Caregivers' and healthcare workers' experiences in the management of childhood pneumonia in lowand lower-middle-income countries: a systematic review of qualitative evidence

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#### Abstract

#### Introduction

Childhood pneumonia is preventable and treatable. Yet, millions of children under five years of age in low-and lower-middle-income countries become sick and die from the illness. These deaths can be averted if caregivers recognise pneumonia symptoms early and seek timely medical care, and if healthcare workers can appropriately diagnose and effectively treat childhood pneumonia.

# Objectives

The systematic review explored the experiences of caregivers and healthcare workers in the management of pneumonia in children under five in low-and lower-middle-income countries.

#### Methods

The systematic review was conducted in accordance with the JBI (formerly known as the Joanna Briggs Institute) methodology for systematic reviews of qualitative evidence, with meta-aggregation as the method of synthesis.

The review considered qualitative studies that explored the experiences of caregivers and healthcare workers in the management of childhood pneumonia in low- and lower-middle-income countries. Only studies published in English were included. The search for relevant studies included both published and unpublished studies and was conducted from 13<sup>th</sup> to 17<sup>th</sup> June 2019. The databases searched were PubMed, CINAHL, Embase and Scopus, with no publication date restrictions. All studies that met the inclusion criteria were assessed for methodological rigor by two independent reviewers using the JBI standardised critical appraisal instrument for qualitative research. Data were extracted from studies using the standardised JBI data extraction form. Extracted findings were pooled using the JBI meta-aggregative approach.

#### Results

Eight studies were included in the review. A total of 54 unequivocal/credible findings were aggregated into 12 categories based on their similarity in meaning. From the 12 categories, three synthesised findings (meta-synthesis) were developed (one synthesised finding focused on healthcare workers and two synthesised findings on caregivers). The synthesised findings are as follows:

- Caregivers can identify common pneumonia symptoms in children under five years of age, including those symptoms leading to severe pneumonia, however some misconceptions, including those of the pneumonia aetiology, still persist.
- Factors, such as financial constraints, use of home remedies or practitioner-provided interventions, inappropriate purchase and use of medicines, caregivers' choice of provider, and responsibility for decision-making for the child, impact the treatment of pneumonia in children under five years of age.
- Healthcare workers experience a number of barriers that impact their ability to manage and treat
  childhood pneumonia in children under five years of age. These barriers occur across all levels
  of care, including the systems level, the individual practitioner level and the caregiver level.

# Conclusions

The review highlights several barriers that impact on caregivers' and healthcare workers' ability to adequately manage childhood pneumonia.

## Implications for practice

The review identifies several barriers that prevent the effective management of childhood pneumonia and offers evidence-based recommendations for health professionals and policy makers. It also provides suggestions for the education of caregivers.

# Implications for research

Further research is required regarding the experiences of caregivers and healthcare workers in the management of childhood pneumonia in developing countries.

Keywords: caregivers; childhood; experience; healthcare workers; pneumonia

# Declaration

Declaration			

I, Sylvia John Karo, certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree. I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Signed			
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Date: 8th July 2020

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## Chapter 1: Introduction

This chapter introduces the topic area and provides a review of the aetiology and pathogenesis of childhood pneumonia, the epidemiology and burden of the disease, the complications associated with the disease, and the strategies for the prevention and treatment of pneumonia in children under five years of age. Issues specific to low- and lower-middle-income countries that impact on the timely treatment of childhood pneumonia are also discussed, along with an overview of the current situation and realities of childhood pneumonia in low-and lower-middle-income countries. This introductory chapter also provides the rationale and specific objectives of the systematic review.

## Aetiology and pathogenesis of childhood pneumonia

Pneumonia is an acute infection of the lungs caused by bacteria, viruses or fungi<sup>(1)</sup> that begins as a mild infection and progressively worsens to a moderate or severe infection if untreated or if treatment is delayed. It is a chest infection where one or both lungs can become inflamed. There are two common bacterial causes of pneumonia in children from low- and lower-middle-income countries. The most common cause is *Streptococcus pneumoniae* and the second is *Haemophilus influenzae type b* (Hib). Viral pneumonia is commonly caused by the respiratory syncytial virus<sup>(4)</sup> while fungal pneumonia is caused by a variety of fungal pathogens which include *Histoplasma capsulatum, Coccidioides immitis, Blastomyces dermatitidis, Paracoccidioides brasiliensis, Sporothrix schenckii or Cryptococcus neoformans.* (5)

Childhood pneumonia typically begins as an upper respiratory tract infection (cold), affecting the nose and throat and moving down to the lung(s) two to three days later, resulting in pneumonia. (6) The condition is characterised by inflammation of the alveoli, which causes the air sacs to fill with fluid or pus, leading to symptoms such as fever, chills, cough, mild chest in-drawing (intercostal recession), fast breathing (tachypnoea), difficulty in breathing (dyspnea) and narrowing of the airway, thus limiting oxygen intake. (7, 8) When the illness progresses to a severe infection, younger children may stop their intake of breast milk

or drinking, experience severe intercostal retraction, become comatose and experience seizures (fits or convulsions).<sup>(3)</sup> To keep an adequate oxygen supply, the child will also fight hard to breathe (increased work of breathing) which can be identified on examination as nasal flaring and increased use of the abdominal and other accessory muscles. The mucus membranes around the lips, inside of the mouth and nailbeds may turn blue (cyanosis), suggesting inadequate oxygenation. If left untreated, the condition can lead to respiratory distress.

Risk factors associated with developing pneumonia include indoor air pollution, undernutrition, non-immunisation, limited education of caregivers, low socio-economic status, lack of safe water and poor sanitation, (9) and inability to gain access to effective health care, all of which, are typically linked to poverty. (10) Other precipitating factors include overcrowded living conditions, lack of exclusive breastfeeding, incomplete immunisation and human immunodeficiency virus (HIV) in children. (11) Although pneumonia can occur in anyone, older individuals and children, particularly those under five years of age, are the most susceptible. This systematic review focuses on children under five years of age who live in low- and lower-middle-income regions of the world which represent more than 50% of the world population. (4) Childhood pneumonia that occurs in low-and lower -middle-income regions of the world is closely linked to poverty. The incidence and burden of this disease will be discussed in the succeeding section.

# Epidemiology and burden of the disease

Pneumonia is one of the leading causes of death in children under five years of age. (12) The Millennium Development Goal (MDG) 4 of the World Health Organization (WHO) was established to reduce child morbidity and mortality. It aimed to reduce pneumonia mortality rate by two-thirds in children under five years of age by 2015. (12) Progress has been made since this goal was set in 1986, with childhood pneumonia decreasing from 178 million to 138 million in 2000. (13) More than 54% of global childhood pneumonia episodes occur in five countries: India, China, Indonesia, Nigeria and Pakistan. From 2000

to 2015, mortality associated with pneumonia in children under five declined substantially in those countries: India (from 390,000 to 350,000), China (from 280,000 to 90,000), Indonesia (from 470,000 to 270,000), Nigeria (from 280,000 to 230,000) and Pakistan (from 250,000 to 170,000). (11) Following the MDG, Sustainable Development Goals (SDG) was established in January 2016. Goal 3 of the SDG aims to keep people of all ages, including children under five years, healthy and to encourage well-being for all. Progress has been made in child health but still needs to accelerate. (11)

Despite the reduction in the under-five pneumonia-related mortality rate, pneumonia remains the leading cause of mortality in this age group, with deaths estimated at 880,000 in 2016. This translates to 2500 deaths per day, 100 deaths per hour and one death every 35 seconds from pneumonia in children under five.<sup>(13)</sup> In 2016, 49% of all childhood pneumonia deaths occurred in India (158,176), Nigeria (140,520), Pakistan (62,782), Democratic Republic of Congo (49,115) and Ethiopia (30,733),<sup>(14)</sup> and were due to poor care-seeking attitude, inability to access health care, or both,<sup>(15)</sup> or lack of medical attention.<sup>(16)</sup> Approximately half of these deaths resulted from air pollution. More children die from the effects of indoor air pollution than from outdoor air pollution. A large number of children reside in regions where outdoor air pollution exceeds the international guideline limits.<sup>(10)</sup> Indoor air pollution results from solid fuels such as wood, animal dung, charcoal, crop waste and coal. This can lead to indoor air pollution that can result to premature deaths of young children. Children are more vulnerable as they spend most of their time with their mothers near the domestic hearth. <sup>(10)</sup> Currently around 90% of all pneumonia-related deaths occur in low-and lower-middle-income countries where poverty is severe<sup>(17)</sup> and the rate is increasing, predominantly in sub-Saharan Africa and South Asia. These deaths pose a threat to the sustainable development of the world's underprivileged people.<sup>(18)</sup>

The annual cost associated with the treatment of childhood pneumonia is USD109 million, and an estimated USD4.5 million is spent on public health interventions. (12) Childhood pneumonia places an enormous economic burden on families and the health care system, particularly for resource–limited settings. (19) However, considering the severity of the childhood pneumonia burden, and its distribution

and impact throughout the low-and lower-middle-income countries, it has not been well funded or given enough attention at the global level. (20) Aside from the huge economic burden, children with severe pneumonia are at risk of developing pneumonia-related complications later in adulthood.

## Complications of pneumonia

Edmond et al.<sup>(21)</sup> demonstrates that every child who contracts pneumonia is at risk of developing long-term respiratory complications. The evidence indicates that childhood pneumonia is associated with decreased lung function and asthma.<sup>(13)</sup> Infants (first 12 months of life) are particularly vulnerable to pneumonia-related complications,<sup>(22)</sup> supporting the theory that early childhood pneumonia episodes damage the developing lungs, leading to long-term respiratory complications later in adulthood,<sup>(22)</sup> and further explains that during the first five years of a child's life the lungs are still developing, the alveoli increases in numbers and the airway dimensions expand.<sup>(22)</sup> Any insults to the lungs or respiratory illness during this stage of development damage the structural and functional characteristics of the lungs, thereby leading to on-going pulmonary disease in childhood or respiratory complications in adulthood.

Children hospitalized with severe or life-threatening pneumonia are at an increased risk of developing long-term effects. (22) Those with underlying health conditions, such as HIV (immunosuppression) or cystic fibrosis, suffer from respiratory complications and recurrent pneumonia throughout their lives. (21) Approximately 10% of all episodes of pneumonia are severe or life threatening and require hospitalization, and about 6-7% of these hospitalized cases are at a greater risk of restricted airway disease later in the adult's life because of the duration of illness and seriousness of the infection. (21)

The available data indicates that an estimated 200 million adults currently suffer from chronic obstructive pulmonary disease, and 235 million people worldwide have asthma as a consequence of childhood pneumonia. (22) Other long-term consequences of childhood pneumonia include restrictive airway disease and abnormal lung function, which are dependent on the frequency and severity of pneumonia

episodes.<sup>(21, 23)</sup> Prevention or early identification and treatment of pneumonia can prevent or minimise such complications.

## Prevention and treatment of childhood pneumonia

Prevention of pneumonia can be achieved in two ways: through vaccination or non-vaccination interventions. (18) Most childhood pneumonia is caused by two main pathogens: *Haemophilus influenzae* type b (Hib) and *Streptococcus pneumoniae* (pneumococcus). Vaccinations against these pathogens are available and have the potential to prevent childhood pneumonia. However, pneumococcal vaccines are predominantly available in higher-income countries. If these vaccines are available in low- and lower-middle-income countries, millions of lives could be saved. Another cause of childhood pneumonia is seasonal influenza, which can also be prevented by vaccination. The World Health Organisation (WHO) recommends that all children should be given pneumococcal, Hib and Influenza vaccines. In Immunisations for other conditions, such as measles, mumps and rubella (MMR) and diphtheria, are also recommended because children who contract these diseases are at risk of developing pneumonia, (24) however obtaining and distributing these vaccines are also a major challenge. The situation and challenge in low-and-lower-middle-income countries is that, not all children can easily receive immunisation because of ineffective, non-existent or poorly functioning immunisation systems. (18)

Childhood pneumonia can also be prevented through non-immunisation interventions. The United Nations International Children's Emergency Fund's (UNICEF) approach to preventing pneumonia targets the following major areas: 1) protecting children from pneumonia by improving breastfeeding practices and ensuring adequate nutrition; 2) diagnosing and treating all children by increasing care seeking, speeding up integrated service delivery and improving the quality of care, making sure that children are able to easily access essential services, ensuring that universal health coverage is achieved for all children and investing in health workers; and 3) preventing pneumonia in children by reducing air pollution and by improving access to safe water, sanitation and hygiene.<sup>(10)</sup>

The WHO in its recently updated classification and treatment of childhood pneumonia emphasised that the basis of adequate management of childhood pneumonia is the use of a case management approach. This strategy involves identifying symptoms of pneumonia (cough, fast breathing, chest in-drawing and danger signs such as tachypnea, intercostal recession, stridor and laboured breathing), classifying the illness as non-severe or severe, and treating it according to its severity. (17) Bacterial pneumonia is the most serious form of the infection which typically begins as a mild infection (18) and can be effectively treated with antibiotics. (8) Any delay in the identification and treatment of pneumonia early in the disease course can lead to severe illness and may cause death. Initiating antibiotic therapy soon after the onset of symptoms can reduce child mortality and long-term complications associated with pneumonia. However, only 33.3% or 46 million (one third)(3) of 138 million pneumonia cases annually(11) are able to receive adequate antibiotics. (25) Viral infections on the other hand are less serious and are treated symptomatically. (8) Fungal pneumonia is less common and not as serious as bacterial infection and can be easily treated with anti-fungal medication. (5) The evidence shows that using these evidence-based strategies has had a large impact on the management of childhood pneumonia in low- and- lower middle-income countries. (17)

Prevention and treatment of childhood pneumonia by using simple low-cost effective interventions are key to reducing pneumonia-related mortality. However, due to limited availability of resources, medical supplies, a knowledgeable and competent workforce and functional health systems, children are unable to receive adequate medical care.

Issues in low and lower middle-income countries that impact on timely treatment of childhood pneumonia

Pneumonia usually begins as a mild infection<sup>(16)</sup> that can be treated with proven, cost-effective interventions, as highlighted above. The evidence shows that most children who die have severe or very severe pneumonia, which could have been averted if identified and treated early.<sup>(26)</sup> Delayed identification

and treatment of pneumonia early in the course of the disease can lead to severe illness that may cause death. (23) Initiating antibiotic therapy soon after the onset of symptoms can reduce mortality and complications associated with pneumonia. (23) However, only one-third of the world's children receive antibiotics. (16) Globally, around 400 million children in low-and-lower-middle income countries are unable to access health care, including antibiotics, because of its high costs. (14) For instance, out of pocket health expenditure is 41% in Uganda and 65% in India, making it impossible for ordinary citizens to purchase much-needed antibiotics. (27) Lack of appropriate antibiotics is one factor that hinders appropriate care. (14) Of the 151 million global episodes of pneumonia every year, 300,000 children die due to poor care seeking attitudes, inability to access health care, or both. (14) In 2010, seven million pneumonia-related deaths in children occurred in low- and lower-middle-income countries, and the majority of these deaths occurred due to lack of medical attention. (15) Caregivers play an essential role, as their ability to detect early symptoms of pneumonia and seek prompt medical care is fundamental to decreasing the long-term effects of pneumonia, as well as pneumonia-related mortality. According to Noordam et al., (28) only two out of five children with symptoms of pneumonia are taken to a reliable healthcare provider in sub-Saharan Africa. The authors concluded that caregivers lacked knowledge regarding the symptoms of pneumonia and were unable to identify the more severe symptoms of pneumonia, such as intercostal retraction and central cyanosis. (28) Another study found that only 30% of caregivers in rural Bangladesh were able to identify one of the two main symptoms of pneumonia (fast breathing and difficulty breathing), and caregivers reported being unable to seek medical care due to poor road conditions and long waiting times at the hospital. (26) A study by Muro et al. (16) reported that caregivers had good understanding of the symptoms of pneumonia, but accessing health care was a hindrance due to distance, security and financial barriers. Moreover, Kallander et al. (29) indicated that the majority of caregivers chose to selfmedicate their children with either antibiotics obtained from private clinics or herbal or traditional medicines.

The management of childhood pneumonia also depends on the ability of healthcare workers to correctly diagnose and initiate early and effective treatment. According to Rabbani et al., (30) healthcare workers in a district in Pakistan identified pneumonia as the leading cause of death in children under five years, but lacked the expertise to initiate appropriate treatment and attributed this to inadequate training, delayed wages and lack of medical supplies. Furthermore, a report released by The *Lancet: Global Health* in 2015 indicated that only 54% of children with symptoms of pneumonia received medical care, (31) and this was likely due to healthcare workers' lack of ability to adequately diagnose and treat pneumonia. 12 Additionally, a study by Wanduru et al., (32) that assessed the performance of community healthcare workers in northern Uganda reported that 88% scored poorly on knowledge of pneumonia. The evidence shows that when healthcare workers use appropriate clinical protocols, pneumonia is managed rapidly and appropriately, thereby reducing mortality rates.<sup>3</sup>

In Malawi, where there is poor adherence to clinical guidelines, one in five children is misdiagnosed and mistreated for pneumonia. Even experienced clinicians who are familiar with protocols misdiagnose pneumonia. Factors such as education and supervision have been shown to improve the use of treatment algorithms.<sup>(33)</sup> Other factors, such as reduced workload, regular training and availability of medicine and other medical supplies, enhance healthcare workers' performance and increase motivation.<sup>17</sup>

## Rationale for a systematic review

Many factors influence caregivers' care seeking attitudes and behavior as well as healthcare workers' performance. It is important to understand these factors by exploring caregivers' and healthcare workers' experiences in the management of childhood pneumonia, as this understanding will enable health professionals, clinicians, and policy makers to address these issues appropriately.

An initial search of *JBI Evidence Synthesis*, the *Cochrane Database of Systematic Reviews* and PubMed for existing systematic reviews on the topic was conducted on the 18 of August 2018. The search revealed no current qualitative synthesis on the experiences of caregivers and healthcare workers in the management of childhood pneumonia. Given the current global situation with childhood pneumonia, it is

timely to undertake a systematic review that identifies and summarises the existing qualitative literature on caregivers' and healthcare workers' experiences in the management of childhood pneumonia in children under five years of age in low- and lower-middle-income countries.

This chapter has provided an overview to childhood pneumonia and the current situation in low-and lower-middle-income countries. Chapter 2 will discuss the methodology and methods utilised in the review.

## Chapter 2: Methodology and methods

This chapter provides an overview of the importance of evidence-based health care and introduces the systematic review as the gold standard approach in evidence synthesis. It also outlines the methods undertaken to conduct the review. This systematic review followed an a *priori* published protocol,(34) which was also registered in PROSPERO (registration number: CRD422019136942).

## Introduction to evidence-based health care

Evidence-based health care (EBHC) is defined as the 'conscientious use of current best evidence in making decisions about the care of individual patients or the delivery of health services'.(10,p2para.1) It has been described as 'a process involving creating an answerable question based on a client need, locating the best available evidence to answer the question, evaluating the quality of the evidence as well as its applicability, applying the evidence, and evaluating the effectiveness and efficiency of the solution'.(3,para.4).

Evidence-based health care is also referred to as evidence-based medicine and evidence-based practice and these terms are used interchangeably. <sup>6</sup> Professor Archie Cochrane, the late British epidemiologist and a pioneer in this area, is considered the father of evidence-based medicine. <sup>(35)</sup> His book, "Effectiveness and Efficiency: Random Reflections on Health Services", was influential in promoting the use of reliable evidence from scientific studies when providing the best medical care. <sup>(36)</sup> Cochrane <sup>(37, 38)</sup> advocated for the use of randomised controlled trials (RCTs) and suggested that all types of medical treatment be based on this type of research evidence. He emphasized the principles of efficiency, effectiveness, equality, as well as the concept of cost-effectiveness and argued that medical doctors should use treatments according to these principles. Cochrane also expressed his concerns regarding the absence of a valid and organised summary of all RCTs related to each specialty or subspecialty of medicine. He argued that the valid collection of all RCTs would facilitate clinicians to reach accurate conclusions regarding patient treatment. This represented a milestone and paved the way for the

emergence of systematic reviews as the most important and reliable source of evidence for clinical practice. Since then, EBHC has evolved and is increasingly being utilised in many countries.

What then constitutes evidence in the context of EBHC? The notion of evidence has been described with respect to the idea of proof and rationality. Regardless of how the evidence is assembled, it must be observed and verified independently to ensure that the evidence being generated and utilised to inform practice has been subjected to scrutiny. Molone et al. proposes that evidence is knowledge that has been extracted from different origins which have been rigorously tested and proven to be reliable. (39) Knowledge in this circumstance refers to information generated from research, individual medical or professional experiences, or from patients, clients, carers and local surroundings. (40)

JBI, a global leader in EBHC, utilises different types of evidence to address different types of clinical questions to produce evidence-based information and resources. Quantitative evidence, which is generated from numerical data commonly RCTs, typically addresses questions related to the effectiveness or impact of a therapy or treatment. Qualitative evidence, which originates from studies that focus on human experiences, and cultural and social phenomena, answers questions which are related to the appropriateness of care or meaningfulness of an experience. Text and opinion evidence originate from experts' views or thoughts, agreement, current written communication, notes or remarks, and assertions or presumptions found in a variety of publications and reports. Discourse refers to evidence that is available through written messages (communication) or discussions regarding an individual narrative or experience. (41) These different forms of evidence are synthesised and disseminated all over the world with the aim of equipping health professionals and policy makers to make informed clinical decisions.

Evidence synthesis, one of the core components of the JBI model of Evidence-Based Healthcare, leads to the generation of systematic reviews, evidence summaries and clinical practice guidelines.<sup>(41)</sup> Systematic reviews are performed using a wide range of methodologies to address different types of

clinical questions. Their findings commonly have significant implications to clinical practice and are useful in informing decision-making. Unlike systematic reviews, evidence summaries are shorter documents which present the key findings of systematic reviews and/or other rigorous studies related to day-to-day clinical problems. (42) Clinical guidelines, which are typically based on systematic reviews and expert consensus, provide recommendations for practice intended to help health practitioners make decisions about appropriate care and optimise client care. For clinical guidelines to be reliable, strict processes must be followed. These include adhering to thorough methodology which takes into consideration the evidence, client morals and choices, and availability of resources. JBI recommends that evidence syntheses in the form of systematic reviews, evidence summaries and clinical guidelines consider where possible the feasibility, appropriateness, meaningfulness and effectiveness of healthcare practices. (41)

## Introduction to systematic reviews

Globally, health care has changed rapidly in the last few decades. Health professionals and clinicians are relying more and more on evidence-based information. Due to the rapid increase in knowledge and access to a wide range of information origins, it is not possible for health professionals to remain well-informed and up-to-date with health information in any given specialty field. (43) Hence, systematic reviews play an important role.

A systematic review is a form of secondary research that aims to integrate and synthesise all the available evidence relating to a particular question. The approach follows internationally recognised, rigorous and transparent methods (refer to Table 1 below for the steps undertaken for this systematic review) that ensure that the outcomes are reliable. (43) Systematic reviews are considered the gold standard in providing evidence for clinical practice because of the rigorous methods that are used to synthesise evidence. (44) To ensure transparency, an *a priori* protocol that describes the review question, inclusion criteria and methods should be developed to provide clear direction and guidance for the review. (34)

Table 1: Steps in the systematic review<sup>(45)</sup>

	Steps	Description
1	Formulating the review question	The PICo (population, phenomena of interest, context) mnemonic was utilised to frame the review objectives as the current review used the qualitative method. The objective of the review was to identify and synthesize the evidence regarding caregivers' health seeking behaviors and healthcare workers' experiences concerning the management of childhood pneumonia in low- and-lower middle-income countries.
2	Developing the protocol	Before a systematic review is carried out, it is essential that a protocol that clearly outlines the review process is developed. A protocol was developed that included the review objectives, inclusion/exclusion criteria, as well as methods outlining the search strategy, study selection, assessment of study quality, data extraction and data synthesis processes.
3	Defining inclusion and exclusion criteria	The PICo mnemonic was used to define the inclusion and exclusion criteria and considered the participants, phenomenon of interest, context, and types of study. The review included caregivers of children who were under five years of age who exhibited symptoms of pneumonia. It also included healthcare workers who were involved in identifying and treating pneumonia in children. Data were collected from participants in lowand-lower-middle-income countries.
4	Locating studies through searching	A search strategy customised to each database was developed and a search for published and unpublished literature in the relevant databases and sources was undertaken.
5	Selecting studies for inclusion	The search results were screened for studies meeting the inclusion criteria. All the studies that met the inclusion criteria were collated and uploaded into EndNote X8 (Clarivate Analytics, PA, USA).

6	Assessing the methodological quality of studies	Studies that met the inclusion criteria were critically appraised independently by two reviewers to assess their quality.
7	Extracting data	Relevant data from included studies were extracted using a structured data extraction tool, initially by the principal reviewer and subsequently verified by the other reviewers.
8	Analysing and synthesising the relevant studies	Data from included studies were pooled in the JBI System for the Unified Management, Assessment and Review of Information (SUMARI) for analysis and synthesis, using the meta-aggregation approach. <sup>(45)</sup>
9	Presenting and interpreting the results, which includes a process to establish confidence in the body of evidence (through systems such as ConQual) <sup>(46)</sup>	Review results were presented and confidence in the body of evidence was assessed using a structured approach.

Traditional systematic reviews (discussed in more detail below) rely heavily on quantitative evidence, (17) focus on evidence of efficacy and examine the degree to which an intervention, when used correctly, accomplishes the desired outcome. (43) However, over the years, it has become apparent that a quantitative review alone is insufficient and inappropriate for answering other equally important questions such as why or how an intervention might work. These are questions which can only be addressed by qualitative evidence which focuses on human experiences, and cultural and social phenomena. (41) Quantitative and qualitative studies may have different objectives but the evidence they produce are equally essential to adequately inform clinical practice, policy making or organisational decisions. (43)

## The JBI approach to qualitative evidence synthesis

The current systematic review utilised the JBI approach to qualitative synthesis, i.e. meta-aggregation.<sup>(47)</sup> Synthesis using the meta-aggregation approach aims to produce statements in the form of 'lines of action' rather than a theory, which is typical of other qualitative systematic review approaches. In this approach, findings from individual primary studies are aggregated into categories, which are then further aggregated

into synthesised findings. Finally, the results of the synthesised findings are assigned grades of recommendations that can be used to inform policy or practice. (48)

The meta-aggregative approach considers primary studies from a wide range of methodological designs to encapsulate the entire phenomenon of interest, rather than a single dimensional perspective. (49, 50) It provides a reliable unprejudiced synthesis using a thorough and clear process, and locates and uncovers all the evidence that is relevant to a given topic. (51)

# Objectives of the current review

The overall objective of this review was to identify and synthesise the evidence on caregivers' health seeking behaviors and healthcare workers' experiences in the management of childhood pneumonia in low- and lower-middle-income countries.

The specific objectives of this review were:

- To explore the health-seeking behaviours and experiences of caregivers of children under five years suffering from pneumonia.
- ii. To explore the experiences of healthcare workers in the management of pneumonia in children under five years of age.

## Criteria for considering studies in the review

## **Participants**

This review initially considered studies that included caregivers of children under five years diagnosed with pneumonia as stated in the published protocol. However, due to the limited number of primary studies, the review team agreed to also include studies which investigated caregivers of children who presented with pneumonia-like symptoms. Caregivers refer to the parents of children, immediate family members, an extended family member or anyone in the community who participated in caregiving responsibilities.

This review also considered studies that included healthcare workers who were involved in the identification and treatment of pneumonia (or pneumonia-like symptoms or acute respiratory illness) in children under five years. Healthcare workers refer to nurses, doctors, community health workers and lay health workers.

#### Phenomena of interest

This review considered studies that explored caregivers' experiences related to their health-seeking practices. This review also considered studies that explored healthcare workers' experiences of identifying and treating childhood pneumonia.

#### Context

The review included studies undertaken in low- and lower-middle-income countries, identified according to the World Bank Classification system.(52) The review considered studies conducted in any healthcare setting such as hospitals, healthcare or community centres, ambulatory care or homes.

## Types of studies

This review considered primary qualitative studies including phenomenology, grounded theory, ethnography, case studies, action research and qualitative descriptive studies. Only studies published in English were included. No date restrictions were applied as the review aimed to retrieve all relevant data to ensure the strength and validity of the findings.

# Search strategy

The search strategy aimed to locate both published and unpublished studies. An initial limited search of PubMed was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant studies, and the index terms used to describe the article, were used to develop a full search strategy for PubMed. The search strategy, including all identified keywords and index terms, were adapted for each included information source. The reference list of all studies selected for critical

appraisal was screened for additional studies. Database searching was undertaken from 13th to 17th June 2019. Detailed search strategies for the individual databases are provided in *Appendix 1*.

# Information sources

The databases searched for published studies included PubMed (National Library of Medicine), Embase (Elsevier), Scopus (Elsevier) and CINAHL (EBSCOhost). The search for unpublished studies and grey literature was undertaken in ProQuest Dissertations and Theses and Networked Digital Library of Theses and Dissertations.

### Study selection

Following the search, all identified citations were collated and uploaded into EndNote X8 (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts were then screened by the principal reviewer for assessment against the inclusion criteria of the review. Potentially relevant studies were retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI). (45) The full texts of selected citations were assessed in detail against the inclusion criteria by the principal reviewer. Secondary reviewers were contacted to discuss uncertainties in inclusion of some papers so that a consensus could be reached. Reasons for exclusion of full-text studies that did not meet the criteria were recorded and reported. Studies were selected following the process outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. (53)

## Assessment of methodological quality/critical appraisal

Eligible studies were critically appraised by two independent reviewers for methodological quality using the standard JBI Critical Appraisal Checklist for Qualitative Research. (48) The primary reviewer contacted the author of one study (54) to request additional data for clarification. The researcher responded with appropriate information and the study was included in the review. Disagreements between reviewers

were resolved through a discussion, so a third reviewer was not needed. All the studies were included, regardless of methodological quality. The critical appraisal checklist is provided in Appendix 2.

#### Data extraction

Data were extracted from studies included in the review by the primary reviewer using the standardised JBI data extraction tool. (45) The data extracted included specific details about the population, context, culture, geographic location, study methods and phenomena of interest relevant to the review objectives. Findings and their illustrations were extracted and assigned a level of credibility. Extracted findings were verbatim extracts of the author's analytic interpretation, accompanied by a direct quotation representing the participant's voice (i.e. illustration). Findings included the 'themes' reported in the individual studies, however, in some studies subthemes (54, 55) provided better contextual data than the themes. Where this was apparent, data were extracted at the sub-theme level. Extracted findings and illustrations were verified by a second reviewer.

Following extraction, findings were assigned a level of credibility. There are three levels of credibility based on the JBI approach to qualitative systematic reviews: i) unequivocal, where findings are accompanied by an illustration that is beyond reasonable doubt and is therefore not open to challenge; ii) credible, where findings are accompanied by an illustration that lacks clear association with it and is therefore open to challenge; and iii) not supported, where findings are not supported by the data. (56) The data extraction tool is provided in Appendix 3.

## Data synthesis

Qualitative research findings were pooled in JBI SUMARI using the meta-aggregative approach. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorising these findings based on similarity in meaning. These categories were then subjected to a synthesis to produce a single comprehensive set of synthesised findings that was used as a basis for evidence-based practice.

# Assessing confidence in the findings

The final synthesised findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and is presented in a Summary of Findings.(57) The Summary of Findings includes the major elements of the review and details how the ConQual score has been developed. Included in the Summary of Findings is the title, population, phenomena of interest and context for the review. Each synthesized finding from the review is presented along with the type of research informing it, scores for dependability and credibility, and the overall ConQual score.

This chapter focused on introducing EBHC and systematic reviews and outlined the methods that were used to undertake this review. Chapter 3 will present the review findings, including the search results, description of included studies, methodological quality of the included studies and results of the meta-aggregation.

## Chapter 3: Results

This chapter provides an overview of the search results, description of studies, methodological quality of included studies and review findings.

#### Search results

An extensive search of the literature was conducted from 13<sup>th</sup> to 17<sup>th</sup> June 2019. Following the search, 3086 titles were identified (CINAHL = 246; Embase = 227; PubMed = 195; Scopus = 2120 ProQuest Dissertations = 126 and Theses and Networked Digital Library of Theses and Dissertations = 172). The search for additional literature in the reference lists generated seven studies which were added to the total number of titles identified, resulting in 3093 records identified through a systematic search. There were 60 duplicates identified by the automated duplicate finding function of EndNote X8 which were removed, leaving a final total of 3033 titles. These studies, through their title and abstract, were screened for eligibility; 32 studies were identified for full text retrieval. After reading the 32 full-text papers, 24 articles were excluded and eight(30,58-64) were considered to have met the inclusion criteria and selected for critical appraisal. Two of the included studies(63, 64) contained findings which were deemed 'unsupported' and are provided separately in Appendix 4. Findings for these two studies were not included in the meta-aggregation. Reasons for exclusion were inappropriate study design and incorrect study population (children over five years of age were selected as participants). Overall, eight articles were included in the systematic review. Refer to Figure 1 below. Reasons for exclusion of full text studies that did not meet the inclusion criteria are provided in Appendix 5.

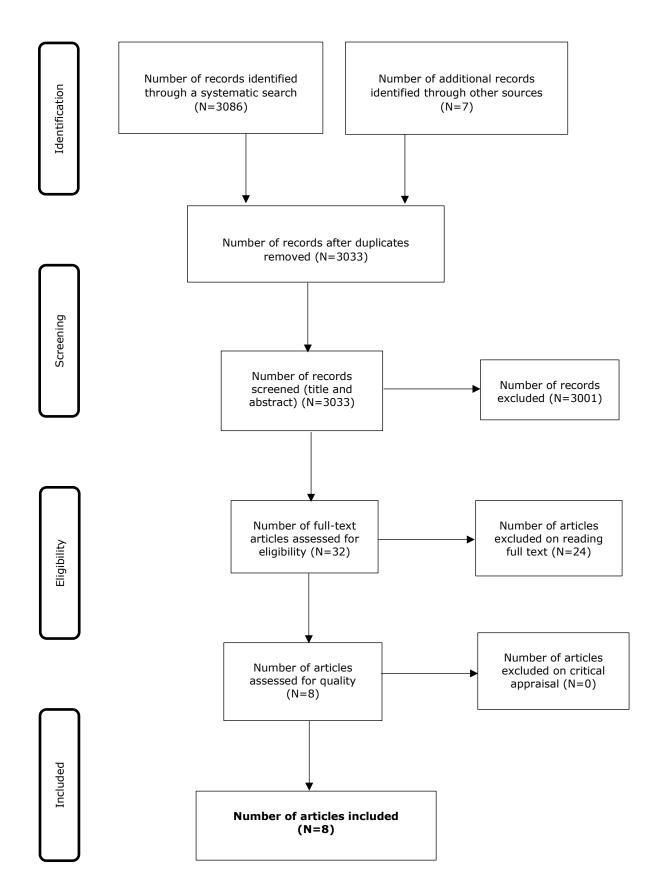


Figure 1: PRISMA flow diagram of search results, study selection and inclusion process

#### Characteristics of included studies

A total of eight studies were included. Six studies (58, 59, 61-64) explored the experiences of caregivers and two studies (30, 60) investigated the experiences of healthcare workers. The findings of two studies (63, 64) that explored caregivers' experiences were deemed 'unsupported' and are listed separately in the appendix as indicated above. Therefore, only the findings from six studies were included in the synthesis.

There was a total of 416 participants. Out of this, 272 were caregivers and 144 were healthcare workers. Four studies reported that the participants' age ranged from 15 years to 45 years. (59-61, 63) One study (64) reported that the participants' age ranged from 25 years to 40 years. The remaining three studies (30, 58, 62) had no record of the participants' age. For the majority of studies (n=7), interviews and focus groups took place in an appointed area within the local community where the participants lived, while one study was conducted at the participants' homes.

All study participants were female except for the study by Sato et al.<sup>(62)</sup> The participants in the study by Sato et al.<sup>(62)</sup> consisted exclusively of fathers. Six studies<sup>(30, 58-61, 63)</sup> focused on children with pneumonia and two<sup>(62, 64)</sup> focused on children with pneumonia-like symptoms (upper respiratory tract infections). Healthcare providers consisted of community health workers, allopathic doctors, lay health workers, lay health supervisors and AYUSH (Ayurveda, Yoga, Unani, Siddha, Homeopathy) providers.

The qualitative studies included one grounded theory study,<sup>(58)</sup> one ethnographic study,<sup>(59)</sup> and the rest (six studies) had no clearly stated methodologies.<sup>(30, 60-64)</sup> Methods of data collection were focus group discussions (FGDs) and in-depth individual interviews (IDIs), and data were analysed using appropriate qualitative tools and software such as NVivo version 10 ( QSR International ) and N6 (NUD\*IST v.6 2002; QSR International, Doncaster, Victoria, Australia). All eight studies were published papers. Two studies were published in 2016<sup>(30, 58)</sup> and the rest were published in 1993,<sup>(63)</sup> 1994,<sup>(64)</sup> 1997,<sup>(59)</sup> 2006,<sup>(61)</sup> 2017,<sup>(60)</sup> and 2018.<sup>(62)</sup> Three of the studies were conducted in Pakistan<sup>(30, 59, 63)</sup> and the rest were conducted in

Western Uganda,<sup>(61)</sup> Ghana,<sup>(58)</sup> Philippines,<sup>(62)</sup> India<sup>(60)</sup> and Bangladesh.<sup>(64)</sup> Detailed descriptions of the included studies are provided in <u>Appendix 6</u>.

# Methodological quality of included studies

There were 10 questions for the critical appraisal of the included studies (refer to Table 2 below). All eight studies rated 'unclear' for Q1 which addresses congruity between the stated philosophical perspectives and the research methodology. Two studies rated 'yes' for the following criteria: congruity between the research methodology and the research question (Q2), congruity between the research methodology and data collection methods (Q3), congruity between the research methodology and representation and data collection (Q4) and congruity between the research methodology and the interpretation of the results (Q5). The remaining six studies were rated 'unclear' for Q2-Q5 as their methodology was not stated explicitly in the paper.

None of the studies scored a 'yes' for Q6 which relates to the influence of the researchers' cultural and theoretical orientation on the study, and Q7 which refers to the influence of the researcher on the study and vice-versa. Six studies met the quality criterion (Q8) which addresses adequate representation of participants' voices and two scored a 'no'. Five studies scored a 'yes' to Q9 which refers to ethical approval from an appropriate body and three were rated as 'no'. All eight studies rated 'yes' to Q10 which addresses the congruence of conclusions with the analysis or interpretation of the data.

Overall, the quality of included studies was poor, however, they can still be considered the best available evidence for this topic area. Therefore, the results and recommendations may still be considered useful for practice but should be interpreted with caution due to their methodological shortcomings.

Table 2: Critical appraisal results

	Rafat et al. 1997	Rabbani et al. 2016	Brunie et al. 2017	Abbey et al. 2016	Mari Sato et al. 2018	Kallander et al. 2006	Stewart et al. 1994	Kundi et al. 1993
Q1: Is there congruity between the stated philosophical perspective and the research methodology?	U	U	U	U	U	U	U	U
Q2: Is there congruity between the research methodology and the research question or objectives?	Y	U	U	Y	U	U	U	U
Q3: Is there congruity between the research methodology and the methods used to collect data?	Y	U	U	Y	U	U	U	U
Q4: Is there congruity between the research methodology and the representation and analysis of data?	Y	U	U	Y	U	U	U	U
Q5: Is there congruity between the research methodology and the interpretation of results?	Y	U	U	Y	U	U	U	U
Q6: Is there a statement locating the researcher culturally or theoretically?	N	N	N	N	N	N	N	N
Q7: Is the influence of the researcher on the research, and vice- versa, addressed?	N	N	N	N	N	N	N	N
Q8: Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	N	N
Q9: Is the research ethical according to current criteria or, for recent studies, and is	N	Y	Y	Y	Y	Y	N	N

	Rafat et al. 1997	Rabbani et al. 2016	Brunie et al. 2017	Abbey et al. 2016	Mari Sato et al. 2018	Kallander et al. 2006	Stewart et al. 1994	Kundi et al. 1993
there evidence of ethical approval by an appropriate body?								
Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y

U: unclear; Y: yes; N: no

## Review findings

The review findings are presented in two sections. The first part reports on caregivers' experiences while the second part reports on the experiences of the healthcare workers.

Overall, a total of 54 findings were extracted; 50 were rated as 'unequivocal' and four were rated as 'credible'. These were categorised into 12 categories and three synthesised findings. A detailed description of the review findings and illustrations is provided in Appendix 7.

## I. Experiences of caregivers

Findings and illustrations were extracted verbatim from four studies that considered the experiences of caregivers. A total of 38 findings were extracted and aggregated into nine categories. From the nine categories, two synthesised findings were developed. These synthesised findings are:

- Caregivers can identify common pneumonia symptoms, including those symptoms leading to severe pneumonia in children under five years of age, however some misconceptions, including those of the aetiology of pneumonia, still persist.
- Factors, such as financial constraints, use of home remedies or practitioner-provided interventions, inappropriate purchase and use of medicines, caregivers' choice of the provider,

and decision-maker for the child, impact on the treatment of pneumonia in children under five years of age.

Synthesised finding 1: Caregivers can identify common pneumonia symptoms in children under five years of age, including those symptoms leading to severe pneumonia, however some misconceptions, including those of the aetiology of pneumonia, still persist.

Caregivers identified symptoms that they associated with mild or non-severe pneumonia. Most mothers mentioned cough, fever, and fast and difficulty breathing as commonly observed symptoms during the early phase of pneumonia or what they considered mild or non-life threatening. Many also recognised symptoms suggestive of worsening symptoms. However, some caregivers were unable to clearly identify pneumonia. This synthesised finding was generated from the aggregation of three categories underpinned by 11 extracted findings. Ten of the findings were rated as 'unequivocal' and one was rated as 'credible'. The categories are as follows:

- Caregivers were able to recognise common symptoms of mild or non-life-threatening pneumonia in children under five years of age.
- Caregivers were able to identify symptoms of severe or life-threatening pneumonia in children under five years of age.
- Caregivers had misconceptions about the aetiology of pneumonia in children under five years of age.

Category 1.1: Caregivers were able to recognise common symptoms of mild or non-lifethreatening pneumonia in children under five years of age.

Generally, mothers were able to identify symptoms of pneumonia using local terms and were able to clearly link these symptoms to pneumonia. This category was supported by four findings.

1. In 'narrow space' breathing [Akafundi] the child had cough with difficult/painful breathing and stridor: (U)

"In Akafundi [narrow space] the child tries to take in more air and is breathing with a lot of difficulties.

Breathing out seems painful and the child makes a whistle like noise in the chest." ((61)p960)

2. When asked how they noticed that their children were sick, most caregivers mentioned a cough, and/or difficulty breathing. Among those, over a third reported fever and a quarter reported fast breathing or intercostal retractions. In many cases, symptoms were readily attributed to sardi (cold) or jakda (congestion), though those two conditions were not strictly defined or necessarily seen as mutually exclusive: (C)

"[Sardi, jakda, pneumonia] Its all the same thing... if it gets bad, then one says that sardi-pneumonia has happened, take him to the doctor quickly. He's got jakda, he's caught pneumonia. If its slight, they play, they are active and roam around. If it's bad, they stop playing and walking around, (they) stay inside." ((60)p3)

- 3. Their recognition of symptoms of pneumonia varied, covering cough, asthma, weakness, irritability, fever, difficulty in breathing, crackling sound in the chest and convulsions: (U) "She had a hard cough, she had difficulty breathing, a crackling sound could be heard when she would breathe. That's what I observed in my child."((62)p5)
- 4. (However) after FGD participants and key investigators (KIs) viewed the video of a child with high respiratory rate, cough and lower chest in-drawing, indicating severe pneumonia, majority of the discussants generally described the child in the video as having breathing problems. Very few (about 11% of 56 FGD participants) including a herbalist spontaneously identified the child as suffering from pneumonia. In another FGD session, a female participant also explained: (U) "...that is pneumonia; because pneumonia causes a child to cough and breathe like this." ((58)p6)

# Category 1.2: Caregivers were able to identify symptoms of severe or life-threatening pneumonia in children under five years of age.

Pneumonia could progress to a fatal illness or even death if left untreated or if treatment was delayed.

Many of the participants in the studies reported that they could recognise symptoms that indicated pneumonia progression from a mild to a severe infection. This category was supported by three findings.

- An increase in pasli chalna (chest indrawing), tez saans (rapid breathing) leading to breathlessness, abdominal distension and increase in fever were the commonly agreed upon terminologies to describe double numonia. The following quote from one of the mothers typifies most of the responses of most child caretakers: (U)
- "... the child had halki khansi [mild cough] for one week, and then she developed bukha [fever]. Within the same day the fever increased... and the child started to have pasli chalna [chest indrawing] and also tez saanz [fast breathing] .... I immediately took her to a doctor [allopathic] and he confirmed my suspicion that nazla seeney pe jam gaya hai [chest congestion] which is what numonia is all about." ((59)p996)
- Most mothers considered numonia and double numonia as potentially fatal conditions. The most commonly cited indicator of severe illness was pasli chalna. Other indicators were continuous or increasing bukkar (fever), refusal to feed and lethargy termed kamzori or girnay lagta hai. As one mother said: (U)
- "I... do not worry when my children have cough and cold, but the moment they have bukhar [fever] I start worrying... when there is pasli chalna [difficult breathing] and / or san mey mushkil [difficult breathing] ... I know the illness is khatarnak [life threatening] ..."((59)p995)
- 3. The third child had a normal respiratory rate with severe stridor. 'Narrow space' [Akafundi] together with 'abrupt attack' [Obukoni] were the illness concepts mentioned by most. Some,

however, suggested that this was 'groaning breathing' [Ekyikenyero]. All agreed that the first action would be to rush the child to a hospital: (U)

"This is Akafundi [narrow space], exactly Akafundi! He is breathing with pain; it is like he also has Obukoni [abrupt attack]. The child is in a critical condition." ((61)p961)

# Category 1.3: Caregivers had misconceptions about the aetiology of pneumonia in children under five years of age.

Some caregivers were unable to clearly recognise symptoms of pneumonia. Caregivers had varying perceptions regarding the causes of childhood pneumonia. However, the general belief was that pneumonia was caused by exposure to low temperatures (eating cold food, drinking cold water or sleeping on the cold concrete floor) and poor, unhygienic conditions where a child picked objects from the dirt and ingested it. Fathers were certain that soft tissue injuries and fractures and random pains caused pneumonia-like symptoms. This category was supported by four findings.

 Furthermore, other views sampled attributed the cause of pneumonia to ingesting cold drinks or food; they indicated that: (U)

"One gets pneumonia from drinking cold water, eating cold food or chewing ice cubes." ((58)p7)

2. The perception of caregivers who have heard about pneumonia differed. The general belief was that exposing a child, to cold temperature or windy weather conditions could result in the child getting pneumonia. The most common factors mentioned in all discussion groups included "sleeping on the bare cemented floor". For instance, one female participant said: (U)

"What I know is that pneumonia is caused by sleeping on the bare cemented floor; because the bare floor is cold, if the child is not adequately clothed and sleeps on it for a long time, the cold penetrates the body and causes pneumonia."((58)p7)

3. Poor hygiene practices were also mentioned as one of the factors that could cause the child to get pneumonia; as explained by a male participant: (U)

"When a child picks anything from the ground and puts it in his mouth, there can be contamination which can cause the child to have pneumonia. Crawling children get it easier than toddlers." ((58)p7)

4. Fathers believed that suffering from a sprain, fracture or some other pain made the child sick with fever, cough, or vomiting: (U)

"Sometimes when the child had fever, people said the child had piang (sprain or dislocation of tissues or bones). Sometimes when the child experienced body pain, the child had fever."((62)p6)

Synthesised finding 2: Barriers, such as financial constraints, use of home remedies or practitioner-provided interventions, inappropriate purchase and use of medicines, caregivers' choice of healthcare provider, and responsibility for decision making for the child, impact the treatment of pneumonia in children under five years of age.

Financial issues were considered a major reason many caregivers were unable to receive adequate care. Some caregivers kept their children at home and gave them home remedies or traditional medicines. Others inappropriately purchased or obtained and used medicines. Most caregivers took their children to a traditional healer, whereas others refused to consult traditional healers. Some fathers took their children to the hospital, but a doctor was not always available for patient consultations. Fathers were the main decision makers regarding when and where care was sought. In their absence, however, women made these decisions.

This synthesised finding was generated from the aggregation of six categories and underpinned by 27 extracted findings. Twenty-six of the findings were rated as 'unequivocal' and one was rated as 'credible'. The categories are as follows:

- Financial constraints prevented caregivers from seeking and receiving treatment for their child with pneumonia.
- Caregivers used home remedies to treat their child with pneumonia.

- Pharmacological interventions were used by health practitioners to treat children with pneumonia.
- Caregivers medicated their sick child on their own.
- Caregivers sought care from either traditional or allopathic health practitioners.
- Fathers were typically the decision makers, however, in their absence, mothers took the responsibility for seeking treatment which also included seeking advice from significant others.

# Category 2.1: Financial constraints prevented caregivers from seeking and receiving treatment for their child with pneumonia.

Fathers often worried about money, stating that they were unable to buy medicines whenever their child got sick. Some fathers mentioned they saved money for future needs when they had extra income and others relied on a loan. Sometimes, caregivers paid for medicines when the free stock ran out. This category was supported by five findings.

- Most of them borrowed money from their relatives and friends. Some fathers asked for financial help from politicians for their children's hospital expenses. Some of them were still repaying debt:
   (U)
- "I felt different. I was afraid. I was worried because I did not have any money. I looked for money and asked for it from my neighbors."((62)p5)
- 2. One father who had lost his first child saved money whenever he had extra income: (U) "We usually save even 50 pesos if we make extra, because we do not know when the child may need to go to a hospital again."((62)p5)
- 3. Some of them could not afford to buy medicines because they did not have enough money: (U) "Rural Health Unit (RHU) staff gave me a prescription. But I could not buy the medicines as I did not have enough money."((62)p6)

4. Fathers mostly complied with the doctor's recommendation to go to a hospital. One father did not comply with such a recommendation when he did not have any money: (C)

"If it is an emergency, surely, I bring my child to a hospital. The important thing is for my child to be okay."((62)p6)

5. RHU provides medicines for free if they have a stock. However, when there was no stock of medicines at RHU, they had to buy medicines themselves: (U)

"When my child's condition became worse with a cough with sputum, we brought him to RHU. But they did not have a stock of medications. I paid 105 pesos for amoxicillin."((62)p6)

## Category 2.2: Caregivers used home remedies to treat their child with pneumonia.

Caregivers commonly kept their sick children at home and gave them herbal or other forms of home treatment. This was recognised as a common practice among caregivers. Various forms of herbal medicines were given. Fathers believed in the effectiveness of the herbal remedy, however sometimes the symptoms relapsed. This category was supported by eight findings.

- 1. For internal usage, ingesting or inhaling melted Shea butter is believed to clear the nasal congestion and restore proper breathing as explained by one female participant in a FGD: (U) "Catarrh also causes the child to have difficulty in breathing so when my child gets 'catarrh' I normally put shea butter into the nose and give him some to eat then the blockage opens, and the child begins to breathe properly." ((58)p7)
- A less common practice indicated by a few caregivers is to give the child water drained from soaked uncooked rice, or honey to treat the difficulty in breathing as cited by one grandmother in an FGD: (U)

"We soak rice in water and give the cloudy water to the child to drink. This cleans up the child's system and health is restored." ((58)p7)

3. Most fathers believed that oregano and five-leaved chaste tree leaves were effective for a cough and asked mothers to make herbal medicines for the child: (U)

"We used oregano because it is easy to use. A cough was relieved by the herbal medicine but relapsed after getting better once." ((62)p5)

4. Herbs in different forms were reportedly used for treatment of pneumonia in children. Some are boiled or made into powder and mixed with certain substances obtained from an herbalist for use as described by one male participant: (U)

"The herbs are boiled and given to the child to drink or given as enema. This flushes out the illness through the passing of stool." ((58)p7)

5. Fathers considered themselves the leader of the family who solves any problem that occurs in the family. They took various actions to improve their child's health, such as seeking information from other people: (U)

"I look after my children, wipe them if they are sweating, and I ask other people about what to do."((62)p5)

One father gave what his own mother used to give him when he was sick in his early childhood:
 (U)

"If I have money, I buy eggs for my sick child. If I don't, just buy royal (soft drink), because that was what my mother used to give me." ((62)p4)

7. Seven fathers knew that applying cold water reduced fever: (U)

"We knew how to give first aid. If my child has fever, we wipe him with a wet towel to lower his temperature." ((62)p4)

8. Fathers assisted mothers in caring for a sick child: (U)

"I gave my wife some ice. I waited for the ice to melt and then wiped the child." ((62)p4)

# Category 2.3: Pharmacological interventions were used by health practitioners to treat children with pneumonia.

Caregivers indicated that chloroquine was prescribed to children who presented with symptoms of pneumonia. Caregivers were upset because of the long waiting time and complained about the care received at the Primary Health Care (PHC) clinic. Several fathers observed that, at the Rural Health Unit (RHU), healthcare workers listened to the lungs, tried to bring the temperature down by fanning the child and gave oxygen or a nebulizer treatment to those who needed it. This category was supported by three findings.

- Although fast and difficult breathing were associated with problems in the lungs or airways, many
  of the ARI illness concepts were frequently related to 'fever' [Omutsutsa] and were perceived to
  need antimalarial treatment: (U)
- ". . .chloroquine is given to all children with Omutsutsa owe Ekyikenyero [The fever of groaning breathing] as long as the child has Ekibugumu [hot body]."((61)p960-961)
- 2. The curative services of the PHC programme were minimally utilised in both the study areas. The community, used to physicians pronouncing a diagnosis after minimal history taking and examination and getting a multiple drug prescription (in addition to an injection and some medicines from the doctor's own pharmacy), felt angry and somewhat cheated by the doctors at the PHC center. The subsequent quote from one of the respondent's typifies the general attitude towards curative care offered by the PHC programme: (U)

"They take an hour just to take the history and then more time for examination..., it makes me very angry when at the end all I get is a prescription for drugs such as Calpol [paracetamol] which I can easily buy on my own from the drug store..., why should I waste my time going there and not a private doctor..., the latter takes half the time and gives injections to speed recovery".((59)p999)

3. Some fathers had witnessed RHU staff listening to the child's chest sounds, fanning a child to bring down the fever and using oxygen or a nebuliser when the child had difficulty breathing: (U) "RHU staff used a fan for my child to relieve fever. Only in the case that he suffers from difficulty in breathing, they use something like oxygen and nebulizer. It heated and made steam"((62)p6)

## Category 2.4: Caregivers medicated their sick child on their own, often using medicines they are not sure about.

Caregivers often purchased medicines from the local pharmacy without proper prescriptions. Some of the fathers gave antibiotics to their children but had no idea what these medicines were and how much to give. This category was supported by two findings.

- Some of them bought medicines without prescription at a pharmacy, while some asked neighbors and relatives to give them medicines: (U)
- "I asked my mother-in-law for medicine since she had a stock of medicines from the congressman." ((62)p5)
- 2. Although fathers used Western medicines such as antibiotics, they did not know their names or dosage. Mothers handled these aspects. One father had no idea what antibiotics were: (U) "We gave the child paracetamol liquid, but I do not know the dosage. I don't have any idea what antibiotics are. What is that? I think it is cephalexin."((62)p5)

## Category 2.5: Caregivers sought care from either traditional or allopathic health practitioners.

It was a common practice for caregivers to seek care from the traditional healer and believed that their (traditional healer) treatment was effective. However, one father thought it was risky and refused to seek medical help from a traditional healer. Other caregivers took their children to the hospital, preferably to be seen by a medical doctor, but this was not always possible. This category was supported by five findings.

- 1. Taking a sick child to a traditional healer was a common choice of fathers: (U)

  "If my child has fever, we bring him to the traditional healer. In a few days, he gets better."((62)p6)
- 2. Fathers believed a traditional healer's treatment to be effective as they had seen their child recover after receiving such treatment: (U)

"When my child was treated by a traditional healer, he seemed at ease. I was free from worry." ((62)p6)

3. One father did not like to go to a traditional healer as he thought it risky: (U)

"I don't like traditional healers. I cannot take a risk when it comes to my child. I prefer to bring him to RHU first. I don't like to take him to a traditional healer." ((62)p6)

4. Fathers took their children to RHU to be checked, particularly by a doctor: (U)

"I think that only a doctor knows what kind of medicines my child needs, and we are not convinced unless a doctor checks my child."((62)p6)

5. However, they recognised that a doctor was not always available and that only some nurses and midwives might be available at RHU: (U)

"Once, a nurse prescribed antibiotic for a cough when I brought my child to RHU. I argued with her because she was not a doctor."((62)p6)

Category 2.6: Fathers were typically the decision makers, however, in their absence, mothers took the responsibility for seeking treatment which also included seeking advice from significant others.

Fathers were regarded as the main decision maker concerning outside care. This often involved consulting other elderly members of the family who might have helpful information and knowledge about the child's illness or which health facility to go to. In some instances, in the absence of the fathers, mothers or other caregivers present at the time made these decisions. This category was supported by four findings.

1. It often involved seeking the opinion or assistance of significant others who were considered knowledgeable in managing the child's illness. Such persons included grandparents of the child, other older relatives and neighbours as explained by a female participant: (U)

"I don't know any medicines for any illness and since my parents are older than I am, and they know what is wrong with the child they take the decision on what medicine to give to the child." ((58)p8)

2. The mothers reported to be the primary decision-makers regarding outside care in the group discussions. In reality, too, in over two-thirds of pneumonia cases, mothers were the key decision-makers for seeking outside care, with grandmothers making the decision in less than a quarter of the cases (in two of the three cases the mother was out of town and the grandmother had the primary responsibility of taking care of the child): (U)

"When the child is sick, and the father is away at work, the child's treatment is the mother's responsibility. In fact, if I do not take my child to the doctor, my husband would get extremely upset with me about my negligence." ((59)p1000)

- 3. Fathers were also the main decision makers regarding which facility to use. Although fathers discussed such matters with mothers, they were proud to be the primary decision maker: (U) "If I see that my child is unwell, I bring him to RHU. I talk to my wife, but I am the one who decides." ((62)p5)
- 4. Nonetheless, there are instances where the decision rests on the caregiver present at the time when the illness is observed, as pointed out by one male participant: (U)

"My wife is the one who takes care of the children when I am not in the house, but when I am in the house, I take the decision on what to do." ((58)p8)

## II. Experiences of healthcare workers

Findings and illustrations were extracted verbatim from two studies that considered the experiences of healthcare workers. A total of 16 findings were extracted and aggregated into three categories. From the three categories, one synthesised finding was developed:

Synthesised finding 3: Healthcare workers experience a number of barriers that impact their ability to manage and treat childhood pneumonia in children under five years of age. These barriers occur across all levels of care, including the systems level, the individual practitioner level, and the caregiver level.

Delivery of appropriate health care was found to be compromised at various levels of the health care continuum, with three major challenges in the management of pneumonia in children under five years of age identified. Healthcare workers highlighted that, at the systems level, structural constraints to prescribing practices and unavailability of medicines hindered adequate medical care for children with pneumonia. Healthcare workers also indicated that if incentives such as salaries and reward were available to them, their knowledge and performance would improve. At the individual practitioner level, the studies identified several factors that influenced healthcare worker performance, which included the provision of feedback, supervision and training. Healthcare workers also experienced barriers at the caregiver level that could potentially hinder the effective management of childhood pneumonia. They identified that caregivers care seeking attitudes, such as switching providers, financial constraints, perceived resolution of illness and limited access to health care, prevented caregivers from seeking and receiving care. They also noted that caregivers lacked knowledge and understanding of the differences between practitioners. As a result, they sought and received care from unqualified practitioners.

This synthesised finding was generated from three categories and underpinned by 16 findings. Fourteen findings were rated as 'unequivocal' and two were rated as 'credible'. The categories are as follows:

- At the systems level, structural constraints to prescribing behaviour and unavailability of medicines prevented appropriate treatment for pneumonia in children under five years of age. Additionally, healthcare workers' ability to perform and gain knowledge was hampered by lack of incentives and medicines.
- At the individual practitioner level, the need for further training that included supervised field visits and the provision of feedback were identified as influencing healthcare workers' ability to manage pneumonia in children under five years of age. This was demonstrated by some healthcare workers not being able to correctly identify pneumonia.
- At the caregiver level, financial constraints, access to hospital, perception of disease resolution and lack of understanding of the different types of practitioners prevented caregivers from seeking and receiving medical treatment for pneumonia in children under five years of age.

Category 3.1: At the systems level, structural constraints to prescribing behaviour and unavailability of medicines prevented appropriate treatment for pneumonia in children under five years of age. Additionally, healthcare workers' ability to perform and gain knowledge was hampered by lack of incentives and medicines.

Healthcare workers were concerned that treatment for childhood pneumonia was hampered due to several issues. They highlighted factors, such as structural constraints to prescribing behaviour, and lack of incentives and medicines, as issues that compromised care at this level. This category was supported by four findings.

 Structural constraints to prescribing behaviour were noted in several interviews, including lack of equipment to ascertain diagnosis, prior treatment by village doctors, costs, and pressures to relieve symptoms. An allopathic provider said: (U) "In a private set-up, you can't... just admit the patient... without any treatment, just investigations are going on. He'll say I'm wasting my money. And if by the way you are wrong at a diagnosis and you end up with complications, he'll just think that you did not give any treatment, that's why my child is [in a] serious [condition]. You have to give a prophylactic antibiotic. In a private practice, what I'm doing is, we are giving oxygen, bronchodilator, and an antibiotic." ((60)p4)

- A considerable number of health workers highlighted the unavailability of oral rehydration solutions (ORS), zinc, and antibiotics as demotivating factors in terms of improving knowledge and performance: (C)
   (People in the community say) "You do not give us medicines; you pocket them yourselves."
- 3. Additionally, a significant number of healthcare workers highlighted lack of salaries and reward as demotivating factors: (U)
  "If we get these four things then we can perform our duties easily: salary, material, training, reward." ((30)p5)
- 4. While training was understandably mentioned as important to improve level of knowledge, availability of medicines was considered equally important: (U)

"Our level of knowledge will increase if we get medicines." ((30)p5)

Category 3.2: At the individual practitioner level, the need for further training that included supervised field visits and the provision of feedback were identified as influencing healthcare workers' ability to manage pneumonia in children under five years of age. This was demonstrated by some healthcare workers not being able to correctly identify pneumonia.

Healthcare workers indicated that if they received proper training, supervision and feedback, their performance would improve. Some lay health supervisors (LHSs) lacked the knowledge to accurately identify pneumonia. This category was supported by nine findings which were all extracted from one paper.

 Most lay health workers (LHWs) and LHSs were able to correctly define pneumonia as chest indrawing, high fever and fast breathing. However, a few misconceptions were noted among LHSs regarding pneumonia: (U)

"Pneumonia is inflammation of hands." ((30)p5)

 LHWs and LHSs were of the opinion that enhanced presence of LHSs during their household visits would be a source of encouragement and improved LHWs performance. According to many LHWs the supervision would be significantly improved if the LHSs accompany them on field visits more often: (U)

"It is better to go and check (LHWs) in the field than to ask only." ((30)p5-6)

- 3. LHWs and LHSs perceived feedback as being important to improving their performance: (U) "Feedback is very important; in this way our capabilities are exposed." ((30)p6)
- 4. Generally, LHWs prefer group feedback as compared to individual feedback: (U) "Individual feedback is useless; no one know what we did." ((30)p6-7)
- 5. Most LHWs consider verbal feedback given in a group to be adequate: (U)

  "It will be beneficial to give feedback in a group." ((30)p7)
- 6. On the other hand, LHSs preferred written and individual feedback to LHWs, rather than group and verbal feedback: (U)

"Feedback should be handwritten and given individually." ((30)p7)

- Further training would improve LHW knowledge, performance, motivation and LHS supervision:
   (U)
  - "More training should be provided to improve knowledge regarding diarrhea and pneumonia." ((30)p7)
- 8. A strong desire to gain more training was also expressed especially in the absence of formal training for several years: (U)

"The more increased in knowledge, the better it is. It is definitely possible that there are things which we do not know." ((30)p7)

9. The last training for most LHWs and LHSs was conducted several years ago, but they desired additional observational-based training to enhance their knowledge and skills: (U)

"Training is very important, if we forget anything training helps to recall and stimulates our memories." ((30)p7)

Category 3.3: At the caregiver level, financial constraints, access to hospital, perception of disease resolution and lack of understanding of the different types of practitioners prevented caregivers from seeking and receiving medical treatment for pneumonia in children under five years of age.

Most caregivers did not follow-up with the doctor when they perceived their children's illness had resolved and this was attributed to financial constraints. Some caregivers switched practitioners when they assumed that their child did not respond to treatment. Other caregivers sought care from 'village' doctors instead of from qualified practitioners. There were also caregivers who kept their children at home and gave them home remedies instead because they were unable to access health care. Some caregivers were not aware of the differences in the knowledge, skills and services provided by various practitioners (village doctors, AYUSH practitioners and allopathic providers). As a result, they sought care from unqualified practitioners. This category was supported by three findings.

1. Two thirds of formal providers described follow-up strategies requiring multiple visits to monitor the child's condition and or dispense more drugs. Most noted that caregivers did not systematically come back. According to providers, the main reasons for this behaviour were switching to other providers if expectations for fast relief were not met, financial constraints and perceived resolution of illness. Allopathic providers charged a consultation fee that typically covered any visit made within a period of five days, while AYUSH (practitioners of alternative systems of medicines which consists of Ayurveda, yoga, unani, siddha and homeopathy)

providers rarely charged a consultation fee but only gave a few days' worth of medicine at each visit: (U)

"Ten to 20% of people only are able to pay [afford] the full course of treatment. So as soon as they start feeling comfortable, they stop coming... they don't know whether they're cured or relieved. They don't know the difference... the capacity to pay is very low. So, for that we've planned something. For Rs.50, for five days, they can come and avail of free consultation... they come on one day and pay, then all they need to do is buy medicines on the other days. Because of this follow-up is comparatively better." ((60)p6)

- Limited access to LHWs in some areas was also mentioned as a reason for compromised care at household level: (U)
  - "People can't reach the hospital and use traditional remedies at home instead." ((30)p4)
- 3. Caregivers indicated consulting 'village' doctors, including RHPs (rural health practitioners) and possibly other doctors practicing locally much more often than they did allopathic providers. At the same time, caregivers were not oblivious to the fact that there were differences between providers. For instance, several caregivers who initially consulted a village doctor or an AYUSH practitioner, made a conscious decision to experiment with those providers for initial care, as illustrated here by the mother of a four-year-old boy who consulted a unani doctor: (C)

  "We show our child to Dr. D [Unani doctor] only, first of all. When it is too much, then only we go that nursing home... We think that the child maybe [will] get relief from here so that we do not need to go too far... There is a lot of difference [between the unani doctor and the nursing home] ... We feel that D is cheaper.... We also think that he is a person of our own home; he will give good medicine." ((60)p4)

A detailed list of synthesised findings for caregivers and healthcare workers is provided in Appendix 8.

This chapter outlined the search results, provided a description of included studies, summarised the methodological quality of included studies and presented the review findings. Chapter 4 will discuss the results of the review in more depth and will outline recommendations for practice and further research.

## Chapter 4: Discussion

Chapter 4 expands on the results of the review and outlines recommendations for practice and further research.

This qualitative systematic review was undertaken to gain insights into and understanding of caregivers' experiences and their care seeking attitudes and behaviours, as well as healthcare workers' experiences, in the management of pneumonia in children under five years of age in low- and lower-middle-income countries. A total of eight studies were included in the review, however, two studies reported findings which were 'unsupported'. Hence, only the findings of six studies were included in the synthesis of evidence. Four studies focused on the experiences of caregivers and two studies on the experiences of healthcare workers.

A thorough search of the databases identified a very small number of qualitative studies that met the inclusion criteria. Given the importance of the review topic, it was critical that a sufficient number of studies were included, and as a result two studies that focused on pneumonia-like symptoms were subsequently included in the review. The deviation from the protocol regarding the population, i.e. the inclusion of children with pneumonia-like symptoms or acute respiratory infections may have impacted the results since the inclusion of the two studies meant that the review findings may not have included participants who went on to have pneumonia.

## Caregivers' knowledge of pneumonia

Caregivers were able to identify symptoms of pneumonia in children. The review identified that generally caregivers recognised symptoms associated with mild or non-severe pneumonia. Many also recognised symptoms suggestive of severe or life-threatening illness. These findings align with other studies that focused on caregiver's knowledge of symptoms of pneumonia and their ability to recognise pneumonia in children under five years of age. A related study involving Nigerian mothers reported that mothers with adequate knowledge of the danger signs of pneumonia were more likely to recognise pneumonia quickly

and seek immediate medical care than those who were uninformed. (65) Therefore caregivers' ability to identify and recognise symptoms of pneumonia determines their course of action and plays an important role in the reduction of childhood mortality.

Although the review indicated that caregivers could generally recognise symptoms of pneumonia, it also showed that they had poor knowledge of the cause of pneumonia, which could have implications on their overall health behaviour and how they looked after their children. The general belief was that pneumonia was caused by exposure to low temperatures such as drinking cold water, eating cold food, sleeping on cold concrete floors or under a fan, and poor hygienic conditions, such as a child picking up food from dirty floors and ingesting it. Some fathers thought that soft tissue injuries and fractures and random pains caused pneumonia-like symptoms. Poor health literacy is directly linked to increased morbidity and mortality rates. (66) Health literacy enables people to gain access to health information, gain understanding of that information and utilise it to promote health in communities. Having essential information that can promote health, and prevent illnesses and unnecessary deaths empowers people. (67) A Jamaican survey revealed that people who had very little education were unable to comprehend written health information. (66) The study further claimed that these individuals with limited education often did not take care of themselves and that poor health literacy directly interfered with their ability to make informed decisions regarding health issues in general. (68) Findings of the current review underscored the importance of promoting health literacy among caregivers of children with pneumonia, which was critical in ensuring that these children received timely and appropriate care. A general knowledge or understanding of pneumonia-causing agents can help caregivers keep their children healthy. The review suggests the importance of providing caregiver education, which should include teaching of pneumoniacausing pathogens and how they manifest. Caregiver education packages should also include information on the importance of childhood vaccinations, reduction of indoor air pollution (environmental health) and nutrition. (69)

## Barriers that prevent caregivers from seeking and receiving care for childhood pneumonia

The review identified several barriers that prevented caregivers from obtaining medical care that were vital for their sick children. These barriers are discussed below.

## Financial constraints

Financial constraints were recognised as a major barrier that prevented caregivers from seeking and receiving medical care. The findings are consistent with other studies that focused on barriers that hindered care seeking in low- and lower-middle-income countries. The available evidence indicates that limited financial resources to cover childhood illness-related costs including registration fees for consultations, transportation, laboratory tests and prescribed medicines hindered care seeking. (70-72) Similar findings have been reported in other studies from various low- and lower-middle income countries that focused on childhood illnesses other than pneumonia. (73-78) For instance, the study by Aftab et al. claimed that due to challenges in access to health facilities in rural Pakistan, seeking and receiving health care was often delayed and this led to undesirable health consequences. (73) In another study, Navale et al. revealed that in rural Rwanda, the major difficulty for most caregivers in gaining access to timely health care was unavailability of finances and fear of out-of-pocket medical costs. (77) Similarly, caregivers from a study that sought to explore and provide solutions for locally known barriers in Kenya, Nigeria and Niger for childhood diarrhoea and malaria reported that, 'the main challenge is money. Maybe with a disease, if you had money, then the child would be treated and they would be fine, but without money you just sit and hope that the child would get better. There is no where you can go without money". (70), p6) Findings from several other studies also revealed similar results, suggesting that financial barriers delay and prevent timely care seeking of common childhood illnesses in children under five years of age. (79-81) The current review identified that caregivers often worried about money, stating that they were unable to buy medicines or seek medical care whenever their children became sick. Many of the caregivers kept their children at home and gave them home remedies or -medicated them on their own, as described in more

detail in the next section. The review highlights the importance of providing quality care at reasonable costs and that health care should be easily accessed by those who need it.

## Self-medication practices

The second barrier that influenced caregivers' care seeking behavior was reliance on self-medication. The review found that caregivers often kept their sick children at home and medicated them on their own with medicines they obtained from neighbors, family members or drug stores which were often purchased without proper prescriptions. This type of practice, which is typical in low- and lower-middle-income countries, (76) delayed or prevented timely care seeking for children who might have been critically ill and needed urgent medical attention. This finding is consistent with other studies exploring the experiences of caregivers of sick children. Lungu et al. indicated that in Malawi, caregivers kept children at home hoping that their condition would improve. They purchased Panadol for the children, gave them treatment which consisted of leftover antibiotics and oral rehydration solution from previous diarrheal episodes, and when the illness worsened, they gave Bactrim and eventually went to the hospital when the illness became life-threatening. (76) Other studies that explored caregivers' perceptions of the factors interrupting healthcare services in children under five years of age indicated that caregivers medicated their children on their own using leftover medicines from a previous illness, which had been obtained over the counter or purchased without a doctor's prescription. (72, 82) Similar findings were repeatedly reported by various other studies that focused on other childhood illnesses in low- and lower-middle-income countries. (83-86) Although self-medication provides an easy and quick relief, certain risks are involved. The study by Ruiz reported that although self-medication practices had some advantages, the risks involved far outweighed the benefits. These risks include initiating treatment for a disease that has not been properly diagnosed and delaying timely care seeking. Dangerous side effects are rare but can occur. Furthermore, multiple drugs taken at the same time can cause severe drug reactions (drug interaction). Medications can also be administered incorrectly and in the wrong amount. Self-medication practices mislead caregivers into choosing improper treatment, conceal the true nature and seriousness of the illness and increase the risk of misuse and addiction.<sup>(87)</sup> The results of the current review revealed that many caregivers kept their children at home and medicated them on their own. This finding suggests that caregivers require education on the risks associated with self-medication and that if it delays appropriate medical intervention, harmful or adverse effects can occur.

#### Traditional healers and use of herbal medicines

The third factor that prevented caregivers from seeking and receiving timely and appropriate care was the use of traditional healers and herbal medicines. The review showed that traditional healers and/or herbal medicines were widely utilised in many low- and lower-middle-income countries for the management of childhood pneumonia. Caregivers seeking care from traditional healers who provided herbal medicines appeared to be a common practice. Caregivers believed that traditional healers were legitimate health practitioners who could treat illness effectively. This finding aligns with evidence from studies exploring practices related to the management of other childhood illnesses in low-and lowermiddle-income countries. Makundi et al., for example, focused on traditional healers and their role in managing malaria in children in Tanzania, and highlighted that caregivers believed that 'degedege' (which is severe malaria characterised by convulsions) was caused by spirits. As a result, they sought care from a traditional healer to remove the spirit first before receiving modern medicine. (88) Towns et al. revealed that, in Western Africa, treatment for an enlarged spleen included massages and enemas using herbs. Another type of treatment described was the old fashioned 'vaccination' method which involved making small cuts on the child's body using a sharp object and then applying the juice of fresh plants into the cuts. (86) In Ghana, caregivers classified childhood illnesses into groups and would not seek care for illnesses classified as 'not for hospital'. These children were kept at home and given herbal medicines such as teas, baths, enemas and massages. (89) Mothers typically took their children to traditional healers if the illness was thought to have been caused by sorcery or witchcraft, which they believed only a traditional healer could heal. It was only when a child became severely ill with malaria that modern medicine was sought. (86)

The use of herbal remedies for childhood illnesses is a common practice as they are affordable and very accessible, and the practice has been passed down from generations. (90) According to Oyebode et al., aside from being accessible, herbal or home remedies are popular in low- and lower-middle-income countries because of limited availability of medical professionals. They are also cheap, compared to modern medicines or pharmaceutical interventions, and more acceptable by local communities than modern medicines. (91)

Although herbal medicines are widely acceptable and used in low-and lower-middle-income countries, certain risks are involved. Firenzuoli and Gori claimed, in their paper on herbal medicines, that the variability of herbal extracts can cause problems in both pharmacodynamics (which is the biochemical, physiologic and molecular effects of drugs on the body) and pharmacokinetics (which is the movement of drug into, through and out of the body). (92) Many of the herbal extracts have not been adequately tested and their uses are not monitored properly, if at all. Due to poor regulating systems, insufficient information is available regarding their mechanism of action, probable side effects, contraindications and interactions with other pharmaceutical products to allow for their safe use. (93)

The current review recognised that caregivers in low-and lower-middle-income countries often sought care from traditional healers and used herbal or home remedies. For many, this was usually their first option of care for their sick children. Only one caregiver thought it was a risky practice and avoided seeking care from traditional healers. Children who are ill with pneumonia need immediate medical attention. Appropriate medical care is often delayed when caregivers seek care from traditional healers or treat them with home remedies. This review finding once again highlights the importance of caregiver education which should focus on the importance of seeking timely care from qualified medical professionals as well as the harms associated with using herbal medicines.

#### Lack of understanding regarding the different types of practitioners

Caregivers' knowledge and understanding of the different types of health professionals can greatly impact the type and quality of care received.

The fourth barrier that hindered timely care was caregivers' lack of understanding of the different types of practitioners. Some caregivers sought care from 'village' doctors rather than qualified practitioners. This led to delays in seeking appropriate care from a qualified healthcare professional. This finding indicates the importance of having access to legitimate health professionals from whom effective and timely medical care is sought. There is lack of evidence to support this finding in the wider literature.

## Decision making in seeking professional health care

One of the interesting findings of this systematic review is that fathers appeared to be the main decision maker when seeking professional health care for their sick children. This often included consulting other elderly members of the family who might have had helpful information and knowledge about the child's illness or deciding which facility to go to. It was only in their absence that mothers assumed the responsibility of making decisions. The study by Ja et al., which focused on the role of men in care seeking for maternal and newborn health in Tanzania, revealed that in low-and lower-middle-income countries, men and other male household members were the main decision makers when seeking care outside of the home. Their opinions on this issue mattered more than those of the women because of their capacity to earn an income and by virtue of being the head of the family. (94) Mothers and other female household members usually played the role of a caregiver, providing physical assistance and support to the sick family member. Caregiving as a predominantly female role seemed to be a commonly held belief in many regions of low-and lower-middle-income countries.

## Barriers that hinder healthcare workers' ability to manage and treat childhood pneumonia

The review identified several factors that could compromise the care and treatment provided by healthcare workers to children with pneumonia. These factors occurred at different levels: the systems level, the individual practitioner level and the caregiver level.

## Barriers at the systems level

At the systems level, healthcare workers expressed concerns that structural constraints to prescribing behaviour and unavailability of medicines prevented appropriate treatment. These findings are consistent with other studies regarding lack of or unavailability of medicines. Without the availability of good medicines and other pharmaceutical supplies, it is impossible to maintain good health. The WHO reports that globally approximately two billion people do not have access to essential medicines. The report claims that disparities within health systems and infrastructure impede distribution of medicines to billions of people, including children.<sup>(96)</sup> As a result, many children suffer pain and misery and many die from preventable diseases. Furthermore, childhood illnesses become prolonged, and children end up with unnecessary complications from untreated diseases.<sup>(97)</sup> In Africa, 50% of children under five years of age die from preventable diseases such as pneumonia, diarrhoea, measles, HIV, tuberculosis and malaria. These deaths could have been prevented if children had timely access to effective and affordable medicines, vaccines and other health services.<sup>(98)</sup> Most drugs in Africa are imported from overseas and are often sold at high prices, thus making it impossible for most people to access such medications. Nurses in Botswana prescribe painkillers, regardless of the nature of the illness because of lack of appropriate medicines.<sup>(99)</sup>

One of the goals set by the United Nations in 2000 was to reduce morbidity and mortality in children under five. This goal cannot be achieved if the most vulnerable populations of the world are unable to access affordable medicines. (68) Obstacles remain that prevent accessing these services, including system and infrastructure barriers, geographical hindrances to accessing services, challenges with supply chains and research-associated obstacles. (100) Medicines are an important part of health care because they improve health and quality of life. (101) Lack of or unavailability of basic medicines are one reason many people, particularly children under five years of age, become sick and die or develop lifelong complications of illnesses that could have been easily prevented.

The review identified that healthcare workers' ability to perform effective management of sick children was also restrained by lack of incentives from healthcare organisations. This aligns with studies that have focused on factors that demotivate healthcare workers performance. It has been documented that in some parts of Africa, incentives (financial or non-financial) and rewards were given to healthcare workers to retain or to encourage them to perform well in their roles and most health workers migrated to places where salaries and other incentives were favourable.(102) Another study conducted in Cambodia revealed that incentives offered to healthcare workers resulted in increased levels of productivity and performance.(103) The study by Rabbani et al. in a rural community in Pakistan also indicated that incentives in the form of salaries motivated healthcare worker performance.(104) The current review identified that healthcare workers' motivation to perform well would improve if they were given incentives and provided medicines that they could then supply to their patients. The review highlights that a holistic approach that includes multi-disciplinary collaborations is needed to address these issues.

#### Barriers at the individual practitioner level

At the individual practitioner level, the need for further training that comprised supervised field visits and the provision of feedback were identified by the review as influencing healthcare workers' ability to effectively manage pneumonia in children under five years of age. This was demonstrated by some healthcare workers not being able to correctly identify pneumonia. While many healthcare workers were able to identify symptoms of pneumonia, some misconceptions still existed. For instance, the finding of one study revealed that some healthcare workers thought pneumonia was the inflammation of hands. (30)

Another study revealed that healthcare workers misunderstood the condition and confused pneumonia symptoms with those of malaria. As a consequence, children who presented with symptoms of pneumonia were treated with chloroquine for malaria infection. (61) Pujelo et al. indicates that in the tropics it is common for children to present with other febrile illnesses such as dengue or malaria which could mislead caregivers as well as healthcare workers. (82)

Healthcare workers need to be motivated to provide efficient, effective and quality care in their communities. (105) Meeting today's healthcare demands and needs in low- and lower-middle-income countries requires motivated healthcare workers. (106) In circumstances where health professionals are not empowered, job performance declines, which can affect the quality of health care being delivered. (107) The study by Rohan et al. demonstrates that the major factor that brought job satisfaction and increased performance among nurses were the clinical environment and the amount of supervision provided. (108) Nurses were able to perform well in their roles when supportive supervision was provided. Additionally, healthcare workers expressed that if they received proper training and feedback, their performance would improve. The current review's findings indicate the importance of providing continuous professional development opportunities and supervision for healthcare workers for them to maintain or improve their knowledge, expertise and competence, and to develop the personal and professional qualities required to effectively care for their patients. The best possible delivery method of providing that feedback is unclear as some prefer individual, group, verbal, and/or written feedback.

## Barriers at the caregiver level

The review findings demonstrate that healthcare workers were concerned that at the caregiver level, financial constraints, access to hospital, perception of disease resolution and lack of awareness of the differences between practitioners prevented caregivers from seeking and receiving medical treatment for pneumonia in children under five years of age. These findings align with what the caregivers experienced. In Kenya, caregivers of children under five years of age indicated that for many of them getting to a health facility was a significant challenge. Accessing health care was an even greater challenge if one lived in rural or remote areas. (70) According to the WHO, half of the world's population is unable to gain access to adequate health services. (109) Accessing proper health services is a major challenge in low- and lower-middle-income countries. For instance, around 24 million children miss out on basic vaccinations which could have prevented unnecessary illnesses and death from preventable childhood illnesses. (110) Around 45% of illnesses in children under five years of age could have been prevented, if these children had

access to health services.<sup>(110)</sup> The WHO claims that progress in improving health in low- and lower-middle-income countries is being held back by the lack of high quality health services and asserts that provision of quality health services is the cornerstone of universal health coverage.<sup>(111)</sup> The current review identified that most caregivers failed to follow up with the doctor when they perceived their children's illness had resolved. A doctor's follow-up plan would include multiple visits to monitor a child's condition and/or to dispense more medications. However, most caregivers did not return to see the doctor. Several reasons were identified for these behaviours, including caregivers' switching to other practitioners if expectations for fast relief were unmet, financial constraints and perceived illness resolution.

## Limitations of the review

A number of potential limitations to this systematic review need to be acknowledged. Although a thorough systematic search of the literature was carried out and attempts were made to identify all relevant studies, it is possible that some studies may have been overlooked. Additionally, limiting studies to only those published in the English language could have resulted in potential studies that were missed.

Only eight studies (from seven countries) were identified and all but two were from rural settings which may limit the transferability of the review findings. Additionally, six of the included studies (58-61, 63, 64) consisted of caregivers who were female carers of children under five years of age, thus limiting applicability to the male population. The findings from two studies were 'unsupported', thereby limiting the review, although there were some similarities observed.

It is necessary to establish confidence in systematic review findings and ensure that they are reliable and trustworthy and can be safely utilised by health professionals and policy makers when making decisions about health care. Included studies were downgraded by two levels for dependability criteria and downgraded one level for credibility. The overall ConQual score was very low (refer to Table 3 below). This affects the confidence in the body of evidence produced and its applicability in health care.

## **Table 3: ConQual Summary of Findings**

Systematic review title: Caregivers' and healthcare workers' experiences in the management of childhood pneumonia in low- and lower-middle-income countries: a systematic review of qualitative evidence

Population: Caregivers of children under five years of age showing signs and symptoms of pneumonia and healthcare workers involved in identifying and treating pneumonia in children under five years of age

Phenomenon of interest: Caregivers' attitudes and experiences related to their care seeking practices and healthcare workers' experiences of identifying and treating childhood pneumonia

Context: Low- and lower-middle-income countries and healthcare settings, such as hospitals, healthcare or community center, ambulatory care and home

## **Caregivers**

Synthesised findings	Type of research	Dependability	Credibility	ConQual score	Comments
Caregivers can identify common pneumonia symptoms in children under five years of age, including those symptoms leading to severe pneumonia, however some misconceptions, including those of the aetiology of pneumonia, still persist.	Qualitative High	Low (downgraded two levels)	Low (downgraded one level)	Very low	Dependability downgraded as all 4 primary studies were rated 'unclear' on dependability questions (critical appraisal Q1-Q5)
					Credibility downgraded because of mixture of unequivocal and credible findings (Unequivocal 9 and Credible 1)
Factors, such as financial constraints, use of home remedies or practitioner-provided interventions, inappropriate purchase and use of medicines, caregivers' choice of provider, and responsibility for decision making for the child, impact the treatment of pneumonia in children under five years of age.	Qualitative High	Low (downgraded two levels)	Low (downgraded one level)	Very low	Dependability downgraded as all 4 primary studies were rated 'unclear' on dependability questions (critical appraisal Q1-Q5)
					Credibility downgraded because of mixture of Unequivocal and Credible findings (Unequivocal 26 and Credible 1)

Synthesised finding	Type of research	Dependability	Credibility	ConQual score	Comments
Healthcare workers experience a number of barriers that impact their ability to manage and treat childhood pneumonia in children under five years of age. These barriers occur across all levels of care, including the systems level, the individual practitioner level and the caregiver level.	Qualitative High	Low (downgraded two levels)	Low (downgraded one level)	Very low	Dependability downgraded as both studies were rated 'unclear' on dependability questions (Q1-Q5). Credibility downgraded because of a mixture of Unequivocal and Credible findings (Unequivocal 14 and Credible 2)

#### Conclusion

Pneumonia is the leading cause of death among children younger than five years, with most of the deaths occurring in low- and lower-middle-income countries. Each year, millions of children become sick and die; for those who survive, many end up with pneumonia-related complications later in adulthood. Caregivers play an important role in the care of childhood pneumonia as their ability to identify pneumonia early and seek timely medical intervention prevents death and possible complications. Healthcare workers also play an important role as their ability to adequately diagnose and manage childhood pneumonia is crucial to reducing unnecessary deaths and pneumonia-related complications.

Many factors contribute to poor child health outcomes in low- and lower-middle-income countries. This review has identified factors that hinder caregivers from seeking and receiving treatment for childhood pneumonia. The review has also found barriers that prevent healthcare workers from effectively managing children with pneumonia.

This review has highlighted important recommendations for practice for healthcare professionals and policy makers and suggests ideas for further research in the area.

## Recommendations for practice

The following recommendations for practice are based on the JBI Grades of Recommendations<sup>(112)</sup> and rated according to ConQual:<sup>(46)</sup> Primary qualitative studies were assessed for dependability and credibility using a ranking system. Dependability was downgraded by two levels as there was 0-1 "yes" responses. The synthesized findings contained a mixture of unequivocal and credible findings; hence credibility was downgraded by one level.

- Health professionals and policy makers should be aware that some caregivers in low- and lower-middle-income countries lack knowledge of the symptoms and causes of pneumonia. Training initiatives should include education and community awareness of mild or non-life threatening as well as severe or life-threatening symptoms of pneumonia and causes of pneumonia in children under five years of age. (Grade B)
- Caregivers' perceptions of disease resolution and misunderstanding about the various types of
  practitioners often interfere with seeking and receiving medical treatment for pneumonia in
  children under five years of age. Hence, caregivers' health education should include information
  aimed at educating caregivers on the different levels of providers and how this impact on the
  management of childhood pneumonia, and emphasise the importance of follow-up visits as this
  determines the child's condition and whether medication should continue. (Grade B)
- Health professionals and policy makers should be aware of the barriers that hinder caregivers in low- and lower middle-income countries from seeking appropriate care for childhood pneumonia.
   Caregiver education should include:
  - The importance of seeking early and timely care for sick children (Grade B)
  - Discouraging the use of herbal or home remedies or treatment as these delay the seeking of care (Grade B)
  - The importance of using a proper prescription provided by a trained health professional to purchase medicines from a recognised or registered pharmacy (Grade B)

- The importance of seeking care from a properly trained medical professional (Grade B)
- Emphasising that any delays in decision-making regarding care seeking could cost a child's life. It is therefore important that care seeking decisions be made by the caregiver present at the time of illness. The decision to seek care could be complicated by unavailability of medical resources, distance to health facility or financial constraints. These factors should also be considered during caregiver education. (Grade B)
- The importance of female caregiver autonomy so that care seeking decisions can be made anytime without male intervention. (Grade B)
- Healthcare workers in low- and lower-middle-income countries struggle with inadequate medical supplies, medicines and resources that are needed to treat childhood pneumonia. Availability of adequate medical supplies and resources is recognised as a factor that motivates healthcare worker productivity and performance. This is a systems level issue. A holistic approach that includes multi-disciplinary collaboration is needed to address these issues. The issues to address should include:
  - Procedures to obtain medicines and other medical resources through low cost interventions (Grade B)
  - A reliable and effective healthcare delivery system that includes adequate procurement and effective delivery of medical supplies, medicines, and other resources (Grade B)
  - Mechanisms to improve and make available affordable medicines and other medical resources and supplies (Grade B)
  - More health facilities should be built in rural settings as this is where most children come
     from and infrastructure in these areas should be improved. (Grade B)
- It is a fundamental human right to be able to access basic health care. However, caregivers often do not seek and receive adequate care because they are unable to easily access health care.

This is a health systems issue. A holistic approach that includes multi-disciplinary collaboration is needed to address these issues. The issues to address should include:

- Identifying and improving infrastructure, logistical and procurement processes (Grade
   B)
- Strengthening weak health systems and ensuring that people have access to affordable health care that is of high quality (Grade B)
- Interventions to strengthen the health systems so as to promote utilisation of child health services in order to improve child health and survival (Grade B)
- The possibility of establishing new health facilities that are closer to communities. (Grade
   B)
- Lack of incentives and awards decrease staff motivation to perform. It is therefore important that
  health managers and supervisors recognise these barriers and provide incentives and rewards,
  where possible. (Grade B)
- Some healthcare workers lack the knowledge to recognise symptoms of pneumonia, therefore at the individual practitioner level:
  - Healthcare workers should be offered regular training in order to improve the standard of care (Grade B)
  - Adequate field supervision should be provided to healthcare workers (Grade B)
  - Sufficient feedback should be provided regarding identification and management of childhood pneumonia. (Grade B)
- Healthcare workers should be aware that caregivers often face financial difficulties which prevent
  or delay timely care seeking. Where possible, health facilities should reduce user fees so that
  the most vulnerable can access health care. (Grade B)

Health professionals should be conscious of factors that prevent caregivers from returning for a
follow-up visit. Where possible, healthcare professionals should educate caregivers of the
importance of follow-up visits and arrange for these visits at low or no cost. (Grade B)

#### Recommendations for research

- Although childhood pneumonia is an infection of global significance, insufficient attention has been given to address the disease. Only eight primary studies from seven countries were included in the systematic review: of those, only two explored healthcare workers experiences. More studies that explore the experiences of healthcare workers attitudes and behaviours regarding the management of childhood pneumonia from different regions in low- and lower-middle-income countries would provide further understanding of this complex phenomenon. Moreover, studies that explore healthcare workers' attitudes and behaviours, and that compare rural versus urban settings and large health care facilities versus small independent settings would provide insights into the magnitude of the problem.
- Healthcare workers' attitudes toward caregivers can influence caregivers' care seeking behaviours. Exploring the relationship between caregivers and healthcare workers would shed light on this phenomenon.
- Considering the global significance of childhood pneumonia, studies from a wider geographical setting that investigate factors that influence the quality of care being provided to children could potentially reduce childhood pneumonia-related mortality.
- Access to child health services is an important determinant of child health. Further studies that
  explore determinants of access to healthcare services and identify potential strategies to reduce
  inequities could significantly improve the health outcomes of children with pneumonia.
- Poor health literacy has been linked to increased childhood morbidity and mortality in low- and lower-middle-income countries. Further qualitative inquiry that focuses on the relationship

between health literacy and disease incidences would shed light on the extent of the issues faced in developing countries and provide possible solutions.

- In low- and lower-middle-income countries, the decision to seek care outside of the home is
  typically made by men or other male members of the household. More research that investigates
  this cultural dynamic may provide a better understanding of how this might affect the care
  received by children.
- Herbal and or traditional medicines are part of the traditional method of treatment for many lowand lower-middle-income countries that have been passed on from generations. While these methods of treatment provide quick and fast relief, they are not properly regulated and can cause more harm than benefit. Further research that focuses on the role of traditional versus contemporary medicines may lead to possible integration of both practices in health care.
- Self-medication is a growing issue in many low- and lower-middle-income countries. This
  practice hinders the seeking of care from appropriately trained health professionals and
  accredited health facilities. However, in some low and lower middle-income countries, selfmedication using herbal and or traditional medicines are encouraged. Further inquiry to
  understand caregivers' attitudes on self-medication practices may provide possible strategies for
  caregivers to avoid self-medication.
- Healthcare workers regard feedback as a factor that motivates them to perform well in their jobs.
   However, the delivery method of providing that feedback is unclear as some prefer individual, group, verbal and written feedback. A further study that aims to explore this phenomenon and provide specific guidelines for providing feedback would be of benefit to healthcare workers.

#### Conflict of interest

The author declares that there is no conflict of interest.

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Appendix 1: Search Strategy
Searches were conducted between the 13th - 17th of June 2019.

# PubMed (National Library of Medicine)

Topic area	Search string			
Child	child, preschool [mh] OR infant [mh] OR infant*			
	[tiab] OR child* [tiab] OR infant newborn [mh] OR			
	preschool* [tiab] OR newborn* [tiab] OR baby			
	[tiab] OR babies [tiab] OR pediatrics [mh] OR			
	pediatric* [tiab] OR paediatric* [tiab]			
	= 2463580			
Pneumonia	pneumonia [mh:noexp] OR pneumonia* [tiab] OR			
	pneumonia, pneumococcal [mh] OR pneumonia,			
	staphylococcal [mh] OR pneumonia, bacterial			
	[mh:noexp]			
	= 176706			
Low and middle-income countries (LMIC)	developing countries [mh] OR developing countr*			
	[tiab] OR less developed nation* [tiab] OR third			
	world [tiab] OR under-developed countr* [tiab] OR			
	under-developed nation* [tiab] OR low middle			
	income countr* [tiab] OR low middle income			
	nation*[tiab]			
	=121309			

Combined search	(((child, preschool [mh] OR infant [mh] OR infant*			
	[tiab] OR child* [tiab] OR infant newborn [mh] OR			
	preschool* [tiab] OR newborn*[tiab] OR baby			
	[tiab] OR babies [tiab] OR pediatrics [mh] OR			
	pediatric*[tiab] OR paediatric*[tiab]) AND			
	(pneumonia [mh:noexp] OR pneumonia* [tiab] OR			
	pneumonia, pneumococcal [mh] OR pneumonia,			
	staphylococcal [mh] OR pneumonia, bacterial			
	[mh:noexp]) AND (developing countries [mh] OR			
	developing countr*[tiab] OR less developed			
	nation* [tiab] OR thirdworld [tiab] OR under-			
	developed countr* [tiab] OR under-developed			
	nation* [tiab] OR low middle income countr*[tiab]			
	OR low middle income nation*[tiab])))			
	=195			

# CINAHL (EBSCO host)

Topic area	Search string
Child	MH child OR TI child OR AB child OR MH "Child,
	Preschool" OR TI preschool* OR AB preschool*
	OR MH infant OR TI infant* OR AB infant* OR MH
	"Infant, Newborn, Diseases" OR TI "childhood
	disease*" OR AB "childhood disease*" OR MH

"Infant, Newborn" OR TI "newborn infant\*" OR AB

"newborn infant\*" OR MH "Schools, Nursery" OR

TI "nursery school\*" OR AB "nursery school\*"

=667858

Pneumonia

MH Pneumonia OR TI Pneumonia OR AB Pneumonia OR MH "Pneumonia, Bacterial" OR TI "Pneumonia, Bacterial\*" OR AB "Pneumonia, Bacterial\*" OR MH "Community-Acquired Pneumonia" ΤI "Community-Acquired Pneumonia\*" "Community-Acquired OR AB Pneumonia\*" OR MH "Pneumonia, Pneumocystis" OR ΤI "Pneumonia, Pneumocystis\*" "Pneumonia. OR AB Pneumocystis\*" OR MH "Pneumonia, Mycoplasm" OR TI "Pneumonia, Mycoplasm\*" OR AB "Pneumonia, Mycoplasm\*" OR MH "Healthcare-Associated Pneumonia" ΤI OR "Healthcare-Associated Pneumonia\*" OR AB "Healthcare-Associated Pneumonia\*" OR MH "Pneumonia. Ventilator-Associated" ΤI OR "Pneumonia-Ventilator Associated\*" OR AB "Pneumonia-Ventilator Associated\*" "Pneumonia, Aspiration" OR TI "Pneumonia, Aspiration" OR AB "Pneumonia, Aspiration\*"

	=27238				
LMIC	MH "Low and Middle Income Countries" OR 1				
	"Low and Middle Income Countries*" OR AB "I				
	and Middle Income Countries*" OR MH				
	"Developing Countries" OR TI "Developing				
	Countries*" OR AB "Developing Countries*"				
	=26857				
Combined search	MH child OR TI child OR AB child OR MH "Child,				
	Preschool" OR TI preschool* OR AB preschool*				
	OR MH infant OR TI infant* OR AB infant* OR MH				
	"Infant, Newborn, Diseases" OR TI "childhood				
	disease*" OR AB "childhood disease*" OR MH				
	"Infant, Newborn" OR TI "newborn infant*" OR AB				
	"newborn infant*" OR MH "Schools, Nursery" OR				
	TI "nursery school*" OR AB "nursery school*"				
	AND MH Pneumonia OR TI Pneumonia OR AB				
	Pneumonia OR MH "Pneumonia, Bacterial" OR TI				
	"Pneumonia, Bacterial*" OR AB "Pneumonia,				
	Bacterial*" OR MH "Community-Acquired				
	Pneumonia" TI "Community-Acquired				
	Pneumonia*" OR AB "Community-Acquired				
	Pneumonia*" OR MH "Pneumonia,				
	Pneumocystis" OR TI "Pneumonia,				

Pneumocystis\*" OR AΒ "Pneumonia, Pneumocystis\*" OR MH "Pneumonia, Mycoplasm" OR TI "Pneumonia, Mycoplasm\*" OR AB "Pneumonia, Mycoplasm\*" OR MH "Healthcare-Associated Pneumonia" OR TI "Healthcare-Associated Pneumonia\*" OR AB "Healthcare-Associated Pneumonia\*" OR MH "Pneumonia, Ventilator-Associated" ΤI OR "Pneumonia-Ventilator Associated\*" OR AΒ "Pneumonia-Ventilator Associated\*" OR MH "Pneumonia, Aspiration" OR TI "Pneumonia, Aspiration" OR AB "Pneumonia, Aspiration\*" AND MH "Low and Middle Income Countries" OR TI "Low and Middle Income Countries\*" OR AB "Low and Middle Income Countries\*" OR MH "Developing Countries" OR TI "Developing Countries\*" OR AB "Developing Countries\*" =246

### EMBASE (Elsevier)

Topic area	Search string				
Child	'child'/exp OR 'infant'/exp OR 'infant' OR				
	'baby'/exp OR 'newborn'/exp OR 'school child'/exp				

OR 'preschool child'/exp OR 'toddler'/exp OR 'child':ab,ti OR 'infant':ab,ti OR 'baby':ab,ti OR 'newborn':ab,ti OR 'school child':ab,ti OR 'preschool child':ab,ti OR 'toddler':ab,ti OR 'pediatric':ab,ti OR 'paediatric':ab,ti

=2,068,751

#### Pneumonia

'pneumonia'/exp OR 'aspiration pneumonia'/exp 'bronchopneumonia'/exp OR 'neonatal pneumonia'/exp OR 'bacterial pneumonia'/exp OR 'staphylococcal pneumonia'/exp OR 'lower respiratory tract infection'/exp OR 'chest infection'/exp OR 'community acquired pneumonia'/exp 'streptococcus OR pneumoniae'/exp OR 'pneumonia':ab,ti OR 'aspiration pneumonia':ab,ti OR 'bronchopneumonia':ab,ti OR 'neonatal pneumonia':ab,ti OR 'bacterial pneumonia':ab,ti OR 'staphylococcal pneumonia':ab,ti OR 'lower respiratory tract infection':ab,ti OR 'chest infection':ab.ti OR 'community acquired OR 'streptococcus pneumonia':ab,ti pneumoniae':ab,ti

=498293

LMIC	(((Imic OR Imics OR third) AND ('world'/exp OR world) OR lami) AND countr* OR lower) AND middle AND ('income'/exp OR income) AND countries:ab,ti OR Imic:ab,ti OR 'developing country':ab,ti OR lami:ab,ti
Combined search	((('child'/exp OR 'infant'/exp OR 'infant') AND 'baby'/exp OR 'newborn'/exp OR 'school child'/exp OR 'preschool child'/exp OR 'toddler'/exp OR 'child':ab,ti OR 'infant':ab,ti OR 'baby':ab,ti OR 'newborn':ab,ti OR 'school child':ab,ti OR 'preschool child':ab,ti OR 'preschool child':ab,ti OR 'preschool child':ab,ti OR 'baddler':ab,ti) AND 'pneumonia'/exp OR 'toddler':ab,ti) AND 'pneumonia'/exp OR 'aspiration pneumonia'/exp OR 'neonatal pneumonia'/exp OR 'bronchopneumonia'/exp OR 'neonatal pneumonia'/exp OR 'bacterial pneumonia'/exp OR 'staphylococcal pneumonia'/exp OR 'chest infection'/exp OR 'community acquired pneumonia'/exp OR 'streptococcus pneumoniae'/exp OR 'streptococcus pneumoniae'/exp OR 'pneumonia':ab,ti OR 'aspiration pneumonia':ab,ti OR 'neonatal pneumonia':ab,ti OR 'bronchopneumonia':ab,ti OR 'neonatal pneumonia':ab,ti OR 'bacterial pneumonia':ab,ti OR 'staphylococcal pneumonia':ab,ti OR 'lower respiratory tract infection':ab,ti OR 'chest infection':ab,ti OR 'community acquired pneumonia':ab,ti OR 'streptococcus pneumoniae':ab,ti OR 'streptococcus pneumoniae':ab,ti OR 'streptococcus pneumoniae':ab,ti OR 'streptococcus pneumoniae':ab,ti OR lami) AND countr* OR lower) AND middle AND income AND countries:ab,ti OR lami:ab,ti OR 'developing country':ab,ti OR lami:ab,ti OR 'developing country':ab,ti OR lami:ab,ti

# SCOPUS (Elsevier)

Topic area	Search string				
Child	TITLE-ABS-KEY ((child* OR preschool* OR				
	infant* OR newborn* OR baby OR babies OR				
	pediatric* OR paediatric* ))				
	=3, 934,543				
Pneumonia	TITLE-ABS-KEY ((("pneumoni*")))				
	=350 251				
LMIC	TITLE-ABS-KEY (("low and middle income				
	countr*") OR ("Imic*") OR ("developing countr*")				
	OR ("third world countr*"))				
	=254 119				
Combined search	(TITLE-ABS-KEY ((child* OR preschool* OR				
	infant* OR newborn* OR baby OR babies OR				
	pediatric* OR paediatric*) AND (TITLE-ABS-				
	KEY ("pneumoni*") AND (TITLE-ABS-KEY ( "low				
	and middle income countr*") OR ("Imic*") OR				
	("developing countr*") OR ( "third world countr*")				
	AND (LIMIT-TO ( SUBJAREA , "MEDI" ) OR				
	LIMIT-TO ( SUBJAREA , "NURS") AND (LIMIT-				
	TO ( LANGUAGE , "English" ))				
	=2120				

# Appendix 2: JBI Critical appraisal checklist

# JBI Critical Appraisal Checklist for Qualitative Research

Revie	ewerDate_				
Auth	orYear		_Reco	rd Number	
		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?				
2.	Is there congruity between the research methodology and the research question or objectives?				
3.	Is there congruity between the research methodology and the methods used to collect data?				
4.	Is there congruity between the research methodology and the representation and analysis of data?				
5.	Is there congruity between the research methodology and the interpretation of results?				
6.	Is there a statement locating the researcher culturally or theoretically?				
7.	Is the influence of the researcher on the research, and vice- versa, addressed?				
8.	Are participants, and their voices, adequately represented?				
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?				
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?				
	all appraisal: Include	rther inf	ю 🗆		

# Appendix 3: JBI Data extraction tool

# JBI QARI Data Extraction Tool for Qualitative Research

Reviewer	Date	·
Author	Year	Γ
Journal	Rec	ord Number
Study Description Methodology		
Method		
Phenomena of interest		
Setting		
Geographical		
Cultural		
Participants		
Data analysis		
Authors conclusions		
Comments		
Complete	Yes 🗆	No 🗆

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Findings	Mustration form	Evidence			
	Publication (page number)	Unequivocal	Unequivocal Credible		

Extraction of findings complete 11	res 🗆	No 🗔
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### Village "Doctors"

- Generally, the semi-trained allopaths seem to recognize and name appropriately the signs and symptoms of acute lower respiratory tract infection.
- They report a variety of practices ranging from referral to the community health worker or
   Matlab hospital to home treatment with inconsistent combinations of drugs in deferring doses and durations.
- The prevailing explanations of disease aetiology are consistent with those reported by
  mothers, particularly the problem of "exposure to cold" and the transmission of "germs" from
  an ill mother to her child through her breastmilk.
- A number of respondents mentioned not having to "take the risk" of trying to treat severe
  cases of pneumonia because of the availability of treatment through the field station.
- Most of them understand the seriousness of symptoms of acute lower respiratory tract
  infections in very young infants, but often refer such cases for homeopathic treatment,
  explaining that allopathic medicine is "too strong" for newborn babies.

### **Disease Recognition and Differentiation**

- All participants in the four focus groups with mothers recognised pneumonia from the signs
  and symptoms described on the scenario, that is fever, cough, and laboured breathing with
  chest retractions. Sixty percent of the focus group with grandmothers recognised these as
  pneumonia.
- Pneumonia is primarily seen as a worsening of or the natural progression of the common cold (Thanda jor). In this case, cough becomes worse, (more frequent, more congested, more bothersome), fever is higher and uncontrollable, the child is sicker (no appetite, sleepy,

- irritable), and new symptoms of chest retractions, noisy, difficult and (less frequently mentioned) rapid breathing develop.
- This syndrome is perceived in contrast to alga, which occurs as a result of attack by evil spirits and is most common in young infant. While respiratory symptoms and signs are often present in alga, it is usually diagnosed by presence of seizure activity, eyes rolling back in the head and "black "coloration of the child. Hapani, or wheeze, presents very much like pneumonia except without fever. It is reported as being self-limiting in most cases, though it may "develop into" pneumonia.

### Disease aetiology and home care

- Most mothers in both interviews and focus groups attribute the initial illness in the scenario to either the child's or the nursing mother's exposure to cold.
- A minority believed that that attack by evil spirits, bad winds or the evil eye had caused the disease and these women identified the diseases as alga.
- None of the respondents, other than the village doctors, recognised measles or malnutrition
  as causing the illness, but a few mothers mentioned that measles might be associated with
  pneumonia.
- Regardless of whether the disease was attributed to chilling or to supernatural attack, it was
  thought that a nursing mother would pass the illness to the child through breastmilk if she
  was "exposed".
- Many respondents also stated that the disease described progressed to a more serious form
  because mucus was retained in the chest, where it stuck or hardened or became "attached
  to the chest". Accordingly, they felt that home care should emphasise protecting mother and
  child from cold and also attempting to soften and encourage expulsion of the mucus from the
  child's chest.

- Those who thought the illness was due to cold also suggested that the mother or, if weaned,
   the child should be constrained to avoid "cold" foods and chilling the body by wind or water.
- Food is said to be cold if they are stale or left over, although some foods (most often rice and bananas) are said to be intrinsically cold. Eating any food at night is also said to be chilling and therefore dangerous to the patient.
- These beliefs about the role of "hot" and "cold" foods in disease causation are fairly common, however, there are not apparent system to determine how foods are categorised.
- Most mothers say they avoid frequent bathing of their own or their child's bodies. But nearly
  all say they have attempted to reduce a child's fever by giving a sponge bath, though some
  say they apply water to the head only and most insist on drying the skin right away.
- A minority attempt to induce vomiting or stool in the hope that mucus will thereby be expelled, however, many express the belief that the mucus could be expelled through diarrhoea or vomiting.

### Recognition of disease severity

- Signs of severe pneumonia listed by all groups were chest retractions, laboured breathing,
   lethargy, and inability to feed. These signs were recognised and responded to by almost all
   women by seeking some form of treatment outside the home.
- In particular, chest retractions and breathing difficulty are generally understood to be life threatening and beyond the scope of home treatment.
- Rapid breathing was mentioned less frequently in focus group discussions, though almost all
  mothers being interviewed about the course of their child's current illness listed this sign.

#### Decision to seek care

 Traditional attitudes of older or male household members and external constraints often cause delays in seeking care.

- The timing of the mother's decision to try to secure help appears highly correlated with her
  perception of the child's condition. These women, the primary caregivers often feel the need
  to seek allopathic treatment earlier than their husbands or mothers-in-law, the main decision
  makers.
- The factor most strongly associated with the decision to seek allopathic treatment early on is
  previous experience with a successfully treated case of pneumonia.
- In the case history interviews, women who had seen such as case, either in their own or a
  neighbour's family, immediately recognised their child's disease is pneumonia. Most of these
  respondents' report seeking allopathic treatment, either from the community health worker or
  village doctors as soon as they thought the child had pneumonia.
- Three case history mothers said that though they had been told about pneumonia by the
  community health worker, they had forgotten or had not thought to make connection when
  their child felt ill. Usually these women turn to a family member (particularly mother in law)
  for diagnosis and advice when emergencies arise.

### Compartmentalization

- Mothers having no previous experience with allopathic treatment of acute respiratory infection tend to identify pneumonia as alga (illness as a result of attack by evil spirits).
- Those who do have such experience, though, they continue to believe in the existence of alga.
- Women are often able to accept and use new kinds of treatments or practitioners while continuing to utilize traditional healers and cures, either simultaneously or sequentially.

#### Constraints on and factors associated with service utilization

 Most commonly, women attribute their inability to bring their children to the Matlab hospital to there being no one else at home to perform household work, particularly caring for other small children in the home.

- Even when other family members are present and available to assist them, some women are
  constrained by "internal" constraints, beliefs, and attitudes which inhibit mothers from
  seeking or allowing the hospitalization of their children.
- For example, seeking treatment outside the immediate neighbourhood requires the mother to temporarily abandon purdah (religious practice where women are kept in isolation).
- One-woman complained that her in-laws, who have authority over her movements, refused
  to allow her or her sister in law to take their children for care at Matlab, even though both
  children were seriously ill.
- Because these young mothers would be seen by strange men at the hospital, it was deemed socially and religiously unacceptable for them to venture out alone.
- The older women appear to approach allopathic practitioners more cautiously and only after a variety of traditional methods of curing have been attempted.
- In the grandmothers focus group discussions, women often expressed disapproval of their daughters in laws inclination to rush to the doctor at the child's slightest disposition. On the other hand, among case history mothers who do utilize the hospital, some say that it is encouragement from the mother in law that convinced them to do so.
- As a result of living entirely or partially in purdah seclusion, many women in the "referralrefused" category indicate that fear of travelling alone is a significant constraint on their treatment seeking behaviour.
- Even among the mothers whose children were admitted to hospital, two said they delayed travelling until someone trustworthy was available to accompany them.
- Another concern related to purdah is the common belief that going "outside" especially at
  certain times of the day and in certain seasons, invites an attack by disease agents. These
  agents may be supernatural, in the form of evil winds or spirits or natural in so far as
  travelling during monsoon or winter exposes the mother and child to cold wind and water.

 One mother ignored the community health workers' referral because she would have had to travel to Matlab by watercraft in the rain and cold. Such a journey, she felt, would expose the sick child to more danger than benefit.

Disease in a nursing child is contracted through bad breast milk and it is careless exposure
or improper movements on the part of the mother which renders her milk dangerous to the
breast feeding child and puts the even older or non-breast feeding children at risk. Thus, it is
the fault of the mother if the child becomes ill.

Study: Kundi et al 1993

#### Patterns of resort

In recounting the illness episode that has brought them to the hospital, mothers described a threestage sequence of therapy.

The first stage was a period of 2 days during which they kept the child at home for observations or for treatment with remedies.

In order of frequency of mention, these remedies were as follows: green tea (given by 12 mothers); joshanda, a tea brewed from a blend of herbs formerly dispensed only by hakhns (traditional Unani practitioners) but now also sold in shops (10 mothers); kava, weak tea containing a few tea leaves and no milk (10 mothers); honey (9 mothers); ghutti, a liquid preparation of herbs sold commercially and thought to function as a "hot" purgative (7 mothers); ajwain, a spice similar to thyme, sometimes given in paste form (4 mothers); and boiled egg (2 mothers). Given by one mother each were milk in which a few tea leaves had been boiled to make it "hot" (dudh patiy), \* regular tea containing milk (chat), milk mixed with raw egg yolk, long (cloves) and heeng (asafoetida, a spice).

- Two mothers wrapped the child's chest with strips of cotton cloth, a procedure known as
  "tying the pain" (Urdu Bard ko bandna, Punjabi dard nu bunna), which can interfere with
  respiration if done too tightly.
- One mother massaged the chest.
- One massaged the throat and one gave steam inhalation treatment.
- Four gave allopathic medicines that they had on hand in the home-the most dangerous being Piptal drops, which contain phenobarbital as the active ingredient and are widely used in Pakistan as a sedative and cough suppressant.

The second stage of therapy was to consult a health care provider (31 mothers) or two health care providers in sequence (3 mothers). Mothers said that they allowed a maximum of only 2 days for each practitioner's treatment to work before moving on to the next stage of treatment-either a different practitioner or the Rawalpindi General Hospital. (A minimum of 5 days of antibiotic therapy is needed both for clinical efficacy and to avoid creating strains of drug-resistant bacteria. Depending on the child's response to the medicine, up to 10 days of therapy may be indicated.

- The case histories recounted by mothers showed a clearly-visible progression from the less
  costly and often more easily accessible healers such as hakims, homeopaths and selftrained allopaths (referred to by the medical profession as "quacks") upward to licensed
  physicians, who in Pakistan hold the M.B. B. S. degree.
- No one knows how many unlicensed doctors there are in the country, but they certainly outnumber those with licenses.
- Moreover, even the hakims and homeopaths often make use of allopathy, though in
  unconventional ways of their own devising. No longer do such healers limit themselves to
  dispensing Unani herbs on the one hand and tiny quantities of homeopathic substances (on
  the principle that "like cures like") on the other.

Significantly, only 2 of the 50 mothers interviewed in the present study had sought care from a government dispensary (Basic Health Unit or BHU), and in neither case was the physician assigned to the BHU on the premises. Instead of being seen by a doctor, both children were given medicine by auxiliary personnel: in one instance by a compounder (pharmacist) and in the other by a female health worker.

The final stage of therapy was attendance at Rawalpindi General Hospital, the institution where they were interviewed. Mothers who had had prior experience with child pneumonia said that they had waited a mean of 3.4 days after onset of respiratory symptoms before coming to the hospital; those with no prior experience said that they had waited a mean of 4.3 days. Thus the "experienced" mothers reported that they had come to the hospital about a day earlier than the mothers who were inexperienced. The overall mean delay for all 50 mothers, according to the self-reported data was 3.8 days after onset of the child's respiratory symptoms. (In pneumonia, every day of delay is significant since a child can die within 3 or 4 days of the appearance of danger signs such as fast breathing.

- Two mothers were divorced or separated and said that they had had to obtain the consent from a family member before coming to the hospital.
- Those living in nuclear families had had to secure their husband's approval and those living
  in an extended family with their husband's parents had usually had to approach their motherin-law as well.
- Informants explained that this was mainly because coming to the hospital impinged on their ability to care for their other children, cook and do housework.

#### Recognition of pneumonia symptoms

The 5 symptoms most frequently named by 50 mothers of children with pneumonia as: (a) present in the child; and (b) having alarmed them enough to bring the child to the hospital.

### Symptoms volunteered as present in child

- Cough or severe cough-42 (Urdu khansi or khansi tayz/ khans! ziada)
- Fever or high fever-25 (Urdu bukhar or bukhartayz)
- Upper respiratory infection-23 (Urdu nazla, zukam)
- Phlegm or phlegm in chest-9 (Urdu raysha or raysha seena may)
- Blocked nose-8 (Urdu nak band hay)

### Symptoms volunteered as having caused alarm

- Cough or severe cough (Urdu khansl or khans! tayz/khansi zlada)
- Inability to sleep-17 (Urdu so nahi saki)
- Symptoms not improving-13
- Fever or high fever-11 (Urdu bukhar or bukhar rayz)
- Excessive crying-IO (Urdu bahut rothi hay)

Despite the absence of fast breathing in the table presented above, all the 50 children included in the study had it.

- A few mothers mentioned fast breathing, but for most it was clearly not an alarming or even especially salient symptom.
- When mothers were asked a direct question about whether the child had fast breathing,
   32/50 (64%) answered in the affirmative.
- Mothers who had prior experience with child pneumonia were much more likely to say that their child had fast breathing than those who had not.

- 25 of the 35 mothers living in extended families said that their child had fast breathing whereas only 7 of the 15 living in nuclear families did so, suggesting that family members comments may have contributed to accurate recognition of this important diagnostic sign.
- Mothers with prior child pneumonia experience had the tendency to see chest indrawing that
  was not there. In other words, the experienced mothers had a tendency to over diagnose
  severe disease.
- Seven mothers who had thought their child had chest indrawing also thought their child had difficulty breathing.

*In response to direct questioning about specific symptoms:* 

- 37 of the 50 mothers said that they were familiar with the concept of difficult breathing, many volunteering that it was serious.
- 39 said that they knew what chest indrawing was.
- 15 were familiar with nasal flaring.
- 18 knew that cyanosis was serious.
- In each case, the mothers who had had prior experience with child pneumonia were much more likely to indicate familiarity with the diagnostic sign.
- Only 6 mothers said that unusual drowsiness was serious.
- 38 of the 50 said that excessive crying alarmed them.
- 22 of the 38 mothers said that in pneumonia, the child cried because of chest pain.

#### **Gender differences**

Of the 50 children brought to the hospital with pneumonia, 29 (58%) were male and 21
 (42%) were female. This agrees fairly well with the percentage of males among all 22,693

children brought to the respiratory outpatient clinic of the hospital during 1991 (55%). It is also consistent with many other studies indicating that medical care is sought more often for boys than for girls in impoverished areas of South Asia including Pakistan.

#### Concepts of physiology

Mothers' ideas about human anatomy and physiology were explored to see whether they understood the function and location of the lungs and how infected nasal secretions might descend into the lungs to cause pneumonia.

- Fewer than half of the mothers knew that air goes specifically into the lungs when a person breathes in.
- 23 did not know where it went.
- 3 thought it went either into the abdomen or "into the whole body".
- 18 of the 50 mothers knew where the lungs were located, but 20 had no idea and another 12 thought they were located to either side of the heart and extending down below it in an area they referred to as pasli area of the body (Urdu pasli = ribs).
- Some mothers added that when a child had severe pneumonia, the pasli area showed
  abnormal movement (Urdu pasli chelna; literally, "the lower ribs move"), i.e chest indrawing.
  They said that in such cases, "hollows" or "pits" (Urdu tohay) were visible below the lower ribs and sometimes also at the base of the neck.

There was a great deal of anxiety about the perceived presence of mucus or phlegm (Urdu raysha) in the child's body, which was seen as preventing air from entering the chest properly.

Most mothers felt that this phlegm was caused by "coldness" rather than by infection.

- Some said that it should be "vomited up" or "burned away" by "hot" medicines such as
  antibiotics. Most of the home remedies given for pneumonia, described above, were
  designed to loosen up the phlegm so that it could be expelled.
- Coughing was considered to be a sign that the child was unable to do this by himself.
- Certain humorally "cold" foods such as banana, rice, yogurt and plain milk were thought to produce phlegm and were therefore avoided.
- Many mothers believed that if phlegm remained in the body, it would become "frozen"
   (raysha jahrn; literally, "phlegm jam"), which could lead to a chronic cough, a chronic chest problem or even tuberculosis.

The dominant perception-expressed by 19 mothers was that

- phlegm that came out of the child's throat had its origin in the chest and lungs.
- 17 mothers did not know where it came from.
- 7 mothers each thought that it came either from the brain or from the heart (the latter being located low in the chest.
- Phlegm "on the heart" was regarded as particularly worrisome.
- A majority of mothers (29/50) thought that nasal mucus came from the brain, a common belief reflected in the popular saying in this area of Pakistan that a person's brain is "dripping away" whenever there is a profuse nasal discharge.
- Nevertheless, it was thought important to get nasal mucus out of the body just as it was important to get phlegm out.
- Two mothers expressed the view that pneumonia was caused by a "blood clot" (Urdu khun jahm; literally, "blood jam) in the chest and one went on to explain that this was a special problem in the winter when children don't have any fat in them, only blood.

#### Pneumonia treatment preferences

Most mothers held treatment preferences at odds with the protocol proposed for the national ARI program currently being initiated in Pakistan.

- It was clear that many informants focused on the stethoscope as an instrument with almost magical properties.
- Several referred to it as a "mirror" (Urdu shisha) or "telescope" (Pashto durbeen) that could reveal everything within the body-the allopathic successor to the hakim's traditional pulsetaking for diagnostic purposes.
- As one mother put it, "Without a stethoscope the doctor won't be able to see what's
  happening with the pneumonia and also all the other things that might be wrong inside the
  child.

Similarly, the national ARI guidelines mandate treatment of non-severe pneumonia with cotrimoxazole tablets, which are inexpensive and easily stored.

- 80% of mothers said that doctors should give liquid medicines for pneumonia, i.e. suspensions (Urdu sharbats).
- Some remarked that they would not know how to give a tablet to an infant, while others said
  that they would have to grind up the tablet and mix it with water or breastmilk, which was a
  nuisance.
- Finally, 40% of mothers stated that doctors should give at least one injection for pneumonia
   "in order to cure it faster," whereas the official treatment guidelines emphasize use of cotrimoxazole tablets instead. Injections are to be given only if the patient has to be hospitalized with severe pneumonia.

- Historically, however, patients in developing countries have a preference for injections,
   which are seen as the form of medicine that is most powerful and acts most rapidly on the
   body, although some mothers interviewed in the present study did say that injections were
   too "strong" for infants.
- Physicians at the Rawalpindi General Hospital estimate that 100% of the unlicensed practitioners and 60% of the qualified doctors in their area give injections for pneumonia regardless of the severity of the disease. Sometimes these are potentially dangerous cortisone injections, which are increasingly popular in Pakistan as the supposedly most "advanced" form of biomedical treatment for virtually any illness.

## Appendix 5: Reasons for exclusion of full text studies that did not meet the inclusion criteria

A.M. Gadomski, N. Khallaf, S. El Ansary, R.E. Black. Assessment of respiratory rate and chest indrawing in children with ARI by primary care physicians in Egypt. Bulletin of the World Health Organization, 1993;71(5):523–7.

Reason for exclusion: This study focused on Acute Respiratory Infection (ARI) and is a quantitative study.

A. Minz, M. Agarwal, J.V. Singh, V. K. Singh. Caregiver's Knowledge about Childhood Pneumonia: A Study from Rural Areas and Urban Slums of Lucknow. National Journal of Community Medicine. 2019;10(2):62–8.

#### Reason for exclusion: This is a quantitative study.

A.-Haq, H. M. Durrani, R.Kumar, S. M. Durrani. Recognizing the Danger Signs and Health Seeking Behaviour of Mothers in Childhood Illness in Karachi, Pakistan. Universal Journal of Public Health. 2015;3(2):49–54.

#### Reason for exclusion: This is a quantitative study.

S. Q. Bham F. Saeed, M. A. Shah. Knowledge, Attitude and Practice of mothers on acute respiratory infection in children under five years. Pak J Med Sci. 2016;32(6):1557–61.

#### Reason for exclusion: This is a quantitative study that focused on ARI.

C. A. Gálvez, N. Modeste, J. W Lee, H. Betancourt, R. L. Wilkins. Peruvian mothers' knowledge and recognition of pneumonia in children under 5 years of age. Pan Am J Public Health. 2002;11(2):99–108.

#### Reason for exclusion: This is a quantitative study.

E. A. Simoes, E. J. McGrath. Recognition of pneumonia by primary health care workers in Swaziland with a simple clinical algorithm. The Lancet. 1992;340(19):1502–3.

Reason for exclusion: This is a report, not a research article.

E. A. Simoes. Recognizing and diagnosing pneumonia in developing countries. Current Opinion in

Infectious Diseases. 1994; 7:358–63.

Reason for exclusion: This is a report, not a research paper.

U. Ekwochi, I. K. Ndu, C. D. Osuorah, K. S. Onah, E. Obuoha, O. I. Odetunde, et al. Delays in healthcare

delivery to sick neonates in Enugu South-East Nigeria: an analysis of causes and effects. J Public Health

(Oxf). 2016;38(2): e171-7.

Reason for exclusion: This is a quantitative study.

J. Farhad, A. Malihe, A. Fatemeh, S. Mahmood. The knowledge, attitude, and practice of mothers

regarding acute respiratory tract infection in children. Biosciences Biotechnology Research Asia.

2014;11(1):343–8.

Reason for exclusion: This is a quantitative study.

G. Irimu, R. W. Nduati, E. Wafula, J. Lenja. Community understanding of pneumonia in Kenya. African

Health Sciences. 2008;8(2):103-7.

Reason for exclusion: Incorrect population.

A.A Hasan. Assessment of mother's knowledge toward their preschool children with hypostatic

pneumonia in babylon hospital for maternal and child in Babylon city. Indian Journal of Public Health

Research and Development. 2018;9(8):1215–9.

Reason for exclusion: This is a quantitative study.

H. Hildenwall, R. Nantanda, J. K. Tumwine, M. Petzold, G. Pariyo, G. Tomson, et al. Care-seeking in the

development of severe community acquired pneumonia in Ugandan children. Ann Trop Paediatr.

2009;29(4):281–9.

Reason for exclusion: This is a quantitative study.

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K. Kallander. Delayed care seeking for fatal pneumonia in children aged under five years in Uganda: a case-series study. Bulletin of the World Health Organization. 2008;86(5):332–8.

Reason for exclusion: This is a quantitative study.

D Kumar. Recognition and Management of ARI - A KAP Study on Private Medical Practitioners. Indian J Pediatr. 1997;64(2):237–42.

Reason for exclusion: This is a quantitative study.

L. H. Harrison, S. Moursi, A. H. Guinena, A. M. Gadomski, K. S. El-Ansary, N. Khallaf, et al. Maternal Reporting of Acute Respiratory Infection in Egypt. Int J Epidemiol. 1995;24(5):1058–63.

Reason for exclusion: This is a quantitative study that focused on ARI.

J. S. Luque, L. M. Whiteford, G. A. Tobin. Maternal recognition and health care-seeking behavior for acute respiratory infection in children in a rural Ecuadorian county. Matern Child Health J. 2008;12(3):287–97.

Reason for exclusion: This is a quantitative study that focused on ARI.

L. Muhe. Mothers' perceptions of signs and symptoms of acute respiratory infections in their children and their assessment of severity in an urban community of Ethiopia. Ann Trop Paediatr. 2016;16(2):129–35.

Reason for exclusion: This is a quantitative study.

M. Nichter, M. Nichter. Acute respiratory illness: popular health culture and mother's knowledge in the Philippines. Med Anthropol. 1994;15(4):353–75.

Reason for exclusion: This is a quantitative study.

S.K. Kapoor, V.P. Reddaiah, G.V.S. Murthy. Knowledge, Attitude and Practices Regarding Acute Respiratory Infections. Indian J Pediatr. 1990;57(4):533–5.

Reason for exclusion: This is a quantitative study.

D. E. Simiyu, E. M. Wafula, R. W. Nduati. Mothers' knowledge, attitudes, and practices regarding acute respiratory infections in children in Baringo District, Kenya. East Afr Med J. 2004;80(6).

Reason for exclusion: This is a quantitative study.

S. Mishra, H. Kumar, D. Sharma. How do mothers recognize and treat pneumonia at home? Indian Pediatr. 1994;31.

Reason for exclusion: This is a quantitative study.

T. Diaz, A. S. George, S. R. Rao, P. S. Bangura, J. B. Baimba, S. A. McMahon, et al. Healthcare seeking for diarrhoea, malaria and pneumonia among children in four poor rural districts in Sierra Leone in the context of free health care: results of a cross-sectional survey. BMC Public Health. 2013;13(157).

Reason for exclusion: This is a quantitative study.

S. N. Uwaezuoke, I. J. Emodi, B. C. Ibe. Maternal perception of pneumonia in children: a health facility survey in Enugu, eastern Nigeria. Ann Trop Paediatr. 2002;22(3):281–5.

Reason for exclusion: This is a quantitative study.

W. Aftab, L. Shipton, F. Rabbani, K. Sangrasi, S. Perveen, A. Zahidie, et al. Exploring health care seeking knowledge, perceptions and practices for childhood diarrhea and pneumonia and their context in a rural Pakistani community.

Reason for exclusion: This is a mixed methods study focused on diarrhea and pneumonia. The results were combined and pneumonia data could not be extracted separately.

## Appendix 6: Characteristics of included studies

Study	Methods for	Phenomena	Setting/context/	Participant	Description of main
Country	data collection	of interest	oulture	characteristics	results
Abbey et al 2016.  Dangme west district of Greater Accra region of Ghana	and analysis  Grounded theory  8 focus group discussions (FGDs) In-depth, key Informant Interviews (KIIs)  Data analysis: FGDs and KIIs tape-recorded and transcribed verbatim, supplemented with field notes	To determine community perceptions of pneumonia	culture  District has an estimated land size of 17,000 square kilometers and a population of 109 459 and 376 villages  The district has 4 government owned health centers, 6 community clinics, 2 privately owned clinics, 2 privately owned clinics, 2 privately owned retail shops. There were no hospitals in the district.  Severe cases were referred to hospitals in neighboring districts.	and sample size  FGDs (7 were female and 1 was a male group), N = 56 parents or caregivers of under-fives  KIIs with 3  Traditional Birth Attendants (TBAs), 1 herbalist, 3 chemical shop attendants and 1 community leader as Key Informants	Two-thirds of the respondents had never heard the name pneumonia.  Most respondents did not know about the signs and symptoms of pneumonia.  For the few who had heard about pneumonia, causes were largely attributed to coming in contact with cold temperature in various forms.  Management practices mostly were self-treatment with home remedies and allopathic care.
Hussain, et al 1997 Karachi, Pakistan	13 FGDs and 16 sets of case history interviews. Unclear how data were analyzed.	Maternal beliefs and practices regarding pneumonia	Karachi has a population of 12 million and 40% of its population live in squatter settlements. The 2 settlements chosen for the study were Chanesr Goth and Orangi. which were part of the Aga Khan University's urban primary health care (PHC) program. Settlements have at least 6 private practitioner clinics	Each FGD was composed of 6-8 mothers.  Mean age of the Sindhi and Mohajir respondents was 34 and 29 years, respectively.  Case history interviews were conducted with primary caretakers of children under five years of age reported to have pneumonia.  Each interview had a follow-up visit to assess the disease outcome	Pneumonia recognition was universal. The main recognition and severity indicator was pasli chalna which is chest indrawing, followed by signs and symptoms relating to the quality of breathing and the presence of high fever, lethargy, and anorexia. Recognition of fast breathing was low and mostly associated with fever. Most caretakers sought outside care within 1-3 days of the onset of symptoms.
Brunie et al 2017 Uttar Pradesh, India	In-depth individual (IDIs) interviews Interviews were audio-recorded and translated and transcribed in English.	Formal providers' and drug sellers' attitudes and practices related to pneumonia in children and	Uttar Pradesh is organized into 75 districts that are divided into 311 tehsils (administrative subdivisions).	Purposive sample of 36 practitioners (allopathic, AYUSH, and drug sellers) and 34 caregivers in two districts.	Caregivers were generally prompt in seeking care outside the home, but many initially favored local informal providers based on access and cost. Drug sellers were not commonly consulted for

	Field notes reported in transcripts. Coded in NVivo 10 for thematic analysis.	to examine the care- seeking and treatment behaviors of caregivers of children seeking care in the private sector for suspected pneumonia.	Study conducted in 2 tehsils in a different district. (Shahjahanpur and Barabanki).	Caregivers were mothers aged 18 or older who had accompanied a child under age five with suspected pneumonia to one of the practitioners interviewed.  Providers interviewed at their place of practice and received a token gift (US \$8 value) to compensate them for their time. Caregivers were interviewed in their homes and were not compensated.	treatment. Formal providers had reasonable knowledge of pneumonia though some gaps related to lack diagnostic tools were noted. Most practitioners prescribed antibiotics and supportive symptomatic treatment.  Relational and structural factors encouraged overuse of antibiotics and treatment interruption.  Caregivers often had limited understanding of treatment and wanted rapid symptomatic improvements
Rabbani et al 2016 District Badin, Sindh, Pakistan	FGDs (70-80 mins) and IDIs (40-45mins) with semi structured open-ended questions  Audio-recorded and field notes taken. Data transcribed in English and analysis followed Braun and Clark's thematic analysis method using QSR NViVo	Lady Health Worker (LHW) and Lady Health Supervisor (LHS) perspectives regarding the role of supervision in improving LHWs performance and motivation. Their knowledge and skills regarding integrated community case management (ICCM) for diarrhea and pneumonia were also assessed.	District is an area of 6726 square meter kilometers and has a population of 119,3081. LHWs are a major outreach component of the primary health care system and provide preventive and basic curative maternal, newborn and under five child health (MNCH) services. An LHW serves approx 100–150 households. Each LHS supervises approximately 15–25 LHWs and is supposed to visit one LHW twice a month, accompany them during their home visits, guide them and address their concerns.	34 functional LHSs and 5 LHWs working under each LHS (total 170). 2 LHWs were selected randomly from each cluster to participate in FGDs. One LHW was selected from every fourth cluster to participate in IDIs. 14 FGDs and 20 IDIs conducted.	Majority identified pneumonia and diarrhea as two major causes of death among children under five. Other underlying causes of high mortality identified were poverty, illiteracy, poor hygiene, and lack of clean water.  Factors such as lack of training, delayed salaries and insufficient medicines and other supplies were identified as major factors that hindered knowledge and skill development for community case management for diarrhea and pneumonia.
Kallander et al 2006 Kasese, western, Uganda	Ethnographic study  4 FGDs with young and older mothers, a video elicitation task and 2 feedback	Caretaker interpretation of pneumonia symptoms.	District has 3 hospitals and 67 health centers with poor access.	15 young (15-25 years) and 15 older (25-49 years) mothers from 2 sub-counties were invited to participate in FGDs.	Mothers in the community were able to recognize the major symptoms of ARI such as cough, difficulty breathing and chest indrawing. They were also able to identify

	interviews with 2	Ī			other associated
	key informants.  Data analysis was based on the major thematic areas of the local terminologies, labeling of illness, perceived severity, and associated findings using the software N6			Two key informants were interviewed using an unstructured questionnaire.	symptoms such as fever, stridor, and grunting. Children with a fever were often treated with an antimalarial, thus delaying the treatment of pneumonia.
Sato et al 2018  Municipality of Caibiran of Biliran Province in the Eastern Visayas Region, Philippines	Semi-structured interviews (av 32.9 mins) conducted using open-ended questions. One face to face interviews was conducted in English  Interviews were audio-recorded and conducted at the participants' house.  Interviews were transcribed. Meaningful units from the transcript were selected and assigned codes and grouped into subcategories. Subcategories were combined into main categories and themes were identified	Fathers' roles and perspectives with respect to the selection of care and treatment for children with pneumonia.	Caibiran has a population of around 22,500. The Philippines has public sector primary health facilities and hospitals. Barangay health stations (BHS) and rural health units (RHU) provide primary health services. Each province usually has one provincial hospital and some district hospitals.	12 fathers of children under 5 years of age who had pneumonia-like episode in the last six months prior to the interview. Caregivers were requested to record symptoms of ARIs such as a cough, difficulty breathing and chest indrawing.	Fathers took care of their sick children by not entrusting care only to the mothers because they considered this as part of their roles. Notably, fathers considered that arranging money for the child's treatment was a matter of prime importance. They selected a particular treatment based on their experiences and beliefs. Their decision was influenced by not only their perception of the severity of illness but also cultural beliefs on the causes of illness. Visiting a health facility, causes a significant financial burden for the family which was the main concern of fathers.  Fathers tended to take responsibility for caring for their sick children and made treatment decisions when their children had pneumonialike episodes. They usually waited and observed their sick children at home or relied on traditional healers before using formal health facilities. Regarding their role in deciding the treatment options, healthcare providers need to understand fathers' roles

					and perspectives when formulating health education programs.
Kundi et al 1993 Pakistan	Interviews Unclear on how results were analyzed.	Maternal perceptions of pneumonia and pneumonia symptoms with a primary focus on mothers' ability to make an early diagnosis of the disease before it reached an advanced stage.  The study focused on mothers of children between the ages of 1-59 months attending a hospital with non-severe pneumonia.	Study conducted at Rawalpindi General hospital.	Mothers of children aged 1-59 months attending a hospital with non-severe pneumonia.  Mean age of mothers = 27 years. 50 mothers of children participated in the study.	The study revealed that mother's knowledge of the physiology of the respiratory tract was poor.  Mothers also believed in the magical powers of stethoscope and indicated that a doctor should use it. This belief contradicts with the protocol proposed for the national ARI program being initiated.
Stewart et al 1994 Bangladesh	Interviews and FGDs	To describe community perceptions of signs and symptoms of acute respiratory infection, case management behavior and constraints to service untilisation.	Study conducted at the Matlab International Center for Diarrheal Disease Research	Mothers of children under 5 years of age suffering from pneumonia as well as other care givers/care providers: Initially, 20 case history interviews were conducted with mothers of children under five years of age currently suffering from pneumonia: ten with mothers of children receiving treatment at the Matlab ARI ward after referral and ten with mothers at home who failed to go to Matlab after referral.  After the interviews, 12	Mothers were able to recognize pneumonia and thought it was caused by exposure to cold. They were also able to recognize symptoms of severe pneumonia such as labored breathing, chest retraction, lethargy and irritability. They believed that similar illnesses were caused by evil influences and sought care from spiritual healers which delayed receiving care from an allopathic practitioner.

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	FGDs were
	conducted with
	participants from
	each of the
	following
	categories: young
	mothers of
	children (under 25
	years of age),
	older mothers
	(between 25 and
	35 years of age),
	mothers-in-
	laws/grandmothers
	(at least 40 years
	of age), traditional
	birth attendants (at
	least 40 years of
	age), traditional
	spiritual
	healers/kobirajs
	(must be female
	and at least 40
	years of age) and
	untrained or semi-
	trained
	allopaths/village
	doctors.
	There was no
	record of the
	sample size.

# Appendix 7: List of study findings with illustrations that were included in the meta-aggregation

Study: Sato et I	2018
Finding	Seven fathers knew that applying cold water reduced fever. (U)
Illustration	"We knew how to give first aid. If my child has fever, we wipe him with a wet towel
	to lower his temperature".
Finding	one father gave what his own mother used to give him when he was sick in
	his early childhood. (U)
Illustration	"If I have money, I buy eggs for my sick child. If I do not, just buy royal (soft drink),
	because that was what my mother used to give me".
Finding	Fathers assisted mothers in caring for a sick child. (U)
Illustration	"I gave my wife some ice. I waited for the ice to melt and then wiped the child".
Finding	Fathers considered themselves the leader of the family who solves any problem
	that occurs in the family. They took various actions to improve their child's health,
	such as seeking information from other people. (U)
Illustration	"I look after my children, wipe them if they are sweating, and I ask other people
	about what to do".
Finding	Fathers believed that suffering from a sprain, fracture or some other pain made
	the child sick with fever, cough or vomiting. (U)
Illustration	"Sometimes when the child had fever, people said the child had piang (sprain or
	dislocation of tissues or bones). Sometimes when the child experienced body
	pain, the child had fever".

Finding	Their recognition of pneumonia symptoms varied, covering cough, asthma,
	weakness, irritability, fever, difficulty in breathing, crackling sound in the chest
	and convulsions. (U)
Illustration	"She had a hard cough, she had difficulty breathing, a crackling sound could be
	heard when she would breathe. That's what I observed in my child'.
Finding	One father who had lost his first child saved money whenever he had extra
	income. (U)
Illustration	"We usually save even 50 pesos if we make extra, because we do not know when
	the child may need to go to a hospital again".
Finding	Most of them borrowed money from their relatives and friends. Some fathers
	asked for financial help from politicians for their children's hospital expenses.
	Some of them were still repaying debt. (U)
Illustration	"I felt different. I was afraid. I was worried because I did not have any money. I
	looked for money and asked for it from my neighbours".
Finding	Fathers were also the main decision makers regarding which facility to use.
	Although fathers discussed such matters with mothers, they were proud to be the
	primary decision maker. (U)
Illustration	"If I see that my child is unwell, I bring him to RHU. I talk to my wife, but I am the
	one who decides".
Finding	Most fathers believed that oregano and five-leaved chaste tree leaves were
	effective for a cough and asked mothers to make herbal medicines for the child.
	(U)

Illustration	"We used oregano because it is easy to use. A cough was relieved by the herbal
	medicine but relapsed after getting better once".
Finding	Some of them bought medicines without prescription at a pharmacy, while some
	asked neighbours and relatives to give them medicines. (U)
Illustration	"I asked my mother-in-law for medicine since she had a stock of medicines from
	the congressman".
Finding	Although fathers used Western medicines such as antibiotics, they did not know
	their names or dosage. Mothers handled these aspects. One father had no idea
	what antibiotics were. (U)
Illustration	"We gave the child paracetamol liquid, but I do not know the dosage. I don't have
	any idea what antibiotics are. What is that? I think it is cephalexin".
Finding	Taking a sick child to a traditional healer was a common choice of fathers. (U)
Illustration	"If my child has fever, we bring him to the traditional healer. In a few days, he
	gets better".
Finding	Fathers believed a traditional healer's treatment to be effective as they had seen
	their child recover after receiving such treatment. (U)
Illustration	"When my child was treated by a traditional healer, he seemed at ease. I was
	free from worry".
Finding	One father did not like to go to a traditional healer as he thought it risky. (U)
Illustration	"I don't like traditional healers. I cannot take a risk when it comes to my child. I
	prefer to bring him to RHU first. I don't like to take him to a traditional healer".

Finding	RHU provides medicines for free if they have a stock. However, when there was
	no stock of medicines at RHU, they had to buy medicines themselves. (U)
Illustration	"When my child's condition became worse with a cough with sputum, we brought
	him to RHU. But they did not have a stock of medications. I paid 105 pesos for
	amoxicillin".
Finding	Some of them could not afford to buy medicines because they did not have
	enough money. (U)
Illustration	"RHU staff gave me a prescription. But I could not buy the medicines as I did not
	have enough money".
Finding	Some fathers had witnessed RHU staff listening to the child's chest sounds,
	fanning a child to bring down the fever and using oxygen or a nebulizer when the
	child had difficulty breathing. (U)
Illustration	"RHU staff used a fan for my child to relieve fever. 'Only in the case that he suffers
	from difficulty in breathing, they use something like oxygen and nebulizer. It
	heated and made steam".
Finding	Fathers took their children to RHU to be checked, particularly by a doctor. (U)
Illustration	"I think that only a doctor knows what kind of medicines my child needs, and we
	are not convinced unless a doctor checks my child".
Finding	However, they recognized that a doctor was not always available and that only
	some nurses and midwives might be available at RHU. (U)
Illustration	"Once, a nurse prescribed antibiotic for a cough when I brought my child to RHU.
	I argued with her because she was not a doctor".
<u> </u>	

Finding	Fathers mostly complied with the doctor's recommendation to go to a hospital.
	One father did not comply with such a recommendation when he did not have
	any money. (U)
Illustration	"If it is an emergency, surely, I bring my child to a hospital. The important thing is
	for my child to be okay".
Study: Rabbani et	al 2016
Finding	Limited access to LHWs in some areas was also mentioned as a reason for
	compromised care at household level. (U)
Illustration	"People can't reach the hospital and use traditional remedies at home instead".
Finding	Most LHWs and LHSs were able to correctly define pneumonia as chest
	indrawing, high fever and fast breathing. However, few misconceptions were note
	among LHSs regarding pneumonia. (U)
Illustration	"Pneumonia is inflammation of hands".
Finding	While training was understandably mentioned as important to improve level of
	knowledge, availability of medicines was considered equally important. (U)
Illustration	"Our level of knowledge will increase if we get medicines"
Finding	A considerable number of health workers highlighted the unavailability of Oral
	Rehydration Solutions (ORS), zinc, and antibiotics as demotivating factors in
	terms of improving knowledge and performance. (C)
Illustration	(People in the community say) "you do not give us medicines; you pocket them
	yourselves".

LHWs and LHSs were of the opinion that enhanced presence of LHSs during
their household visits would be a source of encouragement and improved LHW
performance. According to many LHWs the supervision would be significantly
improved if the LHWs accompany them on field visits more often. (U)
"It is better to go and check (LHWs) in the field then to ask only".
LHWs and LHSs perceived feedback as being important to improving their
performance. (U)
"Feedback is very important; in this way our capabilities are exposed".
Generally, LHWs prefer group feedback as compared to individual feedback. (U)
"It will be beneficial to give feedback in a group".
Most LHWs consider verbal feedback given in a group to be adequate. (U)
"Individual feedback is useless; no one knows what we did".
On the other hand, LHSs preferred written and individual feedback to LHWs,
rather than group and verbal feedback. (U)
"Feedback should be written and given individually".
Further training would improve LHWs knowledge, performance, motivation and
LHSs supervision. (U)
"More training should be provided to improve knowledge regarding diarrhea and
pneumonia".
A strong desire to gain more training was also expressed especially in the
absence of formal training for several years. (U)

Illustration	"The more increased in knowledge, the better it is. It is definitely possible that
	there are things which we do not know".
Study: Kallander et	al 2006
E. 1.	
Finding	In 'narrow space' breathing [Akafundi] the child had cough with difficult/painful
	breathing and stridor. (U)
Illustration	"In Akafundi [narrow space] the child tries to take in more air and is breathing with
	a lot of difficulties. Breathing out seems painful and the child makes a whistle like
	noise in the chest."
Finding	Although fast and difficult breathing were associated with problems in the lungs
	or airways, many of the ARI illness concepts were frequently related to 'fever'
	[Omutsutsa] and were perceived to need antimalarial treatment. (U)
Illustration	"Chloroquine is given to all children with Omutsutsa owe Ekyikenyero [The
	fever of groaning breathing] as long as the child has Ekibugumu [hot body]."
Finding	The third child had a normal respiratory rate with severe stridor. 'Narrow space'
	[Akafundi] together with 'abrupt attack' [Obukoni] were the illness concepts
	mentioned by most. Some, however, suggested that this was 'groaning breathing'
	[Ekyikenyero]. All agreed that the first action would be to rush the child to a
	hospital. (U)
Illustration	"This is Akafundi [narrow space], exactly Akafundi! He is breathing with pain; it is
	like he also has Obukoni [abrupt attack]. The child is in a critical condition"
Study: Brunie et al 2	<u> </u> 2017

Finding	When asked how they noticed that their child was sick, most caregivers mentioned a cough, and / or difficulty breathing. Among those over a third reported fever and a quarter reported fast breathing or intercostal retractions. In many cases, symptoms were readily attributed to sardi (cold) or, jakda (congestion), though those two conditions were not strictly defined or necessarily
Illustration	"[Sardi, jakda, pneumonia] Its all the same thing If it gets bad, then one says that sardi-pneumonia has happened, take him to the doctor quickly. He's caught jakda, he's caught pneumonia. If its slight, one says that its sardi, put something warm on him, like oil If its slight, they play, they are active and roam around. If it's bad, they stop playing and walking around, (they) stay inside."
Finding	Caregivers indicated consulting "village" doctors, including RHPs (rural health practitioners) and possibly other doctors practicing locally much more often than they did allopathic providers. At the same time, caregivers were not oblivious to the fact that there were differences between providers. For instance, several caregivers who initially consulted a village doctor or an AYUSH practitioner, made a conscious decision to experiment with those providers for initial care, as illustrated here by the mother of a four-year-old boy who consulted a unani doctor. (C)
Illustration	"We show our child to Dr. D [Unani doctor] only, first of all. When it is too much, then only we go that nursing home We think that the child maybe [will] get relief from here so that we do not need to go too far There is a lot of difference [between the unani doctor and the nursing home] We feel that D is cheaper We also think that he is a person of our own home; he will give good medicine."

Finding	Structural and interpersonal constraints were noted in several interviews,
	including lack of equipment to ascertain diagnosis, prior treatment by village
	doctors, cost, and pressure to relieve symptoms (C)
Illustration	"In a private set-up, you can't just admit the patient without any treatment,
	just investigations are going on. He'll say I'm wasting my money. And if by the
	way you are wrong at a diagnosis and you end up with complications, he'll just
	think that you did not give any treatment, that's why my child is [in a] serious
	[condition]. You have to give a prophylactic antibiotic. In a private practice, what
	I'm doing is, we are giving oxygen, bronchodilator, and an antibiotic."
Finding	Two thirds of formal providers described follow-up strategies requiring multiple
	visits to monitor the child's condition and or dispense more drugs. Most noted
	that caregivers did not systematically come back. According to providers, the
	main reasons for this behaviour were switching to other providers if expectations
	for fast relief were not met, financial constraints and perceived resolution of
	illness. (U)
Illustration	"Ten to 20% of people only are able to [afford] the full course of treatment. So as
	soon as they start feeling comfortable, they stop coming they don't know
	whether they're cured or relieved. They don't know that difference the capacity
	to pay is very low. So, for that we've planned something. For Rs. 50, for five days,
	they can come and avail of free consultation they come on one day and pay,
	then all they need to do is buy medicines on the other days. Because of this
	follow-up is comparatively better."
Study: Hussain et a	1 al 1997

Finding	Most mothers considered numonia and double numonia as potentially fatal
	conditions. The most commonly cited indicator of severe illness was pasli chalna.
	Other indicators were continuous or increasing bukkar (fever), refusal to feed and
	lethargy termed kamzori or girnay lagta hai. As one mother said. (U)
Illustration	"I do not worry when my children have cough and cold, but the moment they
	have bukhar [fever] I start worrying when there is pasli chalna [difficult
	breathing] and / or san mey mushkil [difficult breathing] I know the illness is
	khatarnak [life threatening]"
Finding	An increase in pasli chalna (chest indrawing), tez saans (rapid breathing) leading
	to breathlessness, abdominal distension and increase in fever were the
	commonly agreed upon terminologies to describe double numonia. The following
	quote from one of the mothers typifies most of the responses of most child
	caretakers. (U)
Illustration	" the child had halki khansi [mild cough] for one week, and then she developed
	bukha [fever]. Within the same day the fever increased and the child started to
	have pasli chalna [chest indrawing] and also tez saanz [fast breathing] I
	immediately took her to a doctor [allopathic] and he confirmed my suspicion that
	nazla seeney pe jam gaya hai [chest congestion] which is what numonia is all
	about."
Finding	The curative services of the primary health care (PHC) programme were
	minimally utilized in both the study areas. The community, used to physicians
	pronouncing a diagnosis after minimal history taking and examination and getting
	a multiple drug prescription (in addition to an injection and some medicines from
	the doctor's own pharmacy), felt angry and somewhat cheated by the doctors at

	the PHC centre. The following quote from one of the respondent's typifies the			
	general attitude towards curative care offered by the PHC programme. (U)			
Illustration	"they take an hour just to take the history and then more time for examination			
	it makes me very angry when at the end all I get is a prescription for drugs such			
	as Calpol [paracetamol] which I can easily buy on my own from the drug store,			
	why should I waste my time going there and not a private doctor, the latter takes			
	half the time and gives injections to speed recovery."			
Finding	The mothers reported to be the primary decision- makers regarding outside care			
	in the group discussions. In reality, too, in over two-thirds of pneumonia cases,			
	mothers were the key decision-makers for seeking outside care, with			
	grandmothers making the decision in less than a quarter of the cases (in two of			
	the three cases the mother was out of town and the grandmother had the primary			
	responsibility of taking care of the child). (U)			
Illustration	"When the child is sick, and the father is away at work, the child's treatment is			
	the mother's responsibility. In fact, if I do not take my child to the doctor, my			
	husband would get extremely upset with me about my negligence".			
Finding	An increase in pasli chalna (chest indrawing), tez saans (rapid breathing) leading			
	to breathlessness, abdominal distension and increase in fever were the			
	commonly agreed upon terminologies to describe double numonia. The following			
	quote from one of the mothers typifies most of the responses of most child			
	caretakers. (U)			
Illustration	" the child had halki khansi [mild cough] for one week, and then she developed			
	bukha [fever]. Within the same day the fever increased and the child started to			

	have pasli chalna [chest indrawing] and also tez saanz [fast breathing] I
	immediately took her to a doctor [allopathic] and he confirmed my suspicion that
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	mothers were the key decision-makers for seeking outside care, with
	grandmothers making the decision in less than a quarter of the cases (in two of
	the three cases the mother was out of town and the grandmother had the primary
	responsibility of taking care of the child). (U)
Illustration	"When the child is sick, and the father is away at work, the child's treatment is
illustration	
	the mother's responsibility. In fact, if I do not take my child to the doctor, my
	husband would get extremely upset with me about my negligence".
Study: Abbey et al 2	2016
Finding	(However) After FGD participants and KIs viewed the video of a child with high
	respiratory rate, cough and lower chest in-drawing, indicating severe pneumonia,
	majority of the discussants generally described the child in the video as having
	breathing problems. Very few (about 11 % of 56 of FGD participants) including a
	herbalist spontaneously identified the child as suffering from pneumonia. A
	female participant in one of the FGDs exclaimed. (U)
Illustration	"That is pneumonia; because pneumonia causes a child to cough and breathe
	like this."

Finding	The perception of caregivers who have heard about pneumonia differed. The					
	general belief was that exposing a child, to cold temperature or windy weather					
	conditions could result in the child getting pneumonia. The most common factors					
	mentioned in all discussion groups included "sleeping on the bare cemented					
	floor". For instance, one female participant said. (U)					
Illustration	"What I know is that pneumonia is caused by sleeping on the bare cemented					
	floor; because the bare floor is cold, if the child is not adequately clothed and					
	sleeps on it for a long time, the cold penetrates the body and causes pneumonia."					
Finding	Furthermore, other views sampled attributed the cause of pneumonia to ingesting					
	cold drinks or food; they indicated that. (U)					
Illustration	"One gets pneumonia from drinking cold water, eating cold food or chewing ice					
	cubes."					
Finding	Poor hygiene practices were also mentioned as one of the factors that could					
	cause the child to get pneumonia as explained by a male participant. (U)					
Illustration	When a child picks anything from the ground and puts it in his mouth, there can					
	be contamination which can cause the child to have pneumonia. Crawling					
	children get it easier than toddlers."					
Finding	For internal usage, ingesting or inhaling melted Shea butter is believed to clear					
	the nasal congestion and restore proper breathing as explained by one female					
	participant in FGD. (U)					

Illustration	"Catarrh also causes the child to have difficulty in breathing so when my child
	gets "catarrh" I normally put shea butter into the nose and give him some to eat
	then the blockage opens, and the child begins to breathe properly."
Finding	A less common practice indicated by few caregivers is to give the child water
	drained from soaked uncooked rice, or honey to treat the difficulty in breathing
	as cited by one grandmother in a FGD. (U)
Illustration	"We soak rice in water and give the cloudy water to the child to drink. This cleans
	up the child's system and health is restored."
Finding	Herbs in different forms were reportedly used for treatment of pneumonia in
	children. Some are boiled or made into powder and mixed with certain
	substances obtained from a herbalist for use as described by one male
	participant. (U)
Illustration	"The herbs are boiled and given to the child to drink or given as enema. This
	flushes out the illness through the passing of stool".
Finding	It often involved seeking the opinion or assistance of significant others who are
	considered knowledgeable in managing the child's illness. Such persons
	included grandparents of the child, other older relatives and neighbours as
	explained by a female participant. (U)
Illustration	"I don't know any medicines for any illness and since my parents are older than I
	am, and they know what is wrong with the child they take the decision on what
	medicine to give to the child."

Finding	Nonetheless, there are instances where the decision rests on the caregiver			
	present at the time when the illness is observed as pointed out by one male			
	participant. (U)			
Illustration	"My wife is the one who takes care of the children when I am not in the house,			
	but when I am in the house, I take the decision on what to do."			

Appendix 8: Synthesized findings for caregivers and health care workers

## Caregivers

Findings	Categories	Synthesized Findings
In 'narrow space' breathing	Caregivers were able to	Caregivers can identify common
[Akafundi] the child had cough	recognize common symptoms	pneumonia symptoms including
with difficult/painful breathing	of mild or non-life-threatening	those symptoms leading to
and stridor. (U)	pneumonia in children under	severe pneumonia in children
	five years of age.	less than five years of age,
When asked how they noticed		however some misconceptions
that their children were sick,		including those of pneumonia
most caregivers mentioned a		etiology still persist.
cough, and / or difficulty		
breathing. Among those over a		Caregivers identified symptoms
third reported fever and a		that they associated with mild or
quarter reported fast breathing		non-severe pneumonia. Most
or intercostal retractions. In		mothers mentioned cough,
many cases, symptoms were		fever, fast and difficulty
readily attributed to sardi (cold)		breathing as commonly
or jakda (congestion), though		observed symptoms during the
those two conditions were not		early phase of pneumonia or
strictly defined or necessarily		what they considered mild or
seen as mutually exclusive. (C)		non-life threatening. Many also
		recognize symptoms suggestive
Their recognition of pneumonia		of worsening symptoms.
symptoms varied, covering		However, some caregivers were

cough, asthma, weakness,		unable	to	clearly	identify
irritability, fever, difficulty in		pneumor	nia.		
breathing, crackling sound in the					
chest and convulsions. (U)					
(However) After FGD					
participants and KIs viewed the					
video of a child with high					
respiratory rate, cough and					
lower chest in-drawing,					
indicating severe pneumonia,					
majority of the discussants					
generally described the child in					
the video as having breathing					
problems. Very few (about 11 %					
of 56 of FGD participants)					
including an herbalist					
spontaneously identified the					
child as suffering from					
pneumonia. In another FGD					
session, a female participant					
also explained. (U)					
An increase in pasli chalna	Caregivers were able to identify				
(chest indrawing), tez saans	symptoms of severe or life-				
(rapid breathing) leading to					

breathlessness, threatening abdominal pneumonia in distension and increase in fever children under five years of age. were the commonly agreed upon terminologies to describe double numonia. The following quote from one of the mothers typifies most of the responses of most child caretakers. (U) Most mothers considered numonia and double numonia as potentially fatal conditions. The most commonly cited indicator of severe illness was pasli chalna. Other indicators were continuous or increasing bukkar (fever), refusal to feed and lethargy termed kamzori or girnay lagta hai. As one mother said. (U) The third child had a normal respiratory rate with severe stridor. 'Narrow space'

[Akafundi] together with 'abrupt

attack' [Obukoni] were the		
illness concepts mentioned by		
most. Some, however,		
suggested that this was		
'groaning breathing'		
[Ekyikenyero]. All agreed that		
the first action would be to rush		
the child to a hospital. (U)		
Furthermore, other views	Caregivers had misconceptions	
sampled attributed the cause of	related to the etiology of	
pneumonia to ingesting cold	pneumonia in children under	
drinks or food; they indicated	five years of age.	
that. (U)		
The perception of caregivers		
who have heard about		
pneumonia differed. The		
general belief was that exposing		
a child, to cold temperature or		
windy weather conditions could		
result in the child getting		
pneumonia. The most common		
factors mentioned in all		
discussion groups included		
"sleeping on the bare cemented		

floor". For instance, one female		
participant said. (U)		
Poor hygiene practices were		
also mentioned as one of the		
factors that could cause the		
child to get pneumonia as		
explained by a male participant.		
(U)		
Fathers believed that suffering		
from a sprain, fracture or some		
other pain made the child sick		
with fever, cough or vomiting.		
(U)		
Most of them borrowed money	Financial constraints prevented	Factors such as financial
from their relatives and friends.	caregivers from seeking and	constraints, use of home
Some fathers asked for financial	receiving treatment for their	remedies or practitioner-
help from politicians for their	child with pneumonia.	provided interventions,
children's hospital expenses.		inappropriate purchase and use
Some of them were still repaying		of medicines, caregivers' choice
debt. (U)		of provider, and the decision-
		maker for the child impact on the
		treatment of pneumonia in

One father who had lost his first child saved money whenever he had extra income. (U)

Some of them could not afford to buy medicines because they did not have enough money. (U)

Fathers mostly complied with the doctor's recommendation to go to a hospital. One father did not comply with such a recommendation when he did not have any money. (C)

RHU provides medicines for free if they have a stock.

However, when there was no stock of medicines at RHU, they had to buy medicines themselves. (U)

children less than five years of age.

Financial issues were considered a major reason many caregivers were unable to receive adequate care. Some caregivers kept their children at home and gave them home traditional remedies or medicines. Others inappropriately purchased or obtained and used medicines. Generally, most caregivers take their children to a traditional sometimes healer, but caregivers refuse to consult traditional healers. Some fathers took their children to the hospital and expected a doctor's consultation, but a doctor was not always available for patient consultations. Fathers were the main decision makers regarding when and where care was

		sought. Nevertheless, in their
		absence, women made these
		decisions.
For internal usage, ingesting or	Home remedies were used by	
inhaling melted Shea butter is	caregivers to treat their child	
believed to clear the nasal	with pneumonia.	
congestion and restore proper		
breathing as explained by one		
female participant in FGD. (U)		
A less common practice		
indicated by few caregivers is to		
give the child water drained from		
soaked uncooked rice, or honey		
to treat the difficulty in breathing		
as cited by one grandmother in		
an FGD. (U)		
Most fathers believed that		
oregano and five-leaved chaste		
tree leaves were effective for a		
cough and asked mothers to		
make herbal medicines for the		
child. (U)		

Herbs in different forms were reportedly used for treatment of pneumonia in children. Some are boiled or made into powder mixed and with certain substances obtained from an herbalist for use as described by one male participant. (U) Fathers considered themselves the leader of the family who solves any problem that occurs in the family. They took various actions to improve their child's health, such as seeking information from other people. (U) ... one father gave what his own mother used to give him when he was sick in his early childhood. (U)

Seven fathers knew that	
applying cold water reduced	
fever. (U)	
Fathers assisted mothers in	
caring for a sick child. (U)	

Although fast and difficult breathing were associated with problems in the lungs or airways, many of the ARI illness concepts were frequently related to 'fever' [Omutsutsa] and were perceived to need antimalarial treatment. (U)

Pharmacological interventions
were used by health
practitioners to treat children
with pneumonia.

The curative services of the PHC programme were minimally utilized in both the study areas. The community, used to physicians pronouncing a diagnosis after minimal history taking and examination and multiple getting drug prescription (in addition to an injection and some medicines from the doctor's pharmacy), felt angry and somewhat cheated by the doctors at the PHC center. The subsequent quote from one of the respondent's typifies the

general attitude towards	
curative care offered by the PHC	
programme. (U)	
Some fathers had witnessed	
Rural Health Unit (RHU) staff	
listening to the child's chest	
sounds, fanning a child to bring	
down the fever and using	
oxygen or a nebulizer when the	
child had difficulty breathing. (U)	

Caregivers self-medicated their	
sick child.	
Caregivers sought care from	
either traditional or allopathic	
health practitioners.	
	Sick child.  Caregivers sought care from either traditional or allopathic

Fathers took their children to		
RHU to be checked, particularly		
by a doctor. (U)		
However, they recognized that a		
doctor was not always available		
and that only some nurses and		
midwives might be available at		
RHU. (U)		
It often involved seeking the	Fathers were typically the	
opinion or assistance of	decision makers, however, in	
significant others who are	their absence, mothers took the	
considered knowledgeable in	responsibility for seeking	
managing the child's illness.	treatment which also included	
Such persons included	seeking advice from significant	
grandparents of the child, other	others.	
older relatives and neighbors as		
explained by a female		
participant. (U)		
The mothers reported to be the		
primary decision- makers		
regarding outside care in the		
group discussions. In reality,		

in over two-thirds of too, pneumonia cases, mothers were the key decision-makers for seeking outside care, with grandmothers making the decision in less than a quarter of the cases (in two of the three cases the mother was out of town and the grandmother had the primary responsibility of taking care of the child). (U)

Fathers were also the main decision makers regarding which facility to use. Although fathers discussed such matters with mothers, they were proud to be the primary decision maker:

(U)

Nonetheless, there are instances where the decision rests on the caregiver present at the time when the illness is

observed as pointed out by one	
male participant. (U)	

#### Health care workers

Findings	Categories	Synthesized findings		
Structural and interpersonal	Health care workers expressed	Health care workers experience		
constraints to prescribing	concerns that from a systems	a number of barriers that impact		
behavior were noted in several	level, structural and	their ability to manage and treat		
interviews, including lack of	interpersonal constraints to	childhood pneumonia in children		
equipment to ascertain	prescribing behavior and	less than five years of age.		
diagnosis, prior treatment by	unavailability of medicines	These barriers occur across all		
village doctors, costs, and	prevented appropriate treatment	levels of care including at a		
pressures to relieve symptoms.	for pneumonia in children under	systems level, an individual		
An allopathic provider said. (U)	five years of age. Health care	practitioner level as well as a		
	workers ability to perform and	caregiver level.		
A considerable number of health	gain knowledge was restrained			
workers highlighted the	by lack of incentives and	Delivery of appropriate health		
unavailability of oral rehydration	medicines.	care was found to be		
solutions (ORS), zinc, and		compromised at various levels		
antibiotics as demotivating		of the health care continuum		
factors in terms of improving		with three major challenges in		
knowledge and performance.		the management of pneumonia		
(C)		in children under five years of		
		age identified. Health care		

Additionally, a significant number of health care workers highlighted lack of salaries and reward as demotivating factor.

(U)

While training was understandably mentioned as important to improve level of knowledge, availability of medicines was considered equally important. (U)

workers highlighted that, at the systems level, structural and interpersonal constraints prescribing practices, and unavailability medicines of hindered adequate medical care for children with pneumonia. workers Health care indicated that if incentives such as salaries and reward were available their to them, performance and knowledge would improve. At the individual practitioner level, the studies identified several factors that influenced health care worker performance. These factors included the provision of supervision, feedback. training. Health care workers also experienced barriers at the caregiver level that could potentially hinder effective childhood management for pneumonia. They identified that

caregivers seeking care attitudes such as switching provider, financial constraints, perceived resolution of illness and limited access to health care prevented caregivers from seeking and receiving care. They also noted that caregivers lacked knowledge and understanding of the differences between practitioners. As a result, they sought and received care from unqualified practitioners.

Most Lay Health Workers (LHWs) and LHSs were able to correctly define pneumonia as chest indrawing, high fever and fast breathing. However, a few misconceptions were noted among LHSs regarding pneumonia. (U)

LHWs and LHSs were of the opinion that enhanced presence

At an individual practitioner level, the need for further training that includes supervised field visits and the provision of feedback were identified as influencing health care workers ability to manage pneumonia in children under five years of age. This was demonstrated by some health care workers not being

of LHSs during their household	able	to	correctly	identify	
visits would be a source of	pneur	nonia.			
encouragement and improved					
LHW performance. According to					
many LHWs the supervision					
would be significantly improved					
if the LHWs accompany them on					
field visits more often. (U)					
LHWs and LHSs perceived					
feedback as being important to					
improving their performance.					
(U)					
Generally, LHWs prefer group					
feedback as compared to					
individual feedback. (U)					
Most LHWs consider verbal					
feedback given in a group to be					
adequate. (U)					
On the other hand, LHSs					
preferred written and individual					

feedback to LHWs, rather than		
group and verbal feedback. (U)		
Further training would improve		
LHWs knowledge, performance,		
motivation and LHSs		
supervision. (U)		
A strong desire to gain more		
training was also expressed		
especially in the absence of		
formal training for several years.		
(U)		
The last training for most LHWs		
and LHSs was conducted		
several years ago, but they		
desired additional		
observational-based training to		
enhance their knowledge and		
skills. (U)		
Two thirds of formal providers	Health care workers expressed	
described follow-up strategies	concerns that at the caregiver	
requiring multiple visits to	level, financial constraints,	
monitor the child's condition and	access to hospital, perception of	

or dispense more drugs. Most noted that caregivers did not systematically come back. According to providers, the main reasons for this behavior were switching to other providers if expectations for fast relief were not met, financial constraints and perceived resolution of Allopathic providers illness. charged a consultation fee that typically covered any visit made within a period of five days, while AYUSH (practitioners of alternative systems medicines which consists of Ayurveda, yoga, unani, siddha homeopathy) provider and rarely charged a consultation fee but only gave a few days' worth of medicine at each visit. (U)

disease resolution and lack of awareness of differences between practitioners prevented caregivers from seeking and receiving medical treatment for pneumonia in children under five years of age.

Limited access to LHWs in some areas was also mentioned as a

reason for compromised care at household level. (U) Caregivers indicated consulting "village" doctors, including RHPs (rural health practitioners) and possibly other doctors practicing locally much more often than they did allopathic providers. At the same time, caregivers were not oblivious to the fact that there were differences between providers. For instance, several caregivers who initially consulted a village **AYUSH** doctor or an practitioner, made a conscious decision to experiment with those providers for initial care, as illustrated here by the mother of a four-year-old boy who consulted a unani doctor. (C)