0.069^
	Hospital	35 (47%)	45 (47%)		58 (47%)	23 (49%)	
	Health centre	20 (27%)	31 (32%)		33 (27%)	18 (38%)	
	Community health worker	3 (4%)	2 (2%)		3 (2%)	2 (4%)	
	Private clinic	2 (3%)	3 (3%)		4 (3%)	1 (2%)	
	Traditional	3 (4%)	3 (3%)		6 (5%)	-	
	Unknown	4 (5%)	5 (5%)		6 (5%)	3 (6%)	
Location of death	Home	25 (34%)	39 (41%)	0.634^	53 (43%)	11 (23%)	0.028^
	Health centre or private clinic	4 (5%)	8 (8%)		7 (6%)	5 (11%)	
	Hospital	34 (46%)	38 (40%)		46 (37%)	27 (57%)	
	In transit	11 (15%)	11 (11%)		18 (15%)	4 (9%)	
Ever visited hospital	No	27 (36%)	25 (26%)	0.143	41 (33%)	11 (23%)	0.220
	Yes	47 (64%)	71 (74%)		83 (67%)	36 (78%)	
Ever admitted to hospital**	No	12 (26%)	23 (32%)	0.424	27 (32%)	9 (25%)	0.463
	Yes	35 (75%)	48 (68%)		56 (68%)	27 (75%)	
Received oxygen***	No	26 (74%)	36 (75%)	0.845	38 (68%)	24 (89%)	0.058^
	Yes	9 (26%)	12 (25%)		18 (32%)	3 (11%)	

* In one case, the child's sex is missing

**Amongst those who ever attended hospital (N=118 for sex analysis; N=119 for age group analysis)

***Amongst those who were ever admitted to hospital (N=83)

^ Fisher's exact test used.

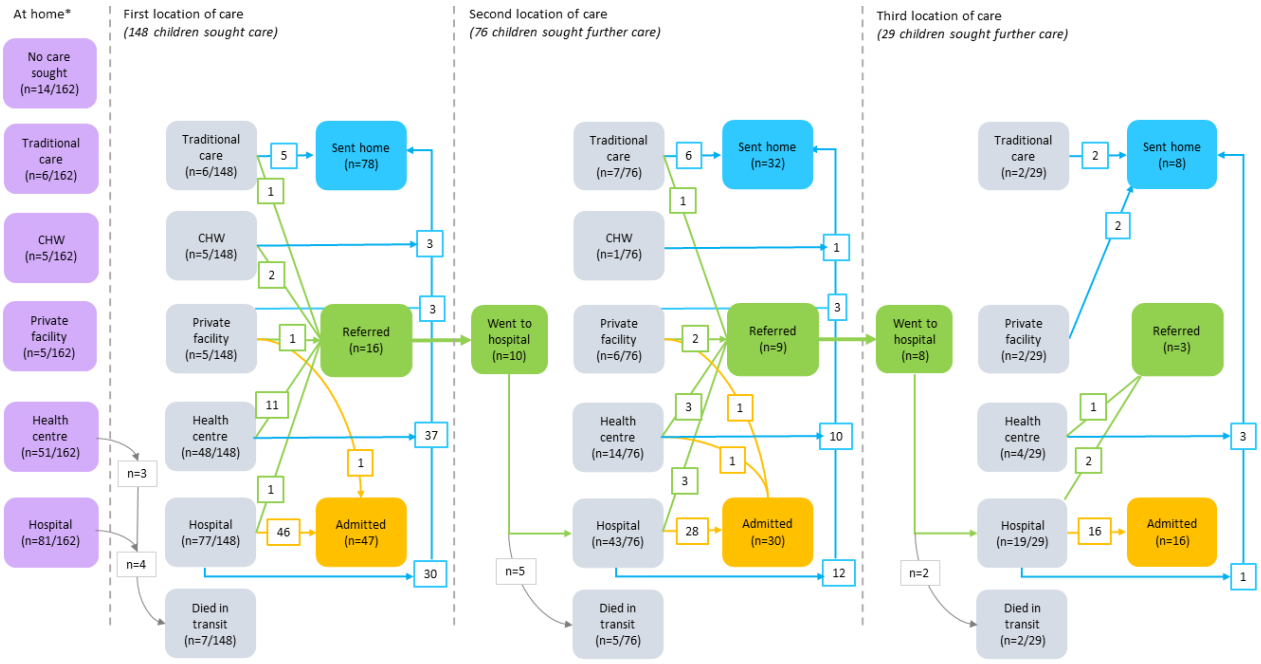

Figure 2. Summary of care-seeking according to the Pathways to Survival framework, for first, second and third location.

term was 'weakness' of the child (e.g. "*we just saw our child was weak"*, 12 months, female), and this was often provided as the trigger to seek care. This, and "dizzy eyes" may reflect the WHO general danger sign of lethargy. A child's failure to breast-feed was also understood as being a sign of them being severely ill, and led to several caregivers stating that their children had died of starvation.

"I believe that the child died of hunger because she was not feeding and coughing." (10 months, female.)

Care-seeking decisions. Sub-themes within care-seeking decisions included: delaying seeking care until the illness was severe; and the plurality of care. In several cases the respondent stated that they recognised the child was unwell, but did not seek care immediately. Rather they waited until a more severe sign of illness was seen (e.g. weakness, failing to feed or difficulty breathing).

In Malawi, traditional and western medicine exist in parallel. This plurality in healthcare systems was apparent in several narratives with caregivers reporting attending both types of care for the same episode of illness.

"the baby kept on crying and could hardly be stopped. We thought it could be evil spirits… therefore traditional medicine was given but there was no change, so we decided to visit the health centre." (4 months, male.)

The sequential access of different types of care, was attributed to the failure of the care sought either to cure the child or a perception that the care was not sufficient, or on the advice of neighbours and relatives:

"the child was given some panadols […] we therefore resorted to traditional drugs." (6 months, female.)

Referral procedures. Referral procedures, covering both healthcare worker's recommendation to seek further care and the process of getting to further care, included the sub-themes of: community advice; transportation barriers; and advice to wait and see. Advice to initially seek care and further care, was received from different community sources, namely relatives, traditional birth attendants and community healthcare workers. It should be noted respondents reported that community members recommended further care be sought both through formal and informal providers.

"when we reached home we were advised to proceed to [the hospital] and indeed we started off for the hospital." (10 months, female.)

Following community and healthcare provider referrals, challenges in getting to the facility due to transportation issues were reported. These barriers included lack of ambulance access, issues in finding the funds to arrange private transport and in the example given, the inappropriate use of an ambulance.

"the ambulance that carried us also took some nurses who had different errands, and we stopped at the market. By the time we reached [the hospital] the child was pronounced dead." (10 months, male.)

There were several stories of children taken to health centres, given treatment and sent home with the advice to return if the child did not improve –in line with WHO IMCI protocols for children without severe illness.

"the doctor said that if we see no signs of any change, we should go to bigger hospital… there was no change and indeed we went to [the hospital]." (16 months, female.)

Quality of care. Several quality of care challenges were reported during the open narratives, relating both to pneumonia specific issues, and wider health system challenges. Sub-themes include challenges in oxygen provision, barriers to blood provision, inappropriate discharge, missed opportunities to treat, and delays in care provision.

Oxygen was reported by many caregivers as being given at the time of the child's death, with many children dying shortly after being given oxygen. There were three specific narratives where caregivers reported the power going out while receiving oxygen, resulting in the child's death.

"He was put on oxygen for 50 minutes… shortly after the electricity at the hospital went out and the doctors removed the child from the oxygen machine. After 20 minutes the electricity was on again and the doctors came to take the child and put them on the oxygen machine. […] unfortunately they found that the child was already dead." (7 months, male.)

Many caregivers also reported that their child was prescribed a blood transfusion, but issues inserting intravenous lines and the lack of available blood meant they didn't receive it. A major gap in quality of care reported from caregivers was that their child was discharged from hospital while they were still unwell:

"Although she was discharged the child was not okay…very shortly after, it's when the child died here at home, the same day she was discharged from hospital." (8 months, female.)

Caregivers reported several situations of missed opportunities for diagnosis and treatment, including lacking medications and failing to diagnose the child with any illness during their examination. In these cases, children were sent home with no diagnosis, treatment or referral, leading to delays in care provision.

"we took the baby to [the clinic] and there was no medication at the facility. We went back home and the coughing continued… come the next day, the baby did not survive." (2 months, male.)

Within facilities, some reported delays in the child being seen by a healthcare provider, and in one such case the caregiver attributed her child's death to this delay:

"I blame the negligence of medical personnel at the hospital for delaying admission, and the time they took to start assisting the baby." (8 months, male.)

Discussion

In this mixed-methods analysis, we found high levels of caregiver recognition of illness, the majority of children who died of suspected pneumonia had accessed formal healthcare, and multiple interactions with healthcare were common. The narratives highlighted several missed opportunities for earlier intervention, including challenges in pneumonia recognition and diagnosis, getting to healthcare, attending referrals and issues in quality of care.

In absolute numbers, there were more deaths in girls than boys (96 versus 74). Hospital data from the same setting reported more male than female admissions, however, and being female was a predictor of inpatient pneumonia mortality[20]. This echoes evidence from LMICs that females have a higher pneumonia mortality risk[2]. One hypothesis for this is differential gendered care-seeking[21], but we found no clear supporting evidence; rather, female children were taken to hospital more often (74% versus 64%, p-value = 0.143). A more in-depth investigation into the biological and cultural reasons for these sex differences is still needed.

We observed interesting distinctions in care between infants (1–11 months) and older children (12–59 months). Pneumonia symptoms were less frequently recognised by caregivers in older children, but they were more likely to be admitted and die within a hospital setting. One explanation could be due to infants having more compliant chest walls, chest indrawing as clinical sign is less specific to pneumonia in this group[22]; alongside the inability of younger children to express themselves, this may result in poorer case management. Further investigation of how illness recognition by caregivers and healthcare providers changes with age could provide important insights for improving care.

The most common location to first seek care was the hospital. Further, of those who first attended a health centre and were referred to hospital, 63% (n=10/16) adhered to this recommendation. A study from central Malawi found caregivers accepted referrals from health centres to hospitals in 58% of critical cases but in just 4% of severe cases[23]. This suggests caregivers recognise the seriousness of their child's condition. However, the short interval between illness recognition and death (median three days), could mean early and non-severe signs of illness which can be treated at the community level were missed; a notion supported by research from Mozambique[24]. Caregivers rarely reported seeking care at the community-level despite Malawi's mature iCCM programme. A recent study reported caregiver preferences for non-community health workers and that issues in service coverage and quality of care remain[25], possibly explaining why community care was bypassed. We did not ask caregivers about their decision making processes and motivations around care-seeking, which would give more insight.

Multiple deficiencies in quality of care, as outlined in WHO Quality of Care Framework[26], were described. Namely the lack of drugs, availability of staff, functionality of referral systems and respectful communication - leading to multiple delays in

care. Indeed, data from this setting shows that children referred from health centres have an increased odds of in-patient mortality, compared to those coming directly from home (aOR: 1.90; 95% CI: 1.25-2.89)[27]. Similar to caregivers bypassing CHWs, we also found that caregivers bypassed health centres despite often being closer and able to provide treatment for pneumonia. Efforts to strengthen emergency case management, including effective triage, alongside routine IMCI provision in primary care may allow for quicker access to treatment in critical cases. However, sustainable strategies to improve healthcare worker performance need to go beyond basic training[28], and be supported with access to essential resources.

A key quality of care issue for pneumonia is access to reliable oxygen, and several caregivers reported their child dying while receiving oxygen, often after a short treatment period. Group discussions with caregivers in Malawi found negative community perceptions of oxygen, with oxygen equated with child deaths[29]. While we did not see this conception reflected, it may have contributed to delayed oxygen treatment. Pulse oximetry was implemented in all health centres and hospitals in the district as part of a concurrent research project, with 89% of routinely documented clinical pneumonia patients having an oxygen saturation[30]. Despite access to pulse oximetry, children in need of oxygen were still not effectively treated. Unreliable power supplies have been repeatedly reported as a barrier to effective oxygen delivery in LMICs[31], and we observed cases where this contributed to child deaths. However, oxygen provision with cylinders and back-up power or solar-powered oxygen systems should allow for solutions to this issue[32]. It is important that investment in oxygen systems consider wider targeting of pulse oximetry screening, on-going mentorship and supervision, equipment maintenance, and locally appropriate power solutions to maximise impact[33].

Our study had three key limitations. Firstly, we only considered caregiver perspectives of the circumstances surrounding their child's death and were unable to verify clinical details (e.g. oxygen). Secondly, while the narratives were purposefully collected in an unstructured manner, we were unable to distinguish if the absence of reporting means it didn't happen, was not stated by the caregiver, or not documented by the fieldworkers. As caregivers narrated the story of the child's death from their own perspective, it may be subject to both recall and social desirability biases. Thirdly, not all of the deaths defined as suspected pneumonia are necessarily due to pneumonia and we may have missed pneumonia deaths. There were clear overlaps in the narratives between pneumonia, malaria and asthma. Given most deaths were assigned as 'pneumonia' by InterVA, which is designed to give population level cause-specific mortality fractions, pneumonia-specific conclusions should be interpreted with caution.

Paediatric pneumonia is a complex condition, requiring a whole systems perspective, covering protect and prevent interventions, through to quality delivery of healthcare services. We observed shortfalls across this spectrum, but particularly around missed opportunities to better manage cases which presented to healthcare. Most caregivers brought their child to healthcare, and many sought care multiple times from different healthcare providers, suggesting sub-optimal pneumonia case management. Improved implementation of existing iCCM and IMCI protocols with feedback and accountability systems are needed, in conjunction with further research on optimised diagnosis, treatment and referral approaches in primary care, to reduce paediatric pneumonia deaths.

Data availability

Underlying data

Harvard Dataverse: Replication Data for: "Care-seeking patterns amongst suspected paediatric pneumonia deaths in rural Malawi: a mixed method study"

https://doi.org/10.7910/DVN/66YIME[34]

This project contains the following underlying data:

- VA_OH_CleanRepositoryData.xls (Fully anonymised quantitative data used in analysis.)

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC0 1.0 Public domain dedication).

The open narratives cannot be sufficiently anonymised, as they contain detailed accounts of individual death events with locations, dates, demographic and clinical details. These are therefore not available in an open repository. For researchers wishing to duplicate or re-analyse these data for data for research purposes only, contact Dr Carina King (carina.king@ki.se) or Prof. Neil French (N.French@liverpool.ac.uk), to discuss the signing of a data sharing agreement, following review by the National Health Sciences Research Ethics Committee in Malawi (contact: infor@ncst.mw).

Acknowledgements

We would like to thank the communities and families participating in the study, the key informants for volunteering their time and the Traditional Authorities of Mchinji district and Chilumba, Karonga district for their support. We are very grateful for the hard work of our field and data staff. We thank the other VacSurv Consortium members for their advice: Nigel Cunliffe (University of Liverpool); Rob Heyderman and Anthony Costello (University College London); Osamu Nakagomi (University of Nagasaki); Charles Mwansambo (Ministry of Health Malawi); Sonia Lewycka (Oxford University); Jacqueline E. Tate and Umesh D. Parashar (Centers for Disease Control & Prevention, Atlanta, GA, USA) Cynthia Whitney (Emory University) Jennifer Verani (The National Center for Immunization and Respiratory Diseases, Centers for Disease Control & Prevention, Atlanta, GA, USA) The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the US Centers for Disease Control and Prevention.

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✔ **Christopher J. Gill**

Department of Global Health, Boston University School of Public Health, Boston, MA, USA

The authors present a useful mixed methods analysis of verbal autopsy data collected In Malawi among children who died of suspected pneumonia. Overall, the methodology was rigorous and logical and I only had a few queries around areas that were not quite clear. The conclusions drawn were persuasive and consistent with similar analyses regarding the role of delays in care seeking.

Minor comments/queries:

1. I wasn't clear about why a free text narrative was not done in all verbal autopsies. The authors mention that there were theoretical concerns about the impact of the interview (leading to the narrative) on data quality and rapport with the person being interviewed. However, the free text narrative typically occurs at the end of the VA interview, so I'm not clear how this could then affect the rest of the interview, which should have occurred already. I don't see this as a source of bias, since it was driven by randomization. But it did reduce the information available to the team in half of the children. Please explain this further.

2. Table 2 refers to 'reported signs' as part of the pneumonia classification process. However it is not clear what this means. Earlier in the methods the authors mention use of several of the VA questions as being part of the classification strategy, but the terminology 'signs' is not used there. Please clarify.

3. Minor issue, explain what 'attended hospital' means.

4. I'm curious about the much higher proportion of home deaths among infants. Is that because there is a tendency against care seeking? Is it that signs of Pna are often subtle and therefore easily missed in infants? Is it that progression to death is more rapid? Or possibly a combination of these factors? Please comment.

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

Yes

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

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

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

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

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Pediatric pneumonia and respiratory infections

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

Author Response 01 Mar 2021

Carina King, Karolinska Institute, Stockholm, Sweden

1. I wasn't clear about why a free text narrative was not done in all verbal autopsies. The authors mention that there were theoretical concerns about the impact of the interview (leading to the narrative) on data quality and rapport with the person being interviewed. However, the free text narrative typically occurs at the end of the VA interview, so I'm not clear how this could then affect the rest of the interview, which should have occurred already. I don't see this as a source of bias, since it was driven by randomization. But it did reduce the information available to the team in half of the children. Please explain this further.
Response: *The randomisation to have an open narrative or not was done as an opportunistic embedded study to explore the role of narratives in the process of verbal autopsies. While the standard WHO VA tool includes a narrative, this is optional and often not analysed when cause of death is assigned using automated methods. In this study we had decided to conduct the open narrative at the start of the VA interview. We have published a paper which reports our findings on this separate research question, and reference this in the text.*

2. Table 2 refers to 'reported signs' as part of the pneumonia classification process. However, it is not clear what this means. Earlier in the methods the authors mention use of several of the VA questions as being part of the classification strategy, but the terminology 'signs' is not used there. Please clarify.
Response: *Reported signs in Table 2 refers to the caregiver responding "yes" to the child having a*

cough and difficulty breathing in the two weeks prior to death. We have updated the label in the table to use the same language as the methods.

3. Minor issue, explain what 'attended hospital' means.
Response: *This means they went to hospital, but were not necessarily admitted. We have rephrased to "visited hospital" and hope this is clearer language.*

4. I'm curious about the much higher proportion of home deaths among infants. Is that because there is a tendency against care seeking? Is it that signs of Pna are often subtle and therefore easily missed in infants? Is it that progression to death is more rapid? Or possibly a combination of these factors? Please comment.
Response: *This is a really important point, and one which we can only make general comments and reflections on. Rates of care-seeking were similar between infants and older children, but we saw higher rates of hospitalisation and oxygen treatment in the older age group. There are several reasons this may be, firstly that signs of severe respiratory distress were more easily recognised in older children (aided by children being able to say how they are feeling). Secondly, when pulse oximetry is available, it is generally easier to get measurements on older children. It may be that hypoxaemia in older children was identified more often. This is especially important as we've seen in this setting before that a lot of hypoxemic children are missed according to current IMCI guidelines (e.g. McCollum et al., 2016). Finally, there may be cultural perceptions around care and illness in different age groups that we have not accounted for. Further work is definitely warranted to understand motivations, decision making processes and bottlenecks in care-seeking pathways, across a range of contexts. In particular, a study which explores how different clinical signs of pneumonia are recorded across age groups and whether they are seen are equally serious by both caregivers and healthcare workers would be valuable.*

Competing Interests: None to declare

Reviewer Report 21 December 2020

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Prudence Hamade
Malaria Consortium, London, UK

This is a very well written and very important article with comprehensive data from a study using verbal autopsy approach described by WHO. The limitations of this approach are well described.

I think a table of the components and indicators of the Pathway to Survival would have been good to include so it could be compared to the components chosen for this analysis especially as although the data was collected by open narrative they were coded by predetermined themes'

There is a strong description in this paper of what care people sought but little information of why they sought care in those places. The diagram explaining the care seeking behaviour was very interesting but is limited in its explanation of why people sought care where they did and what were the actual pathways chosen. For example if a person sought care from a traditional healer in the first instance where did they go to seek care in the second instance. The belief that medicine is magic and cure will be immediate in my experience leads to going from one care provider to another with prescription of multiple medications and then decision by the care giver of those they can afford to buy and administer causing possible toxicity in the child as well as under dosing of the appropriate therapy.

In the first question I think the recognition of illness should not of excluded witchcraft or curses as this is an important issue around care seeking especially as some people sought care from traditional healers.

No mention in the accounts of seeking care from shops and pharmacies which are a common source of care seeking (cheap and available at all time of day).

The low number of people who sought care from community health workers is interesting but the reason for this is not explained.

It would be interesting to know how many caregivers of children sought care from community health workers whose children did not die to compare with the health seeking behavior of children with symptoms of pneumonia who did die.

The data does not clearly show what percentage of the children had risk factors associated with death although some of these are described such as prematurity failure to thrive etc.

The attribution of asthma is also very interesting. Asthma is not frequently diagnosed or treated in LMICs also non infectious causes of difficulty breathing like bronchiolitis which if not treated correctly can lead to death.

Training of health care workers especially at hospital level in use of supportive measure like use of pulse oximetry, oxygen and bronchodilators needs to be improved as well as what was not fully emphasized is triage at the health facility level to make sure that severely ill children receive urgent care when they arrive at the hospital.

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

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

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

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

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

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: I am a retired Community Paediatrician. I have worked for 10 years in the field with MSF and 11 years with Maria Consortium mainly in the field of infectious disease and child health

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

Author Response 01 Mar 2021

Carina King, Karolinska Institute, Stockholm, Sweden

I think a table of the components and indicators of the Pathway to Survival would have been good to include so it could be compared to the components chosen for this analysis especially as although the data was collected by open narrative they were coded by predetermined themes.
Response: *We have now added a sentence to the methods to highlight the components of the framework which we did not include in the data extraction. These were mostly around contextual wellbeing factors, rather than the indicators for care-seeking and actions taken.*

There is a strong description in this paper of what care people sought but little information of why they sought care in those places. The diagram explaining the care seeking behaviour was very interesting but is limited in its explanation of why people sought care where they did and what were the actual pathways chosen. For example if a person sought care from a traditional healer in the first instance where did they go to seek care in the second instance. The belief that medicine is magic and cure will be immediate, in my experience leads to going from one care provider to another with prescription of multiple medications and then decision by the care giver of those they can afford to buy and administer, causing possible toxicity in the child as well as under dosing of the appropriate therapy.
Response: *This is an excellent point, and the access of different care for different motivations happening concurrently has been described in Malawi previously. Reasons for this have been that some causes of illness need to be treated with traditional medicine, or when treatments do not seem to be working other forms of care are sought. However, in this study we did not probe around motivations for the decisions made, and reasoning or motivations for care-seeking actions was not something which emerged from the narratives. We would love to see more in-depth research into this topic area however, to ensure health systems are responsive to communities.*

In the first question I think the recognition of illness should not of excluded witchcraft or curses as this is an important issue around care seeking especially as some people sought

care from traditional healers.
Response: *In the caregiver recognition of illness, we accepted any plausible clinical symptom (e.g. fever, cough) and phrases such as "the child was sick". These non-specific terms may cover illnesses perceived to be either due to medical causes or witchcraft, and we did not attempt to differentiate. However, we did not actively classify text such as "the child was cursed" as a recognition of illness. Checking the data, there was one narrative where the caregiver reported the child had been cursed ("njazi") and was coded as no illness recognised as no further signs or symptoms was given.*

No mention in the accounts of seeking care from shops and pharmacies which are a common source of care seeking (cheap and available at all time of day).
Response: *This is a great observation, and to confirm care-seeking from pharmacy shops was not explicitly mentioned in the narratives. In the context, care is provided free at government health facilities, and at the time of the study, private facilities and pharmacies within rural settings were relatively uncommon. We have added a statement to make this explicit in the text.*

The low number of people who sought care from community health workers is interesting but the reason for this is not explained.
Response: *As in the response above we did not probe around motivations for care-seeking decisions. However, we agree that in this context with well-established community care it would be valuable to understand when and why caregivers would seek care in the community versus travelling to health centres or the district hospital, which were common.*

It would be interesting to know how many caregivers of children sought care from community health workers whose children did not die to compare with the health seeking behavior of children with symptoms of pneumonia who did die.
Response: *This is a limitation of the data we had available. We did not actively follow-up children who had pneumonia and survived, so do not have a corresponding dataset for surviving children to compare. This analysis however would be valuable to try and identify if care-seeking pathways diverge at any point, and therefore identify the key bottlenecks.*

The data does not clearly show what percentage of the children had risk factors associated with death although some of these are described such as prematurity failure to thrive etc.
Response: *We have now added this in the results.*

The attribution of asthma is also very interesting. Asthma is not frequently diagnosed or treated in LMICs also non-infectious causes of difficulty breathing like bronchiolitis which if not treated correctly can lead to death.
Response: *Yes, this was a really interesting finding and through more informal discussions seems that more chronic difficulties in breathing are talked about as asthma but more acute issues are pneumonia. This does raise questions on how we can improve both the diagnosis and management of asthma, when there has been a lot of focus on diagnosing and treating infections within primary care settings.*

Training of health care workers especially at hospital level in use of supportive measure like use of pulse oximetry, oxygen and bronchodilators needs to be improved as well as what was not fully emphasized is triage at the health facility level to make sure that severely ill

children receive urgent care when they arrive at the hospital.
Response: *We fully agree with this, and have amended the text in the manuscript to make this point about improved triage.*

Competing Interests: None to declare