

Title: Community and caregivers' perceptions of pneumonia and care seeking experience in Nigeria: a qualitative study

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Abstract

Background

Appropriate and timely care seeking can reduce pneumonia deaths, but are influenced by caregivers and community norms of health and illness. We explore caregiver and community perceptions, and care seeking experience, of childhood pneumonia, to understand contexts that drive paediatric service uptake in Nigeria.

Methods

Community group discussions and qualitative interviews with caregivers in Lagos and Jigawa states were completed between 1 November 2018 and 31 May 2019. Participants were recruited from purposively sampled health facility catchment areas with assistance from facility staff. We used episodic interviews, asking caregivers (Jigawa=20; Lagos=15) to recount specific events linked to quests for therapy. Community group discussions (n=3) used four vignettes from real pneumonia cases to frame a discussion around community priorities for healthcare and community-led activities to improve child survival. Data was analysed using the framework method.

Results

We found poor knowledge of pneumonia specific symptoms and risk factors among caregivers and community members, with many attributing pneumonia to cold air exposure. Interviews highlighted that care-seeking decision making involved both husbands and wives, but men often made final decisions. In Lagos, older female relatives also shaped quests for therapy. Cost was a major consideration. In both states, there were accounts of dissatisfaction with health workers' attitudes and, a general acceptance of vaccination services.

Conclusion

There is a need for community-based approaches to improve caregiver knowledge and care seeking for under-five children with pneumonia. Messaging should attend to knowledge of symptoms, risk factors, family dynamics, and community responsibilities in healthcare service delivery and utilization.

Introduction

Through concerted efforts the world has made remarkable progress in reducing under-five mortality, from 12.5 million under-five deaths in 1990 to 5.7 million deaths in 2015.^{1,2} In spite of this progress, under-five mortality remains unacceptably high and distant from global targets set out by the Sustainable Development Goals.³ Most of these deaths occur in lower and middle income countries (LMICs), and are preventable through access to basic health interventions, including early and appropriate treatment of common childhood infections.⁴

Pneumonia ranks as the number one infectious killer of under-five children, accounting for an estimated 0.9 million deaths globally in 2016. Of these Nigeria accounted for about one sixth of global pneumonia deaths.^{2,5} Specifically, in 2017 pneumonia accounted for 18.6% under-five deaths in Nigeria (N=714,188), surpassing diarrhoea (10.4%) and malaria (9.8%).^{5,6} Over the last two decades, pneumonia has received little or no attention in Nigeria, while there has been considerable progress in reducing deaths from other childhood diseases like malaria, diarrhoea and measles.⁷

Increasing community engagement and participation in health is a key priority area in the second National Strategic Health Plan of Nigeria,⁸ and also part of WHO recommendation to support better uptake of health promotion and prevention activities and utilization of health care services.⁹ As care seeking practices are influenced by individual and community factors,

caregivers and their wider community have roles to play to ensure children with pneumonia receive timely and appropriate care. According to the “pathway to survival framework”, caregivers, community and health systems have responsibilities to protect, prevent and provide appropriate care to children to prevent mortality.¹⁰ Illness recognition and appropriate care seeking by caregivers, as well as prompt access to quality care, are critical to reduce child mortality.^{10,11} Delays in care seeking and inappropriate care seeking for children with pneumonia have been documented in Nigeria and other LMICs.^{12–15} Recent national survey data showed that only 25% of under-five children were taken for care with an appropriate provider.¹⁶ In southwest Nigeria, a study found significantly longer delays in care-seeking for children with pneumonia compared with children without pneumonia.¹⁷

Barriers to effective care seeking for children with pneumonia are contextual.¹⁷ Qualitative studies from Uganda¹⁸ and Ghana¹⁹ indicate that local knowledge systems around pneumonia are mixed; reflect poor symptom recognition and, systems of traditional healing.

Understanding local knowledge, contexts and barriers to care is critical for the successful design and implementation of a pneumonia control strategy. To this end, we conducted a qualitative investigation of caregiver and community perceptions of paediatric pneumonia and care seeking experiences in two different states in Nigeria. Each reflected different sociodemographic and cultural characteristics, to inform future patient and family centred strategies targeting pneumonia control across Nigeria.

Methods

We conducted a qualitative investigation of community perceptions, knowledge and experience of paediatric pneumonia, involving semi-structured interviews with caregivers and community focus group discussions, from 1 November 2018 to 31 May 2019. We followed

the Consolidated Criteria for Reporting Qualitative Research (COREQ)²⁰ in presenting our findings below

Setting

This study was conducted in Lagos and Jigawa, states in the southwest and northwest regions of Nigeria respectively. Lagos has a total population of 21,000,000 with an under-five population of 3,400,000 and under-five mortality of 50 per 1,000 live births.¹⁶ Lagos state has 20 local government areas (LGA), of which one LGA (Ikorodu) was selected for the study. Health care in this LGA is delivered through a blended public and private sector, including Mission hospitals²¹. In Lagos, a primarily oil-based economy contributes to lower levels of severe poverty, with more than 85% of its population living in the highest wealth quintiles²². Conversely, Jigawa has the highest proportion of people belonging to the lowest wealth quintile (over 50%) with nearly 70% of its population living in severe poverty. The total population is 5,600,000 and it has under-five population of 900,000. Jigawa state has a high under-five mortality of 192 per 1,000 live birth, considerably higher than the national figure.¹⁶ Jigawa is predominantly rural, driven by an agrarian economy, with over 80% of the population working as farmers²². Jigawa state has 27 LGAs, of which Kiyawa LGA was selected. Health services in Jigawa are organised largely around primary care level, with only one Tertiary hospital in the region, located outside of Kiyawa LGA. LGAs in both states were selected through consultation with state Ministry of Health, using agreed scoring system (access to functional health facility, pneumonia and malnutrition burden, ongoing nutrition project, political support and lack of ongoing similar intervention).

Study design

We conducted episodic interviews²³ with caregivers of children under-five who were known to have had a child with pneumonia in the previous three-months. The approach anchors

discussion to retelling of specific experiences linked to a meaningful life event (episode). In this case the focus was on a recent episode of paediatric pneumonia, broken down into stages of care-seeking and referral, to explore understanding, decision-making processes and how gender and wider power dynamics shape quests for therapy, treatment and care.

We also conducted focus group discussions with existing community groups, including representation from young people, men and women, and those currently involved in health, child nutrition and environmental activities. In these meetings, four vignettes with different stories, based on real clinical cases of pneumonia, were presented to frame a discussion around community priorities for healthcare and community-led activities to improve child survival. These discussions included reflection on a range of infectious diseases, but through the use of vignettes we were able to direct attention to topics related to pneumonia cases and symptoms across a range of severity of symptoms.

Recruitment

Participants and community group discussion members were recruited from the catchment areas of sampled health facilities, by the local assistants supported by facility staff and local health managers. We aimed to purposively recruit a maximum of twenty caregivers in each state and tried to have representation of male and female caregivers, and a varying severity of pneumonia cases including deaths outcome.

Data Collection

We conducted 20 interviews and one community discussion in Jigawa; and 15 interviews and two discussions in Lagos (Table 1). No participants declined to be interviewed. Caregiver interviews were conducted solely with women. This gender imbalance reflects a widely accepted cultural norm, that associates women with caregiving responsibilities in the country. Focus groups were mixed, including men and women. The inclusion of men in these groups

reflects, the role that men play in supporting women's transport in order to access health services, particularly in Jigawa where women cannot travel independently. Further details on the impact of these norms on quests for therapy are described in the discussion section. Our convenience sampling is associated with potential limitations. Firstly, the inclusion of men in group discussions could have limited the ability for women to speak freely during group discussion settings, given the gender norms at play, particularly in Jigawa. However, we feel that combining group conversations with individual interview data created an opportunity for us to gather perspectives from women in spaces where they could express their opinions freely.

Data collection was completed by one qualitative researcher in each state (FS and AI), assisted by two local assistants. Researchers were female, have masters degrees in public health and previous qualitative research experience. None of the data collectors were related to the study participants. Caregiver interviews were conducted at locations that were convenient for the caregivers, which sometimes included home visits. Community discussions took place at healthcare facilities. Interviews and discussions were audio recorded, transcribed and translated to English for analysis. After an initial round of data collection, the interview schedules and focus groups were refined following discussion with senior author (RAB) and other project members. Interviews were conducted in Hausa in Jigawa, and English or Pidgin English in Lagos.

Analysis

Data was analysed using the framework method, blending inductive and deductive coding²⁴. A coding framework was developed by RAB and CK, based on the topic guides and discussion of initial themes noted by local data collectors. The framework was then used by RAB to code interviews and focus groups, elaborating on the content of codes, deleting

irrelevant codes and adding emergent codes as needed. Transcripts were then read by AAB, and codes were checked for consistent interpretation with the local context.

Conceptual framework

Analysis was informed by two conceptual frameworks. In order to map the complexity of knowledge systems presented by participants, we applied Social Representations Theory²⁵, a social psychological framework that explains the development and operation of everyday knowledge. The model has been applied with respect to health-related knowledge in various African settings,²⁶ including Nigeria to understand local understandings of vaccines among communities.²⁷ According to social representations theory, all knowledge is socially constructed, and its development and use is mediated by social and cultural factors as people engage with others and objects in their social worlds. This is important for understanding the relationship between context, knowledge and action in complex environments²⁸.

In order to explore knowledge systems in the context of decision making and pathways to treatment and care in communities, we applied Janzen's (1987) seminal theory of Quests for Therapy.²⁹ Developed to understand health seeking in kinship oriented societies, the method traces decisions and actions linked to diagnosis, selection and evaluation of treatment, and support for the affected individual, in a contextually sensitive process that draws on cultural values, behaviours and social and economic structures that influence the therapeutic process.

Ethics

Ethical approval was granted by University College London (3433/002), UI/UCH Ethics Committee (UI/EC/19/0033), and the Ministry of Health in Lagos (LSMH/5869/140) and Jigawa (MOH/SEC.3/S/738/I). Written informed consent was given by interview and discussion participants.

Results

Our analysis identified four global themes that highlighted contexts shaping quests for therapy for paediatric pneumonia by communities. Data from interviews and focus groups were compiled together, as there were no significant differences between themes and concepts identified in the two forms of data collected. Furthermore, we identified a great deal of overlap between the two geographical settings, with many common themes. In instances where there were differences, we explicitly state them below.

Gendered dynamics of care seeking—shared (and impossible) responsibility

Despite the presence of strong gender norms that dictate social relationships and behaviours in Jigawa, caregiver interviews highlighted that decision making around care seeking almost always involved joint decision making. The care-seeking pathway was most often initiated by women, as childcare and household responsibilities falls predominantly on the shoulders of wives. These cultural norms dictate that women were responsible for the identification of illness, and notification of their husbands in the event that action required the mobilisation of financial resources. This was also the case in households where both men and women worked, noting that overall financial decision making remained the purview of husbands. As noted by one caregiver:

“I look after the children, because he goes out, but when he comes back he also takes care of them too.... My husband is the one that makes the decision about finances, but you know how things have changed now, sometimes if I have money I also contribute to food and finances.” (Caregiver 8, Jigawa)

Gendered dynamics also placed the responsibility to prevent the onset of illness with women. Community discussion groups in both settings confirmed interview accounts that women were tasked with preventing illness

“Before going to the hospital, mothers should take care of their children by putting on thick clothing’s and taking care of them as the Chemist advice that they should bath them with hot water especially during Harmattan or raining season” (participant 8, Community Meeting at Kiyawa LGA, Jigawa)

In Lagos, we found contributions of female relatives in the care seeking processes, particularly relating to application of traditional or herbal solutions when modern biomedicine appeared to yield little or no change:

“The only thing I use is what my mother in law gives my son - but it is only for babies when they are small - called agbo ile tutu - if they have a high temperature you take it and give it to them” (Lagos caregiver, 3)

Finally, it is worth noting that caregiver interviews did not seem to indicate that there was a gendered impact of the illness. Caregivers did not speak about differences in resilience against illness between boys and girls, and there were no differences in the quests for therapy used for daughters or sons. Instead, caregivers reported finance as the leading barrier to care seeking and/or determinant of choice of service provider.

“the only thing is the issue of money that is why I don’t go far away to seek for care; I always go to the nearest hospital here because of lack of money” (caregiver 5, Jigawa)

Respondent: “I know say I get card here (PHC) but on that day is when is only cough. I believe say if I buy 300-naira thing here the cough will disappear”

Interviewer: “is it about the 300 naira? If you come to PHC, how much would you spend, is it the same 300 naira? Is it because of the money?”

Respondent. “It is because of the money”

Interviewer: “if you come to the PHC would you spend more than 300?”

Respondent: “Hahahaha I will spend more than that” (Lagos, caregiver 3)

Interviewer: “then tell me, what was your biggest challenge?”

Respondent: “to be honest, as of then it was not easy for me because the father was not having money and he was not doing any business, so thank God I was having some of my items, so I sold them out and used the money for treatment.”

Interviewer: “what did you sell out?”

Respondent: “it was groundnut, because I sell groundnut, I buy and sell out, so I could not continue with the business then because it was the money I used for his treatment.” (Caregiver 7, Jigawa)

Understanding of illness experience- complex local knowledge systems

The recognition of illness was initiated by female caregivers in both Jigawa and Lagos, who noted re-occurring symptoms of heavy cough, catarrh, and fever. In Jigawa, most women had very little or no prior knowledge of pneumonia, and those who had, acquired this understanding through diagnosis of other children. While, some women believed the condition to be something that did not impact children, most caregivers noted the dangers of exposing children to cold – speaking specifically about bathing practices, being either the wrong time of day or with cold water.

In Lagos, many respondents claimed to have awareness of pneumonia, but lacked knowledge of pneumonia specific symptoms.

“I know pneumonia that they will say breeze is entering the chest I don’t know the meaning but people say it. talk about it” (Lagos, caregiver 3)

“Pneumonia is cold, cold in somebody chest or ribs” (Lagos, caregiver 1)

“Me I did not even think towards that because I know that pneumonia is a very dangerous disease. I was kind of afraid but later I was like nothing will happen to this baby. But I know that it is not pneumonia because pneumonia is very difficult to treat. How can a month-old baby will be having cough constant cough like that from night

till morning & she won't be able to breath? I was kind of confused” (Lagos, caregiver 2)

In Jigawa state, where strict Islamic culture often dictates movement of women and decision making pathways in the home, participants were adamant that religious influences did not shape their uptake of biomedical services, for example, making reference to immunisation and a general willingness to engage with health services. This was also noted in Lagos among participants of Islamic tradition:

“In my own religion, especially... that is the Muslim religion, if a child is sick like that, if we bring them to a hospital, that's the first thing to do bring her here, after that we can pray inside water and use it to rub the child's body after.” (Caregiver 3, Lagos)

For caregivers in our study, belief in traditional medicine co-existed alongside a belief in modern biomedicine and its services. However, traditional medicine was viewed as a better option than modern biomedicine among some participants.

“Yes very good, they will discourage because the reason is that ehh the people cherish traditional medicine than the medical one, they said the medical one will only cure it but traditionally, it will purify everything out, in which to the best of my knowledge (Caregiver 8, Lagos)

Experience of care and quality of care

In both settings, quests for therapy often included attendance at local pharmacies, particularly given their lower cost treatment options. In Jigawa, the primary response was cough medicines, and in Lagos, participants made explicit mention of the purchase of a specific drug cocktail by women: paracetamol, vitamin C and saline drops.

When these interventions were unsuccessful, participants reported slightly more elaborate assessments at the primary care settings – with explicit mention of stethoscopes for assessing children’s breathing and blood tests. In Lagos, some caregiver interviews described the use of pulse oximetry and chest radiograph, but this was not the norm. Typically, patients described self-referral to primary care centres and local hospitals, based on the advice of others in the community, or their self-identification of the worsening of symptoms.

Acceptance of treatment and care

Caregivers in Jigawa and Lagos accepted and valued the care provided to them at primary care facilities. However, there were accounts of dissatisfaction with health workers attitude, and participants called for increased government supervision to improve service delivery.

“To be honest, our hospital here in Kiyawa they don’t give us good attention”
(caregiver 7, Jigawa)

“I think they should have the well-known people to observe and supervise the workers. For example, one day like that, I heard Fashola (former state governor) went to general hospital, he just went there to check up on them, they are now rushing, most of those nurses, they will just sit down there and be doing “shakara” (fashion). They will just tell you “e gbe si be yen” (put him there), it is not good, they are losing peoples’ lives. So, there should be supervision for the health care workers, so they can work better.”
(participant 9, Lagos community discussion)

“well, our problem in the hospital is that the health workers are always ignoring the patients and keeping us waiting without attending to us, sometimes you will only meet few health workers in the hospital and they keep ignoring the patients, even sometimes the parents quarrel with the health workers.” (caregiver 9 Jigawa)

“the only thing I want is for government to keep supervising our hospitals and ensure health workers are doing the right thing” (caregiver 7, Jigawa)

Participants in Lagos and Jigawa also asserted their uptake of vaccinations, as well as a general community acceptance of the importance of vaccinations.

Discussion

Our study explored caregivers and community perceptions of pneumonia, as well as experiences of seeking care for childhood pneumonia in two different contexts in Nigeria.

Previous studies have emphasised maternal knowledge of disease and perception of illness symptoms as influencers in the care seeking pathway.^{12-15,27,30} In our study however, attention to wider social contexts within quests for therapy highlight the importance of gendered and economic dynamics of care.

For example, findings highlighted that women were expected to assume responsibility for the most important aspect of the care-seeking pathway – initial recognition of symptoms. The intersection of this need, with a limited knowledge about pneumonia and its symptoms, limited freedom to access this knowledge, as well as the high cost of treatment, meant that women were posited in difficult situations. In cases where women identified a problem early on, limited power and ownership of financial resources in the household meant they needed to consult with husbands before taking action, particularly in Jigawa. Even in spaces where decision making was deemed as joint – the final action on where and how money should be spent, was dictated by husbands in both contexts. This reality poses a significant barrier to quick care seeking, with important implications for the ultimate success of a quest for therapy. This finding suggests that any future interventions to increase uptake of care must focus not just on provision of knowledge, but promoting environments where marginalised groups, including women, can act on and utilise this knowledge on their own terms. For example, studies from development contexts³¹ have highlighted the importance of considering women's wider environments and their openness to women's agency and action. This is particularly important in addressing barriers that women face in receiving benefits from increased access to income, when these increases occur in the absence of wider changes in relational dynamics³¹. Interventions which focus on gendered relationships, involving both men and women in debates about women's roles, are crucial to addressing women's limited access to power, as seen in contexts like Uganda³².

While pneumonia is perceived as a serious illness by those with knowledge about it, understanding of its specific symptoms was low among caregivers, which could shape the outcome of care seeking pathways for under-five children with pneumonia. Caregivers and communities lacked knowledge on pneumonia risk-factors, with many participants attributing pneumonia to cold air exposure, and no mention of other known pneumonia risk factors. This finding is similar to others on childhood pneumonia in LMICs, which showed poor knowledge of symptoms and caregivers reporting of exposure to cold air as the main cause of pneumonia.^{10-12,33} With respect to pneumonia, malaria, and diarrhoea - pneumonia specific symptoms are the least recognised by caregivers.^{17, 34} This may explain why progress with pneumonia control has lagged behind compared to other childhood killer diseases.³⁵

Unsurprisingly, finance was a major consideration in the care seeking pathway, though this was more prominent in Lagos compared to Jigawa. Jigawa operates a free healthcare policy for under-fives, so reported financial barriers were related to the procurement of drugs following diagnosis. Previous studies in Nigeria have reported high service costs at public facilities and non-availability of medication and laboratory service despite a free health policy.^{13,36} Since the inception of the National Health Insurance Scheme in 2005, coverage remains low and mostly limited to federal government workers, and less than 3% of Nigerians are covered by private health insurance.^{37,38} Studies have shown that poor households often do not utilize health care services when needed,^{36, 37} so increasing insurance coverage to lower socio-economic groups remains critical. Community Based Health Insurance has been successfully, but partially, implemented and could mitigate financial barriers encountered in care seeking pathways.^{38,39} The National Health Act makes provision for the establishment of Basic Healthcare Provision Funds, to serve as a viable funding opportunity for primary health care.^{40,41} Recent evidence, however, suggest that its

accessibility and implementation is limited, and may be further hampered in the absence of coordinated stakeholders engagement and an accountability framework.⁴²

While most participants felt satisfied with service delivery at health facilities once their child recovered, some expressed dissatisfaction with the attitude of the healthcare workers and called for increased government supervision to improve service delivery. Other settings have highlighted how negative experiences with healthcare providers in primary care impact on patient wellbeing.⁴³ Mentorship programmes for health workers and strategies to improve communication and trust at the facility-community interface could address this issue. We found that vaccination services were well accepted in Jigawa, contrary to previous negative attitudes to vaccination in northern Nigeria.¹⁷ Community acceptance and positive perceptions about vaccination may be the result of efforts from the state government to improve vaccination coverage. Recent evidence indicates a rapid increase in vaccine uptake recorded for Jigawa – increasing from approximately 2% to nearly 24% in just two years⁴⁴. As such, participant accounts may reflect a shift in perceptions of the value of immunisation, as a result of active programmes in other areas. While 24% is still relatively low, lower levels of uptake does not necessarily mean that vaccines themselves are negatively perceived. For example, low uptake could be shaped by misperceptions about cost, (i.e. people do not realise they are free) indicating poor access to information, or other structural limitations. This aligns with some of our findings which suggest caregivers in Jigawa weren't always aware that under-five services should be free. As such, refining and improving existing messaging and immunisation efforts could be leveraged to improve community awareness and care seeking for childhood pneumonia.

This study has a few limitations. Firstly, our sampling of caregiver interviews in Lagos was slightly lower than expected. However, the convergence of themes between individual and focus group settings allowed us to increase our confidence that saturation of themes was

valid. Secondly, we also struggled to recruit male caregivers in both settings, an outcome that was largely explained by our findings which highlight the economic role that men play in childcare in both settings, with the primary burden of identifying needs and initiating the quest for therapy, residing with women.

In our attempt to reduce demands on time and resources for marginalised groups, we held group discussions at a central health facility. However, this meant that we had to hold mixed gender discussions, which could have limited women's ability to speak freely in these sessions. However, we attempted to moderate this impact, through the collection of individual interviews in both settings, as well as using female data collectors. Furthermore, by holding such discussions on site at health centres, there is the possibility that individuals could have felt limited in their ability to criticise health services. However, given that one of our main findings across sites were accounts of mistreatment from nursing staff, we are confident that this was not the case in our study.

Furthermore, holding community discussions at central health facilities could also mean that the families who are most marginalised may not have been able to afford transport to such settings, meaning our findings may not be entirely transferrable to the poorest of the poor in the country. Future studies may want to consider the completion of gender separated focus groups, held in more distal locations to widen the range of perspectives collected. Finally, we had difficulties recruiting families with deceased children, which has limited our ability to understand the differences between successful and unsuccessful quests for therapy.

Though our generalisability is limited due to the qualitative nature of our study, we argue that findings would be consistent in other parts of Nigeria, given the convergence of themes between our two study sites, despite being marked by great differences.

This study has provided insight into community perceptions of, and care seeking experiences for under-five pneumonia. Our findings signal the need for community-based approaches to improve caregiver knowledge and care seeking for under-five children with pneumonia. Findings assert that this knowledge should not be provided without also considering efforts to promote women's successful utilisation of knowledge through empowerment strategies, in contexts where their individual agency may be constrained. Messaging should include knowledge of symptoms and risk factors, and community responsibilities in healthcare service delivery and utilization. Findings also suggests the need for government interventions that can reduce potential impacts of care seeking on household finances. Mentorship for health care workers and managers and effective supervision are also necessary for provision of culturally appropriate and respectful care and health system strengthening.

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Author Contributions

The study was designed by CK, TC, AGF, AAB, HG, EDM and RAB, with input from all authors. Interviews and community group discussions were conducted by IA and SF, with oversight from AGF and AAB. Interviews were analysed by RAB, with input from AAB. The paper was drafted by AAB, with considerable input from RB and CK. All authors commented, read and approved the final manuscript.

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