A scoping review on barriers to case management of neonatal pneumonia in India

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ABSTRACT

Background: Neonatal pneumonia is one of the leading factors contributing to neonatal mortality. The objective of this review was to identify the barriers associated with case management of neonatal pneumonia in India by conducting a scoping review.

Methods: Nine databases (PubMed, ProQuest, Ovid Medline, CINAHL, Web of Science, EMBASE, IndMED, SCOPUS and WHOLIS) were searched to identify relevant studies in India. The population of interest were neonates. Outcome of interest was barriers associated with case management of neonatal pneumonia. Data was charted and reported in accordance with the 'guidance for conducting systematic scoping reviews'.

Results: From 5942 citations screened, 244 articles underwent full text screening and two studies with qualitative information met the eligibility criteria. Barriers were classified as patient-related, caregiver-related and healthcare delivery system-related. Delay in seeking care was due to spiritual healers being first point of contact in addition to traditional and home remedies tried by mothers at home and inaccessible healthcare mostly owing to healthcare delivery system were some of the major barriers associated with case management of neonatal pneumonia.

Conclusion: This scoping review concludes that there is a paucity of studies on neonatal pneumonia in India particularly with respect to barriers to case management and that many of the barriers described here are applicable to a broad range of neonatal disease conditions which occur in the community and not just specific to neonatal pneumonia.

1. Introduction

The first month of life, also called the neonatal period, is the most crucial time for survival of a child. Globally, around 2.5 million neonates died in 2018 (nearly 7000 deaths per day), of which one-third occurred on the first day of life.¹ With a neonatal mortality rate of 22.7 per 1000 live births,¹ India is the leading country in neonatal deaths throughout the world.² Neonatal pneumonia is a serious infection of neonates which accounts to nearly six percent of the neonatal deaths globally.³ Some of the major risk factors associated with pneumonia are malnutrition, economic insufficiency, inaccessibility to healthcare services, unsafe

child-rearing practices and household air pollution.^{4,5}

The World Health Organization (WHO) guidelines for Integrated Management of Childhood Illness were adapted to include neonates, and the strategy is known as Integrated Management of Childhood and Neonatal Illness (IMNCI) in India. The IMNCI strategy, introduced by the Government of India (GoI) in 2003, includes improvement in healthcare service delivery and training of frontline healthcare workers and their supervisors in management of neonatal and childhood illnesses. However, several years since its launch, the burden of neonatal illnesses remains high in India.⁶ Neonatal pneumonia, which forms a major part of neonatal sepsis, contributes substantially to neonatal illnesses and

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related mortality.⁷ The high mortality and morbidity may be based on the complex and overlapping diagnosis of neonatal pneumonia and neonatal sepsis.⁷ The problem is disguised by diseases such as hyaline membrane and compounded by injudicious use of antibiotic therapy leading to resistance or failure and other factors posing challenges in initiating and management of treatment.⁵

Pneumonia-specific child mortality and morbidity can be tackled effectively by early detection, effective case management and timely referral.⁸ Although effective case management is important for pneumonia control among children, barriers in supply side viz. lack of health system infrastructure and unavailability of healthcare workers, demand side issues such as community specific socio-cultural barriers, healthcare opinions and experiences, and other barriers such as cost and complexity of treatment negatively affect the potential of the country in reducing the burden of neonatal pneumonia.^{9–11} Thus, while designing effective strategies for case management of neonatal pneumonia, it is imperative to understand the contextual factors and barriers that exist in a particular region.

This scoping review was undertaken as a part of a mixed-methods project addressing various aspects specific to neonatal pneumonia in India. The objective of this review is to synthesize the evidence on existing barriers associated with case management of neonatal pneumonia in India.

2. Material and methods

A scoping review was planned to explore the barriers that exist in Indian context with regard to case management of neonatal pneumonia.

2.1. Study identification

Search strategy was developed by referring to literature and consulting subject experts and an information scientist was also involved. Detailed search strategy for PubMed is provided in supplementary file 1. Few key terms used for search were Pneumonia OR 'community acquired pneumonia' OR 'congenital pneumonia' OR 'hospital acquired pneumonia' OR 'nosocomial pneumonia' OR 'ventilator associated pneumonia AND Treatment OR 'Patient care management' OR 'Case management programs' OR 'Home based neonatal care' OR 'Case Management' OR 'Clinical case management' AND Barriers OR challenges OR obstacle. Nine online databases (CINAHL, EMBASE, Ovid Medline, PubMed, ProQuest, SCOPUS, Web of Science, WHOLIS and IndMED) were searched. Additionally snowballing, hand-searching and grey literature search (Shodhganga (INFLIBNET) and government of India databases) were also conducted. The search on various databases was conducted from August to December 2016.

2.2. Criteria for inclusion and exclusion

The criterion for inclusion for this review was a primary study of any study design (including intervention studies, descriptive studies, qualitative studies, case reports, case series, editorials, policy papers, guidelines, reports and fact sheets) addressing barriers to case management of neonatal pneumonia in Indian context were eligible to be included in the review. Reports, meta-analysis, reviews and conference papers were excluded from the review. Studies on neonatal sepsis were included if the articles had mentioned the outcomes specifically for neonatal pneumonia. Other criteria were, English language articles published in journals and as grey literature. The studies conducted before 1980 were excluded.

2.3. Study selection and data extraction

Following eligibility criteria, a three-stage (title, abstract and full-text) screening and data extraction was done by two authors independently (MG and TL) with arbitration by a third author (SM). All the

discrepancies during the screening process, data extraction and analysis were resolved in consultation with senior reviewers (SN, LL, and BT) and the advisory group members. Endnote (v. x7) software was used for management and screening of the search results. Data was extracted on pilot-tested Microsoft Excel 2007 form by (MG and TL). Primarily data was charted on study characteristics, methodological characteristics and barriers to case management.

2.4. Reporting of study findings

The "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" (PRISMA) chart was created following PRISMA standards.¹² The 'guidance for conducting systematic scoping reviews' was followed to report review findings.¹³

The protocol for this scoping review was published as a separate publication where operational definitions and methodology are described in detail.¹⁴ The protocol of the entire project was approved by the 'Institutional Ethics Committee', Manipal Academy of Higher Education (MAHE), Manipal, India, and the 'Health Ministry Screening Committee' under the Ministry of Health and Family Welfare, Government of India.

3. Results

A total of 5692 records after removing 250 duplicates, were subjected to title screening where 4482 were excluded. The remaining 1210 records were screened by abstract and 244 studies underwent full-text screening. Two studies were identified for inclusion. PRISMA flow diagram of the study selection process is depicted in Fig. 1. The primary reasons for exclusion of 242 articles at the full-text screening stage were as follows: Location (29), Study design (29), Disease of interest (35), Population (16), No sub-group (6), Documents type (45), Year (7), Outcome of interest (68), Inaccessible full text (7).

4. Methodological characteristics of included studies

Based on eligibility criteria, only two studies were included on barriers to case management of neonatal pneumonia in India.^{15,16} The characteristics of the two included studies which specifically discuss barriers associated with case management of neonatal pneumonia are outlined in Table 1. They consist of a controlled field trial conducted in West India¹⁵ and a mixed-methods study conducted in Central India.¹⁶ Sample sizes were considerably larger in these studies, covering over 100 villages¹⁵ and 326 cases.¹⁶

4.1. Barriers to case management of neonatal pneumonia

While our inclusion criteria clearly restricted us to studies which explicitly described barriers to case management of neonatal pneumonia, many of the described barriers are applicable to a broad range of neonatal disease conditions that occur in the community. In consultation with the experts, the authors grouped and classified the barriers given in the studies as patient-related, caregiver-related and healthcare delivery system-related. A detailed summary of barriers and supplementary quotations from the included studies is presented in Table 2. A number of reasons were cited as barriers to the case management of neonatal pneumonia. A commonly cited reason for why patients presented late was "mostly because parents did not seek care". What is particularly concerning to see is that "although mothers recognized danger signs of severe illnesses", they did not seek care, due to "local beliefs", where, for example, "traditionally, a neonate, even if sick, is not taken outside the home." Other reasons cited were that "hospitals are too far"¹⁵ and treating the neonate with home remedies and seeking alternate therapies such as homeopathy.¹⁶ Additionally, the lack of data was alluded to in our lack of an estimate of the incidence of the disease.

Some barriers to treatment may be more closely related to the

Fig. 1. PRISMA Flow diagram depicting the study selection process for barriers to case management.

Table 1
Characteristics of included studies on barriers to case management of neonatal pneumonia.

Study ID	Study design	Location & setting		Study duration	Sample size
Bang et al. (1993) ¹⁵	Controlled field trial	Gadchiroli, Maharashtra	Rural communities	July 88 – Dec 90	I: 58 villages C: 44 villages
Awasthi et al. (2008) ¹⁶	Mixed-methods study	Lucknow, Uttar Pradesh	Urban, 12 bedded reproductive and child health centre	Nov 05 – July 07	326 cases

pharmacological treatment itself. Cotrimoxazole was described as a “less than an ideal choice of antibiotic” due to its limited sensitivity profile, and owing to the fact that the oral route of administration “may not be reliable in neonates.” The same authors noted that “the addition of gentamicin should overcome these deficiencies”.¹⁵ However, gentamicin, which requires require parenteral administration, often brings its own set of challenges. For example, “most care providers did not prefer giving injectable treatment to the sick newborns” and perceived that “giving injections to newborns is difficult and can lead to complications”, citing a lack of space and muscle mass. It was reported that only 2 out of 11 cases which required injectable medications, actually received them.

5. Discussion

To our knowledge, this scoping review is the first attempt to find out

the magnitude of information on barriers associated with management of neonatal pneumonia in India. A widespread search from both published and unpublished literature and stringent methodology to screen and include every potential study; are strengths of the present review.

Patient-related barriers are largely biomedical risk factors and determinants which are directly or indirectly responsible for unsuccessful efforts at treatment. These are largely addressed by effective maternal nutrition, antenatal care, and neonatal care practices. Most barriers to case management which were described as pertaining to neonatal pneumonia, need not apply only to this disease in particular, but are relevant to many areas in the larger maternal-and-child care continuum.¹⁷ However, as neonatal pneumonia comprises the majority of neonatal sepsis cases,⁵ there is a persistent need to fully understand how the symptoms of neonatal pneumonia in particular are recognized by the parents, the prime caregivers in many cases, and how they are interpreted in the framework of health and disease upheld by the local rural

Table 2
Barriers to case management of neonatal pneumonia.

Barriers	Details	Quotes
Patient-related Neonatal characteristics	Early neonatal period	"Pneumonia in the first week ... was associated with high case fatality despite treatment". ¹⁵
	Comorbidities	"Prematurity, birth injury, and small size ... was associated with high case fatality despite treatment". ¹⁵
Caregiver-related Inappropriate and untimely medical care-seeking	Care seeking from multiple providers	"Thus, care seeking from multiple ... delayed appropriate and timely medical care seeking". ¹⁶
	Traditional or home remedies	"Use of traditional/home remedies delayed appropriate and timely medical care seeking". ¹⁶
	Spiritual healers	"Hence, we went to an 'ojha' (spiritual healer) in the community who performed a ritualistic procedure of Jhada Phunk on the baby". ¹⁶
	Refusal for referral	"Despite the advice of health workers, parents of 10 out of 11 babies needing referral refused to take them to a doctor or hospital". ¹⁵
	Refusal to seek care	"A substantial number of neonates with pneumonia in the intervention area were still unattended, mostly because parents did not seek care". ¹⁵
Health beliefs	Mothers felt competent to self-diagnose the disease	"There were instances where the baby was considered to be severely ill, but mothers did not consider it necessary to seek qualified medical care, as they felt competent enough to self-diagnose the disease". ¹⁶
	Local/traditional beliefs	"Persistent respiratory difficulty or may be 'Upri' ". ¹⁶
	Traditions of home management	"...traditionally, a neonate even if sick is not taken outside the home". ¹⁵
	Delay in consulting qualified medical providers	"Although qualified providers were consulted in most cases of severe illness, this was done after a considerable delay". ¹⁶
	Beliefs in alternative therapies	"Both the therapies [Home remedies and 'ojha'] could not provide sufficient relief to the baby; hence, we went to a homeopathic doctor near our residence". ¹⁶
Healthcare delivery system-related		
Access	Long distance between patient and hospital	"The hospitals are too far". ¹⁵
Healthcare personnel	Healthcare providers refuse to treat (due to high risk case)	"Maruti, our village health worker ... successfully managed a case of neonatal pneumonia that a doctor practising in the rural area had earlier refused to treat because of the high risk". ¹⁵
	Illiteracy of traditional birth attendants	"Illiteracy of the traditional birth attendants limited their learning". ¹⁵
Management	Inappropriate medications	"Co-trimoxazole was less than an ideal choice of antibiotic because not all organisms were sensitive and because the oral route of administration may not be reliable in the neonates". ¹⁵

culture.

In one study which captured the words of a father whose child died on the third day of life, the father said that though "the child was grunting on the night of his second day ... I thought I would take the child to the hospital next day morning." This demonstration of the inability to recognize serious illness in a newborn was followed by his reasoning: "What can we do? Whether the child is big or small, if he has to go, he will go. The one who is endowed with luck survives, and the others will go if they have to".¹⁸ This understanding that neonatal health outcomes are the result of processes beyond their control underpins this fatalistic perception of their own role in securing neonatal health. While such notions may be deeply rooted in age-old belief systems, they have a very immediate and relevant impact on health outcomes of neonates. Vital information such as this can help to identify prevalent cognitive barriers that inhibit and/or delay care-seeking behaviour in parents, and be used to develop interventions that specifically address the issue.

As far as the healthcare delivery system is concerned, what is lacking is an integrated, systemic process of patient/consumer feedback which can identify and report these barriers as they arise in real-time. This would enable immediate monitoring, response, and outcome measurement in the process of addressing barriers.

The barriers related to the infective agent should also be considered, though we found limited evidence of this in the literature pertaining to neonatal pneumonia specifically. However, numerous studies discuss the growing prevalence of antibiotic resistance in neonatal sepsis (of which pneumonia is a component) in India, and around the world.^{19,20} While antibiotics are currently available to handle resistant strains of common pathogens, better surveillance is required. In India, where powerful antibiotics can often be bought over the counter without a prescription,²¹ patients rarely comply to complete antibiotic regimens resulting in resistance even among commensal flora.

There were several limitations with respect to this review. A limitation of this review was that we could only collate evidence from two studies which provided only qualitative data. As the conditions in India vary significantly in terms of economic, sociocultural and geographical aspects, there were not enough studies to represent each region of India. A major limitation was the lack of response from authors of studies of neonatal sepsis that did not explicitly provide data on the pneumonia component of their sepsis cases. Furthermore, neonatal pneumonia is a difficult condition to assess in experimental studies, as a plethora of confounding factors and other factors (such as ethics) are involved in its management. The above reasons considerably limited the information we could include from such studies. A systematic review could have followed this scoping review; however, it was not deemed possible due to the availability of limited evidence reflected through the results of this review.

6. Conclusion

This scoping review concludes that there is paucity of primary studies on case management of neonatal pneumonia in the Indian context. The patient-related, caregiver-related and healthcare delivery system-related barriers described in our review are not just specific to neonatal pneumonia but applicable to a broad range of neonatal disease conditions which occur in the community. It is important to note that all included studies were qualitative, with no studies attempting to quantify the scope and scale of these barriers. There is a need for such studies, to inform policy for effective implementation to address the most prevalent barriers first, so as to achieve optimal health outcomes as economically and quickly as possible.

Declaration of competing interest

None.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.cegh.2021.100713>.

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Ethical approval

The protocol of the entire project was approved by the host institution's ethics body (Institutional Ethics Committee, Manipal Academy of Higher Education, Manipal, India), and the 'Health Ministry Screening Committee' under the Ministry of Health and Family Welfare, Government of India.

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