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## Delayed care seeking for fatal pneumonia in children aged under five years in Uganda: a case-series study

**Recours aux soins trop tardif pour des cas de pneumonie mortelle touchant des enfants moins de cinq ans en Ouganda : étude cas-témoins**

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### Abstract

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#### Objective

To review individual case histories of children who had died of pneumonia in rural Uganda and to investigate why these children did not survive.

#### Methods

This case-series study was done in the Iganga/Mayuge demographic surveillance site, Uganda, where 67 000 people were visited once every 3 months for population-based data and vital events. Children aged 1–59 months from November 2005 to August 2007 were included. Verbal and social autopsies were done to determine likely cause of death and care-seeking actions.

#### Findings

Cause of death was assigned for 164 children, 27% with pneumonia. Of the pneumonia deaths, half occurred in hospital and one-third at home. Median duration of pneumonia illness was 7 days, and median time taken to seek care outside the home was 2 days. Most first received drugs at home: 52% antimalarials and 27% antibiotics. Most were taken for care outside the home, 36% of whom first went to public hospitals. One-third of those reaching the district hospital were referred to the regional hospital, and 19% reportedly improved after hospital treatment. The median treatment cost for a child with fatal pneumonia was US\$ 5.8.

#### Conclusion

There was mistreatment with antimalarials, delays in seeking care and likely low quality of care for children with fatal pneumonia. To improve access to and quality of care, the feasibility and effect on mortality of training community health workers and drug vendors in pneumonia and malaria management with prepacked drugs should be tested.

### Résumé

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#### Objectif

Etudier les histoires cliniques individuelles d'enfants décédés d'une pneumonie dans la partie rurale de l'Ouganda et déterminer pourquoi ces enfants n'ont pas survécu.

#### Méthodes

Cette étude de série de cas a été réalisée sur le site de surveillance démographique d'Iganga/Mayuge, en Ouganda, où 67 000 personnes sont visitées une fois tous les trimestres pour recueillir des données en population et des faits d'état-civil. Les enfants âgés de 1 à 59 mois entre novembre 2005 et août 2007 ont été inclus dans l'étude. Des autopsies verbales et sociales ont été pratiquées pour déterminer la cause probable de la mort et les tentatives de recours aux soins.

#### Résultats

Une cause du décès a été affectée à 164 enfants, soit une pneumonie pour 27 % d'entre eux. Parmi les décès par pneumonie, la moitié se sont produits à l'hôpital et un tiers à domicile. La durée médiane de la pneumonie était de 7 jours et le délai médian pour solliciter des soins à l'extérieur du domicile était de 2 jours. La majorité des malades ont d'abord reçu des médicaments à domicile : 52 % des antipaludiques et 27 % des antibiotiques. La plupart des cas ont été admis dans un établissement pour recevoir des soins, dont 36 % en premier lieu dans un hôpital public. Un tiers des cas qui se sont présentés à l'hôpital de district ont été orientés vers l'hôpital régional et 19 % ont été signalés comme améliorés après le traitement hospitalier. Le coût de traitement médian d'une pneumonie mortelle chez un enfant était de US \$ 5,8.

#### Conclusion

Il y a eu des traitements erronés par des antipaludiques, des retards dans le recours aux soins et probablement des soins de qualité médiocre pour les enfants décédés d'une pneumonie mortelle. Pour améliorer l'accès aux soins et la qualité de ces prestations, il faudrait tester la faisabilité et les effets sur la mortalité de la formation des agents de santé communautaires et des vendeurs de médicaments à la prise en charge du paludisme et de la pneumonie avec des médicaments préconditionnés.

### Resumen

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#### Objetivo

Examinar las historias clínicas de niños que habían muerto de neumonía en la Uganda rural e investigar las razones de que no sobrevivieran.

#### Métodos

Este estudio de serie de casos se llevó a cabo en el centro de vigilancia demográfica de Iganga/Mayuge, Uganda, donde se visita una vez cada

tres meses a unas 67 000 personas para registrar datos poblacionales y eventos vitales. El estudio abarcó a una serie de niños de 1 a 59 meses fallecidos entre noviembre de 2005 y agosto de 2007. Se llevaron a cabo autopsias verbales y sociales para determinar la causa probable de defunción y las medidas de búsqueda de atención.

## Resultados

Se determinó la causa de defunción de 164 niños, el 27% de ellos con neumonía. De todas las muertes por esta enfermedad, la mitad se produjeron en el hospital y una tercera parte en el hogar. La duración mediana de la neumonía fue de 7 días, y el tiempo mediano transcurrido hasta buscar atención fuera del hogar fue de 2 días. Los primeros medicamentos recibidos en el hogar fueron en su mayoría antimaláricos, 52%, y antibióticos, 27%. La mayoría fueron trasladados a otros lugares para recibir atención, y entre ellos el 36% fueron ingresados de entrada en hospitales públicos. Una tercera parte de los que llegaron al hospital de distrito fueron derivados al hospital regional, y un 19% mejoraron al parecer después del tratamiento hospitalario. El costo mediano del tratamiento de un niño con neumonía mortal fue de US\$ 5,8.

## Conclusión

Los niños con neumonía mortal fueron tratados incorrectamente con antimaláricos, sufrieron retrasos en la búsqueda de atención, y recibieron probablemente una atención de mala calidad. A fin de mejorar el acceso a la atención y la calidad de la misma, deberían analizarse la viabilidad y el efecto en la mortalidad de la formación de los agentes de salud comunitarios y los vendedores de medicamentos en materia de tratamiento de la neumonía y la malaria.

## ملخص

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### الهدف

مراجعة تواريخ حالات فردية لأطفال ماتوا بسبب الالتهاب الرئوي في أرياف أوغندا واستقصاء أسباب موتهم.

### الطريقة

نفذت دراسة لسلسلة من الحالات في موقع ترصد ديموغرافي في منطقة إيفانغا/مايوغ في أوغندا بزيارة 67 000 شخص مرة كل 3 شهور لجمع معطيات مرتكزة على السكان وعلى الأحداث الحياتية؛ وشمل ذلك الأطفال الذين تراوحت أعمارهم بين شهر و59 شهراً في الفترة بين تشرين الثاني/نوفمبر 2005 وأب/أغسطس 2007؛ وذلك بإجراء العينة التثريبية اللغوية والاجتماعية للتعرف على السبب المحتمل للموت والإجراءات التي اتخذت للتماس الرعاية.

### الموجودات

لقد حدد الالتهاب الرئوي كسبب للموت لدى 27% من بين 164 طفلاً، وقد مات نصفهم في المستشفى وتلقم في المنزل، وكانت المدة الوسطية للالتهاب الرئوي 7 أيام، والمدة الوسطية التي استغرقتها عملية التماس الرعاية خارج المنزل يومان، وقد تلقى معظم الأطفال معالجتهم في البدء في المنزل، حيث تلقى 52% منهم مضادات الملاريا وتلقى 27% منهم المضادات الحيوية. وقد أخذ معظمهم للرعاية خارج المنزل، فيما ذهب 36% منهم في البدء إلى مستشفى عام، وقد حوّل ثلث من استطاع الوصول إلى مستشفى المنطقة إلى مستشفى الإقليم وأبلغ عن تحسن 19% منهم بعد المعالجة في المستشفى. وبلغت التكاليف الوسطية للمعالجة لكل طفل أصيب بالالتهاب الرئوي المميت 5.8 دولاراً أمريكياً.

### الاستنتاج

كان هناك إساءة في المعالجة بمضادات الملاريا، وتأخر في التماس الرعاية، مع إمكانية وجود ضعف في جودة رعاية الأطفال المصابين بالالتهاب الرئوي المميت. وتحسين إتاحة الرعاية وجودتها يجب اختبار مدى جدوى وتأثير تدريب العاملين الصحيين وبنائهم الأدوية في المجتمع على معالجة الملاريا والالتهاب الرئوي بالأدوية المعيبة مسبقاً وتأثير ذلك على معدل الوفيات الناجمة عنهما.

## Background

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Reduction of childhood mortality due to acute respiratory infections is a worldwide health priority.<sup>1</sup> More than 2 million children die annually of acute respiratory infections, most often pneumonia.<sup>2</sup> In sub-Saharan Africa, the estimated proportion of death in children aged under 5 years attributed to pneumonia is 17–26%.<sup>3</sup> Prompt recognition and treatment with an effective drug is crucial, as the case-fatality rate in untreated children is high (sometimes exceeding 20%)<sup>4</sup> and death can occur after 3 days of illness.<sup>5</sup> In areas with endemic malaria, symptom overlap led to common mistreatment of pneumonia with antimalarials rather than appropriate antibiotics, probably increasing incidence of severe pneumonia.<sup>6</sup>

Risk factors for fatal pneumonia include poor socioeconomic status, incomplete immunization schemes, malnutrition, late care seeking and inadequate treatment.<sup>4,5</sup> Yet cheap and effective tools exist for pneumonia prevention and care. Generally, the recommendations focus on improvement in vaccine coverage for measles, *Haemophilus influenzae* type B and pertussis, community education, improved nutrition, training of health providers in diagnostic and treatment algorithms, use of effective antibiotics, and timely referral of severely ill cases.<sup>5,7–9</sup> However, in 2004, only 29% of Ugandan children with symptoms suggestive of pneumonia were reported to have used first-line or second-line antibiotics during illness.<sup>6</sup>

We use two hypotheses to investigate the contributing barriers for appropriate care seeking: most children live, fall ill and die beyond the reach of public health facilities and are treated at home or in the private sector; and interventions target single diseases, rather than febrile children with either multiple concurrent infections or overlapping symptoms, thus risking incorrect treatment.<sup>10</sup> Weak public health systems, with deficient financial and human resources, poor organization of health services, and lack of information about the local disease burden, are an underlying cause of these constraints.<sup>11</sup> In Asia, several countries successfully treat childhood pneumonia in the community with oral antibiotics delivered by lay health workers.<sup>12</sup> Despite WHO/United Nations Children's Fund (UNICEF) recommendations that countries can reduce pneumonia mortality in community settings by "integrating community pneumonia treatment activities with other efforts and initiatives that promote child health, especially malaria and diarrhoea treatment at the household and community levels",<sup>13</sup> no country in Africa has made such interventions policy.

In low-income countries, where most children die outside the formal health system, likely cause of death is determined by interviews with carers on symptoms preceding death. These interviews are referred to as verbal autopsies. However, a few studies have investigated care-seeking behaviour preceding a child death<sup>14–17</sup> to identify inadequacies in the home, community, health facilities and the referral mechanisms. We propose to call these social autopsies. Previous studies have mostly looked at care seeking before malaria deaths<sup>18–20</sup> and we found only one for pneumonia deaths.<sup>5</sup> Our aim was to review case histories for children who had died of possible pneumonia to investigate child mortality on the basis of the carers' experience.

## Methods

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### Study area and population

This case-series study was done in the Iganga/Mayuge Demographic Surveillance Site (DSS) in Uganda. This DSS encompasses 67 000 people in 13 400 households. About 17% are children aged less than 5 years. There is one hospital, eight public health centres, three nongovernmental organization (NGO) clinics, and 122 drug shops in the DSS. The site is a member of the international DSS organization InDepth and largely follows its standard methods. The DSS generates population-based data on key demographic events three times a year, and household, socioeconomic and education data once a year. Furthermore, community informants continuously relay information on deaths. All reported deaths in children aged 1–59 months in the DSS from November 2005 to August 2007 were included in the study. Collection and analysis of DSS data were ethically reviewed by Makerere University Institutional Review Board and approved by Uganda National Council of Science and Technology.

#### Data collection

For all deaths in the DSS, verbal autopsies are used to assign likely cause of death and social autopsies to elucidate care-seeking actions before death. An InDepth standard verbal-autopsy questionnaire was merged with a social-autopsy questionnaire developed in Bolivia.<sup>21</sup> Whenever a death was reported, after a mourning period of 4–6 weeks, the merged questionnaire was used by one of three trained native interviewers. Because no standard manuals for coding of verbal autopsy information exist, we developed our own guidelines and coding sheets. Three coding physicians summarized each patient's history and independently ascribed primary and differential cause of death. Causes of death were later compared between coders and a final primary and differential cause of death was ascribed when at least two coders agreed. Where no definite cause of death was found, or when there was disagreement between all coders, the form was coded as "cause unknown". The International Statistical Classification of Diseases and Related Health Problems, 10th revision, (ICD-10) codes were used as in other InDepth sites. Children who had been assigned pneumonia as primary or differential death cause were included in the analysis.

#### Data analysis

Data were entered in FoxPro (Microsoft Corporation, Seattle, WA, United States of America) and analysed in STATA 10 (Stata Corporation, College Station, TX, USA). Children who had died of pneumonia were analysed for care seeking before death, including timing of actions and illness duration, types of treatments used at home, sources of care sought, and treatment costs. Sample means were compared with Student's *t*-test for normally distributed data, and the Mann–Whitney test was used for non-parametric data, such as medians. Bivariate analyses were done with  $\chi^2$  tests and variables significant at the 0.25 level were included in a multiple logistic regression for determination of risk factors for late care seeking. The cut-off time for the dependent variable delay was set at 2 days, since anything more than 2 days was above the median duration of illness before outside care was sought. Confounding effects of age, sex, concurrent death cause, source of care sought, and distance to nearest health facility were explored. Age was grouped into 1–11 months and 12–59 months. Distance was grouped into < 1 hour and  $\geq$  1 hour walking distance.

#### Results

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During the study period, 164 postneonatal (children aged 1–59 months) deaths in the DSS had been assigned a likely cause of death. Of these, 62 (38%) were infants. Altogether, 44 (27%) of the dead children had been coded as pneumonia deaths. In 12 (7%), pneumonia was the likely primary cause of death and in 32 (20%) the differential cause. Most children with pneumonia ascribed as cause of death also had a differential cause: 16 (36%) of 44 with AIDS/malnutrition, 11 (25%) anaemia, 14 (9%) malaria, and 3 (7%) diarrhoea. Of the 44 children who died from suspected pneumonia, the median age at death was 16 months [interquartile range (IQR) 8–23]. The mortality ratio of girls to boys was 1:1. Of these 44 children, 14 (32%) had died at home, 21 (48%) in hospital, 4 (9%) en route to a health facility, and the remaining 5 (11%) in clinics or health centres.

[Table 1](#) shows the timing in care seeking before death. Overall, a child that died of pneumonia had been sick for 7 days (IQR 2–30). The median reported duration was 4 hours (IQR 1–24) from illness recognition until home care was initiated, and 2 days (IQR 0–4) until care was sought outside the home. Children were taken earlier to private clinics than to hospital, 10.5 hours versus 3 days after illness recognition, respectively ( $P = 0.01$ ). The median reported duration from first treatment to death was 7 days (IQR 2–14).

[Table 1](#)

#### Timing in care seeking

Of all children dying from suspected pneumonia, 31 (70%) of 44 had been treated with drugs at home. Of these, 12 (27%) had reportedly been given antibiotics and 23 (52%) an antimalarial drug. A quarter had been given both. The antibiotic most commonly used at home was co-trimoxazole (trimethoprim + sulfamethoxazole), which was used by 11 of 12 children; 1 child had used amoxicillin. The most commonly used antimalarial drug was chloroquine, used by 16 (70%) of 23 children. Fansidar (sulfadoxine + pyrimethamine) was used by 6 (26%), and 2 (9%) used a combination chloroquine, sulfadoxine and pyrimethamine (Homapak). Forty-two percent of the drugs were obtained from drug shops or ordinary shops, whereas the rest were leftovers or obtained from neighbours.

Most cases of fatal pneumonia, 39 (89%) of 44, were taken for care outside their homes during the illness ([Table 2](#)). For the first outside consultation, 16 (36%) went to a government hospital, 9 (20%) to government health centres, and another 11 (25%) went to private providers and 3 (7%) went to NGO clinics. Sixty percent were within 1 hour walking distance of the facility visited. Fewer of those who had gone to a hospital [2 (13%) of 16] were within 1 hour walking distance than of those who went to a public health centre [6 (67%) of 9 ( $P = 0.005$ )] or private clinic [7 (64%) of 11 ( $P = 0.005$ )]. A qualified health worker, nurse, or midwife was reportedly seen at least once during the acute illness for most, 37 (84%), pneumonia deaths. Six (14%) cases were reportedly never taken outside the home. Overall, 22 of the 44 dead children were taken to only one provider, 13 (29%) sought care from two providers, and 3 (7%) from three or more providers.

[Table 2](#)

#### Sources of care sought

Referral was common and of the children who had seen a formal provider, 13 (34%) of 38, were reportedly referred to another

facility. Two (22%) of the 9 children taken to health centres were referred to the district hospital, and 5 (31%) of the 16 children who reached the district hospital were referred to another hospital (2 to regional, 2 to the national and 1 to missionary). The rest of the referrals were from private clinics to the district hospital. Most children were reportedly referred to get better care or because there was no blood available for transfusion. Eleven (85%) of 13 referred children were taken to the recommended referral facility after a median of 0.5 days (IQR 0–7). The rest died before reaching the referral facility.

Of the 16 children who had received the first treatment from a hospital, only 3 improved after treatment, 6 reported no change, 2 worsened and 5 died. Only 1 of the 44 children who died of pneumonia reportedly received oxygen during the illness. Overall, the median expenditure by the carers on treatment for a child who died of pneumonia was 10 000 Ugandan Shillings (IQR 4500–20 000), about US\$ 5.8.

Table 3 shows the characteristics of the two groups that sought care outside the home within or beyond 2 days after recognizing the illness, as well as the risk factors potentially causing delayed care seeking. Delayed care seeking was only associated with home treatment with antibiotics. All variables with *P*-values less than 0.25 were included in the multivariate analysis. Apart from having used antibiotics at home, the other variables included were concurrent anaemia as cause of death and having taken the child to a private clinic. The full model indicates that having used antibiotics at home (odds ratio 4.8, 95% confidence interval, CI: 1.0–23; *P* = 0.047) was the only independent risk factor for delaying care seeking outside the home more than 2 days after illness recognition (Table 4).

Table 3

**Potential risk factors for delaying > 2 days from symptom recognition to reaching an outside care provider for fatal pneumonia, *n* = 44**

Table 4

**Multivariate analysis of potential risk factors for delaying to reach an outside care provider for fatal pneumonia (*n* = 44)**

## Discussion

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As hypothesized, most carers opted to give drugs at home before seeking care elsewhere, despite the fact that most lived less than a 1 hour walk from the health facility first visited. Although 1 hour walking distance from a public health facility is commonly deemed reasonable access, a private-sector representative can probably be found within 5–15 minute walk. Indeed, those who had first gone to a private clinic reached outside care much earlier after recognizing the illness than those who went to hospital. However, geographic barriers are not the only factors that compel carers to first use home treatment with drugs obtained from the private sector before seeking formal care. Other barriers include gender aspects of decision-making, other responsibilities at home, and local perceptions of illness and care providers.<sup>22,23</sup> These barriers could not be elucidated by the present semistructured social autopsy method, but may require more in-depth qualitative methods of investigation (e.g. case narratives with probing).

Although most sick children were taken to qualified providers at some stage, most carers waited more than 24 hours after illness recognition before seeking any care outside the home. A median of 2 days passed before any professional practitioner was seen. Waiting for self-prescribed drugs to have effect likely explained some of the later attendance at formal providers, because having used antibiotics in the home was the only risk factor for late care seeking. As we collected information only on children that died, we cannot conclude whether waiting 2 days is a risk factor for death, nor whether home treatment with antibiotics has a negative effect on survival from pneumonia, as this would require a case-control approach. However, given the likelihood that some mothers missed the early pneumonia symptoms and only took action when the child was severely sick,<sup>24</sup> a 2-day delay could be detrimental for sick children. In addition, although the dosing, duration, type, and quality of the antibiotics reported were unknown in our study, previous research confirmed that insufficient dosing with low-quality drugs is common in developing countries, leading to resistance development and treatment failures.<sup>25,26</sup> Hence, further studies on community drug use and the quality of the drugs sold by private providers are needed.

Our findings are in accordance with other studies on fatal childhood illnesses in Guinea-Bissau and the United Republic of Tanzania, which showed high attendance at health facilities before child death.<sup>14,18</sup> The fatal outcomes are likely explained by a combination of factors, such as late arrival of very sick children and district hospital incapacity to cater for critically ill children; every third child who sought hospital care before dying of pneumonia was referred to the regional or national hospital to get better care. Care in district hospitals is of poor quality in both Kenya and neighbouring Uganda.<sup>27,28</sup> Hence there is a great need to improve quality of care at the first referral level. Similarly, quality of care for severely ill children in health centres needs to be determined and improved.

Most children who died from pneumonia were reportedly first treated at home with antimalarials. The common practice of treating children with respiratory symptoms with antimalarial drugs has been shown previously,<sup>29</sup> and causes delays in care seeking for children with pneumonia.<sup>30</sup> Higher suspicion of malaria in this region was previously found and possibly reinforced by the home-based management of fever strategy that directs people to use antimalarial drugs for all fevers.<sup>31</sup> Hence, we find support also for our second hypothesis that single disease management strategies may contribute to inappropriate treatment for children presenting with multiple symptoms. Given the preference for antimalarial drugs and that mothers do not always recognize symptoms of respiratory illness<sup>24,32</sup> or take appropriate action,<sup>33</sup> increasing awareness about pneumonia is necessary. Locally adapted behaviour change communication may reduce incidence of severe pneumonia<sup>34</sup> and should be a key component in national child-health strategies such as home-based management of fever.<sup>31</sup>

Interventions that improve case management of sick children must be integrated across diseases, even nutritional problems,<sup>35</sup> not only in the home but also in the community, private-sector and public health-care system. Whereas presumptive treatment of fever with antimalarials at community level is a recommendation in malarious areas,<sup>36</sup> policy recommendations for antibiotics suggest prohibiting the dispensing of antimicrobials without prescription by a qualified health-care professional.<sup>26,37</sup> Yet presumptive treatment with antibiotics occurs widely and often incorrectly with poor-quality drugs.<sup>6</sup> However, while cough in combination with rapid breathing is both a sensitive and specific predictor for pneumonia,<sup>38,39</sup> the sensitivity of fever to detect malaria is 100%, but specificity barely reaches 10%.<sup>39</sup> Prospects for presumptive treatment with antibiotics are therefore better for pneumonia than for malaria. Because shopkeepers can be trained in fever case

management<sup>40</sup> and community health workers can be trained, supported and supervised to dispense high-quality antibiotics for rapid breathing,<sup>12,29,41</sup> the feasibility and effect on mortality of full-scale implementation of integrated home and community management of the sick child should be tested. Meanwhile, the feasibility of using socially marketed, prepacked drugs in the private sector and the effects on drug resistance development should be investigated.

This study has some limitations. The illness history and care-seeking information are based on interviews by non-medical personnel. Interviews depending on recall pose reliability and validity problems.<sup>42</sup> However, severe symptoms are normally remembered longer than mild symptoms.<sup>43</sup> Since most interviews were made within 4–6 weeks of death, recall bias was low.

The diagnostic coding may not be highly specific. In particular, the well known overlap between malaria and pneumonia symptoms<sup>10</sup> can lead to misclassification of cause of death. Given the lack of standard guidelines for the coding of cause of death based on verbal autopsy, the use of probabilistic models for interpreting verbal autopsy data should be explored further.<sup>44</sup>

Carers' reported use of drugs is inaccurate compared with blood analyses.<sup>45</sup> As a result, misreporting of drug intake may have occurred. Blood analyses in the community should be done to validate carer reporting of drug-intake in community surveys.

In these retrospective interviews we were not able to determine the actual quality of care provided to these children, nor were we able to adequately determine social processes in the family affecting the care seeking. Other methods (e.g. clinical audits and in-depth interviews) will be needed to investigate these factors.

### Conclusions

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In light of the obstacles to accessing formal health care, there were delays seeking professional care for children later dying of potential pneumonia. Most carers instead resorted to home treatment with drugs from the private sector, often with antimalarials. To improve quality of care where it occurs and to reduce inappropriate use of drugs, integrated child-health interventions in the home, community and private sector are needed. The feasibility and effect on mortality of training community health workers and drug vendors on management of pneumonia and malaria with prepacked drugs should be tested, while the quality of health-facility care needs to improve. ■

### Acknowledgements

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KK, SP and PW are also affiliated to the Makerere University School of Public Health, Uganda. In addition, SP is affiliated to International Maternal and Child Health (IMCH), Uppsala University, Sweden.

### Footnotes

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**Competing interests:** None declared.

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