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AN IN-DEPTH STUDY ON NEONATAL HEALTH IN THREE DISTRICTS OF UTTAR PRADESH

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FOREWORD

The demise of a child is considered the ultimate tragedy in any society. It is an inconsolable loss for the family, community and society. Preventable deaths of children are collective system failures, from which there is no redemption; the fact that children whose deaths could have been prevented are dying is wholly unacceptable and unjustifiable. India is among the top 5 countries in the world for child mortality. Although India has witnessed progress in reducing infant and neonatal deaths recently, yet the absolute numbers are comparatively high. Neonatal deaths, i.e., death during the first 28 days of a child's life account for 72 percent of all infant deaths. In India, 23 out of every 1000 newborns die in the first four weeks of their lives.

Multiple investments, interventions and responses have been designed by the Government of India and Civil Society Organisations (CSOs) to reduce infant and neonatal deaths in the country. CRY – Child Rights and You has over 40 years of experience working for children at the grassroots, which highlights and confirms the vulnerability, and the critical health and survival risks faced by infants and neonates. CRY currently supports a large number of programmes for addressing the issues of infant health and survival in 19 Indian states in partnership with various grassroots organisations. CRY has been committed to positively changing the way children are perceived and treated in society. But despite a myriad of efforts, we as a society are collectively failing to protect infants by not meeting their basic needs critical for their health, wellbeing and survival. The survival of a child is dependent on a host of factors – adequate quality maternal care (ante-natal and post-natal), safe and institutional deliveries, access to emergency health services and affordable primary health care, child-safe practices, nutrition, timely and proper immunisation. The CRY model encompasses a host of measures designed to provide holistic care and protection to infants - early registration of pregnant women in the Integrated Child Development Scheme (ICDS), proper Ante-natal care (ANC) services, care of pregnant women and anaemia testing and follow-ups, identification of High-Risk Pregnancies (HRP) for early referral services, immunisation and community engagement, birth preparedness and sensitisation towards the best practices of child care. Neonatal deaths have lessened significantly due to these collective efforts over the years; however, the issue persists.

FOREWORD

One of the most powerful insights from CRY's programming experience of over 40 years is that for change to be truly transformational, it has to be realised at three interconnected levels of 'Self', 'Society' and 'System'. It is in this context that CRY felt the need to conduct this research – to delve deep into the causal factors leading to neonatal deaths, and the required actions at all three levels.

CRY seeks to drive this fundamental change through a multitude of continuing efforts, and this study serves as a critical resource to inform and guide programming and policy interventions for any individual, institution or system working towards the cause of child survival. We, therefore, deliver you this report – the compelling result of our inquiry that we hope will aid policymakers, CSOs and relevant stakeholders in devising strategies and actions to drive the required changes.

With faith and hope,

Soha Moitra

Regional Director

CRY - North Region

ACKNOWLEDGEMENTS

CRY would like to express gratitude to all those who have contributed to this study. We recognise the valuable contribution of CRY partner Jan Mitra Nyas (JMN), Varanasi, Sonbhadra Vikas Samiti (SVSS) Sonbhadra and Doaba Vikas Evum Utthan Samiti (DVEUS) Kaushambi for providing invaluable support during the field visits and conducting in-depth interviews with the sampled women.

Last but not least; we thank all the mothers, for their participation, time, and sincere responses during this study.

EXECUTIVE SUMMARY

Background and Rationale

The first 28 days of life (the neonatal period) is the most vulnerable time for a child's survival. Children face the highest risk of dying in their first month of life (UNICEF, 2018). The Right to Life as enshrined in Article 21 of the Indian Constitution, and the United Nations Conventions on the Rights of the Child (UNCRC) is a Fundamental Right, and Goal 3 of the Sustainable Development Goals (SDGs) states that by 2030, the aim is to end preventable deaths of newborns and children under five years of age, and reduce neonatal mortality rate (NMR) to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births. In the National Plan of Action (NPA) 2016, India has committed to reducing neonatal mortality to 21 by 2021. India currently contributes to one-fifth of global live births and more than a quarter of neonatal deaths. In India, the NMR stood at 23 deaths per thousand live births in 2018 (SRS 2018). Around 72 percent of total infant deaths and more than half of under-five deaths fall in the neonatal period; deaths in the first week alone account for 55 percent of total infant deaths (SRS 2018). The latest round of the National Family Health Survey (NFHS-IV) 2015-16 indicates that only 24 percent of children received a health check-up from a qualified medical personnel within 2 days of birth, and that less than 3 percent of children born at home were taken to a health facility for check-up within 24 hours of birth. The causes, drivers and determinants of these occurrences are myriad and multifaceted which includes infrastructure gaps, parental education and non-optimal health seeking behaviours along with other socio-economic drivers. There are medical causes also of neonatal deaths like prematurity and low birth weight, birth asphyxia, etc. Over the years, consistent efforts to address the above issues have been made by both the State and Civil Society Organisations (CSOs). While the steps taken to reduce mortality have shown some positive trends over the last few decades, India still has a higher neonatal mortality rate compared to the world average. The state of Uttar Pradesh has one of the highest neonatal mortality rates in the country with 32 deaths for every 1000 live births (SRS 2018). The rural-urban differential in the state is also one of the highest in the country with rural areas witnessing 34 deaths for every 1000 live births and urban areas recording 21 deaths for every 1000 live births in the neonatal period.

In Uttar Pradesh, CRY- Child Rights and You, recognising the pressing need for improving the maternal and child health, has a range of holistic interventions both at the system and the community levels in the grassroots, through a host of measures. The CRY experience shows that the issue of infant and neonatal deaths is complex with a cluster of interlinked drivers and a need was felt for the study to further explore the socio- cultural determinants and different health aspects of the occurrence. The study findings will guide CRY and other civil society organisations' (CSOs) endeavours to address issues related to neonatal health and mortality in Uttar Pradesh and also strengthen the policy dialogue with different stakeholders including policy makers and influencers at different forums.

Objectives of the study

The main objectives of the research were as follows:

- To understand the sociocultural determinants of neonatal deaths;
- To understand the beliefs, traditions and practices of the community regarding newborn care among mothers;
- To document the accessibility, availability and utilisation of healthcare services in relation to neonatal health.
- To document the experiences of mothers in relation to newborn health and community systems.

Research Design

The study was conducted in rural areas of three districts of Uttar Pradesh namely – Kaushambi, Sonbhadra and Varanasi. CRY has intervention programmes in all these three districts. Presently, CRY has presence in 60 villages of Kaushambi, 50 villages of Varanasi (Rural) and 28 villages of Sonbhadra district through various program initiatives.

As part of the research methodology in the above districts, the field staff of implementing NGO partners of CRY visited and studied all neonatal deaths in detail and collected detailed information from the families including demographics, socio-economic status, health-seeking practices etc. (neonatal deaths that were reported between April 2018 and 31st March 2019). Out of the 55 identified cases, a random sub-sample of 29 mothers was additionally chosen (distributed proportionately with respect to number of deaths in the respective districts) for in-depth interviews. In-depth interviews were conducted in the month of February 2020 and mothers who had lost their child in the last one year prior to the survey were interviewed for detailed exploration. Reflexive notes during the field visits were also documented to substantiate the findings. Descriptive analysis was carried out as per the variables of interest.

Ethical Considerations

During the data collection, the best practices of ethical research were strictly followed. All mothers were duly informed about the objectives of the study beforehand in the local language. Informed consent was obtained for the interview. Mothers were interviewed at their homes and participation in the interview was voluntary.

Limitations

The study documented the responses of a limited sample, hence offers scope for limited generalizability. However, the findings give an in-depth understanding of sociocultural aspects and access, availability and utilisation of healthcare services related to children in the study areas, and can be used for programmatic interventions and initiating policy dialogues. Also, the reported responses are self-reported and were not cross verified with the registration agencies such as register of AWCs.

Key findings based on the Case Studies and In-depth Interviews

Age of the Mothers: Overall, 74.5 percent of women were between 20-30 years of age and 11 percent were below 20 years of age. In rural areas of Varanasi, a large number of women i.e. 46 percent were within the age group of 22-25 years, and 31 percent were below 20 years of age. In Kaushambi, none of the women was below 20 years and most of them (71.4%) were within the age group of 20 to 30 years. In Sonbhadra, most of the women (64.3%) were within the age group of 20-25 years and 14 percent were less than 20 years.

Educational qualification of the respondents: Overall, a majority of the women (61.8%) were non-literate and an additional 20 percent had completed primary education. In rural areas of Varanasi, 77 percent were non-literate and almost same percentage was in Kaushambi (75%), which is concerning in relation to health. In Sonbhadra, only 21 percent of women were non literate.

Factors related to neonatal deaths

Sex of the Child: It was found that girl children accounted for a slightly higher proportion of neonatal deaths (52.7%) compared to boys (47.3%). This was the case in rural areas of Varanasi (53.8%) and Kaushambi (60.7%). However, in Sonbhadra, boys accounted for 64.3 percent of the neonatal deaths.

Birth order: Overall, a significant percentage of neonatal deaths were attributed to 1st (31%) and 4+ (29%) birth orders. In rural areas of Varanasi, the highest proportion of deaths was among children who were first-born and 2nd born (30% each respectively). In Kaushambi, 32 percent cases were first births and the highest deaths occurred among children having 4+ birth orders (39%). In Sonbhadra, there was not much difference of birth order as they were comparatively evenly distributed – 28 percent of the cases each were from first and second birth order, while 21 percent cases of neonatal deaths were from the third and fourth birth order each.

Registration, ANC & Counselling: Out of the total women, majority of them (93%) were registered with Anganwadi centres and got counselling from the AWW or ASHA workers (88%). In Varanasi Rural, all the women were registered with their local AWCs but only 53 percent received counselling. In Kaushambi, 96.4 percent women were registered and all of them received counselling. In Sonbhadra, the proportion of women registered with AWCs was comparatively lesser (78.6%); however, all the women received counselling.

A majority (94%) of the women got IFA tablets during the pregnancy and two doses of tetanus toxoid injection (86%). However, only one in every ten women stated that they got full ANC check-ups (11.8%). All the women in Sonbhadra received Tetanus toxoid injections and IFA tablets; however only 18 percent received all the 4 antenatal check-ups. In Varanasi Rural, 84 percent of the women received both the Tetanus toxoid injections and IFA tablets; however only 8 percent received all the 4 antenatal check-ups. In Kaushambi 82 percent of women received Tetanus toxoid injections and 96 percent received IFA tablets; however only 11 percent received all the 4 antenatal check-ups.

In-depth interviews with mothers revealed that most of the interviewed mothers (83%) reported being visited by an ASHA during the time of their pregnancy and were registered by ASHA. Most of the registered mothers

(88%) reported that they received counselling from ASHA but only nutrition was the most frequently cited topic by mothers (94%) when asked about the counselling topics discussed by ASHA, followed by institutional delivery (83%), government schemes (78%), safe motherhood (50%) and personal hygiene respectively (56%). Information about importance of ANC somehow was not cited by the mothers. However, it was observed during the interview that most of the mothers did not know the benefits of nutrition or institutional delivery but they had more knowledge about government financial schemes.

Mothers' interviews also suggested that one in every five mothers did not visit any health facility during pregnancy. Only 41 percent pregnant women had visited a health facility for check-ups more than two times. Only around half of the mothers (55%) were allowed or permitted to go a health care facility on their own. Those who were not allowed to go on their own had to be accompanied either by husband or mother-in-law to health facility. Only 13 percent of mothers had 4 antenatal check-ups. Only 7 percent mothers in the study received birth registration certificates and majority of the women (86%) stated that they did not receive any death certificate of the child.

Place of birth: A majority of the births occurred were institutional births (78%), out of which 60 percent were at a public health facility and 18.2 percent at a private health facility. The proportion of home births were highest in Sonbhadra (28.6 %), followed by Varanasi Rural (23.1%) and Kaushambi (10.7%).

Mothers during interview also gave similar information - 62 percent of the deliveries took place in government health facilities, 24 percent of the births took place in private clinics, and 10 percent deliveries took place at home and 3 percent during transit. Among the women who delivered in an institution, 69 percent were discharged on the same day as the delivery and only 28 percent mothers reported the child receiving post-natal check-ups in the first week after birth. 31 percent of the women approached the Sub Centre (SC) and 24 percent opted for Primary Health Centre (PHC) for their delivery and 7 percent delivered in a Government hospital. One in every fourth delivery took place in a private hospital or clinic. 52 percent of the respondents were within a range of 2 to 3 km of nearest health facility and 59 percent of the respondents were within a reach of 10 km from a community health centre (CHC). The average range of the distance for the nearest Sub-Centre (SC), Primary Health Centre (PHC), Community Health Centre (CHC) and District Hospital (DH) in kms are 2.3, 5.1, 11.5 and 13.6 km respectively. Private facilities were found within a range of 3 to 5 km by around 34 percent respondents.

Health facilities and assistance during the delivery: Among the women who had institutional delivery, only one in every ten deliveries (14%) were assisted by a doctor. A majority of them were conducted by an ANM (86%). District wise, in Varanasi rural 80 percent of the deliveries were assisted by an ANM, while 20 percent were done under the supervision of a Doctor. In Kaushambi 88 percent were assisted by an ANM and only 12 percent by a Doctor. The data from Sonbhadra shows that 87.5 percent of institutional deliveries were assisted by ANMs and 12.5 percent by a doctor. In the in-depth interviews, findings also highlighted that 17 percent of the deliveries were not assisted by any skilled or trained birth attendant (attended to by *Dais* and relatives). The experiences related to the facilities available shows that many respondents were satisfied with the availability of ASHA, ANM, and Trained Birth Attendant etc. but less than 5 percent of the respondents replied positively about the cleanliness and hygiene of the facility. The other problems reported by the respondents were un-

availability of doctor, electricity problems, having to purchase their own blades, medicines, gloves and unfavourable conduct from the support medical staff. . Qualitative responses stated that though women stated that beds, medicines, ANM, ASHA, Dai and doctors were available in the facility, yet many complained about the unavailability of doctor at the time of emergency. Some shared their views that the behaviour of the nurse was not good and that they had to pay extra money.

Delivery and pregnancy risks: A majority of women had normal delivery (89%), and approximately half of them (44%) had high risk pregnancy in terms of low Haemoglobin counts and low weight of women etc. Out of these high risk pregnancies, 29 percent were home deliveries. The percentage of high risk pregnancies was the most in Sonbhadra (64.3%), followed by Kaushambi (39.3%) and Varanasi Rural (30.8%). Complications during pregnancy were also the highest in Sonbhadra (28.6%). The proportion of women having had a normal delivery was 85 percent or more in all the 3 districts.

Cultural and local practices followed during delivery: In one in every ten cases, old or unsterilised instrument/blade was used to cut umbilical cord. This was highest in Varanasi Rural (23.1%), followed by Sonbhadra (14.3%), and did not occur in Kaushambi. Half of the newborns (51%) were not breastfed immediately and/or within an hour of birth and one in every tenth child (12.7%) was fed with something other than breast milk (e.g. cow milk or honey due to varied cultural practices followed in the study areas). Only 28.6 percent of the newborns were breastfed within an hour of birth in Sonbhadra, followed by 38.5 percent in Varanasi Rural and was the highest in Kaushambi (64.3%). Mothers' interviews also revealed that only 35 percent children were given colostrum within an hour. Among women who did not give colostrum within an hour, 56 percent reported that the child was never given colostrum.

During interviews, mothers reported that care from family was lacking. One in every ten women did not have anyone in the family to provide care during pregnancy. There existed a wide range of beliefs, taboos and practices related to pregnancy. Half of the mothers (52%) followed some or all of the locally popular practices on pregnancy and child birth which included restrictions on travelling, personal hygiene related practices and spiritual/ religious beliefs.

During the in-depth interviews, 69 percent of the mothers reported post-delivery complications for their child. 10.3 percent of the mothers reported using home remedies for the complications (remedies mentioned were wrapping the child in hot cotton to get relief from cold, going to traditional healers who knew black magic, witchcraft solutions and having belief in/ praying to Gods/ Goddesses).

Birth Weights of the newborns: 36.4 percent of the neonates were Low Birth Weight (LBW). This was the highest in Sonbhadra (57%), followed by Varanasi Rural (31%) and Kaushambi (27%).

Probable causes of newborn death – There were multiple causes leading to the deaths of neonates. Neonatal Pneumonia and Respiratory Distress Syndrome emerged as the two highest probable causes accounting for 27 percent and 24 percent of the deaths overall. In Varanasi Rural, Neonatal Pneumonia and Respiratory Distress

Syndrome accounted for 23 percent and 31 percent of the deaths respectively. In Kaushambi similarly, Neonatal Pneumonia and Respiratory Distress Syndrome accounted for 21 percent and 32 percent of the deaths respectively. In Sonbhadra, 43 percent of the deaths are likely to have occurred due to Neonatal Pneumonia, and in none of the cases, Respiratory Distress was reported. Overall, in 31 percent of the cases, the immediate cause of deaths were not known.

Number of Days after which deaths occurred: Overall, children died within 4 days of birth on an average, ranging from 5 days in Varanasi rural to 3.6 days in Sonbhadra. 82 percent of the deaths took place within 7 days of birth, and hence are conclusively early neonatal deaths. This was highest in Kaushambi (86%), followed by Sonbhadra (79%) and Varanasi Rural (77%). Range of days was lower in Sonbhadra (0 to 15 days) indicating that children survived for very less number of days in the district. 35 percent of the deaths were same-day deaths.

In the interviews with mothers it was revealed that deaths of girl children, among the sub-sample chosen for in-depth interviews, were also slightly higher accounting for 51.7 percent of the total neonatal deaths. 62 percent of the neonatal deaths (as revealed in case studies also) were early deaths i.e., within 7 days; 31 percent of the deaths were same-day deaths.1st order and 4+ order births accounted for 72.3 percent of the deaths, in line with the findings from the larger sample presented in the section above.

Place of death: A majority of the deaths occurred at home (58%) and 38 percent occurred in a health facility (private-20% and public-18%). In all 3 districts, most deaths occurred at homes - Varanasi Rural (53.8%), Kaushambi (57.1%) and Sonbhadra (64.3%).

Benefits under Central/ State Schemes: Around one third respondents (39%) received benefits provisioned under central/state maternity benefit schemes though most of them were registered at AWCs. In Varanasi rural, 30 percent of the women received benefits under any Central/ State schemes. This figure was the highest in Kaushambi with 59 percent of the women reporting benefits under various schemes. It is notable that none of the women (mostly schedule tribe) from Sonbhadra reported receiving any benefit under any central or State level maternity related schemes.

IDIs revealed that Most of the women (93.1%) had MCPC cards. It was also observed that although pregnant mothers were registered, the MCP card was not kept with them. Around 79 percent mothers reported to have had three meals a day during the pregnancy period, whereas 17 percent did not have access to three meals a day, although a maximum number of the respondents were counselled by the ASHA, AWW, and ANM about the importance of nutrition diet and calcium intake during pregnancy. 93 percent of the women reported receiving Take-Home-Ration, but 22 percent did not use it to supplement their own dietary needs.

Conclusions and Recommendations

The research adequately demonstrates a host of factors which constrain and hinder effective healthcare for mothers and newborns. The systemic and the socio-cultural factors leading to non-optimal healthcare and childcare practices emerge clearly. On the supply-side, lack of availability of adequate and trained medical staff (only 14 percent of respondents reported doctor-assisted deliveries), lack of adequate health infrastructure (beds and trained medical personnel were available to less than 1/4th of the respondents) and affordability (less than 40 percent of the mothers had any financial assistance from schemes (despite a majority being from BPL families) emerged as chief barriers.

These constraints combined with the inherent disadvantages faced by mothers due to lack of education, low incomes, poor awareness and unfavourable socio-cultural practices were found to lead to non-optimal health-seeking behaviours and childcare practices. This is evidenced by salient indications from the study such as 41 percent of the women choosing to opt for deliveries at home or in Sub-Centres where doctors were not available, only 28 percent of the mothers visiting any health facility for check-up within 7 days of birth, colostrum-feeding being done only by 35 percent of the respondents etc. These were coupled with other unfavourable childcare practices, leading to a high risk for the survival of the newborns. The study showed that the factors that can influence the key decision to seek and practice appropriate care include the beliefs of the woman and her relatives. availability and the competence of trained dais (traditional birth attendant), the socio-economic status of the family, illness characteristics (recognition and severity), distance from the health facility (accessibility), financial and opportunity costs (affordability), previous experience and perceived quality of care. Other factors are the physical accessibility, travel time from home to facility, the availability and cost of transportation and the condition of the roads. The study throws up a multitude of barriers and gaps which paves way for tangible recommendations for ensuring adequate, effective and timely healthcare for mothers and newborns.

Preventative Care – Complete Ante-natal-care (ANC), which is vital for safe deliveries, requires urgent attention. Less than 15 percent of the mothers had received complete ANC, putting the health of both the mother and child at risk. The study takes cognisance of the fact that ASHA workers can play a significant role here and should promote effectively the importance of full ANC check-ups. Proactive measures to identify high risk pregnancies (as experienced by 44 percent of the mothers) and adequate referral mechanisms are also pressing concerns. Outreach workers such as ASHA, ANM and Anganwadi workers should be provided training, as well as adequate additional resources in terms of 'untied funds' that can be used for emergency situations.

Best Practices of Safe Deliveries - The study found that though the home-deliveries has significantly decreased but still it's an existing practice in the study areas (for instance - 29 percent of mothers in Varanasi Rural delivered at home). To promote, institutional deliveries, more outreach workers such as ASHA, ANMs etc. should be recruited. Also the quality of institutional care needs to be improved so that maximum newborn deaths can be prevented and health complications can be addressed. It will also be beneficial if *'Dais'* (unskilled birth attendants) can be trained so that they can refer the complicated pregnancies to the health systems on time and thus, could promote institutional deliveries.

To demote the deaths during the transits, transport facilities in terms of pick up and drop facility of the existing 102 and 108 ambulance services should be strengthened by the health authorities and should act timely so that the lives of the mother and the child may be saved during emergencies. Community collectives and groups should be formed to meet the emergency needs of the family and pregnant women like transportation, etc. and also to support the health and nutrition needs of the pregnant woman from the most marginalised families.

Medical Care and Protocols during delivery - The study findings suggest that hardly any institutional delivery in a government facility was assisted by the doctors (less than 15 percent). Likewise, qualitative findings suggested that in most of the health facilities, there was an acute shortage of human resources such as neonatologists, obstetricians, lab technician, anaesthetists and midwives. Vacant positions of healthcare staff should be filled on an urgent basis and specialised doctors such as gynaecologists and paediatrician should be recruited in the remotest rural areas of Uttar Pradesh like Sonbhadra. The study findings also reflected poor clinical practices in medical facilities (for instance 69 percent of the mothers who delivered at institutions got discharged on the same day, thus, grossly compromising the need of postnatal care to mother and her child). There is an urgent need to train, monitor and ensure strict implementation of best practices of maternal and child care, including discharge protocols. Proper institutional care can significantly bring down neonatal deaths especially early neonatal deaths which constitute a significant portion of deaths.

Ensuring Postnatal Check-ups (PNCs) – Post-Natal-Visits are accepted as one of the best practices to reduce neonatal mortality and infant mortality. Once again, the potential role that can be played by the ASHA worker is significant in ensuring the mandated 3 post-natal contacts within the first 7 days following the birth. Urgent attention needs to be given, with adequate allocations, training and monitoring to ensure that PNCs are instituted.

Improving health-seeking behaviours and child care practices - Information should be disseminated using short films, '*nukkar natak'* etc. to the community on the issues pertaining to maternal and child care, ante natal care, danger signs of complications and post natal care using a smart mobile van as these methods are more effective in a community where large proportions of the population is non-literate. Delayed breast-feeding especially to LBW/ premature babies can cause serious medical repercussions including deaths, and therefore it is imperative to impart the right knowledge to the community (the mother and the child's family). Active participation of men should be sought through government sponsored and promoted community based intervention programmes. Inter-spousal communication seems to be an effective means of enhancing birth preparedness. Therefore, it should be encouraged through active participation of husbands in antenatal care services.

Community Awareness and Sensitisation - Individual and family preparedness for birth should be promoted via training on various aspects such as positive attitudes, favourable perceptions towards birth preparedness, high self-efficacy and familial and social support. Several cultural beliefs and traditions that exist in different communities influence care practices (52 percent the respondents confirmed following practices that were culture-induced). Due to neglect in care of the female child and poor access to healthcare for girls, the data reflected that more girls (53%) compared to boys (47%) died in their first month of life. Realizing the presence of such

traditions in the community, intensive Information, Education, and Communication (IEC) campaigns should be formulated to address myths and misconceptions and promote healthy and equitable practices. Detailed counselling of the family members should be promoted and conducted to address taboos associated with the prevailing practices.

Policy Recommendations

This study shows that there is a need to adopt state-specific strategies and multi-sectoral approaches to bring down neonatal mortality, and move closer towards achieving the targets and goals of INAP, NHM, NAPC and SDGs. Policy options for newborn and child survival should include community awareness, adopting preventive strategies, enhancing local health infrastructure and increasing investment in child health and related maternal and adolescent health polices and schemes; the recommendations are as follows:

This study shows that there is a need to adopt state-specific strategies and multi-sectoral approaches to bring down neonatal mortality, and move closer towards achieving the targets and goals of INAP, NHM, NAPC and SDGs. Policy options for newborn and child survival should include community awareness, adopting preventive strategies, enhancing local health infrastructure and increasing investment in child health and related maternal and adolescent health polices and schemes.

1. Birth and death registration should be strictly mandated. Civil Registration and Vital Statistics (birth and death registration with cause of death assignment) should be progressively strengthened for counting every newborn.
2. Micro level research, information and reliable data about mortality are required for improving programmes. The system of reporting NNM should be strengthened and each neonatal death should be audited to improve newborn health.
3. Periodic monitoring of Annual Implementation Plans should be encouraged by state authorities. Annual health plans should reflect local needs and effective budgeting processes should be put in place. Periodic health facility audits and needs assessment studies at the facility level should be promoted by health authorities to assess gaps in services and take corrective measures.
4. Trained mobile health teams should be deployed for screening and early detection of risks so that immediate actions can be taken during emergencies to reduce the risk of death.
5. Periodic training and assessment of training should be promoted for outreach workers on varied topics related to maternal and child health. Though incentives are inbuilt in national programmes for promoting institutional deliveries, healthy practices such as colostrum feeding, exclusive breastfeeding, nutritious food intake during pregnancy and lactation and maintaining personal hygiene could also be incentivised.
6. Intensive awareness programmes should be promoted to disseminate information about maternal/ child care and available government schemes to enhance coverage. Efforts should also be made to address issues such as early marriage of girls and nutritional deficiencies among adolescent girls through school and community level programmes and activities.
7. Focus should be on promoting postnatal visits, as across the world this strategy has been accepted as the best practice to reduce neonatal and infant mortality. Hence the role of ASHA is significant. The

government guidelines specify 3 post-natal contacts within 7 days of birth. This is extremely vital and should be monitored and implemented strictly.

8. Also need to focus on improving the quality of institutional care and formulating and implementing the delayed discharge protocols. The institutional care can significantly bring down NMR especially early NMR which in the study findings was also a significant percent (82%) all the NMRs.
9. Steps to be taken by the Health department and government health workers to improve the quality of ANC especially focusing 4th ANC and more so the last ANC within last week of pregnancy and BP/ CR (birth preparedness and complication readiness) can be addressed.
10. Urgent need to shift from generalised strategy to focused approach (narrowed down approach) needs to be applied to reduce NMR to attain the targets of SDG. One strategy is focussing on the tribal pockets as significant numbers of deaths are happening there. Further focus needs to be on the 1st born as it increases the NMR significantly.
11. Most of the recommendations related to addressing adequacy of human resources as per IPHS standards, their training, availability of quality infrastructure etc. are contingent on adequate budgetary allocations. Trends in budgetary allocations for child health as a proportion of overall child budget has been progressively declining from 3.9 per cent (2018-19 BE) to 3.57 percent (2019-20 BE) to 3.4 percent (2020-21 BE). Thus, there is an urgent need to universalise quality health services by increasing public provisioning for child health.

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ABBREVIATIONS

ANC	Antenatal Care
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
BEmOC	Basic Emergency Obstetric Care
BPL	Below Poverty Line
CEmOC	Comprehensive Emergency Obstetric Care
CHC	Community Health Centre
CSSM	Child Survival and Safe Motherhood Programme
DCM	District Community Mobiliser
DRC	District Resource Centre
EmNC	Emergency Newborn Care
EmOC	Emergency Obstetric Care
EmONC	Emergency Obstetric and Newborn Care
FBNC	Facility-Based Newborn Care
FRU	First Referral Unit
HBNC	Home-Based Newborn Care
HMIS	Health Management Information System
HR	Human Resource
HRH	Human Resources for Health
IAP	Indian Academy of Paediatrics
IGR	Intrauterine growth restriction
IMNCI	Integrated Management of Neonatal and Childhood Illnesses
IMR	Infant Mortality Rate
IPHS	Indian Public Health Standards
IMCI	Integrated Management of Childhood Illnesses
IMNCI	Integrated Management of Newborn and Childhood Illnesses

JNNURM	Jawaharlal Nehru National Urban Renewal Mission
JSSK	Janani Shishu Suraksha Karyakram
JSY	Janani Suraksha Yojana
KMC	Kangaroo Mother Care
MDG	Millennium Development Goal
MNH	Maternal Newborn Health
NFHS	National Family Health Survey
NHM	National Health Mission
NMR	Neonatal Mortality Rate
NNF	Neonatal Forum
NRHM	National Rural Health Mission
NUHM	National Urban Health Mission
PHC	Primary Health Centre
PPP	Public Private Partnership
RCH	Reproductive and Child Health
RBSK	Rashtriya Bal Swasthya Karyakram
RMNCH+A	Reproductive, Maternal, Newborn, Child and Adolescent Health
SBA	Skilled Birth Attendant
SNCU	Special Newborn Care Unit
TBA	Trained Birth Attendant
U5MR	Under-Five Mortality Rate
UNICEF	United Nations Children's Fund
UPHC	Urban Primary Health Centre
USHA	Urban Social Health Activist
VHND	Village Health & Nutrition Day
VHSNC	Village Health Sanitation and Nutrition Committee
WASH	Water Sanitation and Health
WHO	World Health Organisation

CHAPTER 1

Introduction

Thirty years ago, the world made a commitment to protect and fulfil children's rights as enshrined in the United Nations *Convention on the Rights of the Child.*[1] The right to survive is the most fundamental of these rights. While India accounts for one-fifth of global live births, it also accounts for more than a quarter of neonatal deaths (2016),[2] which occur within the first 28 days of a child's life, also known as the *neonatal period.* Children face the highest risk of dying during the neonatal period, and the average neonatal mortality rate in 2018 was 18 deaths per 1,000 live births globally.[3] Around 2.5 million children died in the first month of their life across the world in 2018, accounting for approximately 7,000 neonatal deaths every day, and one-third of the deaths were reported on the first day itself. The neonatal mortality rate in India, where the chances of death during the neonatal period is 30 fold higher than that in the post-neonatal period,[4] stood at 23 deaths per 1,000 live births in 2018 (SRS 2018).

The WHO defines an infant as a child who is less than a year old.[5] During the first four weeks in an infant's life, which are most critical for survival, they are called neonates. The early neonatal period comprises the first six days post birth, and a majority of neonatal deaths are concentrated in this period (WHO, 2016).[6] The perinatal period comprises 7-28 days after birth. The Sample Registration System (SRS), Registrar of Census, GoI also follows the same definitions in indicators pertaining to child health and mortality. SRS 2018 data indicates that 72 percent of all infant deaths were neonatal deaths.

The Indian government (Ministry of Health and Family Welfare) and apex organisations like the WHO have published detailed guidelines on neonatal and newborn care.[7] While the guidelines for care of newborns

1 The United Nations Convention on the Rights of the Child (commonly abbreviated as the CRC or UNCRC) is a human rights treaty which sets out the civil, political, economic, social, health and cultural rights of children. ... Nations that ratify this convention are bound to it by international law.

2 Sankar MJ, Neogi SB, Sharma J, et al. State of newborn health in India. J Perinatol. 2016; 36(s3):S3-S8. doi:10.1038/jp.2016.183

3 https://www.unicef.org/india/what-we-do/newborn-and-child-health retrieved on 20.04.2020

4 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

5 WHO Key terms retrieved from https://www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/

6 Global Health Observatory Data retrievable from https://www.who.int/gho/child_health/mortality/neonatal_text/en/

7 See WHO recommendations on newborn health: guidelines approved by the WHO Guidelines Review Committee. Geneva: World Health Organisation; 2017 (WHO/MCA/17.07). Licence: CC BY-NC-SA 3.0 IGO and Child Health Guidelines under RMNCH+A retrievable from https://nhm.gov.in/index1.php?lang=1&level=3&sublinkid=1182&lid=364

are very extensive, evidence from India indicates post-natal care practices in the country are poor. The latest round of the National Family Health Survey (2015-16) shows that only 24 percent children received health check-ups from qualified medical personnel within 2 days of birth. This data also shows that less than 3 percent children who were born at home were taken to a health facility for check-up within 24 hours of birth. Only 21 percent mothers received complete antenatal care, whereas 62 percent mothers received adequate post-natal care.

Neonatal mortality receives little attention in the broader public health discourse in India. Goal 3 of the SDGs aims to end preventable deaths of newborns and children by reducing neonatal mortality to at least 12 per 1,000 live births and under-5 mortality to at least 25 per 1,000 live births by 2030. The National Plan of Action for children 2016, India commits to reducing neonatal mortality to 21 per 1,000 live births by 2021. Emerging consensus around newborn and child health suggests access to quality, comprehensive pre- and post-natal care, immunisation and nutrition are vital for the health and survival of infants and children. The major concern for families, communities, and nations throughout the world is ensuring the survival and well-being of children.

Neonatal Mortality

Death within the first 28 days of a child's life (0-27 days)[8] is classified as a neonatal death, and the neonatal mortality rate is computed according to the following formula:

$$\frac{\textit{Number of neonatal deaths}}{\textit{Total number of life birth}} \; x\,1000$$

The neonatal mortality rate is a key outcome indicator for newborn care and directly reflects availability of pre-natal, intrapartum, and neonatal care. Neonatal deaths may be divided into early neonatal deaths, occurring within the first 7 days of life, and late neonatal deaths, occurring between 7-28 days after birth.

8 WHO - Maternal and perinatal health www.who.org

Table 1: Terminology and definition of neonatal death[9]

Terminology	Definition
Neonatal mortality rate (NMR)	Number of deaths among all live births during the first 28 days of life expressed per 1000 live births.
Early neonatal mortality rate (ENMR)	Number of neonatal deaths <7 days of life expressed per 1000 live births.
Late neonatal mortality rate (LNMR)	Number of neonatal deaths between 7 and 28 days of life expressed per 1000 live births.
Perinatal mortality rate (PMR)	Perinatal mortality rate (PMR) is defined as the number of still births and infant deaths of less than 7 days per one thousand live births (LB) and still births (SB) taken together during the year

Infant and child mortality rates are important indicators of human development and general health conditions of any community.[10] There has been a steady decline in infant mortality in India over the years, particularly after the 1970s, owing to governmental efforts to increase quality and access to healthcare. The Infant Mortality Rate in India currently stands at 33 deaths per 1,000 live births (SRS 2017).

While these efforts and interventions brought down death rates among children under five years of age, their biggest impact lay in reducing mortality due to diseases among infants and children who were over a month old. Yet, a large proportion of infant mortality occurs during the neonatal period, when a child's risk of dying is nearly 15 times higher than later in life (WHO 2011). Although many efforts to improve the health of children have been made across the world over the past four decades with some notable successes, child mortality rates continue to remain high. Globally, it was estimated that 5.3 million children under five years died in 2018 (WHO, 2018). Roughly, 46 percent of under-five deaths occur in the first 28 days (WHO 2016).

Background

The current Neonatal Mortality Rate (NMR) in India is 23 per 1,000 live births (SRS 2018). Nearly 0.75 million neonates died in India in 2013, the highest for any country in the world.[11] Around 70 percent of total infant

9 Sample Registration System, Census of India

10 Ravindra G. Amonker and Gary D. Brinker *International Review of Modern Sociology* Vol. 27, No. 2 (Autumn 1997), pp. 1-22

11 https://www.unicef.org/india/what-we-do/newborn-and-child-health retrieved on 20.04.2020

deaths and more than half of under-five deaths occur in the neonatal period. Indeed, with the early NMR of 18 per 1,000 live births, deaths in the first week alone account for 55 percent of total infant deaths (SRS 2018).

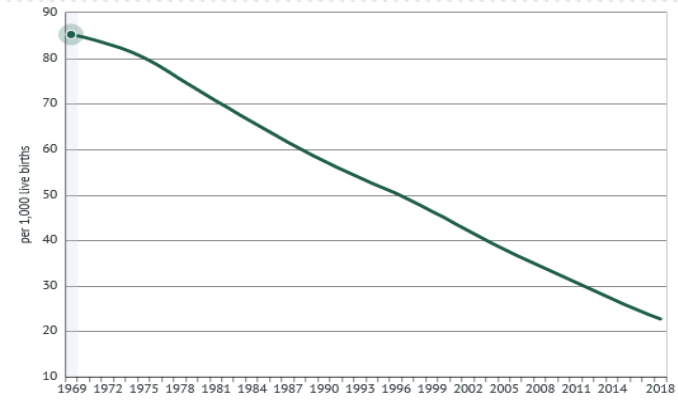

Figure 1: Prevalence of Neonatal Deaths in India[12]

Mortality rate of neonates in India fell gradually from 85.2 per 1,000 live births in 1969 to 23 per 1,000 live births in 2018. The rate fell by 25 percent between 1980 and 1990, from 69 to 53 per 1,000 live births. It fell another 15 percent, from 51 to 44 per 1,000 live births, between 1991 and 2000, and a further 15 percent, from 40 to 34 per 1,000 live births, between 2001 and 2009. The NMR dropped further to 23 to per 1000 in 2018.[13] Currently, around one million babies in the country die every year before they complete their first month of life.[14]

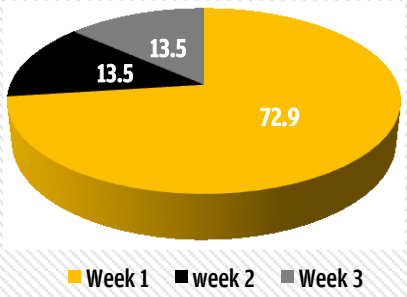

Figure 2: Distribution of Neonatal Deaths by time since birth

Source: India Newborn Action Plan (MOHFW, 2014)

12 Source https://knoema.com/WBWDI2019Jan/world-development-indicators-wdi
13 Source https://knoema.com/WBWDI2019Jan/world-development-indicators-wdi
14 Leena KC, Koshy DA, Thankachen D, Thomas D, Varghese DR, Fernandes DS. Knowledge of common problems of newborn among primi mothers admitted in a selected hospital for safe confinement. J Family Med Prim Care. 2014 Jul; 3(3) 204-206. doi:10.4103/2249-4863.141609. PMID: 25374854; PMCID: PMC4209672

The distribution of deaths over the neonatal period shows that most deaths (72.9%) occur in the first week after birth, whereas an equal number of deaths (13.5%) occur in the second and the third weeks (India Newborn Action Plan (MOHFW, 2014).

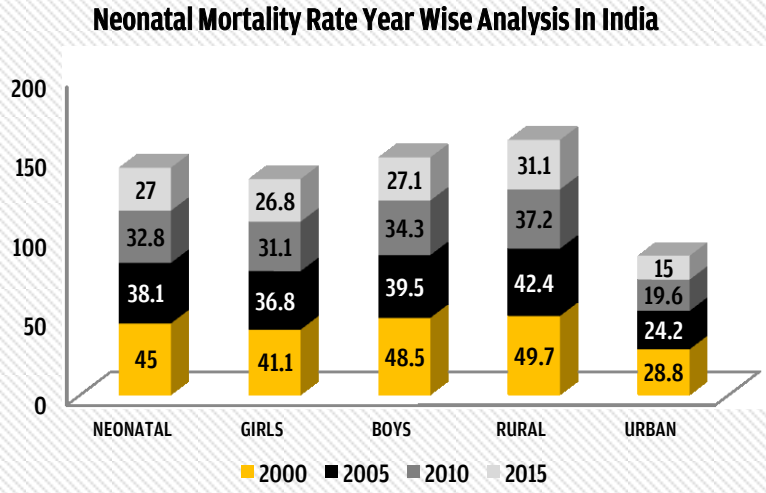

Figure 3: Gender and Geographical differences in Neonatal Death

Source: INAP 2014 MoHFW

Data shows that in the year 2000, the neonatal mortality rate in India was 45 (41.1 for girls and 48.5 for boys); the figure was 49.7 in rural areas and 28.8 urban areas. In the year 2005, NMR reduced to 38.1 (36.8 for girls and 39.3 for boys); it was 42.4 in rural areas and 24.2 in urban areas. In 2010, the NMR was 32.8 (31.1 for girls and 34.3 for boys); it was 37.2 in rural areas and 19.6 in urban areas. Although the NMR fell to 27 in 2015 (26.8 for girls and 27.1 for boys), the mortality rate in rural areas at 31.1 was more than double the rate in urban areas at 15. According to the National Family Health Survey (NFHS-4), 22.1 percent male children died in comparison to 18 percent female children. The death rate for boys was higher than that for girls for all years under consideration.

Analysis shows that efforts to reduce the neonatal mortality rate have had some positive impact. Urban areas have recorded lower death rates compared to rural areas primarily because health facilities are concentrated in urban areas. The latest state-wise data on NMR (2018) is represented below:

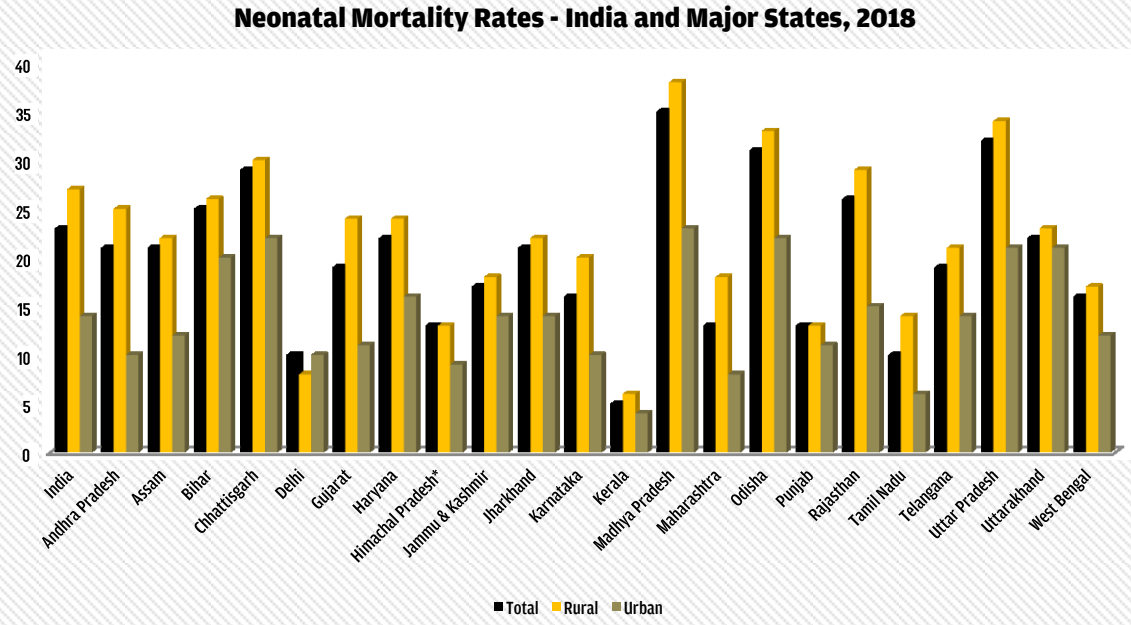

Figure 4: Difference between Rural and Urban of Major States in India

Source: SRS Statistical Report 2018[15]

Table 2: State wise neonatal mortality in India (SRS Statistical Report 2018)

Range	States
Less than 10	Kerala
10-15	Tamil Nadu, Himachal Pradesh ,Delhi ,Punjab, Maharashtra
16-20	Jharkhand, Karnataka, Jammu &Kashmir, Gujarat, Telangana, West Bengal
21-25	Andhra Pradesh, Assam, Bihar, Uttarakhand, Assam, , Haryana, Jharkhand
26-30	Rajasthan, Chhattisgarh
More than 30	Madhya Pradesh, Orissa, Uttar Pradesh

The difference between urban and rural neonatal mortality rates was lowest in Kerala, at four and six respectively, whereas in states like Orissa, Madhya Pradesh and Uttar Pradesh, the difference was steep. Uttar Pradesh had among the highest NMRs in the country at 32 deaths per 1,000 live births. Rural areas in the state witnessed 34 neonatal deaths per 1,000 live births compared to 21 in urban areas, indicating children in rural areas were more vulnerable.

15 SRS Statistical Report 2018, Office of the Registrar General and Census Commissioner, India Ministry of Home Affairs Government of India

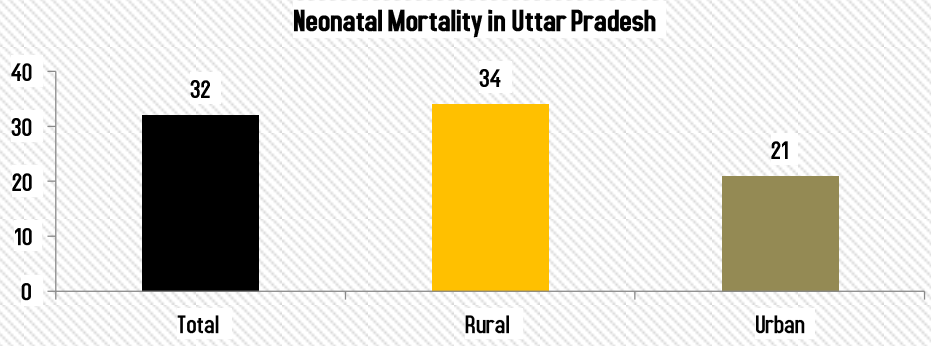

Figure 5: Status of Neonatal Mortality in Uttar Pradesh

Source: SRS Statistical Report 2018

Socioeconomic trends in neonatal mortality in India

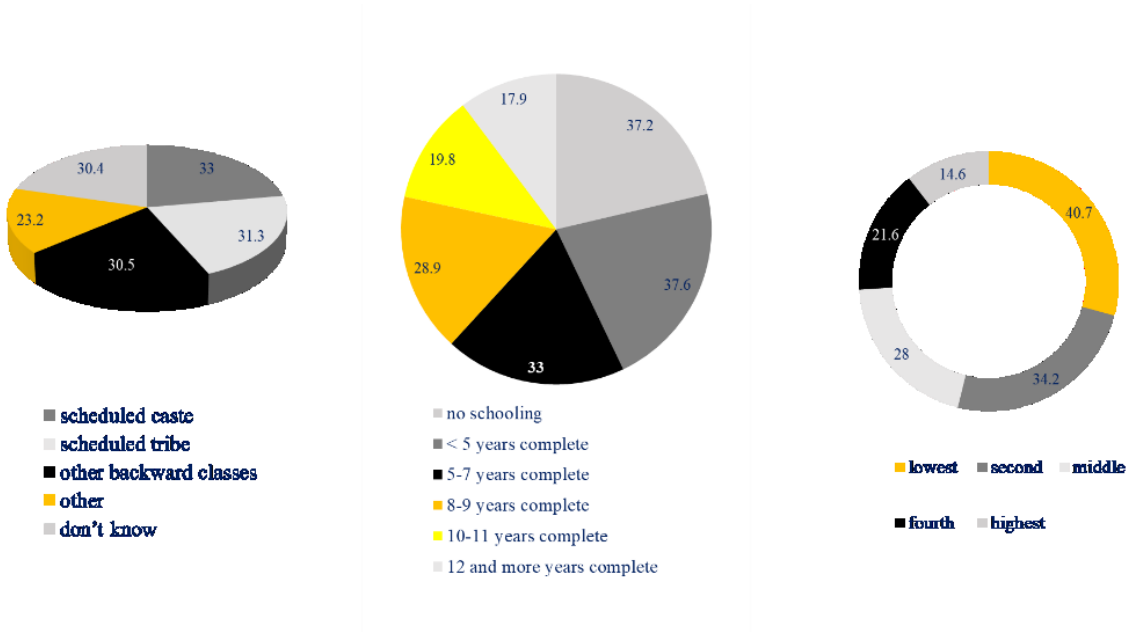

Figure 6: Schooling, Caste, Wealth Index wise neonatal deaths

Source: NFHS, Round-4, 2015-16

According to NFHS-4, the highest number of neonatal deaths (37.2%) took place in families where parents had no schooling, followed by Scheduled Caste (SC) families (33%). The lowest number of neonatal deaths (23.2%) was recorded among Other Backward Classes (OBCs) families. Neonatal deaths were highest (40.7%) for the lowest income group, and the lowest for the highest income group. This indicates that families from higher income groups can avail better medical facilities compared to lowest income groups.[16]

16 NFHS-4. ; Ministry of Health and Family Welfare Government of India , IIPS, chapter 7 Infant mortality Rate , pg no 186

A recent study has documented that in rural areas, SC children are 28 percent more vulnerable to neonatal death than Scheduled Tribe (ST) children.[17] Family characteristics play a key role in determining the health of the newborn. A study by Upadhyaya found that low educational status of parents (odds ratio (OR) 2.1, 95% CI; 1.4, 3.3), father's occupation (OR 1.8, 95% CI; 1.0, 3.0) and caste (OR 2.0, 95% CI; 1.2, 3.4) appear to explain a major fraction (45.7%) of neonatal deaths in Haryana[18].

Accessibility of Health Services

In India, there are poor links for neonatal specific care, and availability of and accessibility to emergency obstetric care.[19] India has a three-tier public health system, which includes primary, secondary, and tertiary level healthcare providers. States in India are administratively divided into districts, which are further divided into blocks and panchayats. The district health system constitutes the base for implementing health policies, managing deliveries, and providing healthcare services for a defined area. Every district is supposed to have a District Hospital (DH) that is linked to health centres such as sub-district or Community Health Centres (CHC), Primary Health Centres (PHC), and Sub Centres (SC). District hospitals are meant to provide effective and affordable healthcare services for a pre-defined population.

Neonatal mortality prevention requires a skilled workforce, and adequate quality, quantity and distribution of neonatologists, obstetricians, anaesthetists and midwives. Availability of good emergency obstetric care is necessary for improving the quality of birth services and treatment of complications that arise during pregnancy and at the time of childbirth. The weakest factor in India's emergency obstetric care is the availability of well-trained and appropriate staff at district and referral hospitals who can provide care at the time of delivery and neonatal care.[20]

Sub Centres

The Sub Centre is the most peripheral health facility and first contact point between the healthcare system and the community. Sub Centres are assigned tasks relating to interpersonal communication in order to induce be-

17 Singh A, Kumar A, Kumar A. Determinants of neonatal mortality in rural India. 2007-2008. Peer J 2013;1: e75.

18 Upadhyaya RP, Dwivedi PR, Rai SK, Misra P, Kalaivani M, and Krishnan A. Determinants of neonatal mortality in rural Haryana: a retrospective population based study. Indian Pediatrics 2012; 49(4): 291-294

19 Rammohan, A., Iqbal, K., & Awofeso, N. (2013). Reducing neonatal mortality in India: critical role of access to emergency obstetric care. PloS one, 8(3), e57244. https://doi.org/10.1371/journal.pone.0057244

20 Kant, S., Kaur, R., Malhotra, S., Haldar, P., & Goel, A. D. (2018). Audit of emergency obstetric referrals from a secondary level hospital in Haryana, North India. Journal of family medicine and primary care, 7(1), 137-141. https://doi.org/10.4103/jfmpc.jfmpc_16_17

haviour change and provide services in relation to maternal and child health, family welfare, nutrition, immunisation, diarrhoea control, and control of communicable diseases. Each Sub Centre must be manned by at least one auxiliary nurse midwife (ANM) / female health worker and one male health worker.

As on 31 March 2019, a total of 1, 60,713 SCs (1, 57,411 rural + 3,302 urban) were functioning in India. Out of the 1,57,411 SCs in rural areas and 3,302 SCs in urban areas, 7,821 and 98 centres respectively had been converted to Health and Wellness Centres (HWCs).[21]

In Uttar Pradesh, the average rural population serviced by every SC and HWC-SC as on 31 March 2019 ranged 7001 – 15000 (projected as per mid-year Population as on 1 July 2019), as against the norm of one SC for 5,000 people in rural areas. It was estimated that 517 posts for ANM/ Health Worker (Female) were lying vacant in the state in March 2019 (RHS 2019). The number of SCs for the districts where the study was conducted in Uttar Pradesh is represented below.

Table 3: Availability of SC

Availability of health centres	Sonbhadra	Varanasi	Kaushambi	Uttar Pradesh (Total)
Number of SCs	173	298	175	20056
Number of HWC – SCs	0	22	0	726

Primary Health Centres (PHCs)

The PHC is the first point of contact between the village community and the Medical Officer. PHCs were envisaged as providers of integrated healthcare to the rural population with emphasis on preventive and promotive aspects of healthcare. PHCs are established and maintained by state governments under the Minimum Needs Programme (MNP)/ Basic Minimum Services (BMS) Programme.[22] As per minimum requirements, a PHC should be manned by a medical officer supported by 14 paramedical and other staff. The activities of a PHC involve curative, preventive, promotive and family welfare services.

There are 30,045 functional Primary Health Centres (24,855 rural + 5,190 urban) in India. Out of 24,855 rural PHCs, 8,242 have been converted into HWCs, whereas 1,734 out of 5,190 PHCs in urban areas have been converted into HWCs (RHS 2019).

21 Rural Health Statistics 2018 -19, Government of India, Ministry of Health and Family Welfare, Statistics Division

22 The Minimum Needs Programme was introduced in the Fifth Plan with the objective of providing the rural population, particularly the rural poor, with access to certain items of social consumption which form an integral part of the basic needs. Initially, there were eight components under the MNP - Elementary Education, Rural Health, Rural Water Supply, Rural Roads, Rural Electrification, Rural Housing, Environmental Improvement of Urban Slums and Nutrition. During the Sixth Plan, Adult Education was added. In the Seventh Plan the list was further expanded with three more components namely Rural Domestic Energy, Rural Sanitation and Public Distribution System (Planning Commission, Eighth Five year plan).

In Uttar Pradesh, the average rural population serviced by a PHC as on 31 March 2019 ranged 50,001-95,000 (projected as per mid-year Population as on 1 July 2019), as against the norm of one PHC for 30,000 people in rural areas. It was estimated that 1,329 posts for doctors at PHCs were lying vacant in the state in March 2019 (RHS 2019). The number of PHCs and their details for the study districts is represented below.

Table 4: Availability of PHCs

	Sonbhadra	Varanasi	Kaushambi	Uttar Pradesh (Total)
Number of PHCs	26	20	24	2227
HWC – PHCs	5	31	12	1333

Community Health Centres (CHCs)

The **Community Health Centre** (CHC), the third tier in the network of rural healthcare institutions, was required to act primarily as a referral centre for patients requiring specialised healthcare services and treatment. As per minimum norms, a CHC must be manned by four medical specialists, including a surgeon, a physician, a gynaecologist and a paediatrician, who are supported by 21 paramedical and other staff. CHCs serve as a referral centre for four PHCs and provide facilities for obstetric care and specialist consultations.

There are 5,685 functional Community Health Centres (5335 rural + 350 urban) in the country (RHS 2019). In Uttar Pradesh, an average rural population of 2, 00,001 – 2, 55,000 (mid-year population as on 1 July 2019) was covered by a CHC as on 31 March 2019, as against the norm of one CHC per 80,000- 1, 00,000 people. The number of CHCs in the study districts is represented below (RHS, March 2019).

Table 5: Availability of CHCs

	Sonbhadra	Varanasi	Kaushambi	Uttar Pradesh (Total)
Number of CHCs	7	12	5	691

It is noteworthy that in Uttar Pradesh, there is a massive shortfall of specialists (surgeons, obstetricians and gynaecologists, physicians and paediatricians) in CHCs. As against a requirement of 2,716 specialists, there are only 484 specialists, resulting in a shortfall of 82 percent (RHS 2019).

An existing facility (District Hospital, Sub-divisional Hospital, and Community Health Centre etc.) can be declared a fully-operational First Referral Unit (FRU) only if it is equipped to provide round-the-clock emergency obstetric and newborn care services, in addition to other emergencies services that any hospital is required to provide.

Shortfalls in the government health sector

Shortfall of doctors in PHCs was 6 percent of the total requirement for the existing infrastructure.[23] In case of CHCs in Uttar Pradesh, there was a shortfall of surgeons (85.6%), obstetricians and gynaecologists (75%), physicians (87.2%) and paediatricians (79.9%). Overall, there was a shortfall of 82 percent specialists at CHCs in 2019 in comparison with IPHS norms. In addition to 3,881 Specialists and 15,395 General Duty Medical Officers (GDMOs) posted at CHCs, 13,347 and 3,197 AYUSH doctors were available at PHCs and CHCs respectively. A total of 1,152 and 1,920 Dental Surgeons were available at PHCs and CHCs respectively[24]. The availability of trained health staff in Uttar Pradesh for a population of one lakh was 4.133 as against the national average of 26. There was also a scarcity of hospitals and bed in the state.

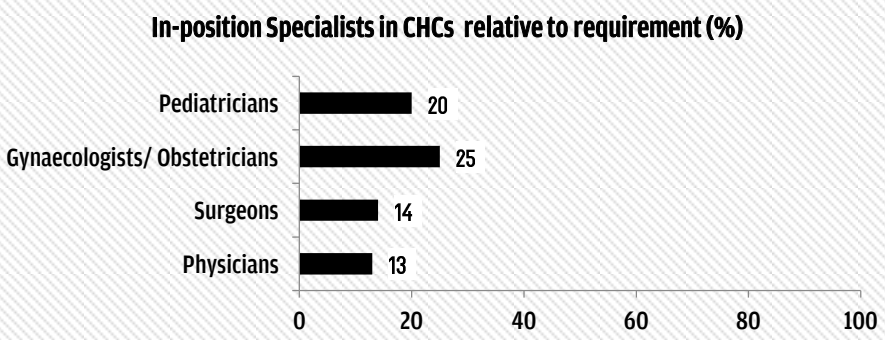

Figure 7: Shortfalls in doctors and specialists at CHCs

Source: Rural Health Statistics, 2019, MoHFW

Lack of doctors and adequate infrastructure adversely affects women and children's access to healthcare. According to the 71st round of the NSSO (January–June 2014), more than 70 percent (72% and 79% in rural and urban areas respectively) spells of ailments were treated at private facilities (comprising private doctors, nursing homes and hospitals, charitable institutions, etc.). The highest percentage of total medical expenditure by households was towards buying medicines (72% in rural and 68% in urban areas).[25]

23 https://main.mohfw.gov.in/sites/default/files/Final%20RHS%202018-19_0.pdf
24 Rural Health Statistics 2018 -19, Government of India, Ministry of Health and Family Welfare, Statistics Division
25 National plan of action for children2016

Causes of neonatal death

Major causes of neonatal deaths as per the latest Sample Registration System Report (SRS 2010-13) include prematurity and low birth weight (48.1%), birth asphyxia and birth trauma (12.9%), neonatal pneumonia (12.0%), other non-communicable diseases (7.1%), sepsis (5.4%), defined or cause unknown (5.0%), congenital anomalies (4.0%), diarrhoeal diseases (3.1%), injuries (0.9%), Tetanus (0.5%) and other causes (0.9%).[26] The figure below outlines the causes of neonatal deaths as identified in INAP 2014. These causes are discussed in detail in the subsequent sections.

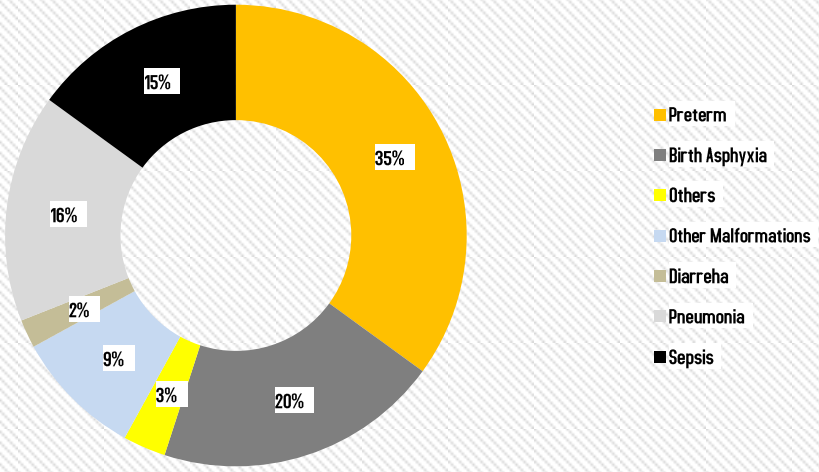

Figure 8: Causes of neonatal deaths Source: INAP 2014 MoHFW

Low birth weight[27]

Neonatal death is substantially influenced by birth weight and intrauterine growth restriction (IGR). Intrauterine growth restriction is a condition in which the foetus doesn't grow to normal weight during pregnancy. Although there are varied causes for intrauterine growth restriction, key reasons include placenta abnormalities, high blood pressure in the mother, infections and smoking or alcohol abuse.[28] Nearly 7.5 million children are born with a LBW (<2500 g) in India. This accounts for 42 percent of the global burden, the largest for any country.[29]

26 https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=819&lid=219

27 Low birth weight (LBW) is defined by the World Health Organisation as a birth weight of an infant of 2,499 g or less, regardless of gestational age. Subcategories include very low birth weight (VLBW), which is less than 1500 g (3 pounds 5 ounces), and extremely low birth weight (ELBW), which is less than 1000 g (2 pounds 3 ounces).[2] Normal weight at term delivery is 2500–4200 g (5 pounds 8 ounces – 9 pounds 4 ounces).

28 https://www.webmd.com/baby/iugr-intrauterine-growth-restriction#1

29 Pabbati J, Subramanian P, Renikuntla M. Morbidity and mortality of low birth weight babies in early neonatal period in a rural area teaching hospital, Telangana, India. Int J Contemp Pediatr 2019; 6:1582-7.

The prevalence of SGA (Small in Gestational Age) is 46.9 percent, higher than all but two countries in the world.[30] Each year, ~3.5 million preterm (<38 weeks of gestation) neonates are born in India. Community-based studies indicate that the LBW infants are at 11–13 times increased risk of dying than NBW infants. Indeed, >80 percent of total neonatal deaths occur among LBW/ preterm neonates.[31]

Neonatal sepsis

Neonatal sepsis is a blood infection that occurs in an infant younger than 90 days in age. Early-onset sepsis is seen in the first week of life. Late onset sepsis occurs after week one through three months of age. Although many babies with bacterial infections recover completely and have no other problems, neonatal sepsis is a leading cause of infant death.[32]

The burden of neonatal sepsis in the country is massive. Hospital-based studies suggest an incidence of 30 per 1,000 live births, whereas community-based studies indicate an incidence of 2.7–17 percent of all live births.[33] A recent prospective study by Baqui *et al.* (2006) in rural India provided data on the timing of cause-specific neonatal deaths: <50 percent neonatal deaths secondary to sepsis occur in the first week of life. About 30 percent sepsis-related deaths occur in the second week, whereas around one-fifth occur in weeks three and four.[34] Infants with sepsis also stay longer in the hospital and are at a high risk of major neurodevelopmental disabilities at a later age.[35]

Perinatal asphyxia

Perinatal asphyxia is lack of blood flow or gas exchange to or from the foetus in the period immediately before, during, or after the birth process.[36] Perinatal asphyxia not only leads to neonatal deaths, but also accounts for a significant proportion of stillbirths. It is difficult to estimate the true burden of asphyxia because of the differ-

30 Baitule S, Deshmukh M, Reddy MH Indian Pediatr. 2001 Burden of morbidities and the unmet need for healthcare in rural neonates--a prospective observational study in Gadchiroli, India. 2001 Sep; 38(9):952-65.

31 National Neonatal Perinatal Database, report for the year 2002-03. Available at http://www.newbornwhocc.org/pdf/nnpd_report_2002-03.PDF (accessed on 2 April 2020).

32 NIH, US National Library of Medicine retrieved from https://medlineplus.gov/ency/article/007303.htm

33 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

34 Baqui AH, Darmstadt GL, Williams EK, Kumar V, Kiran TU, Panwar D, Srivastava VK, Ahuja R, Black RE, Santosham M Bull World Health Organisation. 2006 Sep; 84(9):706-13.

35 Pawar, S. J., Oleti, T., Bharathi, S., Tipparaju, S., & Mustafa, E. (2018). Growth and Neurodevelopmental Outcome in Preterm LBW Infants with Sepsis in India: A Prospective Cohort. International journal of Pediatrics, 2018, 5735632. https://doi.org/10.1155/2018/5735632

36 Gillam-Krakauer M, Gowen Jr CW. Birth Asphyxia. [Updated 2020 Apr 23]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2020 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK430782/

ent definitions used in various studies. The reported incidence varied from two to 16.2 percent with reported case fatality rates ranging from 38.5 to 74 percent. About 2.8 and 5.6 percent of all live births had moderate and severe asphyxia, respectively, in a large hospital-based study; the case fatality rate was relatively low at 8.7 percent.[37]

Neonatal jaundice

Neonatal jaundice is yellowish discoloration of the skin, conjunctiva and the sclera from elevated serum or plasma bilirubin in the newborn period.[38] Other symptoms may include excess sleepiness or poor feeding. Complications may include seizures, cerebral palsy, or kernicterus. In many cases, there is no specific underlying disorder (physiologic). In other cases, it results from red blood cell breakdown, liver disease, infection, hypothyroidism, or metabolic disorders (pathologic). A bilirubin level more than 34 µmol /l (2 mg/dL) may be visible. Concerns, in otherwise healthy babies, occur when levels are greater than 308 µmol/L (18 mg/dL);[39] jaundice is noticed in the first day of life, there is a rapid rise in levels, jaundice lasts more than two weeks, or the child appears unwell. Globally over 100,000 late-preterm and term children die each year as a result of jaundice.[40]

Neonatal pneumonia

The onset of lung infection in a neonate may be within a few hours of birth and part of a generalised sepsis syndrome, or after 7 days and confined to the lungs. Pneumonia contributes to between 750,000 and 1.2 million neonatal deaths each year worldwide.[41] *Streptococcus pneumonia* probably causes about 25 percent of neonatal pneumonia. It is estimated that 3.9 million of the 10.8 million deaths of children annually worldwide occur in the first 28 days of life. More than 96 percent of all neonatal deaths occur in developing countries, and pneumonia accounts for a substantial proportion of these.[42] Pneumonia is the single largest infectious cause of death in children worldwide. Pneumonia killed 808,694 children under the age of five in 2017, accounting for 15

37 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

38 Ansong-Assoku B, Ankola PA. Neonatal Jaundice. [Updated 2020 Jun 25]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2020 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK532930/

39 Hyper bilirubinemia in Term Newborn Meredith L.Porter, CPT, MC, American Family Physician Feb 15 2002 https://www.aafp.org/afp/2002/0215/p599.htm Retrieved on 6 APRIL 2020

40 Olusanya, BO; Teeple, S; Kassebaum, NJ (February 2018). "The Contribution of Neonatal Jaundice to Global Child Mortality: Findings from the GBD 2016 Study". Pediatrics. 141 (2): e20171471. doi:10.1542/peds.2017-1471. PMID 2930539

41 Nissen MD. Congenital and neonatal pneumonia. Paediatr Respir Rev. 2007; 8(3):195-203. doi:10.1016/j.prrv.2007.07.001

42 Duke T Neonatal pneumonia in developing countries Archives of Disease in Childhood - Fetal and Neonatal Edition 2005; 90: F211-FF219.

percent of all deaths of children under five years old.[43] Pneumonia affects children and families everywhere, but is most prevalent in south Asia and sub-Saharan Africa. Children can be protected from pneumonia; it can be prevented with simple interventions, and treated with low-cost, low-tech medication and care.[44]

Diarrhoea

Diarrhoea is the passage of three or more loose or liquid stools per day, or more frequently than is normal for the individual. It is usually a symptom of gastrointestinal infection, which can be caused by a variety of bacterial, viral and parasitic organisms. Severe diarrhoea leads to fluid loss, and may be life threatening, particularly in young children and people who are malnourished or have impaired immunity (WHO).[45]

Diarrhoea represents a major condition responsible for paediatric mortality worldwide. The onset of neonatal diarrhoea may rapidly lead to life threatening dehydration and malnutrition. Thus, early diagnosis and timely treatment are both crucial in the management of diarrhoea in neonates. NFHS-4 data showed that 8.2 percent of children under five years of age in India had diarrhoea in the two weeks preceding the survey. In UP, the prevalence was much higher, with 15 percent children under five years reporting diarrhoea in the two weeks preceding the survey. However, only 38 percent of the children in UP reporting diarrhoea were given ORS.

Neonatal Tetanus

Tetanus is acquired through exposure to the spores of the bacterium *Clostridium Tetani,* which are universally present in the environment, including soil, dust and manure. The disease is caused by the action of a potent neurotoxin produced during the growth of the bacteria in dead tissues. It is particularly common and serious in newborn babies, and is called neonatal tetanus. Neonatal tetanus is particularly common in rural areas where most deliveries are at home without adequate sterile equipment. NFHS-4 data showed that 87 percent expecting mothers in UP had their births protected against neonatal tetanus.

Home delivery by unskilled persons: Unskilled health workers or the Traditional Birth Attendants (TBA) are seen as contributing to maternal mortality and undesired neonatal outcomes in home deliveries in a major

43 https://www.who.int/news-room/fact-sheets/detail/pneumonia
44 https://www.who.int/news-room/fact-sheets/detail/pneumonia.
45 Retrieved from https://www.who.int/topics/diarrhoea/en/

way. People in rural areas prefer home deliveries over institutional deliveries because of low income and owing to the belief that the former is better than the latter. This is due to lack of awareness and knowledge among people about the importance of trained professionals for proper management and care during pregnancy. Home deliveries by unskilled persons can lead to death of newborns due to mismanagement of the delivery.[46] Moreover, improper use of techniques and medications causes death of neonates as well as mothers. NFHS-4 (2015-16) data indicates that 20 percent of births in the country are home births. In Uttar Pradesh, only 68 percent of the births were institutional births.

Lack of essential newborn care for asphyxia and hypothermia: Despite improvements in perinatal practice and neonatal care in recent years, the incidence of long-term neurological sequelae, such as cerebral palsy, has remained essentially unchanged.[47]

Poor child care practices: Rural areas in India have a shortage of medical professionals, as urban areas account for 74 percent of doctors who serve 28 percent of the population.[48]

Lack of awareness: There is a general lack of awareness about maternal and child health, partly due to lack of information about the importance of safe motherhood practices, which in turn plays an important role in the health of neonates. The level of healthcare awareness and specific child care awareness is low because of low educational status, poor functional literacy, low accent on education within the healthcare system, and low priority for health in the population, among others.[49]

Affordability: Most healthcare facilities pertaining to deliveries and maternal health are so expensive that the poor, who constitute a significant portion of the population, are not able to afford it. The public sector, on the other hand, offers healthcare at low or no cost but is perceived as being unreliable, of inferior quality and generally not the first choice, unless one cannot afford private care. Even with free and accessible public healthcare, the average out of pocket expenditure for a delivery was Rs 1,956 in Uttar Pradesh (NFHS-4). Only 48 per-

46 Oliver Ezech, Karen Odberg Patterson 2012 Perinatal Mortality, BoD publishing 2012, p.7
47 Cornette L. (2012). Therapeutic hypothermia in neonatal asphyxia. Facts, views & vision in ObGyn, 4(2), 133-139.
48 Ministry of Health and Family Welfare, Government of India, Chapter I: Overview of the National Health System. Report: Task Force on Medical Education for the National Rural Health Mission; p. 9.
49 Kasthuri A. (2018). Challenges to Healthcare in India - The Five A's. Indian journal of community medicine: official publication of Indian Association of Preventive & Social Medicine, 43(3), 141-143. https://doi.org/10.4103/ijcm.IJCM_194_18

cent of pregnant women in UP reported having received financial assistance under the Janani Suraksha Yojana, the flagship scheme for maternal health in the country.

Lack of facilities for early detection of anomalies and care of sick newborns: Lack of access to proper healthcare facilities and medication, lack of adequate mechanisms for early detection of abnormalities, and lack of adequate number of trained personnel affect care for sick newborns in major ways. Lack of availability of proper infrastructure and facilities for proper child-care practices leads to the early death of neonates. Many small healthcare facilities, for instance, don't have incubators (neonatal intensive care unit) that are necessary in every hospital because they mostly treat neonates with respiratory problems.

Harmful local practices: Lack of awareness also leads to many harmful local practices such as unhygienic cord cutting and delayed breastfeeding, which can be potentially fatal.

Early marriage and early pregnancies: NFHS-4 data showed early marriages and consequent pregnancies have increased propensities for negative outcomes. The data showed that pregnancies in the 15-19 years age group had the highest number of miscarriages, still births and early deaths of infants. One in every seven pregnancies in this age group had a negative outcome, and 48 percent neonatal deaths occurred due to prematurity and low birth weight (NPAC 2016).

Poor nutritional levels of adolescent girls/ gender discrimination: The NFHS-4 2015-16 data showed high prevalence of iron deficiency anaemia among girls aged 15-19 years in India at 54 percent. The number reduced marginally over the preceding 10 years, from 56 percent in NFHS-3 2005-06.[50] NFHS-4 data also showed that half of the pregnant women aged 15-19 years were anaemic. The Comprehensive National Nutrition Survey (CNNS) showed that 28.4 percent adolescent girls aged 10-19 years were anaemic and around 21.5 percent had iron deficiency. In Uttar Pradesh, 31 percent adolescent girls aged 10-19 years were anaemic and 21.5 percent had iron deficiency. Inadequate nutrition can cause non-optimal pregnancy outcomes including mortality.

50 National Family Health Survey 2005-06

Poor or lack of antenatal care/ visits: Complete antenatal care comprises at least four antenatal visits, at least one tetanus toxoid (TT) injection and iron folic acid tablets or syrup taken for 100 or more days. Full antenatal care of the pregnant mother is vital for appropriate care of the mother and the baby. In India, only one out of five expectant mothers received complete antenatal care. In Uttar Pradesh, less than 4 percent expectant mothers in rural areas received complete antenatal care (NFHS-4 2015-16).

Rationale of the study

The human development index of the past few decades shows a steep fall in neonatal mortality rate in India. In 1960, the rate was 12 percent, and has reduced to 3 percent presently (SRS data). Neonatal deaths comprise over three-fifths of infant deaths in the country. Although India has a large population, its share of neonatal mortality is disproportionately large. One of the major reasons for neonatal deaths, especially later born neonatal deaths, in India is lack of access to nutrition, which in turn leads to underweight/ malnutrition of the mother. India envisions a healthcare system that eliminates all preventable deaths of newborns and stillbirths, and where every pregnancy is wanted, every birth is celebrated, and where women, babies, and children survive, thrive, and reach their full potential.

The commitments in the India Newborn Action Plan (INAP)[51] were framed in alignment with the global ENAP.[52] INAP aims to lower preventable newborn deaths and preventable stillbirths in a staggered manner, with specific targets for 2017, 2020 and 2025, to eventually reduce them to single digits (fewer than 10 per 1,000 live births) by 2030, five years ahead of the global ENAP deadline. All Indian states are required to achieve this target individually by the end of 2035. The INAP is expected to serve as a roadmap that redefines and focuses national and subnational strategies and actions till 2020, when India will review progress and revise its strategy.

More efforts are needed to fully eradicate a wide range of diseases and address persistent and emerging health issues. Sufficient funding and effective utilisation, improved sanitation and hygiene and increased access to healthcare personnel can play a significant role in saving the lives of millions newborns. Uttar Pradesh currently is one of the worst performing states in terms of achieving INAP targets. While the state was required to achieve a NMR of 21 per 1,000 live births by 2020, the figure is still at 32 (SRS-2018). Goal 3.2 of the SDGs on

[28] The India Newborn Action Plan (INAP) was launched in September 2014 with the aim of ending preventable newborn deaths and stillbirths by 2030. The salient features are: INAP has set the goals for neonatal mortality and stillbirths. The goal is to attain Single Digit Neonatal Mortality and Stillbirth Rates by 2030

[52] The global Every Newborn Action Plan (ENAP), launched in 2014, provides a road map of strategic actions for ending preventable newborn mortality and stillbirth and contributing to reducing maternal mortality and morbidity.

Child Health aims to end preventable deaths of newborns and to reduce NMR to at least 12 by 2030. There is also an urgent need to understand what contributes to the nigh rates of neonatal mortality in Uttar Pradesh in light of the national target of reducing NMR to <12 by 2030.

CRY intervention in UP's health sector and grassroots experiences

In Uttar Pradesh, CRY focuses on creating community awareness on maternal and child health related issues through community orientation/ training, home visits and counselling. Emphasis is placed on early registration of pregnant women in the ICDS system to prevent neonatal deaths, as this helps in ensuring proper antenatal care (ANC) services through ANM/ sub-health centre and anaemia testing. Follow-ups are done with pregnant women on a regular basis along with identification of High Risk Pregnancies (HRP) for referral services through government hospitals. While working with the families of pregnant women, discussions are held with male members for their engagement, preparedness and follow ups on the delivery plan (to ensure institutional deliveries, persons who will accompany the pregnant woman, items/ materials to kept ready, reference emergency numbers, among others). Awareness is also created among communities about institutional deliveries, best practices of post-natal care, early initiation of breastfeeding, timely immunisation, exclusive breastfeeding, ensuring proper nutrition for pregnant and lactating mothers etc.

CRY has also set up five Counselling and Monitoring Centres (CMCs) that focus on first the 1,000 days of newborn children to ensure their survival and reduce neonatal/ infant mortality in the study areas. CMC counsellors provide training to ANMs to provide specific counselling support at the community level, undertake home visits and follow up HRP cases for referral services. Health camps for maternal and child health are also organised in coordination with the state health department.

To ensure effective functioning of healthcare services, coordination and interface meetings are also organised with block and district officials. Various operational issues are discussed in these meetings so as to influence the district plan for recruitment of health workers and improvement of health infrastructure. CRY partners also ensure documenting the neonatal deaths/ infant child deaths/ maternal deaths through case stories to identify reasons of death based on the 3D model (delay in decision-making, delay in transportation and delay in access to healthcare facilities).

Objectives of the study

The main objectives of this study were:

1. To understand the sociocultural determinants of neonatal deaths;
2. To understand the beliefs, traditions and practices of the community regarding newborn care among mothers;
3. To document the accessibility, availability and utilisation of healthcare services in relation to neonatal health.
4. To document the experiences of mothers in relation to newborn health and community systems.

Scope of the study

The study findings will guide CRY and other civil society organisations' (CSOs) endeavours to address issues related to neonatal deaths in Uttar Pradesh. Findings will also strengthen policy dialogue with different stake-holders such as policy makers and influencers at various forums.

CHAPTER 2

Review of literature

India has made significant progress in reducing newborn mortality over the past few decades and its share in the global newborn mortality burden has come down from one-third in 1990 to less than a quarter now. India's under-five (U-5), infant and neonatal mortality rates witnessed significant decline in the past decade, but are still relatively high. Neonatal deaths constitute the largest contributor to under-five and infant deaths in the country. The percentage of neonatal deaths to total infant deaths in 2018 was 72 percent (SRS 2018). There are nearly one million fewer newborn deaths and ten thousand fewer maternal deaths each month in India in 2017 compared to 2000.[53] Policies and initiatives to increase access to maternal health services largely account for this progress. Although the real incidence of neonatal deaths in India is unknown due to the lack of diagnoses and under-reporting, with the birth of 25 million children each year, India accounts for nearly one-fifth of the world's annual child-births. These patterns suggest much progress remains to be made as regards newborn health in India.

The literature review in this chapter describes current issues and interventions as regards newborn health and care in India. It highlights differences in opinions, contradictory findings and evidence, and the varied explanations offered by different authors. This helps understand multiple facets and complexities of the issue, opening up scope for new possibilities.

International studies on neonatal mortality

In the UNICEF report on newborn mortality rate that ranked countries according to the number of deaths per 1,000 live births,[54] India was ranked 12th amongst 52 lower middle-income nations. The Central African Republic, Afghanistan, Somalia and Lesotho followed by Pakistan were among the worst five countries on this list. The report, however, identified one positive aspect for India wherein the country successfully halved the number of deaths among children under the age of five years. The under-five mortality rate reduced by 66 percent be-

53 Newborn and child health https://www.unicef.org/india/what-we-do/newborn-andchild-health retrieved on 20 .3. 2020
54 Levels & Trends in Child Mortality Estimates developed by the UN Inter-agency Group for Child Mortality Estimation Report 2019

tween 1990 and 2015, which helped India remain in the run to meet the Sustainable Development Goals target for achieving under-five mortality of 25 per 1,000 live births by 2030.

Lucia Hug, 2019[55] showed that south Asian countries and African countries shoulder 77 percent of the global burden of neonatal deaths. It also stated that the UN is focusing on the causes of neonatal deaths, which occur predominantly due to preterm birth and intrapartum-related complications and infections such as sepsis, meningitis and pneumonia. The study also stated that according to the WHO and Maternal and Child Epidemiology Estimation Group, 35 percent of all neonatal death in 2017 were due to complications associated with poor resources and preterm delivery.

Amani Abu-Shaheen, 2019[56] investigated the knowledge and experience of mothers and caregivers about neonatal danger signs identified by WHO. A community-based study was conducted on mothers who had delivered or nursed a baby in the preceding two years. The findings showed that the proportion of mothers with knowledge of at least three neonatal danger signs was low.

Walellign Anmut, 2017[57] revealed that mothers' knowledge regarding care of neonates, neonatal danger signs, and factors related to death of neonates are of primary importance. The study showed that there was poor knowledge among mothers regarding neonatal dangers signs, and that mothers' practices were unsafe – most mothers took their sick child to traditional healers and relied on home remedies.

Carlo, 2010[58] sought to study the effect of training in newborn care and resuscitation on seven-day (early) neonatal mortality rates for very low birth weight (VLBW) infants. The study was designed to test the hypothesis that these training programmes reduced neonatal mortality rates for VLBW infants. As part of the study, local instructors trained birth attendants from 96 rural communities in six developing countries in protocol and data collection, the WHO Essential Newborn Care (ENC) course, and a modified version of the American Academy of

55 Lucia Hug, D. S. (2019). Levels & Trends in Child Mortality. Estimates developed by the UN Inter-agency Group for Child Mortality Estimation, 52.

56 Amani Abu-Shaheen, I. A. (2019, March 28). Mothers' and Caregivers' Knowledge and Experience of Neonatal Danger Signs: A Cross-Sectional Survey in Saudi Arabia. Biomed research International

57 Walellign Anmut, B. F. (2017). Mother knowledge and Practice about Neonatal Danger Signs and Associated Factors in Wolkite Town, Gurage Zone, SNNPR, Ethiopia, 201. Journal of Biomedical Sciences,

58 Carlo, W. A. (2010). High Mortality rates of very low birth weight infants in developing countries despite training. Pediatrics, 126, 1072-1080.

Paediatrics Neonatal Resuscitation Programme (NRP) using the train-the-trainer model. To test the impact of ENC training, data on infants of who weighed 500-1499 gms at birth were collected using a before/ after, active baseline, controlled study design. A cluster-randomised, controlled trial design was used to test the impact of the NRP. A total of 1,096 VLBW (500–1499 gms at birth) infants were enrolled, and 98.5 percent of live-born infants were monitored to seven days. All-cause, seven-day neonatal mortality, stillbirth, and perinatal mortality rates were not affected by ENC or NRP training. Neither ENC nor NRP training of birth attendants decreased the seven-day neonatal, stillbirth, or perinatal mortality rates for VLBW infants born at home or at first-level facilities. The study concluded that encouragement of delivery in a facility where a higher level of care is available may be preferable when delivery of a VLBW infant is expected.

L Gary, 2008[59] found that infection is one of the major causes of neonatal death. The study provided information about different types of infections that led to the death of neonates, like acute respiratory infections, diarrhoea, tetanus and HIV. It discussed incidence of Neonatal Sepsis, Bacteraemia, and Meningitis and associated mortality. It also provided information about indirect causes of infections and suggested strategies to prevent and treat infection in neonates. Strategies outlined in the study pertain to maternal immunisation to prevent neonatal diseases, neonatal immunisation, antenatal care and prevention of neonatal infection, delivery care and prevention of delivery-related neonatal infections, postnatal care and prevention of related neonatal infections, breast-feeding, and proper management of various neonatal infections, identification of neonates with infection, and treatment of neonates with infection.

WHO, 2006 stated that socio-cultural beliefs contributed to the practice of applying substances to the umbilical stump to heal it instead of letting it fall off naturally. This posed a major risk of infection in the stump. Religious or cultural beliefs played a major role in such practices. Since every community has its own culture and traditions, practices differ from community to community. Use of unsterilised rubber nipples, plastic bottles and pacifiers is unsafe. It is important to identify traditional and cultural practices and evaluate their impact. They can be categorised as beneficial practices that should be promoted, harmful practices that should be stopped, harmless practices that can be ignored for the time being or practices that need to be researched before being applied.

59 Lee, A. C., Mullany, L. C., Tielsch, J. M., Katz, J., Khatry, S. K., LeClerq, S. C., Adhikari, R. K., Shrestha, S. R., & Darmstadt, G. L. (2008). Risk factors for neonatal mortality due to birth asphyxia in southern Nepal: a prospective, community-based cohort study. Pediatrics, 121(5), e1381–e1390. https://doi.org/10.1542/ peds.2007-1966

Parlato, 2004[60] found that hygiene and uninfected conditions are often hard to achieve in poor communities. People are not aware of the dangers an unclean environment poses for a newborn child, and don't take much efforts to take preventive measures. Lack of hygienic practices extended to cord care, drying and wrapping of the newborn, etc.

R Bale, 2003[61] discussed the causes of death in mothers' foetus or neonates in the book *Neonatal Death: Case definition and guidelines for data collection, analysis and presentation of immunisation safety data*. The study showed that death of foetuses or neonatal deaths were disproportionally large in developing countries, and maternal death was 500 times greater in developing countries in comparison to industrialised countries. The study indicated that there was inadequate attention on healthcare programmes and proficiencies were very low, and 40 percent of all deaths in children less than 5 years of age occurred during the neonatal year/ period. Immunisation in maternal care was extremely beneficial for infants and could prevent neonatal deaths. This study defined the level of certainty of a neonatal death.

Costello et al, 2001[62] conducted a study on the State of the World's Newborn. The report identified infections, complications of prematurity, birth asphyxia and injuries as primary causes of newborn mortality, with low birth weight an important secondary factor. Another major cause of neonatal deaths in developing countries was poor maternal health during pregnancy. The study argued that many neonatal deaths could be prevented with three cost-effective solutions that do not depend on highly technical training or sophisticated equipment: (1) immunisation against tetanus; (2) skilled healthcare at delivery; and (3) immediate and exclusive breastfeeding. The report maintained that policymakers, non-governmental organisations, healthcare professionals and community leaders must collaborate to strengthen existing healthcare delivery systems so as to provide expectant mothers and babies the care they need. A key part of this effort lies in advocating and creating policies that address newborns' special needs. The appendices to the report include tables providing information on health status and newborn health services and practices according to countries.

60 Ronald P. Parlato, Gary L. Darmstadt 2004, Saving newborn lives tools for newborn health qualitative research to improve newborn care practices

61 R. Bale, B. J. (2003). Improving Birth Outcomes: Meeting the Challenge in the Developing World. Washington (D C): National Academies Press (US).R. Bale, B. J. (2003).

62 Costello, A. &. (2001). State of the World's Newborns A Report from Saving Newborn Lives,cotectual factors influncing new boen care amongst rural poor westarn2016 vol 4

Neonatal deaths in India

Major causes of neonatal deaths in India as per the Sample Registration System Report (2010-13) include prematurity and low birth weight (48.1%), birth asphyxia and birth trauma (12.9%), neonatal pneumonia (12.0%), other non-communicable diseases (7.1%), Sepsis (5.4%), ill-defined or cause unknown (5.0%), congenital anomalies(4.0%), diarrhoeal diseases (3.1%), injuries (0.9%), Tetanus (0.5%) and all other remaining causes (0.9%).

A nationally representative mortality survey titled **The Million Death Study** showed that more than 2.3 million children died in India in 2005.[63] This study investigated the causes of neonatal and child mortality in India and their differences by sex and region. It showed there were 10,892 deaths among neonates and 12,260 among children aged 1–59 months. When this data was projected nationally, **three causes** accounted for 78 percent (0.79 million of 1.01 million) of all neonatal deaths – prematurity and low birth weight (0.33 million, 99% CI 0.31 million to 0.35 million), neonatal infections (0.27 million, 0.25 million to 0.29 million), and birth asphyxia and birth trauma (0.19 million, 0.18 million to 0.21 million). Diarrhoea and pneumonia were also identified as leading causes. The study concluded that five avoidable causes accounted for nearly 1.5 million child deaths in India in 2005, with substantial differences between regions and sexes. Expanded neonatal and intrapartum care, case management of diarrhoea and pneumonia, and addition of new vaccines to immunisation programmes could substantially reduce child deaths.

Li Liu, 2019[64] showed that India had the largest number of under-five deaths among all countries in 2015, with substantial sub-national disparities. The study indicated that efforts to reduce vaccine-preventable deaths and geographical disparities are necessary to improve upon progress achieved between 2000 and 2015. Enhanced policies and programmes are needed to accelerate mortality reduction in high-burden states and among neonates to achieve the SDG child survival targets in India by 2030.

63 Million Death Study Collabourators, Bassani, D. G., Kumar, R., Awasthi, S., Morris, S. K., Paul, V. K., Shet, A., Ram, U., Gaffey, M. F., Black, R. E., & Jha, P. (2010). Causes of neonatal and child mortality in India: a nationally representative mortality survey. Lancet (London, England), 376(9755), 1853–1860. https://doi.org/10.1016/S0140-6736(10)61461-4

64 Li Liu*, Y. C. (2019). National, regional, and state-level all-cause and specific under-5 mortality in India in 2000–15: a systematic analysis with implications for the Sustainable Development Goals. Lancet Glob Health, 7, 734

Coffey, 2019[65] documented the prevalence of underweight children in comparison to other developing populations. The study examined birth order and early life mortality in developing countries, and recommended policies to reduce maternal under-nutrition. It also cautioned that social forces and household structures could create hurdles in providing nutritional inputs and promoting neonatal survival. Extensive contemporary literature on maternal health and child well-being stresses education of the mother is one of the foremost predictors to adopt anti-natal and post-natal care.

Pathirana J, 2019[66] found that more than 40 percent of all under-five deaths occured during the neonatal period. Immunisation of pregnant women had proven beneficial to both mother and the infant by decreasing morbidity and mortality. With an increasing number of immunisation trials on pregnant women and the roll-out of recommended vaccines for them, there is a need to clarify causal details of neonatal deaths. The study defined the levels of certainty of neonatal deaths and the timing of death during the neonatal period in relation to immunisation of the mother.

Diane Coffey, 2019[67] conducted a study on reducing neonatal mortality in India. Policy measures to reduce the NMR, including a large-scale conditional cash transfer programme, were focused on promoting birth in health facilities rather than at home. Between 2005 and 2015, the percentage of facility births doubled, from 40 to 80 percent. The study sought to assess the hypothesis that facility births reduced NRM by using data from the National Family Health Survey 2015–2016. It found that for babies born outside Uttar Pradesh and Bihar, facility birth was robustly associated with neonatal survival. The controlled association between facility birth and neonatal survival was 7 per 1,000 in the eastern region (West Bengal, Assam, Jharkhand, and Odisha) and 13 per 1,000 in the central region (Madhya Pradesh and Chhattisgarh). In Uttar Pradesh and Bihar, however, birth in a health facility appeared to have little impact on neonatal survival. Documenting the lack of an association between facility births and neonatal deaths in Uttar Pradesh and Bihar was important because these states accounted for 43 percent of India's neonatal mortalities. These findings suggested future research needed to investigate whether and how the quality of maternal and newborn care in health facilities differed across regions.

65 Coffey, D. (2019). The association between neonatal death and facility birth in regions of India. Demographic Research, 40, 417-430. 8

66 Pathiran J, M. F.-K. (2016). Case definition and sample ; guidelines for data collection. *Vaccine Dec 1,34 (49)* , 6027-6037

67 Coffey D 2019 The association between neonatal death and facility birth in regions of India Demographic research Volume 40 Article 16 pg. 417-430

Jayanta Kumar Bora, 2018[68] found that India's contribution in global share of under-five deaths was highest. Continuous monitoring of the reduction of under-five mortality rate (U5MR) at the local level was essential for setting priorities for policy-makers and health professionals. The study sought to provide an update on district-level disparities in NMR and U5MR with special reference to SDG-3 on preventable deaths among newborns and children under five years. It found that it would be difficult for 97 percent of Uttar Pradesh's district to achieve SDG-3 by 2030.

N Sreekumaran Nair, 2018[69] conducted a study on factors associated with mortality due to neonatal pneumonia in India. It showed India's contribution in global neonatal deaths was highest, and the country also has the largest number of pneumonia-related neonatal deaths in the world. The study showed that deaths during the neonatal period that occurred due to pneumonia were primarily related to maternal care. In developing countries like India, adequate immunisation services are not provided to mothers, resulting in neonatal deaths.

Talukdar, 2017[70] examined the association between frequency of antenatal care visits and neonatal mortality in *Frequency and Timing of Antenatal Care Visits and its impact on Neonatal Mortality in EAG states of India*. The study used data from NFHS-4 and showed that mothers who received antenatal care visits in their first trimester reported the lowest pregnancy problems and neonatal deaths. It also showed that in most cases of neonatal death, there was no ANC visit. Health promotion through organised and appropriate education of healthcare personnel could help increase ANC visits to pregnant women.

Jayani Pathiranlor and M Muñozd, 2016 [71] found that immunisation of mothers could lead to decrease in neonatal mortality rates. More than 40 percent of all deaths in under-five children occurred during the neonatal period.[72] Immunisation of pregnant women was beneficial for both mother and infant as it decreased morbidity and mortality. With an increasing number of immunisation trials on pregnant women and the roll-out of recommended vaccines for them, there is a need to clarify these nuanced details of neonatal deaths.

68 Jayanta Kumar Bora, (2018). Neonatal and under-five mortality rate in Indian districts with reference to Sustainable Development Goal 3: An analysis of the National Family Health Survey of India (NFHS), 2015–2016. PLoS One., 13 (7)

69 N Sreekumaran Nair, 1. L. (2018). Factors associated with mortality due to neonatal pneumonia in India: a protocol for systematic review and planned meta-analysis. BMJ Open, 7, e017403.10,

70 Talukda, R. G. (2017). Frequency and Timing of Antenatal Care Visits and Its Impact on Neonatal Mortality in EAG States of India. Journal of Neonatal Biology, 6 (3).5

71 Jayani Pathiranlor M.Muñozd, V.-K. H. (2016). Neonatal death: Case definition & guidelines for data collection, analysis, and presentation of immunisation safety data. Vaccine, 3449, 6027-6037.

72 This figure is currently 72% (SRS 2018)

Coffey D, 2014[73] found that health service providers were focused on capturing economic rents associated with the Janani Suraksha Yojana (JSY, India's flagship cash transfer programme for hospital births) in rural Uttar Pradesh and provided extremely poor quality care. Further, the JSY programme did not provide beneficiaries with a large monetary transfer at the time of birth. The value of transfers to beneficiaries was small, and based on a detailed accounting of the monetary costs of hospital and home deliveries.

Perianayagam Arokiasamy, 2008[74] found that eight socioeconomically backward states – Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Orissa, Rajasthan, Uttaranchal and Uttar Pradesh, also referred to as the Empowered Action Group (EAG) states – lagged behind in demographic transition and had the highest infant mortality rates in the country. Neonatal mortality constituted the highest proportion of infant mortality EAG states.

V Ramlingaswamy, 2008[75] provided further insights into reduction in child mortality by studying the distribution of neonatal deaths in first week of life in the community. The study showed the first three days constituted the most hazardous phase, and postnatal care in health programmes needed to take cognisance of this, especially while formulating training guidelines for ASHA workers in the recently launched NRHM.[76] The study confirmed that most of neonatal and infant deaths occurred within three days after birth.

73 Coffey D. (2014). Costs and consequences of a cash transfer for hospital births in a rural district of Uttar Pradesh, India. *Social science & medicine (1982)*, *114*, 89–96. https://doi.org/10.1016/j. socscimed.2014.05.035

74 Perianayagam Arokiasamy, A. G. (2008). Neonatal mortality in the empowered action group states of India: Trends and determinants. journal of bio social sciences, 40 (2), 183-201

75 V Ramalingaswamy Bhavan, D. R. (2008). Age Profile of Neonatal Deaths. *Indian Academey of Pedriactics, 45*, 991-994.

76 The National Rural Health Mission (NRHM) was launched on 12th April 2005, to provide accessible, affordable and quality healthcare to the rural population, especially the vulnerable groups. The Union Cabinet vide its decision dated 1st May 2013, has approved the launch of National Urban Health Mission (NUHM) as a Sub-mission of an over-arching National Health Mission (NHM), with National Rural Health Mission (NRHM) being the other Sub-mission of National Health Mission.

Other studies

Various other studies showed that financial incentive programmes were widely used to increase demand for quality services under JSY (Khan, 2010[77]; Amudhan, 2013[78]; and Powell-Jackson, 2016[79]). These studies suggested financial incentives may increase demand for institutional deliveries but are not sufficient for improving maternal health outcomes. The quality of services offered once women entered a facility may constitute the missing link in achieving desired outcomes. Studies showed that although cash incentive programmes increased institutional deliveries, this did not translate into reduced maternal mortality rates, leaving much room for improvement in quality of care within institutions (Leon, 2014; Banerjee, 2013).

Some other studies showed that select interventions increased women's demand for qualified healthcare providers, birth preparedness and planning, modern methods of contraception, and discussions with healthcare providers and others about warning signs and symptoms (Kumar, 2012; Banerjee, 2013; Leon, 2014; Achyut, 2016). Some studies also showed that women receiving health education were less likely to experience pregnancy and labour-related issues.

No studies, however, linked JSY to reductions in maternal mortality rates. Several studies provided mixed results on the impact of community-based information and mobilisation campaigns on increasing the knowledge and attitudes of women, their families, or their caregivers as a means of increasing demand for quality care and improving health outcomes. Delivering targeted messages through media campaigns was generally more effective than peer education, and focused messages were more effective than initiatives that provided large amounts of information. Nobel laureate Banerjee (2013) showed that community-based information and mobilisation campaigns resulted in changes in maternal and reproductive health knowledge, attitudes, and, in some cases, demand for quality health services (Kumar, 2011[80]; Banerjee, 2013[81]; Leon, 2014[82];

77 Khan, M.E., A. Hazra, and I. Bhatnagar. "Impact of Janani Suraksha Yojana on Selected Family Health Behaviors in Rural Uttar Pradesh." The Journal of Family Welfare, vol. 56, special issue, 2010

78 Amudhan, S., K. Mani, S.K. Rai, C.S. Pandav, and A. Krishnan. "Effectiveness of Demand and Supply Side Interventions in Promoting Institutional Deliveries: A Quasi-Experimental Trial from Rural North India." International Journal of Epidemiology, vol. 42, no. 3, June 2013, pp. 769–780.

79 Powell-Jackson, T., S.K. Pereira, V. Dutt, S. Tougher, K. Haldar, and P. Kumar. "Cash Transfers, Maternal Depression and Emotional Well-Being: Quasi-Experimental Evidence from India's Janani Suraksha Yojana Programme." Social Science & Medicine, vol. 162, August 2016, pp. 210–218

80 Kumar, V., A. Kumar, V. Das, N.M. Sirvastava, A.H. Baqui, M. Santosham, and G.L. Darmstadt. "Community-Driven Impact of a Newborn-Focused Behavioral Intervention on Maternal Health in Shivgarh, India." International Journal of Gynecology and Obstetrics, vol. 117, no. 1, April 2012, pp. 48–55

81 Banerjee, A., and E. Duflo. "Addressing Absence." The Journal of Economic Perspectives, vol. 20, no. 1, winter 2006, pp. 117–132.

82 Leon, F.R., R. Lundgren, I. Sinai, R. Sinha, and V. Jennings. "Increasing Literate and Illiterate Women's Met Need for Contraception via Empowerment: A Quasi-Experiment in Rural India." Reproductive Health, vol. 11, no. 74, 2014.

Achyut, 2016[83]). Participating women increased their knowledge about warning signs during pregnancy and labour and the legality of abortion (Kumar, 2012; Banerjee, 2013).

Mothers' Knowledge and Practices

Manju Rahi, 2019[84] conducted a study on newborn care practices including delivery practices, immediate care after birth and breast-feeding in an urban slum in Delhi. Breast milk as the first feed was significantly higher in case of institutional deliveries, the study found. It recommended that there was an urgent need to reorient healthcare providers and educate mothers on clean delivery practices and early neonatal care.

Akhil Bangari, 2019,[85] Reshma and Sujatha, 2014,[86] Rekha Udgi, 2018[87] found that various cultural practices like applying kajal, giving the baby cow's milk, pouring oil into the ears, keeping a knife under the pillow, isolating the mother and baby for 30-40 days were widespread. These studies showed that there was a strong relationship between demographic variables (like type of family and religion) and cultural practices and beliefs around newborn care among mothers.

Rokade Hemlata G1, 2015[88] sought to study various breastfeeding practices and knowledge levels in lactating PNC mothers. It showed that very few mothers initiated breastfeeding at the correct time, and customs like giving pre-lacteals and discarding colostrum were still practiced. Though a majority of mothers had the correct knowledge, breastfeeding practices were not appropriate, and very few mothers received advice regarding breastfeeding from trained personnel.

83 Achyut, P., A. Benson, L.M. Calhoun, M. Corroon, D.K. Guilkey, E. Kebede, P.M. Lance, A. Mishra, P. Nanda, R. O'Hara, R. Sengupta, I.S. Speizer, J. Stewart, and J. Winston. "Impact Evaluation of the Urban Health Initiative in Urban Uttar Pradesh, India." Contraception, vol. 93, no. 6, February 2016, pp. 519–525.

84 Bhandari N, Bahl R, Taneja S, Martines J, Polian MK. Pathways to infant mortality in urban slums of Delhi, India: Implications for improving the quality of community and hospital-based programmes. J Health Popul Nutr. 2002; 20:148–55. 22

85 Bangri A., A. B. (2019). Traditional beleifs and practices in newborn care among mothers in tertiary care centre in Uttrakhand ,India. international Journal of Community Medicine and Public Health (ISSN 2394-6032), 2500-2604

86 Sujata, R. a. (june 2014). Cultural Practices and beliefs on newborn care among mothers ina selected hospital of MangloreTaluka 12. Nitte University Journal of Health an16d Science, 4 (2), 21-26

87 N Nethra, R. U. (2018). A study on traditional beliefs and practices in newborn care among mothers and practices in newborn care among care among mothers in a teritary healthcare centre in vijyapura north karnataka. International Journal of Community Medicine and Public Health, 5 (3), 1035-1040

88 Rokade Hemlata G1, K. A. (2015). Study of breastfeeding practices amongst PNC mothers in urban slum areas in Solapur city, Maharashtra. Sch. J. App. Med. Sci., 3 ((6c)), 2369-2373

Leena KC, 2014[89] conducted a study on the mothers of neonates in the maternity unit of a Medical College and Hospital in Mangalore. A pre-tested, structured questionnaire on danger signs of neonatal health was used to collect information from 60 mothers who were admitted for safe confinement for a one-month period. The study showed there was a need to provide adequate information to first-time mothers about common newborn problems and this would help mothers care for their newborns better.

Ogunlesi and Oufowora, 2010[90] found that in India, traditional medicines were used for the treatment of neonatal conditions like bulging fontanel, chest in-drawing, and rapid breathing.

Bhandari, 2005[91] found that in Haryana, 75 percent newborns were given pre-lacteal feeds of honey, tea and diluted milk, and babies were often not breastfed during the first three days. They were often given sweetened water; this presumed that the colostrum was discarded.

Causes of neonatal deaths (local context)

R Shankar, 2014[92] conducted a study based on verbal autopsy that showed over 75 percent of deaths in India occurred in homes, and more than half of these did not have a certified cause. Further, most deaths in rural areas occurred at home, making certification by a qualified medical practitioner impossible. The cross-sectional epidemiological study was conducted in randomly selected rural areas of Khatauli block of Muzaffarnagar district in Uttar Pradesh. Verbal autopsy data was collected by a team of health workers who were adequately trained for the same well in advance. A total of 24 perinatal deaths were reported, out of which seven (29.2%) were stillbirth and 17 (70.8%) were neonatal deaths. Fourteen mothers (58.3%) received ANC visits and half of the deliveries were conducted by untrained *dais* (local midwives). Home deliveries numbered 20 (83.3%) whereas 10 (58.8%) of the deceased were early neonates. The main causes of death as per to verbal autopsies were pneumonia – 4 (23.5%), diarrhoea – 2 (11.8%), and neonatal jaundice – 3 (17.6%). The study concluded that pneumonia, diarrhoea and neonatal jaundice constituted about 53 percent of total neonatal deaths.

89 Leena KC, K., (2014, July 3). Knowledge of common problems of newborn among primi mothers admitted in a selected hospital for safe confinement. J Family Med Prime Care. , 204-6.

90 TA, O. (2010 May; 14(3) :). Maternal socio-demographic factors influencing the initiation and exclusivity of breastfeeding in a Nigerian semi-urban setting. Maternal Child Health J., 459-65

91 Nita Bhandari, S. M. (01 September 2005). Use of multiple opportunities for improving feeding practices in under-twos within child health programmes. Health Policy and Planning, 20 (05), 328-336

92 R, M. K. (2014, 2 4). verbal austopsy of neonental death in khatuil blook of distric muzaffarnagar.

Sartaj Ahmad, 2012[93] assessed newborn care practices in home deliveries in the urban slums of Meerut and found that the immunisation status was poor, practices regarding newborn care were harmful, and mothers had poor knowledge regarding the same. These inadequacies needed to be addressed through improved coverage of existing health services.

Patil, 2007[94] investigated the feasibility and cultural acceptability of community neonatal death audits in rural areas of Uttar Pradesh. The ideal method to approach the community and discuss the death of a particular neonate, the number and characteristics of participants needed during discussion to ensure maximum participation, and the duration of discussion were explored. Community members' ability to identify avoidable factors leading to the death of the neonate, their suggestions regarding possible solutions, and their acceptance of the process was observed.

Sethi, 2005[95] conducted a study among the rural poor in western Uttar Pradesh to identify factors influencing newborn care, which showed that nearly all newborns were left wet and naked on the floor until the placenta was delivered and bathed immediately after birth. Very few birth attendants washed their hands with soap before assisting the delivery. The study found that birth attendants used new blade dipped in hot water to cut the cord but used unsterilised cord ligature.

Monica Kaushal, 2005[96] sought to evaluate knowledge about breastfeeding and health-seeking behaviour for neonatal sickness among mothers and grandmothers in a rural community. The findings showed that the first response to illness was home remedies, followed by unqualified village practitioners, followed by the government hospital. Knowledge regarding desirable breastfeeding practices was inadequate and several inappropriate beliefs were widely prevalent. Although knowledge regarding infant sicknesses was present, seeking help from qualified healthcare providers was considerably delayed as most respondents preferred village practitio-

93 Sartaj Ahmad, K. G. (2012). Assessment of the Newborn Care Practices in Home Deliveries among Urban Slums of Meerut, UP India. Journal of Community Medicine & Health Education, 2 (8), 1000171

94 Z Patel, V. K. (2007). Feasibility of community neonatal death audits in rural Uttar Pradesh, India. Journal of Perinatology, 27, 556–564

95 Sethi Vani, S. K. (2005). Contextual Factors influencing Newborn care among Rural Poor in Western Uttar Pradesh. Pakistan Journal of Nutrition, 10.9023/pjn2005.273 275

96 Breastfeeding Practices and Health-seeking Behavior for Neonatal Sickness in a Rural Community Journal of Tropical Pediatrics 51(6):366-76 · January 2006

ners to government hospitals. Babies were not breastfed for three days after birth, and were often given sweetened water. The study presumed that the colostrum was left out of the babies' diet altogether.

Garg SK, 1993[97] conducted a household survey of neonatal mortality in Meerut district of Uttar Pradesh in 1991. The study found that although neonatal mortality had declined over the preceding 10 years, the reach of qualified medical personnel among rural communities was limited. Knowledge of some health practices such as immunisation was evident, but the service component was inadequate. This study confirmed that exogenous factors contributed to at least 66 percent of neonatal deaths, which could have been averted with proper and timely maternal and child healthcare services.

Government initiatives to address neonatal health and mortality

India has traversed an eventful journey of evolution and implementation of child healthcare policies and programmes since independence. The vision and focus of these programmes has changed over the years with growth in the understanding of child health. India was one of the first countries to roll out a National Family Planning Programme in 1952 with the aim of lowering the fertility rate and controlling population growth. Although the health of infants and newborns constituted a relatively minor component of this programme,[98] the National Policy for Children in 1974 prioritised child health, nutrition, orphan and destitute children[99] and children with disabilities and the need to implement laws for the same.

The family planning programme transitioned into Family Welfare Programme in 1977. Maternal and child healthcare became an integral part of this programme with the recognition that reduction in infant and child mortality was directly proportional to reduction in birth rate.[100] With an increased thrust on the health of children, the Expanded Programme on Immunisation (EPI) was launched in 1978 to provide vaccination against diphtheria, pertussis, tetanus, poliomyelitis, measles and tuberculosis. The Universal Immunisation Programme (UIP) was launched to overcome the inadequacies of the EPI,[101] initially in a phased manner. It became operational in all districts within a year.

97 Garg SK, M. V. (1993). Neonatal Mortality in Merrut District. Indian J Med Sci., 47 (09), 222-25

98 Mathur, M.R., Reddy, K.S. Child Health Policies in India: Moving from a Discernible Past to a Promising Future. Indian J Pediatr 86, 520–522 (2019). https://doi.org/10.1007/s12098-019-02968-7

99 Jagannadham V. National policy for children. Indian J Publ Admin. 2017;25:533-48

100 Department of Health & Family Welfare, Government of India. Child Health Programme in India; 2010. Available at: http://mohfw.nic.in/. Accessed 10 April 2019

101 Immunisation Programme in India was introduced in 1978 as 'Expanded Programme of Immunisation' (EPI) by the Ministry of Health and Family Welfare, Government of India. In 1985, the programme was modified as 'Universal Immunisation Programme' (UIP) to be implemented in phased manner to cover all districts in the country by 1989-90 with the one of largest health pro-

National health policy and neonatal health

The focus in child health prior to the eighties was the mainly on infections and diseases, preventable disease vaccines, diarrhoea and malnutrition. The birth of the National Neonatology Forum (NNF) in 1980 was a major milestone. The NNF has since played a vital role in all major neonatal healthcare achievements. Although the report of the task force on Minimum Perinatal care was published by the Ministry of Family and Health Welfare in 1982, the recommendations were translated into the Child Survival and Safe Motherhood (CSSM) programme only ten years later, in 1992. In 1997-98, the CSSM was integrated into the country's Reproductive and Health Programme Policy aimed at reinforcing the Oral Rehydration Therapy (ORT) and Acute Respiratory Infection (ARI) programmes for control of diarrhoea and pneumonia in children and control of anaemia in pregnant women. The Reproductive and Child Health (RCH) Programme Phase-I was introduced in 1997-98 to fulfil the unmet need for family welfare services in the country, especially among poor and under-served communities, and was integrated with CSSM in 2005. Experience from RCH Phase-I determined the contours of RCH-II, which brought about a paradigm shift from the 'one size fits all' design to an approach where sub-national requirements, capacities and performances were considered and steered to stimulate demand for services. RCH Phase-II adopted Integrated Management of Neonatal and Childhood Illnesses (IMNCI) in 2005, which consolidated preventive and curative elements to improve the skills of healthcare staff, overall health systems and family and community health practices.

Initiatives in Child Health

1886 Establishment of training of dais

1902 First midwifery Act for safe delivery

1952 Family planning programme

1978 Expanded programme on immunisation

1985 Universal Immunisation Programme

1992 Child Survival& Safe Motherhood Programme

1995 National Maternity Benefit Scheme

1997 RCH Programme Phase-1

2005 RCH Programme Phase-2 (01-04-2005)

2005 National Rural Health Mission

2005 Janani Suraksha Yojana

2009 Navjaat Shishu Suraksha Karyakram

2013 RMNCH+A Strategy 2011

2014 Indian Newborn Action Plan

2016 MAA (Mothers Absolute Affection)

2016 Pradhan Mantri Surakshit Matritva Abhivan (PMSMA)

gramme in the world. Ministry of Health and Family Welfare, Government of India provides several vaccines to infants, children and pregnant women through the Universal Immunisation Programme. Immunisation is the process whereby a person is made immune or resistant to an infectious disease, typically by the administration of a vaccine. Vaccines are substances that stimulate the body's own immune system to protect the person against subsequent infection or disease.

The National Rural Health Mission (NRHM) was launched in 2005 to focus on Reproductive, Maternal, Newborn, Child Health and Adolescent (RMNCH+A) services, and the adolescent health component was added much later. Its objectives included improvement of maternal and child health through a continuum of care and lifecycle approach, and it focused on improving linkages between various levels of healthcare systems and strengthening referral systems. This was subsumed into National Health Mission in 2013 along with the proposed National Urban Health Mission to increase the coverage and quality of healthcare for mothers and children across the country. An estimated 26 million children are born every year under the National Health Mission (NHM). As per Census 2011, children (0-6 years) account for 13 percent of the country's population.

The Child Health Programme under the National Health Mission (NHM) comprehensively integrates interventions that improve child survival and addresses factors contributing to infant and under-five mortality. It is now well recognised that child survival cannot be addressed in isolation as it is intricately linked with the health of the mother, which is further determined by her health and development as an adolescent. Therefore, the concept of Continuum of Care that emphasises on care during critical life stages in order to improve child survival is followed under the national programme. Another dimension of this approach is the stress on ensuring the availability of critical services at home through community outreach and health facilities at various levels (primary, first referral units, tertiary healthcare facilities). Newborn and child health comprise two key pillars of the reproductive, maternal, newborn, child and adolescent health (RMNCH+A) strategic approach, 2013.[102] The provision of healthcare for children, particularly in rural areas, is given priority attention in this approach. The impact of these concerted efforts was clearly visible, as the under-five mortality rate came down from 111 per 1,000 live births in 1990 to 39 in 2018. We now need to be on track to reach the SDG target of 25 by 2030.

Interventions under the National Health Mission focusing on newborns:

Janani Suraksha Yojana 2005: Safe motherhood intervention to increase institutional delivery through demand-side financing and conditional cash transfer

102 National Health Mission Ministry of Health and Family Welfare, Government of India

Integrated Management of Neonatal and Childhood Illness (IMNCI) at the community level and at health facilities 2007: Its main objective was standard case management of major causes of neonatal and childhood morbidity and mortality.

Navjat Shishu Suraksha Karyakram (NSSK) 2009: Its main objective was basic newborn care and resuscitation training for healthcare providers.

Jannani Shishu Suraksha Karyakram (JSSK) 2011: It is a zero out-of-pocket expenditure programme for maternal and infant health services through free healthcare and referral transport entitlements.

Facility Based Newborn Care (FBNC) 2011: Newborn care facilities at various levels of public health services, including newborn care corners (NBCCS) at all points of child birth to provide immediate care; newborn stabilisation units (NBSUS) at CHCs/ FRUs for management of select conditions and stabilisation of sick newborns before referral to highest centres; and special newborn care units (SNCUS) at district/ sub-district hospitals to provide sick newborns with all types of care except assisted ventilation and major surgeries.

Home Based Newborn Care (HBNC) 2011: Provision of essential newborn care to all newborns, special attention on preterm and low birth weight newborns, early detection of illness followed by referral, support to family for adoption of healthy practices by ASHA workers.

The India Newborn Action Plan (INAP) was launched in September 2014 with the aim of ending preventable newborn deaths and stillbirths by 2030.

The salient features are:

- INAP has set the goals for neonatal mortality and stillbirths. The goal is to attain Single Digit Neonatal Mortality and Stillbirth Rates by 2030.
- INAP is to be implemented within the existing Reproductive, Maternal, Newborn, Child and Adolescent health (RMNCH+A) framework of the National Health Mission (NHM).
- Six pillars of intervention packages impacting stillbirths and newborn health have been identified, which include:
  1. Preconception and antenatal care
  2. Care during labour and child birth
  3. Immediate newborn care
  4. Care of healthy newborn
  5. Care of small and sick newborn
  6. Care beyond newborn survival
- For effective implementation, a

Rashtriya Bal Swasthya Karyakram (RBSK) 2013: Screening children with birth defects, diseases, deficiencies, and developmental delays (including disabilities) and implementing various interventions to improve the health of children. These include:

Janani Shishu Suraksha Karyakram 2011: It entitles all pregnant women delivering in public health institutions to free delivery including caesarean sections. Almost 80 percent of live births in India take place in health facilities today, compared to 25 percent 25 years ago.[103]

India Newborn Action Plan 2014 that seeks to reduce neonatal mortality and stillbirths and **Integrated Action Plan for Pneumonia and Diarrhoea** launched in four states with highest child mortality (UP, MP, Bihar and Rajasthan).

Village Health and Nutrition Days for imparting nutritional counselling to mothers and improving child care practices.

Mother and Child Tracking System to ensure registration and tracking of all pregnant women and newborn babies so that provision of regular and complete services to them can be ensured.

National Iron Plus Initiative 2013 to prevent anaemia among vulnerable age groups, women of reproductive age, pregnant and lactating women.

MAA (Mothers Absolute Affection) 2016 to promote breastfeeding through the health system.

Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) 2016 to reduce maternal and infant mortality rates through safe pregnancies and safe deliveries.

The Child Health programme under the RMNCH+A strategy of NHM comprehensively integrates interventions that improve child health and nutrition status and addresses factors contributing to neonatal, infant, under-five mortality and malnutrition. The National Population Policy (NPP) 2000, National Health Policy 2002, Twelfth Five Year Plan (2007-12), National Health Mission (NRHM: 2005 – 2017), Sustainable Development Goals (2016-2030) and New National Health Policy, 2017 have laid down goals for child health.

103 UNICEF, Division of Data, Research and Policy 2016).

Table 6: NHP Target

Child Health Indicator	Current status	NHP Target
Neonatal Mortality rate	23	16 by 2025

The National Plan of Action for Children (NPAC), 2016

The National Plan of Action for Children 2016 is based on principles embedded in the National Policy for Children 2013. It seeks to ensure convergence of on-going programmes and initiation of new programmes so as to focus on pre-determined objectives through well-defined strategies and activities and thus achieve a certain level of outcome. The NPAC 2005 was framed for a period of five years. While no formal evaluation of the plan was undertaken, many of the goals – like reducing IMR to 30 and MMR to 100 per 100,000 live births, 100 percent coverage for rural sanitation, universalisation of early childhood care and education services, elementary education and complete abolition of child labour and child marriage by 2010 – remain unfulfilled. Since the government is committed to achieving these objectives, the new national policy reaffirms this as a national mandate, and the new plan seeks to carry it forward towards realisation. The NPAC 2016 takes into account the current priorities for children in India, and seeks to strengthen and activate the implementation and monitoring of national constitutional and policy commitments and the UN Convention on the Rights of the Child. It provides a roadmap that links policy objectives with actionable programmes and strategies and identifies indicators for monitoring progress. The plan's success in achieving identified outcomes by 2021 is dependent on prioritised action for children by different stakeholders with the necessary vigour and pace. The challenge is to get over the un-even pace of implementation of various programmes and schemes along with inadequate financial and human resources, so that SDG targets can be achieved.

NPAC 2016 focuses attention on the inter-relatedness of deprivations and needs, and outlines measures to address each of them while ensuring all children from all strata of society develop to their full potential in a holistic manner. The plan aims at establishing effective coordination among all stakeholders, including ministries, departments and civil society organisations towards the planning, implementation, monitoring and assessment of all policies and programmes adopted for children. It also provides a framework for states and union territories to develop their own plans to protect and promote children's rights and development within the framework of NPC 2013 and Sustainable Development Goals (SDGs).

Despite significant improvements in child survival, the burden of neonatal mortality remains high. NMR is among the major causes of death among children under five years of age in India, which can be prevented by implementing several simple and effective recommendations on basic birth care practices outlined by WHO, NHM, INAP and NACP. Although several initiatives, such as Janani Suraksha Yojana and Janani Shishu Suraksha Karyakram, have attempted to address these gaps, their impact remains limited due to poor governance, shortage of health workers in primary healthcare facilities and lack of preparedness of healthcare facilities. Despite the presence of a number of programmes and policies for newborn care, India lags behind the SDG target of reducing NMR to 12 for every 1,000 live births by 2030 owing to disparities between geographical areas. Uttar Pradesh fares the worst in terms of neonatal mortality (SRS 2018, NFHS-4), and studies show that there is lack of knowledge, malpractices are widely prevalent, and mothers are not aware of the danger signs of newborn complications. Although schemes like JSSY have boosted institutional deliveries, they have not increased child survival. The present study aims to identify gaps in the knowledge, attitude, and practices of newborn care among mothers in the rural areas of Varanasi, Kaushambi and Sonbhadra.

Uttar Pradesh – maternal and child care programme

Various programmes and schemes under the NHM to improve maternal and child health are implemented in Uttar Pradesh. While these programmes and schemes have been described in the earlier section, Uttar Pradesh also has a few additional programmes that are implemented under the umbrella programme, NHM. They are:

Janani Shishu Suraksha Karyakram (JSSK) scheme provides healthcare benefit to pregnant women who access government health facilities for delivery. This scheme includes entitlements of free and cashless delivery, free C-section, free drugs and consumables, free diagnostics, free diet during stay in health institutions, free provision of blood, exemption from user charges, free transport from home to health institutions, free transport between facilities in case of referral, and free drop back from institutions to home after a 48-hour stay in healthcare facility.

Rashtriya Bal Swasthya Karyakram (RBSK) is an important initiative aiming at early identification and intervention for children between 0-18 years, and covers four Ds: defects at birth, deficiencies, diseases, and

development delays including disability. Early detection and management of diseases including deficiencies prevents them from becoming severe and debilitating in later stages.

Rashtriya Kishor Swasthya Karyakram seeks to build adolescent participation and leadership, equity and inclusion, gender equity and strategic partnerships with other sectors and stakeholders. The programme enables all adolescents in India to realise their full potential by making informed and responsible decisions related to their health and well-being, and provides them with services and support.

Universal Immunisation Programme provides several vaccines to infants, children and pregnant women. The health department's Mission Indradhanush launched in December 2014 seeks to strengthen and re-energise this programme and achieve full immunisation coverage for all children and pregnant women.

Janani Suraksha Yojana (JSY) is a safe motherhood intervention programme under the National Rural Health Mission (NRHM) that seeks to reduce maternal and neonatal mortality by promoting institutional delivery among the poor pregnant women. Launched on 12 April 2005, and under implementation in all states and UTs with special focus on low performing states, JSY is a 100 percent centrally-sponsored scheme and integrates cash assistance with delivery and post-delivery care.

Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) was launched in 2016 under the National Health Mission. The programme aims to provide assured, comprehensive and quality antenatal care free of cost to all pregnant women in their homes on the ninth of every month, across the country. If the ninth day of the month is a Sunday/ holiday, the clinic is organised on the next working day. This service is offered in addition to routine ANCs at health facilities.

Navjaat Shishu Suraksha Karyakram (NSSK) aims to train health personnel in basic newborn care and resuscitation. It was launched to address care at birth issues, i.e. prevention of hypothermia and infection, early initiation of breast-feeding, and basic newborn resuscitation. Newborn care and resuscitation are important starting points for any neonatal programme and are necessary to ensure the best possible start in life.

While the National Nutritional Programme is implemented through the WCD and education department, the health department implements several programmes addressing maternal and child nutritional issues, like the National Iodine Deficiency Disorders Control Programme, the National Iron Plus Initiative for Anaemia Control, and the MAA (Mothers' Absolute Affection) Programme for Infant and Young Child Feeding.

The health department runs programmes for control of communicable diseases like National Tuberculosis Control Programme (RNTCP), National Leprosy Eradication Programme (NLEP), National Vector Borne Disease Control Programme, Pulse Polio Programme, and National AIDS Control Programme (NACP). It also has schemes and programmes to address non-communicable diseases, like National Mental Health Programme, National Oral Health programme, National Programme for Control Treatment of Occupational Diseases, and National Tobacco Control Programme (NTCP), among others.

The health department also has a programme to strengthen the health system, which includes Ayushman Bharat Yojana, Pradhan Mantri Swasthya Suraksha Yojana (PMSSY), LaQshya programme (Labour Room Quality Improvement Initiative), along with the National Health Mission. Under the Ayushman Bharat Yojana, the government has attempted to move from a selective to comprehensive approach for healthcare. The Yojana provides a wide range of services spanning preventive, promotive, curative, rehabilitative and palliative care through HWCs. HWCs are equipped to deliver an expanded range of services beyond maternal and child care, including care for non-communicable diseases, palliative and rehabilitative care, oral, eye and ENT care, mental health and first level care for emergencies and trauma inclusive of free essential drugs and diagnostic services.

CHAPTER 3

Research Methodology

The study used a mixed method research design where information was collected through semi-structured interviews and case studies.

Study sites

The study was conducted in rural areas of three districts of Uttar Pradesh – Kaushambi, Sonbhadra and Varanasi (Rural). CRY has intervention programmes in all these three districts, and its presence in the study area spans 60 villages in Kaushambi, 50 villages in Varanasi (Rural) and 28 villages in Sonbhadra.

Selection of respondents

Implementing partner CSOs of CRY recorded all neonatal deaths as case studies, including information about basic demographics and observed causes of death based on the recall, in CRY programme areas in these districts. Case studies from 1 April 2018 to 31 March 2019 were obtained for the study, containing details of 55 neonatal deaths. CRY organised a 3-days Capacity Building Training on Maternal and Child Health for CRY partner Staff facilitated by Dr Ashish Gupta, MBBS, IRS and former Director of Haryana Health Resource Centre before collecting the case studies. During this training and in subsequent other trainings, capacity building of CRY programme partner's team was done on understanding causes of death among neonates and the mothers, existing government provisions of identifying the causes of death as well as undertaking field visits with the support of the trainer for on-ground training. Since partners have details child to child tracking data of the project areas, all infant/child and maternal deaths were recorded for follow-up and data used in advocacy processes.

The outcome of these trainings is that the field team was able to document the neonatal deaths and its causes as 'case studies'. As the case studies, did not capture the various aspects related to pregnancy, care, experiences with respect to health facilities, cultural beliefs etc, this, out of the 55 cases in the study, a random subsample of 29 mothers was chosen (distributed proportionately with respect to number of deaths in respective districts) for in-depth interviews. Of these 29, eight women were from Sonbhadra, 15 from Kaushambi and seven from Varanasi (Rural).

In case the selected respondent was not available for the in-depth interview, another mother from the same district who was part of the larger sample was randomly chosen. Only those women who had lost their child within a month of their birth between 1 April 2018 and 31 March 2019 were selected for interviews.

Respondents and survey instruments / tools for data collection

In-depth interviews were conducted with mothers using a semi-structured interview guide. Apart from demographic and socioeconomic details, information was collected on varied topics of interest, including:

1. Basic characteristics along with household details
2. Information about marriage and family
3. Information regarding pregnancy
4. Information related to newborn that included data on birth, death, care and health issues.

Timeline and process

Programme data (case stories) related to neonatal deaths was listed and analysed in detail, and the sample was drawn from this list. As stated earlier, the programme data documented the neonatal deaths as 'case studies' collecting qualitative information. 55 such cases stories were analysed in detail and descriptive analysis was carried out.

CRY partner CSOs were provided training on conducting interviews with mothers in January 2020, and they conducted the interviews in February 2020. Reflexive notes during field visits were also documented to substantiate findings.

Data management and analysis

The data collection exercise was conducted in a non-threatening manner and sensitive questions were dealt with due consideration. Personal identifiers were removed while analysing data, and only designated persons in CRY and partner CSOs had access to these identifiers to facilitate sampling, data collection and analysis. The data was entered into EXCEL and transported to SPSS for analysis; responses and observations were pre-coded and text data was analysed separately. Descriptive analysis undertaken as per variables of interest.

Ethical considerations

All mothers were duly informed about the objectives of the study beforehand in the local language, and informed consent was obtained for interviews. Women respondents were interviewed at their homes, and participation in the interview was voluntary. All signed informed consents were procured.

Limitations

The study documented the responses of a limited sample, hence offering scope for limited generalisability. However, the findings provide an in-depth understanding of sociocultural aspects and access, availability and utilisation of healthcare services related to children in study areas, and can be used for programmatic interventions and initiating policy dialogues. Qualitative nature of data collected as case stories also put a limitation regarding inferences drawn. Also, the reported responses are self-reported and were not cross verified with the registration agencies such as register of AWCs.

CHAPTER 4

Findings based on the case studies

This chapter presents descriptive statistics related to the characteristics of women who lost their children during the study period and the distribution of outcome variables *i.e.* neonatal deaths. All the tables presented in this chapter were prepared on the basis of data collected using case stories from programme data, and are meant to aid programmatic and policy interventions by CRY in Uttar Pradesh.

Socioeconomic profile

Data on the demographic and socioeconomic profile of respondents and their family was collected to understand the social and economic conditions of households, since available literature shows that socioeconomic factors considerably impact child health.

Individual background characteristics

Caste is deep-rooted in Indian society and most of those who belong to socially marginalised castes are also economically vulnerable. They also have little or no access to public services owing to a variety of reasons.

The entire community in rural Varanasi comprised Schedule Castes (SC), whereas in Kaushambi, SC and OBC women comprised 42.9 percent and 57.1 percent respectively. In Sonbhadra district, 35.7 percent women were STs and 14.3 percent were OBCs. Overall, maximum numbers of women were SC, 32 percent were OBC and 9 percent were ST.

Age of the mother is an important variable for maternal and child health, as early pregnancies raise serious public health concerns. Adolescent pregnancies, when women are not biologically mature, increase the risk of pregnancy-related complications such as anaemia, pregnancy-induced hypertension, preterm labour, maternal mortality, perinatal and neonatal mortality and stillbirths. Data from NFHS-4 showed 8 percent women in India aged 15-19 had children, 5 percent women had a live birth, and 3 percent were pregnant with their first child.[104]

104 NFHS-4 International Institute of Population Sciences and ICF page no 83 (teenage childbearing) the level of teenage childbearing declined between 2005-06 (16%) and 2015-16 (8%). The decline is higher for women who have had a live birth (from 12% to 5%) than for women who were pregnant with their first child (from 4% to 3%) between 2005-06 and 2015-16.

Early marriage and child bearing affect women's nutritional status in direct and indirect ways. Adolescent girls tend not to gain weight during pregnancy and lactation; instead, they tend to lose weight. Poor pre-pregnancy nutrition with inadequate intake of nutrients during pregnancy diminishes maternal nutrient reserves, resulting in deprived nutritional status of women.[105] Findings show that in rural Varanasi, a majority of women (46%) were in the 22-25 years age group, whereas 31 percent were below 20 years of age. Most women in Kaushambi were aged 26-30 years, and no one was below 20 years if age. In Sonbhadra, most women (64.3%) were in the 20-25 years age group, and 14 percent were less than 20 years old. Overall, almost half the women were within the 20-25 years age group, whereas 10 percent were below 20 years of age. These characteristics are represented in the table below.

Table 7: Individual characteristics

Background characteristics	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Caste				
Other Backward Class (OBC)	0.0%	57.1%	14.3%	32.7%
Scheduled Caste (SC)	100.0%	42.9%	50.0%	58.2%
Scheduled Tribe (ST)	0.0%	0.0%	35.7%	9.1%
Age category				
Less than 20 years	30.8%	0.0%	14.3%	10.9%
20-25 years	46.2%	32.1%	64.3%	43.6%
26-30 years	23.1%	39.3%	21.4%	30.9%
31-35 years	0.0%	21.4%	0.0%	10.9%
> 35 years	0.0%	7.1%	0.0%	3.6%
Educational qualification				
Non-literate	76.9%	75.0%	21.4%	61.8%
Primary	0.0%	17.9%	42.9%	20.0%
Elementary	7.7%	0.0%	28.6%	9.1%
Diploma Holder	0.0%	3.6%	0.0%	1.8%
High secondary	7.7%	0.0%	7.1%	3.6%
Senior Secondary	7.7%	3.6%	0.0%	3.6%
Occupational status				
Agricultural labour	7.7%	85.7%	64.3%	61.8%
Construction labour	30.8%	10.7%	0.0%	12.7%

105 https://www.researchgate.net/publication/272021215 The Effect of Early Marriages and Early Childbearing on Women's Nutritional Status in India

Home-maker	61.5%	0.0%	35.7%	23.6%
Job (Salaried)	0.0%	3.6%	0.0%	1.8%

Earlier studies revealed that if mothers were educated, chances of child mortality were reduced by more than half.[106] This is one of the key reasons why urban, educated women have healthier children who are free of diseases.[107] Also, if either parent had received formal education, chances were that they would have fewer children and better lifestyles, instead of viewing children as working hands. Educated parents were more likely to ensure their children were immunised and were more involved in their growth and development.

Data from the study showed that in Varanasi (Rural), more than 76 percent women were non-literate. The proportion of non-literate women was similar in Kaushambi, whereas in Sonbhadra, only 21 percent women were non-literate. Quality of life also depends on the occupation and earning potential of parents. The table above shows that in Varanasi (Rural), only 7.7 percent respondents were agricultural labourers, while in Kaushambi and Sonbhadra, they comprised 85 percent and 64.3 percent respectively.

None of the women in rural Varanasi and Sonbhadra had a salaried job, whereas 3.6 percent women in Kaushambi had salaried jobs. The proportion of construction workers among women in Varanasi (Rural) and Kaushambi was 30.8 and 10.7 percent respectively, whereas in Sonbhadra, none of the women were engaged in construction work. According to NHFS-4 data, men and women in rural areas were most likely (64% and 47% respectively) to be agricultural workers. NHFS-4 data also shows that 48 percent women were involved in agricultural activities. The findings of this study indicate that study areas have a higher percentage of women involved in agricultural labour,[108] where employment is of a non-formal nature and wages are low.

Household characteristics

Poverty considerably heightens family stress and increases the risk of social, physical and emotional problems in children. Poverty can be even more damaging during the early years.[109] Thus, it is important to understand living conditions and associated factors in order to mitigate the effects of poverty. Household characteristics of the 55 women who reported neonatal deaths during the study period is represented below.

106 Institute of Medicine (US) Committee on Improving Birth Outcomes; Bale JR, Stoll BJ, Lucas AO, editors. Improving Birth Outcomes: Meeting the Challenge in the Developing World. Washington (DC): National Academies Press (US); 2003. 2, Reducing Maternal Mortality and Morbidity. Available from: https://www.ncbi.nlm.nih.gov/books/NBK222105/

107 Baker, D. P., Leon, J., Smith Greenaway, E. G., Collins, J., & Movit, M. (2011). The education effect on population health: a reassessment. Population and development review, 37(2), 307-332. https://doi.org/10.1111/j.1728-4457.2011.00412.x

108 NHFS 4 2015-16 international institute of population sciences and ICF page no 56 and 57 (occupation)

109 https://www.all4kids.org/news/blog/poverty-and-its-effects-on-children/

Table 8: Household characteristics

Household characteristics	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Average monthly family income				
Less than 5000	100.0%	0.0%	0.0%	23.6%
5000-10000	0.0%	0.0%	7.1%	1.8%
10000-15000	0.0%	0.0%	14.3%	3.6%
15000-20000	0.0%	3.6%	14.3%	5.5%
>20000	0.0%	96.4%	64.3%	65.5%
Spouse occupation				
Agricultural labour	38.5%	96.4%	92.9%	81.8%
Construction labour	61.5%	3.6%	0.0%	16.4%
Non-agricultural labour	0.0%	0.0%	7.1%	1.8%
Poverty status				
BPL Families	69.2%	89.3%	78.6%	81.8%
IAY Beneficiaries	46.2%	7.1%	0.0%	14.5%

Overall, 24 percent women belonged to families whose average income was below Rs. 5,000. The poverty line[110] in rural UP is Rs 889.82 and the average household size[111] as per Census 2011 is 6.04. This shows 24 percent families were from BPL households.

In Varanasi (Rural), all women had an average family income below Rs 5,000 per month. At the same time, the average monthly income in a large number of households was above Rs 20,000. Most women from Kaushambi (95%) and Sonbhadra (64.3%) belonged to families whose monthly average income was more than Rs 20000. Earlier studies show that income is an important determinant of child survival.[112]

Income depends considerably on occupational status. This study shows that heads of most households (here, spouses of women) were agricultural labourers. While 16 percent of heads of all households worked in the constructional sector, more than half of them in Varanasi (Rural) were construction labourers, whereas 38 percent were agricultural workers. In Kaushambi and Sonbhadra, more than 90 percent heads of households were agricultural workers. A majority of families were BPL, and had BPL cards, but only 14.5 percent were beneficiaries under the Indira Awas Yojana (IAY).[113] Earlier studies established links between family income,

110 http://rd.up.nic.in/End_poverty/end_poverty_310720191.pdf
111 https://censusindia.gov.in/2011census/hh-series/hh01.html
112 O'Hare, B., Makuta, I., Chiwaula, L., & Bar-Zeev, N. (2013). Income and child mortality in developing countries: a systematic review and meta-analysis. Journal of the Royal Society of Medicine, 106(10), 408-414. https://doi.org/10.1177/0141076813489680
113 Pradhan Mantri Gramin Awaas Yojana (PMGAY), previously Indira Awaas Yojana (IAY), is a social welfare flagship programme, implemented by the Indian Government, to provide housing for the rural poor in India.

education, size of household and other socioeconomic variables and child survival.[114] There is an interplay of different demographic, educational, socioeconomic, biological and care-seeking factors, which are responsible for the differentials in and the high burden of neonatal mortality.[115]

Neonatal related factors

Sex and neonatal deaths

Though it is well documented that NMR is always higher among boys than girls because of gender reasons and greater resilience of girls to survive. However some studies reflect that the NMR for females is likely to be higher than that for males owing to gender-based differences in care-seeking in India. A close proxy of NMR, the IMR, reaffirms this[116, 117]. In the analysed case stories also, 47.3 percent neonatal deaths were of boys, and 52.7 percent of girls.

Table 9: Sex of the child

Sex of the child	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Boy	46.2%	39.3%	64.3%	47.3%
Girl	53.8%	60.7%	35.7%	52.7%

In Varanasi (Rural), girls accounted for 53.8 percent deaths whereas boys accounted for 46.2 percent. In Kaushambi, the proportion of girls and boys was 60.7 percent and 39.3 percent respectively, whereas in Sonbhadra, 64.3 percent neonates who died were boys and 35.7 percent were girls.

The gender differential in neonatal deaths can be attributed to various factors such as neglect in care of the female child and poor access to healthcare for girls. A study conducted in Uttar Pradesh showed the average expenditure on healthcare during the neonatal period was nearly fourfold in households with male newborns compared to those with female newborns. Studies have also shown that households with female new-

114 Condliffe, S., & Link, C. (2008). The Relationship between Economic Status and Child Health: Evidence from the United States. The American Economic Review, 98(4), 1605-1618. Retrieved August 5, 2020, from www.jstor.org/stable/29730136

115 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

116 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

117 https://www.censusindia.gov.in/vital_statistics/SRS_Report_2017/11.%20Chap%204-Estimates%20of%20Mortality%20Indicators-2017.pdf

borns rely on cheaper public healthcare providers, whereas those with male newborns prefer private health-care facilities that are perceived to be superior, and thus better for survival of children.[118]

Place of birth

In the developed world, most deliveries are undertaken in hospitals,[119] while in the developing world, most births occur at home with the support of a traditional birth attendant.[120] NFHS-4 data showed that though there was a significant improvement in institutional deliveries in Uttar Pradesh (20.6% in 2005-06 to 67.8% in 2015-16), a large percentage of deliveries happened at home, aided by unskilled birth attendants.[121] Place of delivery and assistance significantly impact pregnancy outcomes, and skilled birth attendance and institutional delivery are advocated for reducing maternal, perinatal and neonatal mortality (PNMR and NMR).[122] Study findings reflect that two in every five women gave birth at home and this varied among the districts.

Table 10: Place of birth

Place of Birth	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Home	23.1%	10.7%	28.6%	18.2%
Others	0.0%	0.0%	14.3%	3.6%
Private health facility	23.1%	25.0%	0.0%	18.2%
Public health facility	53.8%	64.3%	57.1%	60.0%

In Sonbhadra, compared to other two districts more percentage of home deliveries can be attributed to local cultural practices and the district had a high concentration of ST women. Thus, highlighting that focused actions are needed with Tribal population to increase the institutional care.

118 Gender differences in perception and care-seeking for illness of newborns in rural Uttar Pradesh, India. Willis JR, Kumar V, Mohanty S, Singh P, Singh V, Baqui AH, Awasthi S, Singh JV, Santosham M, Darmstadt GL J Health Popul Nutr. 2009 Feb; 27(1):62-71

119 Olsen O, Clausen JA (September 2012). "Planned hospital birth versus planned home birth". The Cochrane Database of Systematic Reviews (9): CD000352. Doi: 10.1002/ 14651858.CD000352.pub2. PMC 4238062. PMID 22972043.

120 Fossard Ed, Bailey M (2016). Communication for Behavior Change: Volume lll: Using Entertainment Education for Distance Education. SAGE Publications India. ISBN 978-93-5150-758-1. Retrieved on 20 Feb 2020

121 http://rchiips.org/NFHS/pdf/NFHS4/UP_FactSheet.pdf

122 Goudar, S. S., Goco, N., Somannavar, M. S., Vernekar, S. S., Mallapur, A. A., Moore, J. L., Wallace, D. D., Sloan, N. L., Patel, A., Hibberd, P. L., Koso-Thomas, M., McClure, E. M., & Goldenberg, R. L. (2015). Institutional deliveries and perinatal and neonatal mortality in Southern and Central India. Reproductive health, 12 Suppl 2(Suppl 2), S13. https://doi.org/10.1186/1742-4755-12-S2-S13

Place of death

The place of death yields useful insights for designing programmes to reduce neonatal mortality.[123] The table below shows that more than half of the deaths occurred at home (58%) whereas 38 percent deaths occurred in health facilities (private – 20% and public – 18%).

Table 11: Place of death

Place of Death	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Any other	7.7%	0.0%	0.0%	1.8%
Home	53.8%	57.1%	64.3%	58.2%
In transit	7.7%	0.0%	0.0%	1.8%
Private health facility	23.1%	21.4%	14.3%	20.0%
Public health facility	7.7%	21.4%	21.4%	18.2%

Analysis of the place of birth and death showed that all those who were born home also died at home, whereas 63 percent of children who were born in a public health facility (n=33) died at home. Women from Schedule Tribe were reported from Sonbhadra only and historically, it is well documented that health seeking behaviour is quite low among tribal population. Hence, the findings are indicative of the need to have focussed interventions catering to this segment of the population.

Facilities available

The focus in the Pradhan Mantri Matru Vandana Yojana (PMMVY) – a conditional cash transfer scheme of the Government of India to aid antenatal services – is on understanding the factors that drive utilisation of services and thus make way for informed policy implementation. Any woman who registers her pregnancy at the anganwadi centre (AWC) within four months of conception, attends at least one prenatal care session and takes Iron-folic acid tablets and TT (tetanus toxoid) is eligible for a conditional cash transfer under the scheme.[124]

Out of the total 55 women, a majority were observed to be registered with anganwadi centres (93%), had been counselled by AWW or ASHA workers (88%) and had received two doses of tetanus toxoid injection (86%). Around 94 percent women received IFA tablets during pregnancy, but only one out of every ten women re-

123 Dandona, R., Kumar, G.A., Bhattacharya, D. et al. Distinct mortality patterns at 0–2 days versus the remaining neonatal period: results from population-based assessment in the Indian state of Bihar. BMC Med 17, 140 (2019). https://doi.org/10.1186/s12916-019-1372-z

124 MMVY | Ministry of Women & Child Development, GoI [http://www.wcd.nic.in/schemes/pradhan-mantri-matru-vandana-yojana] Accessed on 21 Jan 2020

ported receiving ANC check-ups (11.8%). In the absence of 4 full ANC check-ups, many risks may have gone unnoticed which might have resulted in delays in identifying timely referrals. Among those who were registered with AWCs, 45 women did not receive full ANC and among them, half (21 women) were in High Risk Pregnancy category.

Around one-third women (39%) received benefits under central/ state maternity schemes.

NFHS-4 data shows that in rural Uttar Pradesh, only 3.6 percent pregnant women received full antenatal care and 21.7 percent women received less than four ANC visits. Only 10 percent women consumed IFA for 100 days or more when they were pregnant, while 55.4 percent women received benefits under JSY and 82 percent registered their pregnancies and received the Mother and Child Protection (MCP) card.[125]

Table 12: Facilities available for pregnant and lactating mothers

Status	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Registered with AWC	100.0%	96.4%	78.6%	92.7%
Got Counselling from AWW/ASHA*	53.8%	100.0%	100.0%	88.2%
Got Iron Folic Acid (IFA) Tablets*	84.6%	96.3%	100.0%	94.1%
Got 4 Antenatal Clinic (ANC) Check-ups*	7.7%	11.1%	18.2%	11.8%
Received Benefits Under Central/State Maternity Benefit Schemes*	30.8%	59.3%	0.0%	39.2%
Got Two Doses of Tetanus Toxoid*	84.6%	81.5%	100.0%	86.3%

*conditioned on registered with AWC

The proportion of women who were registered with AWCs was 100 percent in Varanasi (Rural), 96 percent were in Kaushambi and 78.6 percent in Sonbhadra. Among those registered with AWCs, 53 percent in Varanasi (Rural) and 100 percent in Kaushambi and in Sonbhadra received counselling from ASHA workers. Proportion of women who received iron folic acid tablets comprised 85 percent women in Varanasi (Rural), 96 percent in Kaushambi and 100 percent in Sonbhadra. Only 8 percent women in Varanasi (Rural), 11 percent women in Kaushambi, and 18 percent women in Sonbhadra received the required four ANC visits.

Those who received benefits under central/ state schemes comprised 30 percent in Varanasi (Rural) and 59 percent in Kaushambi. None of the women from Sonbhadra (most of them Schedule Tribes) reported receiving any benefits under central or state schemes.

125 http://rchiips.org/NFHS/pdf/NFHS4/UP_FactSheet.pdf

Delivery related information

New WHO guidelines include 56 evidence-based recommendations on care that must be provided throughout labour and immediately after birth for mothers and children. These include having a companion of choice during labour and childbirth, ensuring respectful care and good communication between women and healthcare providers, maintaining privacy and confidentiality, and allowing women to make decisions about pain management, labour, birth positions and the natural urge to push, among others. The Ministry of Health and Family Welfare has also laid down LaQshya Standard Operating Procedures for district hospitals providing safe intrapartum services to pregnant women. The SOPs describe procedures that health personnel should follow in labour rooms, operation theatres and central sterile supply departments. The SOPs also describe at length the points to be considered to ensure respectful maternity care is provided to pregnant women in district hospitals.[126]

Although a majority of women in the study (89%) had normal deliveries, approximately half of them (44%) had high-risk pregnancies owing to low HB count and low weight. Out of these 24 high-risk pregnancies, seven (29%) were home deliveries, and every sixth woman (16.4%) had complications during pregnancy and/ or labour. Among all deliveries that were associated with complications, one-third were home deliveries.

Table 13: Delivery information

Particulars	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Complications during Pregnancy and/or Labour	15.4%	10.7%	28.6%	16.4%
Normal Delivery	84.6%	89.3%	92.9%	89.1%
High Risk Pregnancy (Low HB Counts, Weight etc.)	30.8%	39.3%	64.3%	43.6%

The proportion of high-risk pregnancies (low HB count, low weight, high BP etc.) was 31 percent in Varanasi (Rural), 40 percent in Kaushambi, and 64 percent (n=9) in Sonbhadra. Of them 4 were Scheduled Tribe. Those who had complications during pregnancy or labour comprised 15 percent in Varanasi (Rural), 10 percent in Kaushambi, and 29 percent in Sonbhadra. The proportion of women who had normal deliveries was 84 per-

126 https://www.nhm.gov.in/

cent, 89 percent and 92 percent in Varanasi (Rural), Kaushambi and Sonbhadra respectively. Despite being identified as high-risk Pregnancies (44%), most families preferred normal delivery (88%).

Assistance during delivery

Assistance during delivery plays an important role in defining the risk of death during child birth. It was observed that only one out of every ten institutional deliveries (13.3%) were assisted/ conducted by a doctor, whereas a majority were conducted by an ANM (84%), and nine percent women did not have any assistance during delivery.

Table 14: Assistance during delivery

Assistance during delivery	District			Total
	Varanasi (Rural)	Kaushambi	Sonbhadra	
ANM	8	22	7	37
	80.0%	88.0%	87.5%	86.0%
Doctor	2	3	1	6
	20.0%	12.0%	12.5%	14.0%
Valid total*	**10**	**25**	**8**	**43**

*Institutional deliveries

Around 80 percent deliveries in Varanasi (Rural) were assisted by an ANM, while 20 percent were supervised by a doctor. In Kaushambi, 88 percent deliveries were assisted by ANMs and 12 percent by doctors. Data from Sonbhadra showed that 80 percent of institutional deliveries were assisted by ANMs and 10 percent by doctors. In case of home deliveries (10), around 50 percent had no assistance, 50 percent were assisted by unskilled attendants and only one was assisted by an ANM. Unskilled birth attendants assisted all home deliveries in Varanasi (Rural), one-third deliveries in Kaushambi and one-fourth deliveries in Sonbhadra.

Birth order

In Varanasi (Rural), 30 percent of the neonatal deaths were of first born children, and another 30 percent were second births. In Kaushambi, 29 percent neonatal deaths were of third births, 32 percent of first births, and 39 percent of fourth births. In Sonbhadra, neonatal deaths were comparatively evenly distributed - 28 percent deaths were of the first and the third birth orders each, whereas 22 percent neonatal deaths were third and birth order births. Overall, a significant proportion of neonatal deaths were attributed to the first (31%) and the

fourth (29%) birth orders. Earlier studies also showed that first and last birth order children were more prone to death compared to second and third order births.[127]

Table 15: Birth order of the child

Order	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
1st Order	30.8%	32.1%	28.6%	30.9%
2nd Order	30.8%	3.6%	28.6%	16.4%
3rd Order	23.1%	25.0%	21.4%	23.6%
4 + Order	15.4%	39.3%	21.4%	29.1%

Summary analysis

Table 16: Summary Statistics

	Varanasi (Rural)		Kaushambi		Sonbhadra		Total	
Early neonatal death (within 7 days)	10	77%	24	86%	11	79%	45	82%
Late neonatal death	3	23%	4	14%	3	21%	10	18%
Early neonatal deaths								
Within 48 hours	8	80%	16	67%	8	73%	32	71%
More than 48 hours	2	20%	8	33%	3	27%	13	29%
Average number of days death took place	4.9		3.9		3.6		4.1	
Range (in days)								
Min	0		0		0		0	
Max	28		22		15		28	

On an average, children died within four days of birth in study areas, ranging from five days in rural Varanasi to 3.6 days in Sonbhadra. 82 percent of the deaths occurred within seven days of birth, qualifying as early neonatal deaths. Children in Sonbhadra died between 0-15 days. Overall, 35 percent children died on the same day of their birth. Data on place of birth showed that out of ten home deliveries, seven neonates (70%) died the same day, thus also qualifies as early neonatal deaths within 48 hours. Out of total 33 deliveries that took place in a public health facility, half of neonates (17) died within 48 hours and 7 out of ten private institutional deliveries died within 2 days of birth.

Available data on newborn mortality in India from SRS 2018 showed that 72 percent neonatal deaths occurred within the first week of life.

127 Mishra SK, Ram B, Singh A, Yadav A. birth order, stage of infancy and infant mortality in India. J Biosoc Sci. 2018; 50(5):604-625. doi:10.1017/S0021932017000487

Birth weight of the newborn

Birth weight of the newborn plays an important role in survival of neonates because children with low birth weight are more prone to health issues. LBW is a significant determinant of neonatal mortality, and LBW neonates who survive infancy are at an elevated risk of health, growth, and developmental complications, and more prone to chronic adult disorders such as hypertension, type-2 diabetes, and heart disease.[128]

Table 17: Birth weight of the child

Weight	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Low Weight Babies <2.5	4 (30.8%)	6 (28.6%)	9 (57.1%)	19 (36.4%)
More than equal to 2.5	4 (30.8%)	16 (53.6%)	3 (21.4%)	23 (40.0%)
No Information Available	5 (38.5%)	6 (17.9%)	2 (21.4%)	13 (23.6%)

The proportion of LBW neonates (below 2.5 kg) was 57 percent in Sonbhadra, 30 percent in rural Varanasi and 28 percent in Kaushambi. Out of 10 home and public health deliveries, one third were low birth weight babies.

Causes of death of neonates

As stated earlier, 20 percent newborn deaths occur due to birth asphyxia, 35 percent due to preterm deliveries, 15 percent due to neonatal sepsis, 16 percent due to pneumonia, and some due to other causes like diarrhoea, malformation etc (Ref. chapter 1).

A study based on District Level Household Survey (DLHS) - Round 4 (2012-13) stated that birth injuries, low birth weight and neonatal infections were the leading causes of neonatal deaths. Acute respiratory infection (ARI) was the most common cause of post-neonatal deaths.[129] A high proportion of avoidable deaths still occurred at home.

As stated in the methodology chapter, 'case stories' were used to understand the cause of death, that document the causes as signs and symptoms based on the recall. There is a possibility of having multiple responses as the causes of death are multifactorial occurrence.

The findings suggested that in around 31 percent cases the immediate cause of death was not known. A deep dive analysis of these cases suggested that out of these 17 newborns, 12 were LBW babies.

128 Institute of Medicine (US) Committee on Improving Birth Outcomes; Bale JR, Stoll BJ, Lucas AO, editors. Improving Birth Outcomes: Meeting the Challenge in the Developing World. Washington (DC): National Academies Press (US); 2003. 6, the Problem of Low Birth Weight. Available from: https://www.ncbi.nlm.nih.gov/books/NBK222095/

129 Tripathy JP, Mishra S. Causes and Predictors of Neonatal, Post-neonatal and Maternal Deaths in India: Analysis of a Nationwide District-Level Household Survey-4 (DLHS-4), 2012-13. J Trop Pediatr. 2017;63(6):431-439. doi:10.1093/tropej/fmx009

Table 18: Causes and symptoms of death (based on case stories)

Conditions / symptoms	Varanasi (Rural)		Kaushambi		Sonbhadra		Total	
Secondary causes*								
Premature including LBW	1	7.7%	5	17.9%	9	64.3%	15	27.3%
Multiple pregnancy (Twins/Triplets)	2	15.4%	1	3.6%	2	14.3%	5	9.1%
Causes of death*								
Birth injury/asphyxia	1	7.7%	1	3.6%	0	0.0%	2	3.6%
Neonatal sepsis	0	0.0%	1	3.6%	1	7.1%	2	3.6%
Respiratory distress Syndrome	4	30.8%	9	32.1%	0	0.0%	13	23.6%
Neonatal pneumonia	3	23.1%	6	21.4%	6	42.9%	15	27.3%
Congenital malformation	0	0.0%	1	3.6%	0	0.0%	1	1.8%
Postnatal aspiration	1	7.7%	5	17.9%	0	0.0%	6	10.9%
Neonatal Tetanus	0	0.0%	4	14.3%	0	0.0%	4	7.3%
Diarrheal and dysentery	2	15.4%	1	3.6%	0	0.0%	3	5.5%
Immediate cause of death not known	5	38.5%	7	25.0%	5	35.7%	17	30.9%

*Multiple responses possible

Premature by definition means born before 27th weeks. All preterm are mostly below 2.5 kg and hence LBWs. Case stories reflected that 27 percent were premature including LBW essentially a secondary / additional cause of death, as being premature and LBW, newborns are more likely to develop adverse health conditions and complication, thus, have high probability to die. Likewise, 9 percent stated multiple pregnancies qualify as secondary cause of death. Respiratory distress syndrome and Neonatal pneumonia appeared to be the main cause of death as per case stories among neonates.

Cultural practices followed

In most of the cases studies (n=50, 91%) it was observed that a disinfected and/or new instrument was used to cut umbilical cord. In 4 deliveries, that took place at home, it was not used. Half of the newborns (51%) were not breastfed immediately and/ or within an hour of birth, and one in every tenth child (12.7%) was fed with something other than breast milk (e.g. cow milk or honey due to varied cultural practices in the study areas). Only one neonate was breastfed immediately after the work, else 26 were breastfed within an hour of birth. Half of the children born at home (5) were not breastfed at all. Only one child born at home was breastfed within an hour. Delayed feeding of breast milk can lead to hypoglycaemia in infants especially LBW/ Premature and lead to convulsions and death.

Seven newborns (12.7%) were given anything else to drink than breast milk and three of them were born in private facilities and two each at home and public health facility.

Table 19: Delivery and birth-related practices

Practices	Varanasi (Rural) N =13	Kaushambi N=28	Sonbhadra N=14	Total N=55
Disinfected and/or new instrument used to cut umbilical cord	76.9%	100.0%	85.7%	90.9%
Child was breastfed immediately and/or within an hour of birth	38.5%	64.3%	28.6%	49.1%
Child was given anything other than breast milk to drink	30.8%	10.7%	0.0%	12.7%

CHAPTER 5

Findings based on in-depth interviews

Twenty-nine out of the 55 women, whose cases were analysed in the previous chapter, were randomly selected for in-depth interviews. These interviews sought to document their experiences regarding availability and access to healthcare at systemic and household levels, the care and support mechanisms in place, and the social and cultural beliefs related to pregnancy. The chosen sample was distributed as indicated in the table below.

Table 20: Distribution of Sample

District	Frequency	Percent
Sonbhadra	8	27.6%
Kaushambi	15	51.7%
Varanasi (rural)	6	20.7%
Total	**29**	

Demographic characteristics of respondents

Earlier studies estimated that risks of neonatal mortality and low birth weight were almost 50 percent higher if maternal age at childbirth was less than 20 years.[130] It was found that nearly half (48%) of the interviewed mothers were aged between 18-25 years. Likewise, while earlier studies showed that if a mother was educated, chances of neonatal mortality fell to less than half, this study found that most of the women (66%) were non-literate. Education plays an important role in awareness about ante-natal care during pregnancy, and is a crucial determinant of health-seeking behaviour. According to NFHS-4, infant mortality decreases with an increase in the educational and economic level of the family[131]. The age, educational and occupational characteristics of the respondents are given below:

Table 21: Demographic characteristics of the respondent

Characteristics	Frequency	Percent

130 Paul VK, Sachdeva HS, Mavalankar D, Ramachandran P, Sankar MJ, Bhandari N et al. Reproductive health, and child health and nutrition in India: meeting the challenge. Lancet 2011; 377: 332–349.

131 http://rchiips.org/NFHS/NFHS-4Reports/India.pdf

Age category		
18-25 Years	14	48.3%
25-30 Years	11	37.9%
More than 30 years	4	13.8%
Educational qualification		
Non-literate	19	65.5%
Primary	2	6.9%
Middle	3	10.3%
Secondary	3	10.3%
Senior Secondary	1	3.4%
Above School	1	3.4%
Occupational status		
Home-maker	9	31.0%
Agricultural labour	12	41.4%
Non-agricultural labour	4	13.8%
No Response	4	13.8%
Total	**29**	

Household characteristics

Most women's husbands worked as non-agriculture labourers (83%), and the household size was lesser than the average household size in rural Uttar Pradesh as per Census 2011. Most women were SC (48%), and came from families whose average income was less than Rs. 5,000 (65%); they were essentially from BPL families (ref chapter 4). Around 60 percent women were from nuclear families and 55 percent had more than one earning member in the family.

Table 22: Household characteristics of the respondent

Household Characteristics	Frequency	Percent
Occupation of husband		
Agricultural labour	4	13.8%
Non-agricultural labour	24	82.8%
Small shop/hawker	1	3.4%
Household size		
Less than equal to 5	14	48.3%
More than 5	13	44.8%
No response	2	6.9%
Caste status		

Scheduled Caste (SC)	14	48.3%
Scheduled Tribe (ST)	6	20.7%
Other Backward Categories (OBCs)	9	31.0%
Monthly average family income		
Less than Rs. 5,000	19	65.5%
Rs. 5,000-10,000	7	24.1%
Rs. 10,000-15,000	2	6.9%
Rs. 15,000-20,000	1	3.4%
Earning members in the family		
Only one member	11	37.9%
More than one member	16	55.2%
No response	2	6.9%
Type of family		
Nuclear	17	58.6%
Joint	12	41.4%
Total	**29**	

According to NFHS-4, women and men were most commonly employed as agricultural workers (48% women and 32% men) followed by production workers (21% women, 32% men).[132] This study found that among respondents, the major occupation was non-agricultural labour. Household size is also an important factor that affects the various aspects of childcare. Most women respondents were SC (48%), OBC (31%) and ST (20%). NFHS-4 also showed that neonatal deaths generally occurred in larger proportions in these communities – 20 percent among SCs, 16.5 percent among STs, and 23 percent among OBCs.[133] Poverty plays an important role in the use of maternal health services, linking economic and health statuses with deaths of newborns. Although pregnancy demands extra medical care and proper nutrition, in families employed in the informal sector, this is often severely neglected due to limited resources. This leads to high chances of mothers being malnourished and underweight mothers, giving birth to babies with low chances of survival. Likewise, while the family is the main source of support for pregnant women, mothers in nuclear families may receive less care and support compared to those in joint families due to unavailability of other family members barring the spouse.

Basic amenities

Clean and safe drinking water is essential for good health. Unsafe drinking water may result in poor health and related problems. SDG-6 aims at ensuring availability and sustainable management of water and sanitation for

132 NFHS-4 (2015-16)Ministry of Health and Family Welfare Government of India International Institute of Population Sciences and ICF, page no 56 (occupation).

133 http://rchiips.org/NFHS/NFHS-4Reports/India.pdf

all by 2030.[134] NFHS-4 shows that compared with 82 percent in urban areas, only 58 percent of households in rural areas have water within their premises or delivered to their dwelling.[135] This creates an added burden on girls and women to fetch water.

Table 23: Source of drinking water

Source of Drinking Water	Frequency	Percent
Tap water supply in home	2	6.9%
Public tap	23	79.3%
Tube well/Protected well	1	3.4%
Unprotected well	1	3.4%
Any other	2	6.9%
Total	**29**	

Most respondents (79%) said they depended on public taps (hand pumps) for drinking water. Field visits to Sonbhadra revealed there was scarcity of water in the area, and women fetched water from far-off places. While pregnant women are advised to drink 8-10 glasses of water every day,[136] women in Sonbhadra didn't drink enough water even during pregnancy owing to water scarcity.

"Paani to March ke mahine se milta hi nahi hai. Paani ki supply bhi sarkar se 1 se 2 din ke beech hoti hai, bahut dur-dur se bhar ke laana hota hai. Paani store karna padta hai usi se jaanwaro ko bhi paani dena hota hai, to hum aurtein kam hi paani peeti hain, kya karen paani sambhal ke upyog karna hota hai [There is a scarcity of water March onwards. The ggovernment provides drinking water every one or two days. We have to fetch it from very far off places and store it wisely. We have to provide the water to animals also, that's why we consume less water; we have to use the water wisely]," said a woman.

Marriage

Age is an important variable because it is related to the physical, mental and emotional maturity of a person. As per the Prohibition of Child Marriage Act (PCMA) 2006, the legal age for marriage currently stands at 21 for men and 18 for women.[137] Respondents were asked about the duration of their marriage, which is associated with fertility rate and the average number of children born to a woman. Out of the total respondents, 58 per-

134 https://sustainabledevelopment.un.org/sdg6 retrieved on 20.2 2020
135 NFHS-4, Ministry of Health and Family Welfare Government of India, International Institute of Population Sciences and ICF page, no 14 (drinking water sources and treatment.)
136 https://timesofindia.indiatimes.com/life-style/parenting/pregnancy/how-much-water-should-you-drink-during-pregnancy/articleshow/71516427.cms#:~:text=The%20quantity,the%20same%20amount%20of%20water.
137 https://theprint.in/india/governance/age-of-marriage-retrived on march 12,2020

cent were married for more than five years, 27 percent were married for 3-5 years and seven percent were married for 1-3 years; only one respondent was found to be married for less than a year.

Table 24: Duration of marriage

Years of Marriage	Frequency	Percent
Less than a year	1	3.4%
1-3 years	2	6.9%
3-5 years	8	27.6%
More than 5 years	17	58.6%
No Response	1	3.4%
Total	**29**	**100%**

Pregnancy-related information

Pregnancy is a vital event in the life of a woman. It needs regular attention, adequate nutritional, psychosocial and economic support from the time of conception to the postnatal stage. Likewise, the average number of children born to a woman has a considerable impact on her reproductive health. More than half the respondents had given birth to more than three children in their marriage, which was considerably higher than the national (2.18) and state (2.74) averages for children born to a woman .[138] Studies have documented that short birth intervals are associated with adverse birth outcomes, and birth order and weight greatly impact child health and survival.[139]

Table 25: Number of births given

Number of births given	Frequency	Percentage
1	4	14%
2	7	24%
3	2	7%
>3	16	55%
Total	**29**	**100%**

138 http://rchiips.org/NFHS/NFHS-4Reports/India.pdf
139 http://www.mjmsr.net/article.asp?issn=0975-9727;year=2018;volume=9;issue=1;spage=7;epage=11;aulast=John

Sex of the child

Earlier studies based on nationally representative data, like NFHS-3 and 4, showed that boys were more likely than girls to die in the neonatal period;[140,141] the same was biologically expected too.[142] But this study found that deaths of female neonates were more frequent than for males. The table shows that 48 percent of the neonatal deaths were of boys, whereas 52 percent were of girls. There is a need to further probe this reverse trend and in larger studies and as stated in the earlier chapter, mostly the proportion of boys is more compared to the girls given the varied reasons.

Table 26: Sex of the neonate

Sex of child	Frequency	Percent
Boy	14	48.3%
Girl	15	51.7%
Total	**29**	**100%**

Order of birth

Order of birth has a significant impact on child survival. A study based on NFHS data found a modest J-shaped relationship between birth order and the risk of dying during the neonatal period, suggesting that although both first- and last-born children were at a significantly greater risk of dying compared with those in the middle, last-borns (i.e. fourth and higher order births) were at the worst risk.[143]

Table 27: Birth order of child

Birth order	Frequency	Percent
1	9	31.0%
2	3	10.3%
3	3	10.3%
4	4	13.8%
5	5	17.2%
6	1	3.4%
8	2	6.9%
No response / Missing Value	2	6.9%
Total	**29**	

140 Karlsson O, Kim R, Joe W, Subramanian S. Socioeconomic and gender inequalities in neonatal, post neonatal, and child mortality in India: A repeated cross-sectional study, 20052016. Cambridge, MA: Harvard Centre for Population and Development Studies; 2018 September 13.

141 Mishra SK, Ram B, Singh A, Yadav A. Birth order, stage of infancy and infant mortality in India. J Biosoc Sci 2018; 50(5):604-25.

142 Pongou R. Why is infant mortality higher in boys than in girls? A new hypothesis based on preconception environment and evidence from a large sample of twins. Demography 2013; 50(2):421-44.

143 Mishra SK, Ram B, Singh A, Yadav A. birth order, stage of infancy and infant mortality in India. J Biosoc Sci. 2018; 50(5):604-625. doi:10.1017/S0021932017000487

The findings showed that nine women lost their first child in the first month after the latter's birth. Nine women also lost their fourth/ fifth child within the first month, which aligns with earlier studies. Thus, the findings also indicate that to reduce NMR it is essential to focus on premature birth babies (premies).

Place of birth

Under various initiatives of the National Health Mission, the Government of India promotes institutional deliveries to ensure positive pregnancy outcomes and access to healthcare. Although increasing institutional deliveries is an important factor in reducing maternal and neonatal mortality, a rapid expansion of institutional deliveries in India over the past decade courtesy the government's conditional cash transfer programme has not had a large effect on neonatal survival. Between 2005-06 and 2015-16, institutional deliveries increased from 39 percent to 79 percent, but neonatal mortality fell only from 37 in 2003 to 28 in 2013.[144] Currently, it stands at 23 deaths for every 1,000 live births.

Interviewed respondents reported that 59 percent of the deliveries were undertaken in government health facilities such as PHCs, CHCs and DHs; 24 percent deliveries were in private clinics, whereas 10 percent were at home and 3 percent during transit. Information on whether the 10 percent deliveries at home were conducted by skilled birth attendants was not collected. Among those delivered at the government health facilities (18), nine delivered in a sub-centre, seven in a PHC and 2 in a government hospital.

Table 28: Place of birth

Birth Place	Frequency	Percent
Home	3	10.3%
Government Health facility	18	62.0%
Private Clinic / facility	7	24.1%
During transit	1	3.4%
Total	**29**	

144 Diane Coffey, Dean Spears 2019 Neonatal Death in India: Birth Order in a Context of Maternal Under nutrition Discussion Paper Series IZA DP No. 12288 April 2019

Place of death

Table 29: Place of death

Death Place	Frequency	Percent
Home	11	37.9%
Government Health facility	9	31.0%
Private Clinic / facility	5	17.2%
Someone else's home	1	3.4%
During transit	2	6.9%
Missing / No Response	1	3.4%
Total	**29**	

Respondents said most deaths occurred at home (37%) followed by government health facilities (31%).

Days' Difference in death and birth

There are generally two types of neonatal deaths: (a) early neonatal deaths that happen within 0-6 days of birth (b) late neonatal deaths that happen between 7- 28 days.

Days difference	Frequency	Percent
Early neonatal death	18	62%
Late neonatal death	7	24%
Missing / No information	4	14%
Early neonatal death		
Within 48 hours	11	61%
More than 48 hours	7	39%
Total	**29**	

As reported by mothers during the interviews, findings suggested that 62 percent were early neonatal deaths and among these early neonatal deaths majority of them (61%) occurred within 48 hours of birth.

A further analysis with respect to place of birth suggested that, out of 25 births for which data were available, 22 institutional deliveries (17 public facilities and 5 private facilities), 9 died within 48 hours and 15 were early neonatal deaths. The institutional delivery is much higher than home delivery but containing neonatal death is still a challenge. Also, the study found that 31 percent neonates died on the same day as their birth, while another 31 percent died within seven days, effectively qualifying 62 percent of the deaths as early neonatal deaths. Also, a pooled analysis of data from three studies on the timing of neonatal deaths indicates that

about three-fourths of total neonatal deaths occur in the first week of life. The first 24 hours account for more than one-third (36.9%) of the deaths that occur in the entire neonatal period.[145] The SRS 2018 data also indicates that 72 percent of infant deaths are early neonatal deaths.

145 Sankar, M. J., Neogi, S. B., Sharma, J., Chauhan, M., Srivastava, R., Prabhakar, P. K., Khera, A., Kumar, R., Zodpey, S., & Paul, V. K. (2016). State of newborn health in India. Journal of perinatology: official journal of the California Perinatal Association, 36(s3), S3–S8. https://doi.org/10.1038/jp.2016.183

SECTION B

Access to Health system during pregnancy

Health system accessibility during pregnancy

The National Plan of Action for Children (2016) is committed to improving maternal healthcare, including ante-natal care, safe deliveries by skilled health personnel, postnatal care and nutritional support strategies to ensure universal access to quality ANC and PNC for pregnant and lactating mothers.[146] Additionally, one of the key components of the National Health Mission and Indian Newborn Action Plan [147] is to provide every village in the country with a trained female community health activist ASHA.[148] Most of the interviewed mothers (n=28) reported being visited by an ASHA during their pregnancy.

Registration and counselling

A majority of the pregnancies (83%) were registered by ASHA, whereas one in every ten mothers said that ASHA did not register their pregnancy. One of the key components of INAP is to educate and train mothers and caregivers via counselling about preventive healthcare for newborns.[149] Most of the mothers (88%) who were registered by ASHA reported being counselled as well.

Counselling topics covered by ASHA

The ASHA worker provides counselling on various aspects related to pregnancy and pre- and post-natal care as per the NHM directives. Different schemes have been introduced under NHM to prevent neonatal deaths, such

146 National Plan of Action for Children,, 2016 Ministry of Women and Child Development ,Government of India

147 Indian Newborn Action Plan 2014 , Ministry of Health and Family Welfare; National Health Mission Govt. of India

148 An ASHA (Accredited Social Heath Activist) is a community health worker instituted by the Government of India's Ministry of health and Family welfare (MoHFW) as a part of National Rural Health Mission.

149 ASHA is supposed to take steps to create awareness and provide information to the community on determinants of health such as nutrition, basic sanitation & hygienic practices, healthy living and working conditions, information on existing health services and the need for timely utilisation of health & family welfare services. She counsel women on birth preparedness, importance of safe delivery, breastfeeding and complementary feeding, immunisation, contraception and prevention of common infections including Reproductive Tract Infection/Sexually Transmitted Infection (RTIs/STIs) and care of the young child.

1. ASHA mobilizes the community and facilitate them in accessing health and health related services available at the village/sub-centre/primary health centres, such as Immunisation, Ante Natal Check-up (ANC), Post Natal Check-up (PNC), ICDS, sanitation and other services being provided by the government.
2. She also arrange escort/accompany pregnant women & children requiring treatment/ admission to the nearest pre-identified health facility i.e. Primary Health Centre/ Community Health Centre/ First Referral Unit (PHC/CHC /FRU). She will inform about the births and deaths in her village and any unusual health problems/disease outbreaks in the community to the Sub-Centres/Primary Health Centre.

as promotion of institutional deliveries through cash incentives under Janani Suraksha Yojana and Janani Shishu Suraksha Karyakram, and provision of free antenatal check-ups. Under these schemes, deliveries including Caesarean Section, post-natal care and treatment of sick infants till one year of age are covered. Counselling for Home Based Newborn Care (HBNC) and Home Based Care of Young Children (HBYC) are also to be provided by ASHAs to improve child rearing practices. Likewise, early initiation and exclusive breastfeeding for first six months and appropriate Infant and Young Child Feeding (IYCF) practices are promoted in convergence with Ministry of Women and Child Development. Village Health and Nutrition Days (VHNDs) are observed for provision of maternal and child health services and creating awareness on maternal and child care best [practices including health and nutrition education. Iron and folic acid (IFA) supplementation for the prevention of anaemia among the vulnerable age groups, home visits by ASHAs to promote exclusive breastfeeding and promoting use of ORS and Zinc for management of diarrhoea in children under Intensified Diarrhoea Control Fortnight (IDCF), administration of de-worming tablets to all the children in the age group of 1-19 years during National De-worming Day (in the month of February and August) are carried out. Health and nutrition education through Information, Education and Communication (IEC) and Behavior Change Communication (BCC) are conducted to promote healthy practices and to generate demand and improve service uptake.

Table 30: Topics covered during counselling

Topics of counselling*	Responses N	Percent of Cases
Institutional delivery	15	83.3%
Nutrition	17	94.4%
Government Schemes	14	77.8%
Safe motherhood	9	50.0%
Personal Hygiene	10	55.6%
Total Valid cases	**18**	

*multiple responses possible

Among those who were registered and received counselling from ASHA, a majority reported being counselled on nutrition (94%), which plays an important role in child care because malnutrition among mothers may lead to malnourished/ underweight children and reduced chances of child survival. While it is important to make pregnant women and their families understand the importance of institutional deliveries in decreasing the risk of child mortality, 83 percent of the respondents said they had received counselling about institutional delivery. Those who received counselling about government schemes and safe motherhood practices comprised 78 percent and 50 percent respectively. During interviews with respondents, it was observed that most mothers did

not know the benefits of nutrition or institutional deliveries, but they had more knowledge about government financial schemes.

One of the women said, *"Hame ASHA ne bataya tha lekin kuch samajh nahi aaya, haan ye pata hai centre per baccha janne se paisa milega* [ASHA told me about the diet and importance of nutrition but I didn't understand much; she also said that if the delivery happens at hospital, I will get some money]."

Visit to health facility during pregnancy

Various schemes and initiatives provide different kinds of services to mothers and children during and after pregnancy. LaQshya, a labour room quality improvement programme, has been implemented in over 2,100 health facilities across the country including medical colleges. The Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) has been implemented to provide fixed-day assured, comprehensive and quality antenatal care universally to all pregnant women on the ninth of every month. Universal screening of pregnant women including anaemic pregnant women is carried out at all public health facilities and 180 iron & folic acid (IFA) tablets are given in the antenatal period and 180 IFA tablets are given in the post-natal period to all pregnant women. Double doses tablets are given as a part of treatment regimen to those found to be clinically anaemic. Guidelines on standardisation of labour rooms and creation of Obstetric HDU and Obstetric ICU at district hospitals and medical colleges has also been prepared and disseminated to the States for improving quality of care during delivery and child birth.

Table 31: Visits to health facility during pregnancy

Visits	Frequency	Percent
No Visit	6	20.7%
Less than equal to 2 visits	10	34.5%
More than 2 visits	12	41.4%
No information	1	3.4%
Total	**29**	

Despite these provisions, the study findings suggested that one in every five mothers did not visit any health facility during pregnancy. Only 41 percent pregnant women had visited a health facility for check-ups more than two times.

Mother and child protection card (MCPC)

MCPC is a recording and counselling card for pregnant and postpartum women and under-five children, which is meant to gradually replace the immunisation card. This card was developed jointly by MWCD, MHFW, with support from UNICEF and NIPPCD. It was originally used by ICDS in some states, now adopted by NHM/RCH, NAPC, INAP for record-keeping of services provided during pregnancy, postpartum period and childhood as a childhood for families to learn, understand and follow positive practices for achieving good health of pregnant women, young mothers and children. It helps families know about the various types of services they can access for the health and well-being of women and children. It also outlines health and nutrition care practices for achieving good health for women and children.

Table 32: Mother and Child Protection Card available / registered

Mother and Child Protection Card	Frequency	Percent
Yes	27	93.1%
No	2	6.9%
Total	**29**	

Most women (93%) had MCPC cards, but often did not keep these cards with them, and were at times ignorant about the importance of the card. In some instances, mothers were non-literate and had asked the ASHA/ AWW/ ANM workers to keep the card with them.

Antenatal check-ups

The WHO's recommendations on antenatal care for a positive pregnancy experience prioritised person-centric healthcare, well-being of women and families, and positive perinatal and maternal outcomes (WHO 2016).[150] The NHM mandates four ANC visits, and the target of INAP is to extend the requisite antenatal check-ups to 90 percent of the pregnant women by 2021 and 95 percent by 2025.

150 Schedule of ante natal check-ups according to NHM BOOKLET ON SAFE MOTHERHOOD
Timing of the first visit/registration –
1. The first visit or registration of a pregnant woman for ANC should take place as soon as the pregnancy is suspected;
2. Second visit - Between 14 and 26 weeks;
3. Third visit - Between 28 and 34 weeks;
4. Fourth visit - Between 36 weeks and term

Table 33: Antenatal check-ups 4 Visits

ANC	Frequency	Percent
Yes	3	12.5%
No	20	83.3%
No information	1	4.2%
Valid total*	**24**	

*conditioned on pregnancy registered by ASHA

The study findings showed that among those whose pregnancy was registered by ASHA (24), only 13 percent had four antenatal check-ups, whereas a majority of mothers (83%) did not have the mandated four ANC check-ups. According to NFHS-4, a majority of women (51%) received antenatal care from doctors, followed by auxiliary nurse midwives (ANMs), nurses, midwives, and lady health visitors (20%). Overall, out of 29 mothers, 13.8 percent (four) received four ANC visits.

The findings showed the condition of the study area was very deplorable, and it lagged far behind the national target of antenatal check-up coverage of 90 percent by 2021 (NHM / INAP).

SECTION C

Family level care

Access to health facilities is important because it helps in early detection of complications and risks associated during pregnancy and during child birth.[151] Some schemes associated with healthcare are:

Universal Immunisation Programme (UIP) provides vaccination to children against life-threatening diseases such as Tuberculosis, Diphtheria, Pertussis, Polio, Tetanus, Hepatitis B, Measles, Rubella, Pneumonia and Meningitis caused by Haemophilic Influenza. "Mission Indradhanush" and "Intensified Mission Indradhanush" immunize children who are either unvaccinated or partially vaccinated, i.e., those not covered by routine immunisation for various reasons.

Name-based tracking of mothers and children till two years of age (Mother and Child Tracking System) ensures complete antenatal, intranatal, postnatal care and complete immunisation as per schedule.

Rashtriya Bal Swasthya Karyakram (RBSK) provides comprehensive care to all children aged 0-18 years, including health screening, early detection of birth defects, diseases, deficiencies, development delays and early intervention services.

Nutrition Rehabilitation Centres (NRCs) at public health facilities treat and manage the children with Severe Acute Malnutrition (SAM) admitted with medical complications.

Iron and folic acid (IFA) supplementation for the prevention of anaemia among vulnerable age-groups, home visits by ASHAs to promote exclusive breast-feeding and use of ORS and Zinc for management of diarrhoea in children under Intensified Diarrhoea Control Fortnight (IDCF), administration of de-worming tablets to all the children in the 1-19 years age group during National De-worming Day (February and August) are carried also out.

Table 34: Independence to access to healthcare

Allowed to go on her own	Frequency	Percent
Yes	16	55.2%
No	11	37.9%
No information/Missing information	2	6.9%
Total	**29**	

151 Access to healthcare is very much asymmetric between rural and urban India. While urban residents have a choice between public or private providers, the rural residents face far fewer choices. India has a very vast public health network with sub-centres working at the community level.

The study found that only a little over half of the respondents (55%) were allowed to visit a healthcare facility on their own by their husband or mother-in-law, and access to services during the hour of need was restricted for those who depended on company to visit health clinics. The findings suggest that pregnant women were not allowed to visit health facilities with anyone else except family members.

Table 35: Person accompanying to health facility

Person*	Frequency	Percent
Only Husband	4	50.0%
Mother-in-Law	5	62.5%
Cases	**9**	

*multiple responses possible

Access to three meals a day

A nutritious diet during pregnancy contributes to good foetal brain development and healthy birth weight. It also reduces the risk of birth defects. Maintaining a healthy diet before and during pregnancy helps protect both mother and child from immediate and long-term health risks.

Table 36: Access to three meals during pregnancy

Consumed Three meals a day during pregnancy	Frequency	Percent
Yes	23	79.3%
No	5	17.2%
Missing / no information	1	3.4%
Total	**29**	

Around 79 percent mothers reported having three meals a day during pregnancy, whereas 17 percent did not have access to three meals a day. Most respondents were, however, counselled by ASHA, AWW and ANM about the importance of nutritious diet and calcium intake during pregnancy. Around one in every five women did not have access to three meals a day during pregnancy. This could be attributed to the economic deprivation of the household (most women belonged to BPL families) and the reduced prioritisation of nutritional needs of women in patriarchal families.

Counselling during pregnancy about nutritious food

As stated earlier, ASHA and other frontline workers provide counselling to pregnant women and lactating mothers on varied topics. All mothers stated that they received counselling on the importance of nutritious food during pregnancy. A majority of them (93%) reported being counselled by NGO staff, whereas many (52%) reported being counselled by them anganwadi workers.

Table 37: Counselling about nutritious food during pregnancy

Counselling regarding nutritious food	Frequency	Percentage
No of women who were counselled for importance of nutritious food	29	100.0%
Person who counselled*		
Aanganwadi Worker	15	51.7%
ASHA	21	72.4%
ANM	19	65.5%
Husband	12	41.4%
Any NGO staff	27	93.1%
Any other relative (specify)	2	6.9%
Cases	**29**	

*multiple responses possible

Care provided in the family

Care at home plays an important role in the health of the mother, mentally as well as physically. Family support serves as the foundation of security and growth for a pregnant woman and her baby. It can help lower the anxiety associated with pregnancy and thus, help the mother cope with emotional and physical changes during pregnancy. Therefore, family behaviour and attitude must be pleasant and encouraging. It is important for the mother to have someone by her side who she can rely on emotionally.[152] The study findings however showed that one in every ten women did not have anyone in the family to care for them during pregnancy. Only 57 percent pregnant women received care from their mother-in-law or husband.

152 http://www.nipccd-earchive.wcd.nic.in/sites/default/files/PDF/Family%20Role%20during%20pregnancy-english.pdf retrieved on 10 .04.2020

Table 38: Caregiver in the family

Care provider at home*	Frequency of responses	Percent of Cases
Husband	16	57.1%
Mother -in -law	16	57.1%
Sister - in law	3	10.7%
No one	3	10.7%
Any other relative (Specify)	3	10.7%
Valid total	**28**	

* Multiple responses possible

SECTION D

Help from government schemes during pregnancy

Government schemes

POSHAN Abhiyaan (National Nutrition Mission), the flagship programme of the Ministry of Women and Child Development (MWCD), was launched to achieve the goals of NNM regarding improving the nutritional status of children aged 0-6 years, adolescent girls, pregnant women and lactating mothers in a time-bound manner. The programme ensures convergence with various programmes i.e., Anganwadi Services, Pradhan Mantri Matru Vandana Yojana (PMMVY), Scheme for Adolescent Girls (SAG) of MWCD Janani Suraksha Yojana (JSY), National Health Mission (NHM), Swacch-Bharat Mission, Public Distribution System (PDS), Department Food and Public Distribution, Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS) and Ministry of Drinking Water and Sanitation.[153]

National Rural Health Mission promotes health and nutrition education through Information, Education and Communication (IEC) and Behaviour Change Communication (BCC). It fosters healthy practices and generates demand for and uptake of healthcare services. Pregnant women are provided dietary counselling during antenatal visits through sub-centres, primary health centres and other facilities, as well as through outreach activities at Village Health & Nutrition Days (VHNDs).

Most of the mothers (93%) had received support from the system during pregnancy. Macro-level findings based on NFHS-4 at the national level showed that 46 percent of pregnant women did not receive 'Poshan Ahaar' during pregnancy.

Table 39: System's support during pregnancy

Support received	Frequency	Percent
Yes	27	93.1%
No	2	6.9%
Total	**29**	

Support provided by the system to pregnant women can be in cash or kind. Government schemes provide conditional cash transfer to pregnant women above the age of 18 years for up to two live births. In 2013, IGMSY was amended to cater to the National Food Security Act (NFSA), recognising the unique food and nutritional needs

153 https://www.gibl.in/government-scheme/national-nutrition-mission.htmlretrived on 10 march 2020

of pregnant women. Cash entitlement for pregnant women was also increased to Rs 6,000. In the study, those who reported receiving support from the system were asked to define the kind of support they received - 93 percent said they received support in the form of take-home ration, whereas 7 percent received support in the form of cash incentives. During the interviews, one of the women said that they received a nutrient supplement called *Panjeeri* from the anganwadi centre. Although all 27 mothers received take-home ration, two in every five (22.2%) women did not use the ration to support their own dietary needs during pregnancy.

Table 40: Type of support received

Type of support*	Frequency of responses	Percent of Cases
Cash incentive	2	7.4%
Take Home Ration (THR)	27	100.0%
Cases@	**27**	

* Multiple responses possible; @ conditioned on those who received any support

SECTION E

Prevailing beliefs at community, neighbourhood and family levels

Beliefs and practices

Culture is defined as a shared system of beliefs, values and behavioural expectations that provide social structure for daily living. Not all customs and beliefs are harmful. Some of them have positive values while others may be negative or harmless for neonatal health. There are several beliefs associated with pregnancy at community level and the family level.

Table 41: Beliefs and practices

Types/Practices	Taboos
Travelling related practices	There were taboos and prohibition related to travelling. It was believed that pregnant women should not step out of the house especially at night, as evil spirits could possess them. If had to venture out, they were advised to carry *hing* (asafoetida), *laung* (cloves) or *'addi'* (ginger) with them.
Personal hygiene-related practices	It was believed that pregnant women should not cut their nails – if they did, they would be cursed by witches.
Spiritual factors	There were taboos saying one should not touch trees and plants and should follow astrology and zodiac signs.
Irrational fears and taboos	Avoid visiting religious places, as per community beliefs
General	Men should eat first, and only then women in the house should eat, as it is an old tradition (family belief)
Taboos related to food	Pregnant women should not consume *ghee* (edible oil) and avoid eating outside. They should not eat inflammatory items.

Women were asked if and why they and their families, neighbourhoods and communities followed these beliefs and practices.

Reasons cited for following beliefs

- *'Bhoot pret ka dar'* (fear of ghosts/ witches)
- *'Parivar awem samuday ke dar se'* (Fear of family and community)
- *'Purani Manyta Karan'* (Due to old traditions and practices)
- It could harm the child if they didn't believe in these prevailing practices

Since cultural beliefs and practices around pregnancy and birth are widespread in India, it is essential to have good knowledge about these beliefs and practices in order to understand the health-seeking behaviours of people and utilisation of health services. The findings represented in the earlier table delineate the prevailing beliefs and practices in three study districts in Uttar Pradesh. The most common practice was related to travelling - pregnant women were not allowed to go out alone, or at night; wherever they ventured out, they were required to carry *hing* and *laung* along. Other practices were related to personal hygiene - pregnant women were not allowed to cut their nails. They were also advised against consuming *ghee* and eating outside food. Other beliefs were spiritual, like belief in ghosts/ witches; yet others were irrational. People believed in *jaadu tona* (witchcraft or black magic), and thought that pregnant women would attract the evil eye if they ventured outside home at night. Women also reported that they were advised to pray to plants and not to go on pilgrimage. They believed in '*rasi ko dekhna'* (consulting horoscope and astrology) and *'rashi ko lagana'* (beliefs related to zodiac signs). Other prevailing practices included general advice, such as women should undertake physically strenuous tasks during pregnancy to have a smooth labour, and men in the family should eat first. Respondents also believed that they should eat less during pregnancy, lest the foetus increase in size and create problems during delivery. There were various other taboos stating '*garam cheeze'* (hot edibles) should be avoided during the first trimester as it may lead to miscarriage. Half of the mothers (52%) followed some or all the above beliefs during pregnancy and child birth.

Table 42: Practices followed during pregnancy

Beliefs followed during pregnancy	Frequency	Percent
Yes	15	51.7%
No	14	48.3%
Total	**29**	

SECTION F

Information related to delivery

Information related to delivery

The safe motherhood booklet states that health education be provided repeatedly to pregnant women during visits to health facilities regarding birth preparedness. It is mandated that there should be a plan for the following:

a. A skilled attendant at birth
b. The place of birth (health facility) and how to get there, including how to access emergency transportation if needed
c. Items needed for the birth
d. Money saved to pay the skilled provider and for any necessary medications and supplies
e. Support during and after the birth from family
f. Potential blood donors in case of emergency (NHM)[154]

Place of delivery

Healthcare services are found only in medical facilities, and hence institutional births are encouraged. Home births should be conducted by a skilled birth attendant, at the very least if unavoidable. One in every tenth woman interviewed delivered at home. Nearly one-third (31%) approached the Sub Centre for delivery, 24 percent opted for Primary Health Centre (PHC) for delivery and 7 percent delivered in a government hospital. Thus, majority of the deliveries were conducted at a public health facility (61%). One in every fourth delivery took place in a private hospital or clinic.

154 My Safe Motherhood booklet for expecting mothers Maternal Health Division Ministry of Health & Family Welfare Government of India NHM technical assistance by WHO\UNICEF

Table 43: Place of delivery

Place	Frequency	Percent
Home	3	10.3%
Sub - Centre (SC)	9	31.0%
Primary Health Centre (PHC)	7	24.1%
Government hospital	2	6.9%
Private clinic/hospital	7	24.1%
Any other	1	3.4%
Total	**29**	

Among those who opted for private hospitals, most of them were referred cases from PHCs to government hospitals. They had to approach a private hospital due to unavailability of gynaecologists and/ or refusal of admission in the government hospital (as reported by mothers). According to NFHS-4, 79 percent of the deliveries in India were institutional deliveries,[155] while in UP, only 68 percent women had institutional deliveries.

Assistance during delivery

Assistance during childbirth can influence the birth outcome and the health of the mother and the newborn. A skilled attendant can manage complications of pregnancy and delivery, or can refer the mother and/ or the baby to the next level of care. Delivery should be conducted by skilled and trained personnel only. WHO advocates for "skilled care at every birth." Ensuring quality maternity care services can save the lives of women and newborns. These services require “an accredited health professional – such as a midwife, doctor or nurse who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of complications in women and newborns.” In addition to the appropriate skills, these health professionals should be motivated and located in the right place at the right time; they also need to be supported by appropriate policies, essential supplies including medicines and should be ideally operating under appropriate regulatory frameworks. Home deliveries were assisted by either relatives or *dais*.

155 NFHS-4 (2015-16) Ministry of Health and Family Welfare Government of India, International Institute of Population Sciences and ICF

Table 44: Person who conducted the delivery

Person who conducted delivery	Frequency	Percent
Doctor in a Private health facility	5	17.2%
ANM/Nurse in a Government Health facility	16	55.2%
ANM/Nurse in a private health facility	2	6.9%
Dais	1	3.4%
Relatives	4	13.8%
No information/ Missing	1	3.4%
Total	**29**	

The findings show that ANMs/ nurses in government hospitals conducted the delivery of 55 percent mothers, whereas 17 percent of the deliveries were not assisted by any skilled or trained birth attendant (*dais* and relatives) and were occurred at home or elsewhere. NHFS-4 data indicates that 81 percent of deliveries in the five years preceding the survey were attended by a skilled provider. The majority of births were attended to by doctors (56%), followed by ANMs, nurses, midwives and LHVs (25%), and *dais* (TBAs) (11%).[156] The findings of the study are aligned with the larger findings of NFHS-4.

Types of delivery

Lack of adequate health education during ANC visits and poorly-staffed and ill-equipped health facilities with unfriendly and poorly skilled personnel play significant roles in delivery (Stekelenburg et al 2004).[157] Access to caesarean section (C-section) can reduce maternal and neonatal mortality and complications such as obstetric fistula. However, a caesarean section without a medical need can put a woman at risk of short and long-term health problems. The World Health Organisation advises that caesarean sections should only be done when medically necessary, and does not recommend a target rate for countries to achieve at the population level. The NFHS-4 findings show that 17 percent of live births in the preceding five years were delivered by caesarean section. Forty-five percent of the C-sections were decided on after the onset of labour pains, compared with 55 percent that were decided on before the onset of labour pains.[158]

156 NHFS 4 2015-16 Ministry of Health and Family Welfare Government of India International Institute of Population Sciences and ICF
157 J. Stekelenburg S. Kyanamina M. Mukelabai J. van Roosmalen 2004 Waiting too long: low use of maternal health services in Kalabo, Zambia https://doi.org/10.1111/j.1365-3156.2004.0120
158 NHFS 42015-16 Ministry of Health and Family Welfare Government of India International Institute of Population Sciences and ICF (types of delivery)

Table 45: Type of delivery

Type	Frequency	Percent
Normal delivery	21	72.4%
C- Section	4	13.8%
No information/ Missing	4	13.8%
Total	**29**	

Most of the deliveries (72%) were normal deliveries whereas 14 percent deliveries were C-section and all occurred in a private facility. Many cultural factors also play a role in the preference for home delivery.[159]

Duration of discharge after delivery

Among women who delivered in a facility (n=26), most (n=18) were discharged on the day of the delivery itself. Out of them 8 delivered in a Sub Centre, 6 in PHCs, 2 in Government and 1 in private hospital. According to the WHO, after an uncomplicated vaginal birth in a healthcare facility, healthy mothers and newborns should receive care in the facility for at least 24 hours after birth (WHO 2013).[160]

Table 46: Discharge from the facility

Discharge post delivery	Frequency	Percent
Same day of delivery	18	69.2%
Next day of delivery	2	7.6%
After 2-3 days of delivery	6	23.1%
Total	**26**	

During the interviews, one of the respondents said, ***"Hame prasav ke do ghante ke andar chutti de thi. Koi vahan ki vayaswstha nahi thi hume khud hi aana pada.*** [I was discharged within 2 hours after delivery. There was no transport available and we had to arrange transport on our own]."

The findings are important considering the discharge protocols that suggests first visit by ANM/ASHA within 24 hours, 2nd visit - third day after delivery, 3rd visit - 7th day after delivery [4th visit- after 6 weeks] in case of home delivery or delivery in sub-centre. Similarly, if the delivery took place in PHC/FRU (women discharged after 48 hours), visit by ANM/ASHA 3rd day after delivery and third visit - 7th day after delivery [4 visit -

159 Lefeber Yvonne Voorhoeve Henk, Indigenous customs in childbirth and childcare van Gorcum 1998
160 WHO Recommendations on Postnatal Care of the Mother and Newborn 2013 Geneva: World Health Organisation;

after 6 weeks). There should be three additional visits in the case of babies with low birth weight, on days 14, 21 and 28 (as per the Integrated Management of Neonatal and Childhood Illness [IMNCI] guidelines). Though, information about visits by ANM/ASHA post-delivery was not asked directly, in the scope of the study, information regarding visits to health facility for check-up within 7 days was collected.

Check-ups conducted within seven days

The first 48 hours of life is a critical phase in the life of a newborn and a period in which many neonatal deaths occur. Lack of postnatal health checks during this period can delay the identification of newborn complications and the initiation of appropriate care and treatment. In India, only 24 percent of newborns had a first postnatal check within the first two days after birth. It is necessary for all mothers to ensure medical check-ups within seven days of birth of the child for identification of any risk to the child.[161]

Responding mothers reported that either no check-up was conducted or they do not remember in case of home deliveries. In case of deliveries occurred in sub-centre, 3 reported that check-up was done within 7 days, out of total 13 women, those who delivered in a public facility (including SC), only 4 stated that check-up was done within 7 days. Out of 7 who delivered in a private facility, four stated that check-up was done. Out of total eight women, who stated check-up was conducted, 2 stated it was conducted once and 2 each stated for 2 times and 3 times.

Table 47: Check-ups conducted within seven days

Check-ups conducted within 7 days	Frequency	Percent
Yes	8	27.6%
No	13	44.8%
Do not remember	1	3.4%
Missing/No information	7	24.1%
Total	**29**	

Only one in four mothers confirmed taking their newborn for a health check-up within seven days of birth and all of them had institutional delivery.

Birth registration certificate

Birth registration is the process in which a child's birth is recorded in the civil register by government authorities. It provides the first legal recognition and is also mandatory under the law. As per the Registration of Births and Deaths Act, 1969, it is mandatory to register every birth/ stillbirth with the concerned State/ UT government within 21 days of its occurrence. The government accordingly has institutionalised a system for registration of birth with the Registrar General at the centre and the Chief Registrars in the States, running through District Registrars to the village and Town Registrars at the periphery.[162]

Table 48: Birth certificate received

Birth Registration	Frequency	Percent
Yes	2	6.9%
No	25	86.2%
No information/Missing	2	6.9%
Total	**29**	

However, only 7 percent mothers in the study received birth registration certificates. According to NHFS-4, 80 percent of children under five years of age had births registered with the civil authority. Children in urban areas (89%) are more likely than children in rural areas (76%) to have their birth registered. Birth registration is lowest in Uttar Pradesh (60%) and Bihar (61%).[163] Without a birth certificate, a child may lack access to services like healthcare and education. A lack of legal recognition and support will ultimately make the life of children more complex, since this basic documentation is missing, as they grow older.

Colostrum related information

Colostrum is the first form of milk produced by the mammary glands of mammals (including humans) immediately following delivery of the newborn, typically within the first hour of birth. It is a very potent source of nutrition for infants and provides antibodies for their protection. Timely initiation and exclusive breastfeeding for first six months and appropriate Infant and Young Child Feeding (IYCF) practices are extremely vital for child survival and health.

162 https://www.advocatekhoj.com/library/legalforms/howdoi/index.php?Pno=birthcertificate.phpretrived on 12 march 2020

163 National Family Health Survey (NFHS-4) 2015-16 , Ministry of Health and Family Welfare Government of India, International Institute for Population Sciences Deonar, Mumbai 400 088 page no 18 (birth registration)

Table 49: Colostrum given immediately after birth

Colostrum given	Frequency	Percent
Yes	10	34.5%
No	18	62.1%
Missing/No information	1	3.4%
Total	**29**	

Only 35 percent children were given colostrum within an hour whereas 62 percent did not receive colostrum within an hour. During the interviews, many mothers said that in our culture *"Sabse pehleya to gai ka dhud ya fir shahed dena chaiye, wo halka hota hai, maa ka dhud ek ya fir do din baad dena hota hai* [In our culture either honey or cow's milk is given to the child as it is light, and beneficial for child. Breastfeeding is initiated the next day or post that]."

Fifty-six percent of the women who did not give colostrum to their child immediately or within an hour of birth reported that the child was never given colostrum. Only 22 percent infant were given colostrum after one hour on the same day. NFHS-4 also reported that only 43 percent of the children were breastfed within one hour and in UP this percentage was quite low (25%).[164] Even among those who had institutional delivery (25), only 40 percent stated that colostrum was given either immediately or within an hour of birth.

Table 50: Colostrum timing if not immediately

When was colostrum given	Frequency	Percent
More than an hour later	4	22.2%
Next day	1	5.6%
Never given	10	55.6%
No information/ Missing	3	16.7%
Total	**18**	

164 National Family Health Survey (NFHS-4) 2015-16 Ministry of Health and Family Welfare Government of India International Institute for Population Sciences Deonar, Mumbai 400 088

SECTION F

Complications related information

Complications post delivery

According to the WHO, the most common causes of neonatal deaths are preterm birth complications, newborn infections and birth asphyxia. These account for over 80 percent of all global neonatal deaths. A newborn who is born preterm or has a potentially life-threatening problem is in an emergency situation requiring immediate diagnosis and management. Delay in identification of the problem or in providing the correct treatment may be fatal.

Table 51: Post-delivery complication in infants

Complication post delivery	Frequency	Percent
Yes	20	69.0%
No	8	27.6%
Missing / No information	1	3.4%
Total	**29**	

Most of the mothers (69%) reported post-delivery complications for the child. Place of birth wise analysis suggested that out of these 20, 12 were delivered in a public health facility and 6 in private. The findings also question the quality of services as most of the mothers stated to have institutional deliveries.

Although most mothers reported being registered by ASHA/ ANM/ AWW and being aware of the possible complications, it was found that seeking medical care was determined by various other factors, such as family's decision to seek treatment, delay in transport, doctor availability etc. Forty-three percent of the women reported that they received information about complications from ANMs.

Table 52: Information about complications

Person who told about complications	Frequency	Percent
ANM	7	35.0%
Doctor	7	35.0%
Husband	1	5.0%
ASHA	1	5.0%
Got to know by self	1	5.0%
Any other relative	2	10.0%
Total	**20**	

According to a respondent in Sonbhadra, ***"Hamara baccha to sahi paida hua tha roya bhi tha judwaan bacche the (first child) pehle baccha shaant tha fir pata nahi kya hua, uske baad dusra baccha jeevit tha lekin agle din woh bhi chala gaya, pata nahi kya hua, bhagwaan ko yahi manzoor tha. Barah din baad hum kheton mein kaam per jaane laage*** [I have given birth to healthy children (twins and first pregnancy). At the time of birth, both children cried but after that the first child became silent and died. Next day, the second child also died. May be this was their destiny. After 12 days, I was back at work in the field]." This shows that there is cultural acceptance of dying of a newborn, and mothers are encouraged not to grieve for too long if the baby dies. There is the feeling that some children are not meant for this life, especially in the first week of life.

Home remedies

In Indian society, like in many other societies, traditional or indigenous methods of remedies are preferred over facility based diagnosis and treatment at times.[165] Three women stated using home remedies for the complications.

Table 53: Home remedies

Home remedies	Frequency	Percent
Yes	3	10.3%
No	18	62.1%
No information/ Missing	8	27.6%
Total	**29**	

165 Ong HG, Kim Y-D. Herbal Therapies and Social-Health Policies: Indigenous Ati Negrito Women's Dilemma and Reproductive Healthcare Transitions in the Philippines. Evidence-Based Complementary and Alternative Medicine. 2015; 2015:491209.

During the informal discussions, many women reported that they started traditional medicines for a week before going to a health facility. At times, it was observed that in keeping with traditional practices, the woman and her child was not allowed to leave the house for some time after delivery. Financial constraints made families reluctant to spend money on services in healthcare facilities, and have more trust in traditional healers.[166]

Home remedies suggested:

- Wrapping the child in hot cotton to provide relief from cold
- Going to traditional healer, who knows black magic
- Witchcraft solutions
- Beliefs in god and goddesses

Support for treatment

Among those mothers who reported complications in the child after delivery, only 20 percent received support for medical treatment, whereas 65 percent reported not having received any form of support.

Table 54: Support for treatment

Got support	Frequency	Percent
Yes	4	20%
No	13	65%
No information available	3	15%
Valid total	**20**	

Note: Out of the four who received support, two stated they got support in the form of cash or medicines.

Death certificate received

A death certificate is an official document issued by the government, which declares cause, location, time, and other information about death. Child Death Review is undertaken in the National Health Programme as a strategy for responsive programming. In rural areas, the ASHA worker is the primary informant of child deaths. Others who could also notify authorities regarding death include AWW, ANM, panchayat member and Panchayat

166 Bazzano Alessandra N, Kirkwood Betty R,Tawiah -Agyemang Charlotte,Owuso-Agyei Seth, Baba Adongo Philip Jan 2008 Beyond symptom recognition: care seeking for ill newborn in rural Ghana Tropical medicine and International Health volume 13 no 1 pp 123-128

Secretary. A notification card is handed over to the family.[167] However, a majority of the women (86%) stated that they did not receive any death certificate of the child. The lone woman who received a death certificate had delivered in a Sub Centre.

Table 55: Death certificate received

Death Certificate	Frequency	Percent
Yes	1	3.4%
No	25	86.2%
Missing / No information	3	10.3%
Total	**29**	

During the interviews, it was observed that no one had much information about the death certificate. One woman said, *"Hum log dukhi the. Baccha itna chota tha. Uska bhi mrityu praman patra hota hai kya hume nahi maloom, afra tafri ho gayi bacche ki mrityu sun ker hum logon ko kuch nahi pata. Jab baccha hi nahi hai mrityu praman patra ka kya karenge* [We were sad after hearing the news of death and no one told us about the death certificate. When the child is no more, of what is use is the death certificate]." Findings are also an indicative of lack of ability among ASHA/ ANM/ AWW to provide the notification card to the family, which implies a huge number of neonatal deaths go unreported and are not included in the National Death Register.

Distance of the facility

Studies have documented that women who live farther away from health facilities are less likely to give birth at these facilities. Physical distance from the health facility is one among the key barriers for seeking healthcare, especially among rural populations.[168] Approximately five percent of Indian women live more than 10 kilometres from a health sub centre, where uncomplicated deliveries can be performed. Moreover, almost one-third of the women live more than 10 kilometers away from a PHC, which addresses more complicated deliveries. These long distances are mainly experienced by women living in rural areas. Some of these issues may be addressed through improvement in infrastructure provision, but other helpful measures would include training more staff

167 Child Death review An Operational Guideline , National Health Mission, Ministry of Health & family Welfare, Government of India2014

168 Thaddeus, S., and D. Maine August 1994. "Too Far to Walk: Maternal Mortality in Context." Social Science and Medicine, vol. 38, no. 8, pp. 1091-1110.

at mid-level and lower-level facilities to deliver care and improving incentives for skilled providers to work in rural areas.[169]

Table 56: Distance of the facility

Distance to nearest Sub centre	0-1 km (37%)	2-3 km (52%)	3-5 km (14%)	More than 5 (7%)	Average distance 2.3 km
Distance to PHC	0-5 km (35%)	5-10 km (35%)	10-15 km (7%)	More than 15 (12%)	**5.1 km**
Distance to CHC	0-10 km (59%)	10-20 km (17%)		More than 20 (24%)	**11.5 km**
Distance to district hospitals	0-10 km (38%)	10-10 km (38%)		More than 20 (24%)	**13.6km**

Children born in a health facility are more likely to be vaccinated and breastfed. Policy simulation results indicate that providing access to health facility within 5 km would increase institutional delivery by 10 percent. However in the study, it was found that 52 percent of the respondents were within a range of 2-3 km from the nearest health facility and 56 percent respondents were within a range of 10 km from a CHC. The average range of distance found in the study for the nearest SC, PHC, CHC and DH are 2.4, 5.1, 11.5 and 13.6 km respectively. Ten respondents reported having private facilities within a range of 3-5 km. The average distance from the nearest district hospital was reported to be 13.6 kms.

Complications post delivery

Most of the mothers reported that the child developed complications post-delivery. And 27 percent did not have any record of complications. This can be attributed to improper antenatal care and maternal care as stated in the earlier sections. The information collected was of qualitative nature and mothers mostly reported colloquial terms such as '*neela / pila padhna*', etc. Six mothers stated breathing difficulties in terms of frequent hiccups, two stated premature birth and bleeding from mouth and nose. One responding mother stated low weight as reason for complications.

The complications that were suggested by doctors as reported by mothers during qualitative exploration included fever, jaundice, infection and weak child (need of five units blood). Responding mothers stated

169 So O'Neil Katie Naeve Rajani Ved March 2,2017 An Examination of the Maternal Health Quality of Care Landscape in India https://www.macfound.org/programmes/population/

that the family members told them about complications such as diarrhoea, short breath, bleeding and intake of contaminated water by newborn.

The nature of the complications according to mothers were mainly breathing problems/ hiccups, child not crying after birth, pre-mature delivery, low birth weight, bleeding and anaemia and complications caused by earlier C-sections.

SECTION G

Healthcare delivery

Many facilities are ill equipped to provide maternal health services. Almost one-third of rural health sub centres lack regular water and electrical supply elevating the risk of infection. Running water and electricity have been found as protective factors against maternal mortality among women with uncomplicated pregnancies, who often deliver at sub centres. In addition, one-third of PHCs lack labour rooms, and some hospitals perform surgical procedures such as Caesarean sections with no onsite blood banks or reliable anaesthetics, further increasing the risk for unmanaged pregnancy complications.[170]

In the scope of this study, qualitative experiences of mothers were documented with respect to health facilities, services available, labour room (condition and services) and behaviour of health personnel. The experiences related to the facilities available showed that many responding mothers were satisfied with the availability of ASHA, ANM, Trained Birth Attendant etc., but only one of the respondents was satisfied with the level of hygiene and cleanliness. One of the respondents said, "*Hame district hospital me bharti nahi kiya gaya, wahan se doosre jagah bhej diya* [I was not admitted to district hospital and was referred to another hospital]." One of the respondents complained that the ANM that she did not attend to her in the PHC and was busy in her own work. Another respondent said they had to pay extra for treatment.

When mothers were requested to share their opinion and experiences regarding health facility, only one of them replied positively, saying the facility was clean and hygienic. Various problems were faced by respondents i.e., unavailability of doctor, unhygienic health facilities, electricity problems etc. Respondents also had to purchase their own blades, medicines and gloves.

Six women stated that beds, medicines, ANMs, ASHAs, dais and doctors were available in the labour room. One respondent stated that no services or facilities were available. Though one woman stated that the rooms were clean and doctors were available, during the field visit, it was observed that most of the women complained about the facilities informally. Many respondents complained about the unavailability of a doctor at

[170] So O'Neil Katie Naeve Rajani Ved March 2, 2017 An Examination of the Maternal Health Quality of Care Landscape in India https://www.macfound.org/programmes/population/.

the time of emergency. Some felt that the behaviour of the nurse / ANM was not good and that they had to pay extra money.

Treatment by ANM/ nurse/ other staff in the labour room

Earlier studies in the Indian context found that patients reported general satisfaction with their care; however, they also indicated barriers to explanations about medications and treatment options. Patients also reported a lack of respect, empathy, and compassion (or cultural competence) from their healthcare providers and lack of privacy when seeking care.[171]

Qualitative explorations during the interviews provided anecdotal evidence regarding treatment and behaviour in the labour room, where 11 respondents said they had a positive experience overall. At the same time, many respondents reported that during the time of emergency, doctors were not present but the behaviour of the TBA (Trained birth attendant) was good.

Wherever women mentioned that no doctor was available, they had to buy blade and soap on their own. Few women mentioned that the nurse physically tortured them at the time of delivery. One mother mentioned that ANM were present during the time of emergency but no doctors were available. Hence, it can be inferred that in general, there were issues pertaining to the availability of doctors, rude behaviour of nurse and non-availability of pregnancy kits.

As far as the health-seeking behaviour is concerned, in India, people perceive that private facilities offer better care than public ones, even though the latter are subject to more rigorous standards and regulations.[172] These perceptions are based on factors such as cleanliness, efforts of and interactions with the medical care providers, wait time, and facility supplies; however, research shows that public and private sectors do not differ in terms of appropriate treatments and harmful practices.

In the public health facilities, ANM/ ASHA were available. Some respondents stated that bed and medicines were available. Some respondents also reported buying injections and medicines from outside. Respondents also experienced having to pay more (Rs 700 fee, and Rs. 200 for cleanliness). During interviews and visits to health facilities, it was observed that SCs had no provision for running water or electricity (not in working

171 So O'Neil Katie Naeve Rajani Ved March 2, 2017 An Examination of the Maternal Health Quality of Care Landscape in India https://www.macfound.org/programmes/population/.

172 Das, J., A. Holla, A. Mohpal, and K. Muralidharan June 2015 "Quality and Accountability in Healthcare Delivery: Audit Evidence from Primary Care Providers in India." The World Bank Policy Research Working Paper 7334. New York: The World Bank.

condition) and in Varanasi Baragaon, the trained birth attendant was not available. Regarding private hospitals, respondents said the facilities were well maintained but the behaviour of the staff was not good.

CHAPTER 6

Conclusions, Recommendations and Way Forward

Conclusions

Despite recent developments in the health sector, neonatal survival has remained a cause of concern due to large variations in various parts of the county and the rural-urban divide. Children born in rural areas are more prone to dying due to various existing conditions in terms of accessibility, availability, affordability and utilisation of healthcare services and/ or other socioeconomic/ cultural factors at the household and community level. These factors play a crucial role during pregnancies and significantly determine pregnancy outcomes as cited by various studies.

In this study, an attempt was made to understand the role of these factors in neonatal deaths in three districts – Varanasi (Rural), Kaushambi and Sonbhadra – of Uttar Pradesh. Certain recommendations are proposed here based on the findings that can help strengthen policy and programmatic interventions in preventing neonatal deaths in Uttar Pradesh. To understand the interplay of these factors, both programme data from CRY interventions and primary data collected through this study were used and analysed. A total 55 cases of neonatal deaths from programme data were included in this exploration; out of these 55 cases, 29 mothers whose child died the one year preceding the study were interviewed in detail.

Conclusion based on Case Studies

- An analysis based on programme data suggested that majority of the women whose children suffered neonatal deaths were in the age group of 20-25 (43.6%), non-literate (62%), from Scheduled Caste background (58%), and were from BPL families (82%). Not only this, the primary occupation of majority of women (62%) and their spouses (82%) was agricultural labour. These factors taken together weave in the vicious circle of poverty and historical marginalisation of certain social categories and make it difficult for women from these communities to seek healthcare.

- Due to neglect in care of the female child and poor access to healthcare for girls, the data reflected that more girls (53%) compared to boys (47%) died in their first month of life. The gender differentials can be attributed to various social factors as described in the earlier sections of the report.
- Though a majority of deliveries were institutional (78%), a significant percentage (18%) happened at home. All children those who were born at home also died at home. With timely medical care and services, these deaths could have been averted.
- Though most pregnancies (93%) were registered by ASHA, access to services varied significantly. Only around 12 percent women underwent all four mandated ANC check-ups and 39 percent received benefits under central or state schemes for maternal and child health. These findings suggest that there is a need for proactive engagement from ASHA workers to bring women to health facilities. Clearly, mere registration of pregnancy doesn't suffice the purpose. There is a need to provide active support to women from marginalised communities so that they can access the provisioned services.
- Most of the women stated that they had a normal delivery (89%), yet around 44 percent were high-risk pregnancies in terms of low HB count, weight etc. In Sonbhadra, 64 percent were found to be high-risk pregnancies. Also, 16 percent had complications during pregnancy and/ or labour.
- Among the women who had institutional delivery, only one in every seven deliveries (13.3%) were assisted/ conducted by a doctor, whereas a majority of them were conducted by an ANM (86%). Having no doctor assistance during delivery may be potentially fatal for the mother/ child, especially in high-risk pregnancies. Data shows that although 44 percent of the pregnancies were high-risk, only less than 15 percent deliveries were assisted by a doctor.
- Overall, a significant percentage of neonatal deaths were attributed to the first (31%) and four plus (29%) birth order. Earlier studies also reported similar findings.
- Most of the deaths took place within seven days (82%), and can be called early neonatal deaths Neonatal Pneumonia and Respiratory Distress Syndrome emerged as the two highest probable causes accounting for 27 percent and 24 percent of the deaths overall. Though a disinfected and/ or new instrument/ blade was used to cut the umbilical cord in most of the deliveries (around 90%), the practice of breastfeeding immediately/ or within an hour of birth was largely absent (51%). One in every ten mothers reported that the child was given something other than breast milk to drink. These practices were explored in detail during the interviews with sampled women.

Conclusion based on Interviews

In-depth interviews with selected women (29) provided detailed understanding about access, availability and utilisation of maternal and child healthcare services and other sociocultural factors' role in determining the utilisation of these services.

- Majority of the mothers were in the age group of 18-25 years (48%), non-literate (65%), from Scheduled Caste background (48%), and were from families having monthly income less than Rs 5,000 (66%), essentially classifying as BPL families. These factors significantly determine the access and use of healthcare services and thus survival of the child.

Family and marriage

- Duration of marriage and fertility rate are closely associated. Most of the mothers were married for more than five years (59%) and a minuscule percentage was newly married. More than half of the interviewed women had given birth to more than three children. This was considerably higher than the average number of children born to a woman in India and Uttar Pradesh. Around 31 percent mothers reported that it was their first child who died, and in 17 percent of the cases, it was the fifth child.

Antenatal care

Good care during pregnancy is important for the health of the mother and the child. The National Health Mission mandate matches the WHO's recommendation of at least four antenatal check-ups during pregnancy. However, the findings show that only 13 percent of the interviewed mothers received at least four ANCs during pregnancy. Though a majority of them (93%) received the Mother and Child Protection Card, 20 percent of the women did not visit a health facility during their pregnancy.

- Access to healthcare is also influenced by household factors and women's role in the family. Only half of the mothers (55%) reported that they could access healthcare on their own, in terms of visiting a health facility.
- It is important for the pregnant woman to have full three meals in a day to meet the nutritional requirements. 79 percent of the respondents were found to have access to three meals a day during their pregnancy. Though a considerable percentage of mothers (94%) were counselled by the outreach workers about the importance of nutritious diet and calcium intake during pregnancy, 17 percent reported that they did not have access to three meals in a day. This could be attributed to the socioeco-

nomic condition of the household, neglect of care of women in general and ignorance at the family level regarding the importance of nutritious food for pregnant women.

Newborn delivery related practices

- One in every tenth woman delivered at home. Majority of the deliveries were conducted in a public health facility (61%). One in every fourth delivery took place in a private hospital or clinic. Most of the women had normal delivery (72%).
- Among those who had institutional delivery (n=26), most (18) were discharged on the day of their delivery, although the WHO recommends that a healthy mother and newborn should receive care in a healthcare facility for at least 24 hours after birth.
- Only 35 percent of the children were given colostrum within an hour, though most of the mothers had received counselling about the importance of breastfeeding practices.
- Around 31 percent newborns died on the day of their birth. Another 31 percent children died within seven days of birth. Out of the total deaths, 48 percent were boys and 52 percent were girls.

Beliefs, practices about pregnancy

Societal, familial and communitarian contexts and beliefs affect health decisions during pregnancy considerably.

- Qualitative findings during the interviews showed that various beliefs and practices were prevalent at the family and community levels. These beliefs pertained to travel restrictions for pregnant women, personal hygiene, restrictions on specific food items and religious activities.
- More than half of the mothers (52%) reported that they followed these beliefs when they were pregnant due to fear of family or community, or fear of refuting old practices.
- Qualitative findings also found that mothers reported that in their community, newborns were only given cow's milk or honey immediately after birth.
- 10 percent of the mothers followed home remedies suggested by the neighbours or community members. Suggested remedies included wrapping the child in warm cotton to keep away the cold, getting the child treated by *ojha, jaadh-phoonk* by religious persons. Some mothers also resorted to placing *hing* (asafoetida) on the child's stomach as a remedy.

Post-delivery complications

Sixty-nine percent mothers reported that their child had complications post-delivery and 35 percent of them received this information from their ANM.

- Among those mothers who reported complications in the child after delivery, only 20 percent received support for medical treatment.
- Majority of the mothers reported that they did not get any death certificate of their child. Qualitative findings suggested that they didn't have exact information and awareness about death certificates.
- Complications that were noticed the mothers included premature delivery, head injuries (as told by ANM), child didn't cry, short breath (three cases), low birth weight, fever, body went grey-blue (asphyxia), loose motions etc. One respondent mentioned that she had already had two C-sections before the pregnancy in question, and so the child died. Many respondents did not recognise the danger signs and delayed seeking treatment. Some of them had problems securing transportation and money to reach the hospital on time.

Experience related to services in the health facility

- There were mixed responses regarding delivery experiences in medical facilities. Though most mothers had satisfactory experiences, few raised concerns about negative experiences related to services in the health facility. Mothers from Kaushambi reported misbehaviour of the ANM and inadequate assistance provided during delivery. Delay in referral was also cited by them as a negative experience – the resultant delay in treatment could be a possible reason of death.
- Some respondents were satisfied with the services, and reported that there were beds, ANMs, medicines etc in informal discussions during the interviews. However, many of them complained about unavailability of ANMs, delay in assistance, unhygienic facilities in the labour room, water facility and electricity issues etc. Mothers also said that local dais (untrained) generally conducted deliveries.
- Many mothers reported issues related to disrespectful care as the ANMs were rude to them. They also cited the unavailability of doctors, lack of medical supplies, out of pocket expenses on medicines, unavailability of Oxygen cylinders, etc.

Recommendations

There are various factors determining and contributing to early neonatal deaths. These stem from unhealthy or unfavourable social and cultural practices and belief systems around pregnancy and child births. Similarly, the socioeconomic factors which play a vital role in enabling people to seek healthcare services during pregnancy, delivery and during the postnatal period are identified to be equally important.

In addition to these, the lack of a functional healthcare delivery system plays a vital role. Factors that can influence the key decision to seek care include the views of the woman, her husband and her relatives; the availability and competence of trained dais (traditional birth attendant); the ability to recognise high-risk pregnancies and seek the right advice; socioeconomic status of the family; illness characteristics (recognition and severity); distance from the health facility (accessibility); financial and opportunity costs (affordability); previous experience and perceived quality of care. Other factors include physical accessibility, travel time from home to facility, availability and cost of transportation and condition of roads.

Key recommendations

Need to improve the services in the health facility

- A physical verification and observation of the facilities in the study areas reflected the urgent need to equip the facilities as per norms. Basic amenities such as running water, electricity, generators should be made available and functional in the sub centres and PHCs on an urgent basis.
- Adequate and appropriate facilities for postnatal care should be provided to the mother and her child as the study findings indicate that a significant proportion of mothers who had delivered in a healthcare facility got discharged on the same day, grossly compromising mother and child health.
- Proactive measures should be taken to identify high-risk pregnancies. ASHA workers can play a significant role here. In addition to identification, adequate referral mechanisms should also be put in place to avoid any untoward events. Delays in providing appropriate treatment could be fatal.
- To bring down deaths during transit, pick up and drop facilities under 102 and 108 ambulance services should be strengthened by health authorities. These services should function in a timely manner so that lives of mother and children may be saved during emergencies.

Strengthen human resources at health facilities at all levels for providing improved newborn healthcare

- The study findings suggest that hardly any institutional delivery in a government facility was assisted by doctors. Qualitative findings also suggest that in most of health facilities, there was an acute shortage of human resources such as neonatologists, obstetricians, lab technicians, anaesthetists and midwives. Vacant positions of healthcare staff should be filled on an urgent basis and specialised doctors such as gynaecologists and paediatricians should be recruited in the remotest rural areas of Uttar Pradesh like Sonbhadra.

Strengthen the competency of service providers in the labour room, including medical officers, staff nurses, and ANMs, to render best practices of safe delivery as per established labour room protocols and standards

- Outreach workers such as ASHA and anganwadi workers should be provided training, as well as adequate additional resources in terms of 'untied funds' that can be used for emergency situations.
- The study found that home deliveries were a common practice in study areas. These deliveries were assisted by relatives or *dais* (unskilled birth attendant). This practice significantly increases the risk to the mother and the child. *Dais* can be roped in through various training programmes to promote healthy pregnancy and birth practices in rural settings, so as to minimise the proportion of home deliveries by unskilled birth attendants.
- More emphasis should be placed on early screening of birth defects by service providers in health facilities and in the community by ASHA workers during home visits. ASHA workers should promote effectively the importance of full ANC check-ups.

Engagement of the community and family/ Strengthen Village Health Nutrition and Sanitation Committees

- Formation of Village Health, Nutrition and Sanitation Committee (VHNSC), their training and activation is critical to address issues related to maternal and child health. This Committee is empowered to not only monitor health facilities at community level, but also contribute to developing Annual and Monthly Village Health Plans which feed into the planning process up to the State level.

- Poor domiciliary care practices have often been implicated in causing neonatal illness. Several cultural beliefs and traditions that exist in different communities influence care practices. Certain care practices can be deleterious to the health of the child, like applying ghee/ oil on cord, early bathing, avoidance of colostrum feeding (considering it as harmful for the baby) and not practicing exclusive breastfeeding. Realising the presence of such traditions in the community, intensive Information, Education, and Communication (IEC) campaigns should be formulated with support of VHNSC and civil society organisations to address myths and misconceptions and promote IYCF and safe sanitation practices.
- Detailed counselling of the family members should be promoted and conducted by the frontline workers to address taboos associated with prevailing practices. The study also informs on certain practices and taboos that do not have any scientific basis. To minimise and/ or prevent these practices, user-friendly IEC material should be created and disseminated so that family members understand the importance of antenatal care, adequate nutrition and maternal care.
- Observing important days that are sanctioned by the community to impart important messages, like *godbharai*.
- VHSNC should promote and form community collectives and groups to look after the emergency needs of pregnant women and their family, like transportation. They must also support the health and nutrition needs of pregnant women from the most marginalised families.
- Indigenous and easily available nutritional foods and diversity in the food platter should be promoted so that the dietary intake during pregnancy is appropriate and a pregnant woman gets all required nutrition.

Awareness programmes

- Individual and family preparedness for birth should be promoted via training on various aspects such as positive attitudes, favourable perceptions towards birth preparedness, high self-efficacy and familial and social support.
- Active participation of men should be sought through government sponsored and promoted community-based intervention programmes. Family members of the pregnant women need to be informed about pregnancy and availability of services. They should be encouraged to access healthcare services.

- Inter-spousal communication seems to be an effective means of enhancing birth preparedness. Therefore, it should be encouraged through active participation of husbands in antenatal care services.
- Information on the maternal and child care, antenatal care, danger signs of complications and postnatal care should be disseminated using short films, *nukkad natak* (street play) etc, as they are more effective means of communication in areas where the population is largely non-literate. Short films and street plays can be exhibited on smart mobile vans.
- Community awareness should be created to address regressive practices such as early marriage and gender discrimination, as these practices considerably impact the health of a mother and her child.

Further research

- More research should be facilitated to document the cultural, social and community practices related to child birth and pregnancy so that findings from such studies can be used to better design intervention programmes and national programmes.

Role of NGOs and civil society organisations

- Local NGOs can assist in awareness generation activities, like encouraging pregnant women to seek antenatal care and promoting institutional deliveries and postnatal care visits. NGOs can also use their field base and presence to disseminate information related to government schemes and facilitate access.
- NGOs can organise outreach activities, like camps with the help of local health institutions that can prevent delay in healthcare seeking in remotest areas. These initiatives can alter care-seeking behaviour significantly.
- Through mass media campaigns, home visits, rallies, documentary films etc., NGOs may influence and promote behaviour change communication and practices and generate awareness about breastfeeding and other facets of pregnancy such as antenatal care, neonatal and child health, especially in rural areas.
- Involving NGOs in regular monitoring and tracking of pregnant women may strengthen government initiatives and their acceptability in the larger community.

Policy Recommendations

This study shows that there is a need to adopt state-specific strategies and multi-sectoral approaches to bring down neonatal mortality, and move closer towards achieving the targets and goals of INAP, NHM, NAPC and SDGs. Policy options for newborn and child survival should include community awareness, adopting preventive strategies, enhancing local health infrastructure and increasing investment in child health and related maternal and adolescent health polices and schemes.

1. Birth and death registration should be strictly mandated. Civil Registration and Vital Statistics (birth and death registration with cause of death assignment) should be progressively strengthened for counting every newborn.
2. Micro level research, information and reliable data about mortality are required for improving programmes.
3. The system of reporting NNM should be strengthened and each neonatal death should be audited to improve newborn health. Strict guidelines should be placed and followed by government health facilities and health workers for registration of pregnancies and related follow-ups.
4. Periodic monitoring of Annual Implementation Plans should be encouraged by state authorities. Annual health plans should reflect local needs and effective budgeting processes should be put in place. State governments should prepare plans for effective functioning of the FRUs and increase human resources like skilled birth attendants. Plans should be closely monitored to measure progress.
5. Trained mobile health teams should be deployed for screening and early detection of risks so that immediate actions can be taken during emergencies to reduce the risk of death.
6. Periodic health facility audits and needs assessment studies at the facility level should be promoted by health authorities to assess gaps in services and take corrective measures.
7. Periodic training and assessment of training should be promoted for outreach workers on varied topics related to maternal and child health. Though incentives are inbuilt in national programmes for promoting institutional deliveries, healthy practices such as colostrum feeding, exclusive breastfeeding, nutritious food intake during pregnancy and lactation and maintaining personal hygiene could also be incentivised.

8. Intensive awareness programmes should be promoted to disseminate information about maternal/ child care and available government schemes to enhance coverage.
9. Efforts should be made to address issues such as early marriage of girls and nutritional deficiencies among adolescent girls through school and community level programmes and activities.
10. Focus should be on promoting postnatal visits, as across the world this strategy has been accepted as the best practice to reduce NMR and IMR. Hence the role of ASHA is significant. The government guidelines also talks about 3 contacts within 7 days.
11. Also need to focus on improving the quality of institutional care and formulating and implementing the delayed discharge protocols. The institutional care can significantly bring down NMR especially early NMR which in the study findings was also a significant percent (82%) all the NMRs.
12. Steps to be taken by the Health department and government health workers to improve the quality of ANC especially focusing 4th ANC and more so the last ANC within last week of pregnancy and BP/ CR (birth preparedness and complication readiness) can be addressed.
13. Urgent need to shift from generalised strategy to focused approach (narrowed down approach) needs to be applied to reduce NMR to attain the targets of SDG. One of them is focussing on the tribal pockets as significant numbers of deaths are happening there. Further focus needs to be on the 1st born as it increases the NMR significantly.
14. Most of the recommendations related to addressing adequacy of human resources as per IPHS standards, their training, availability of quality infrastructure etc. are contingent on adequate budgetary allocations. Trends in budgetary allocations for child health as a proportion of overall child budget has been progressively declining from 3.9 per cent (2018-19 BE) to 3.57 percent (2019-20 BE) to 3.4% (2020-21 BE). The overall expenditure on public health was a mere 1.5% of GDP (2018-19 RE)[173], and allocations for the year 2020-21 increased to only 1.6%, which way below the NHM target of 2.5% to be achieved by 2025. Thus, there is an urgent need to universalise quality health services by increasing public provisioning for health.

173 Economic Survey of India 2019-20 (Vol II): Social Infrastructure, Employment and Human Development, Govt. of India

WAY FORWARD

At the macro level, India has witnessed some improvement in neonatal health in recent years. The findings of this study at the micro level, however, reveal huge gaps in terms of accessibility, availability and utilisation of healthcare services. Various social and cultural practices at family and community levels influence the maternal and child care, particularly in rural settings. The interplay of these factors is responsible for the disparities and the high burden of neonatal mortality. The study findings indicate the need for specialised newborn care, emergency obstetric care and efficient ambulance transport systems to promote favourable health-seeking behaviour and strengthen community and health facility linkages. To improve and generate the demand for healthcare and to promote healthy practices at the household level, outreach services need to be strengthened through trained rural health volunteers and women's groups. There is a need to enhance competences of local TBAs for improving home delivery practices and encouraging hospital deliveries by linking them to the public health system. Tailored programmes need to be encouraged to address healthcare needs of pregnant women from the most marginalised sections of society. A stringent system of recording neonatal deaths and their cause is required to minimise deaths due to avoidable circumstances. Thus, adequate financial provisioning through policy measures, strong health infrastructure and referral system through programmatic interventions, promoting uptake of health services at the community level and addressing social myths and misconceptions at length are required to realise the right to survival enshrined under the UNCRC convention.

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CHILD RIGHTS AND YOU
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Child Rights and You (CRY)

CRY is an Indian non-profit organization that believes in every child's right to a happy childhood - to live, learn, grow and play.

We address children's critical needs by working with parents, teachers, Anganwadi workers, communities, district and state level governments as well as the children themselves. We focus on changing behaviors and practices at the ground level and influencing public policy for advocacy at a systemic level - thereby creating an ecosystem where children are made the nation's priority.

In the last **40 years**, with the help of our partners, donors, volunteers and supporters, we have impacted the lives of over **3 million children** across **19 states** in India.

WHAT WE DO

We work in all 4 areas of children's rights:

EDUCATION

Ensuring that children go to school and complete their education

HEALTH & NUTRITION

Increasing access to proper nutrition and quality healthcare

SAFETY & PROTECTION

Addressing issues like child labour, child marriage, trafficking and abuse

PARTICIPATION

Creating an environment where children's voices are heard and considered

OUR IMPACT (2019 - 20)

6,80,490 children impacted overall

1,63,541 children in CRY project areas, between the ages of 6-18 years, in school

97% children in CRY project areas, under the age of 1 year, immunized

88% children in CRY project areas, under the age of 5 years, free from malnutrition

2,064 children in CRY project areas rescued from child labour, child marriage & child trafficking

AWARDS & RECOGNITION

CRY is recognized as India's Most Trusted NGO (Trust Research Advisory Report 2018)

CRY has been chosen as one of the top 100 nonprofits making a difference in the world by The Elders - an international body founded by Nelson Mandela

Puja Marwaha (CEO, CRY) won the Olga Alexeeva Memorial Prize for Best Innovation in Philanthropy