REVIEW ARTICLE



Turning the Gaze from Survive to Thrive for Children in India: Learnings from Two Case Studies

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Abstract

Despite significant efforts and progress made in newborn care programs in India, implementation gaps persist across the continuum of care. The present case studies of two districts in Himachal Pradesh revealed that pathways of care were often fragmented with inconsistent linkages between facility and community due to poor documentation, lack of tiered referral, health system weaknesses, low utilization of primary level institutions, and inadequate post-natal home visits by Accredited Social Health Activists (ASHAs). Involvement of healthcare providers (HCPs) and frontline health workers (FHWs) was low and uneven in generating awareness across the districts with limited participation in supporting care in the community. Ensuring functionality of health centers and first-level care facilities; strengthening referral systems; adequate/trained human resources; strengthening routine health management systems, discharge processes and community-based care with adequate integration with facilities are necessary in closing access gaps.

Keywords Survive · Neonatal thrive · SDG · Primary health care · Community-based care

Introduction

Contributing to a quarter of global newborn deaths, India is striving to achieve the Sustainable Development Goals (SDG) 2030 [1] with significant efforts being made in newborn care programs (Fig. 1). India's large cohort of preterm

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and low birth-weight neonates are at the greatest risk of death and disability largely due to preventable causes and lack of follow-up care [2, 3]. Early growth faltering, a relevant measure for thrive, occurs due to low birth weight, suboptimal feeding, poor maternal nutrition or illness, and deficient childcare [2, 4]. Several studies document growth depreciation in early life [5, 6]. The present case studies of Kangra and Sirmaur Districts, Himachal Pradesh identified poor growth in a significant proportion of term (30%) and preterm infants (52.6%) between 1-4 mo of discharge from hospitals [7]. Current programmatic dimensions do not adequately capture the thrive component, especially for vulnerable babies [4, 8–10] (Box 1). The quantitative findings of this study and detailed methodology have been previously published [7]. This narrative aims to establish the need for reimagining the health system for facilitating optimum care of small and sick babies through the continuum of facilitybased care and follow-up care at home.

Box 1 Enabling environment for reforming care

• India Newborn Action Plan (INAP 2014) proposed evidence-based interventions and implemented within National Rural Health Mission (NRHM) and the Reproductive, Maternal, Newborn, Child, and Ado-



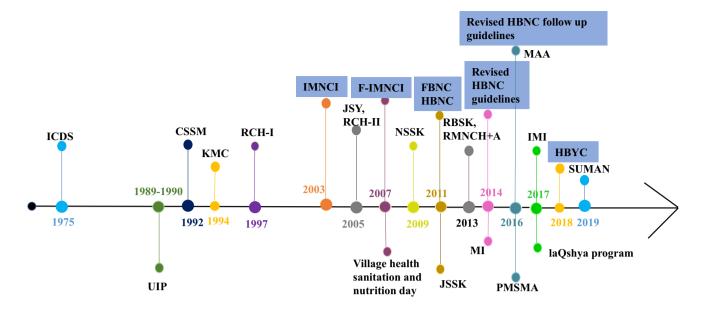


Fig. 1 Programmes/interventions focusing on newborn health in India. CSSM Child survival and safe motherhood, FBNC Facility based newborn care, F-IMNCI Facility based IMNCI, HBNC Home based newborn care, HBYC Home-Based Care for Young Child Programme, ICDS Integrated child development services, IMI Intensified Mission Indradhanush, IMNCI Integrated management of newborn and childhood illness, JSSK Janani Shishu Suraksha Karyakaram, JSY Janani Suraksha Yojana, KMC Kangaroo mother

care, *laQshya* Labour room & quality improvement initiative, *MAA* Mothers' absolute affection, *MI* Mission Indradhanush, *NSSK* Navjaat Shishu Suraksha Karyakram, *PMSMA* Pradhan Mantri Surakshit Matritva Abhiyan, *RBSK* Rashtriya Bal Swasthya Karyakram, *RCH* Reproductive and child health, *RMNCH+A* Reproductive, maternal, newborn child plus adolescent health, *SUMAN* Surakshit Matritva Aashwasan, *UIP* Universal Immunization Programme

lescent Strategy (RMNCH+A), provided attention to newborn health.

- Several interventions focusing on newborn health in India continue providing an enabling environment to strengthen thrive (Fig. 1).
- Gaps exist in newborn health intervention delivery Failure in successful implementation of available interventions by the health and social systems; deficits noted in care competence (e.g., diagnosis and management), system competence (e.g., timeliness, continuity, and referral), and user experience (e.g., respect) [11]; quality concerns in delivery and slower progress in the roll-out [7, 9, 10].
- Opportunities Substantial workforce in the primary care setting to lead the way in prioritizing primary healthcare by optimizing postnatal care provided at the community [8]; emerging experience in several states in India indicate that children with uncomplicated severe acute malnutrition (SAM) being managed successfully through community-based management models that leverage existing health systems [12, 13].
- **Rethinking care provision** with a shift towards effective structural reforms is essential and timely as we move forward to achieve the ENAP/SDG 2030 goals in India.

Understanding Thrive Through a Continuum of Care Lens

With systems in place, greater understanding of existing gaps can help reimagine optimum care of small and sick babies. Adopting a Continuum of Care (CoC) lens allows understanding complex linkages in care provided across dimensions of place, time, and people. CoC relates to three major components: health providers, health system, and community (beneficiary and caregivers) [11, 12]. CoC demands integration, coordination, and collaboration across different levels of care with special focus on case management, where beneficiary is followed across care pathway for; preventing adverse health events, ensuring appropriate (and need-based) care, and avoiding duplication of care [13]. Disruptions in these care pathways lead to fragmentation of services that leads to fragmentation and disruption of responsiveness.

Programmatic Learnings from Two Districts of Himachal Pradesh

Himachal Pradesh has shown significant decline in neonatal mortality rates (NMRs) over the years from 49 deaths/1,000 livebirths in 1992 to 20.5 deaths/1,000 livebirths in 2020, despite the difficult geographical terrain [14].



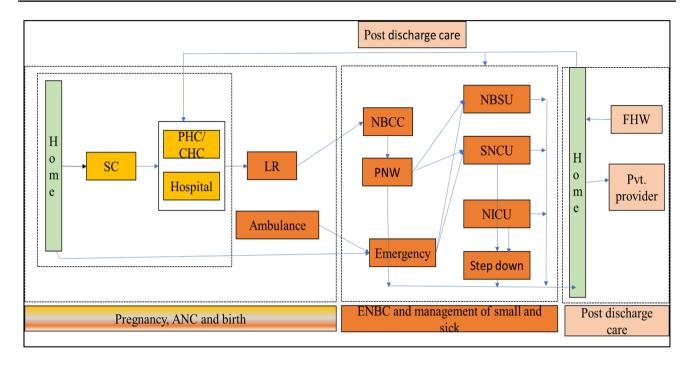


Fig. 2 Multiple care pathways identified for care of small and sick babies across the two districts of Kangra and Sirmaur in Himachal Pradesh. *ANC* Antenatal care, *ENBC* Early newborn care, *FHW* Frontline health worker, *LR* Labour room, *NBCC* Newborn care corner,

NBSU Newborn stabilization unit, NICU Neonatal intensive care unit, PHC/CHC Primary health centre/community health centre, PNW Postnatal ward, SC sub-centre, SNCU Special newborn care unit

However, the indicators (stunting, wasting, and underweight) related to thrive have taken an opposite trajectory with recent increases in malnutrition rates for the state. The decreasing trend in the early childhood mortality rates and increasing trend in malnutrition with a functioning district level care system for newborn care – both at facility and in the community and home – made the state of Himanchal Pradesh a good case study. Different pathways of care (Fig. 2) were identified from birth, early newborn care, care of small and sick newborn, and post-discharge care in the two districts with several strengths along the continuum. Most respondents were content with care provided by the HCPs in the facilities (nurses and doctors) (e.g., regular check-up of the newborn and support of mothers in care of small and sick neonates). In the community, adequate care with timely identification of danger signs, birth preparedness during pregnancy and Accredited Social Health Activist's (ASHA's) effective role usually in facilitating referrals of sick babies to health facilities were reported. The choice of facility for sick neonates was based largely on trust gained on hospital/HCPs through previous experience, perceptions of quality of services, and availability of special health care service for neonates in the special newborn care unit (SNCU) or newborn stabilization unit (NBSU).

However, gaps along the CoC were also documented. Care pathway was noted to be fragmented (management discontinuity) with inconsistent linkages found between community and facility-based care in terms of antenatal care (ANC), postnatal care (PNC) and facility-based integrated management of newborn and childhood illness (F-IMNCI). A poor documentation system unable to enable referrals across the facility and community, with referral advise largely based on proximity to facility or to a higher facility to bypass further referrals was noted. In addition to the lack of a tiered referral process (geographically/demographically), non-availability of adequate skilled nurses, inadequate pediatricians/trained medical officers to handle neonatal emergencies, no referral policy (e.g., referrals from lower levels not honored at higher levels, 'strategic referrals' on account of defensive medicine, referrals due to nonavailability of laboratory services, gaps in referral transport due to lack of fuel at remote stations) and faulty triage/prioritization at call centers contributed to poor linkages. Need for strengthening linkage between SNCUs, NBSUs, and primary health centers (PHCs) and for a tiered referral process has been previously documented [15]. In addition, institutionalizing referral mechanism to ensure to-and-fro referral, between facilities and screening points has been noted as a priority action by India Newborn Action Plan (INAP). As also reported previously [7], majority of ASHAs were not informed about small and sick babies discharged from the facilities in the district leading to inadequate follow-up care. In addition, there was no communication between the facilities and ASHAs regarding community processes and child's



health post-discharge. Non-availability of contact details of the ASHAs with the facilities/SNCU in-charges or designated data entry operators did not help address the issue. Establishing a system to link facility and home through ASHAs can be key in ensuring continuity of follow-up care during early infancy.

Further, the study also noted that despite a SNCU follow-up system in place to understand the status of babies' post-discharge, on-ground difficulties in contacting caregivers due to missing/altered contact details or refusals to provide information was common. This contributed to poor SNCU follow-up rates across both districts. In addition, the data entry operators (where available) had no incentives to ensure improved follow-up rates. Leveraging routine health management information system for regular monitoring of care has been documented previously [16] and the need for strengthening the availability of high quality data, including indicators for small and sick newborns is recognized as a critical need for ensuring survival and thrive [2]. In the state of Himachal Pradesh, non-functional NBSUs closer to home or unavailability of district early intervention center (DEIC) at SNCUs also contributed to poor follow-up rates with parents less motivated to bring SNCU discharged babies at facilities far away or at regular OPDs which had a long waiting period in the SNCUs.

From the perspective of information continuity, involvement of HCPs and frontline health workers (FHWs) was often low and uneven in generating awareness across the two districts. Examples illustrating this include referral transport perceived to be for 'emergency services' due to inadequate and inconsistent explanation of what emergency services entail leading to travel by hired taxies or bus was frequent among those in need. During discharge, emphasis largely was on discharge papers/prescribing medicines with little attention in advising post-discharge care and consequently, follow-up being grossly deficient. In addition, capacity building of mothers/community members by FHWs or HCPs at facilities - on postnatal/discharge care - was grossly inadequate. Strengthening of discharge counseling in the facilities and further empowerment of mother-caregiver in the communities by the FHWs can play a critical role in improved and timely care seeking and ensuring a seamless linkage of care provided for vulnerable babies.

In the study, participation of HCPs and FHWs in supporting care at the community level was found to be limited (relational discontinuity). Number of home visits by FHWs for monitoring and screening (healthy, small, or sick neonates) was inadequate with most home visits by FHWs largely limited to updating Mother and Child Protection (MCP) card and informing about immunization. High workload and geographic challenges limiting community access for FHWs (in position) were seen to hinder service delivery and inter-personal relationships within the community. This was contrary to the priority

action outlined by INAP which requires capacity building of ASHA and Auxiliary Nursing Midwife (ANM) for newborn care at community level including to strengthen counseling for breastfeeding, postnatal care, and community and home care practices.

Lastly, a low utilization of sub-centers (SCs) and PHCs for neonatal care (Human resource shortages, vacancies) with treatment seeking from higher levels often without referral contributed to fragmented care and over-crowded higher-level institutions (medical colleges). Adequate number of skilled workforce and adherence to guidelines determines the quality of care provided both at facility and community level. Previous data documented the same with need to focus on task shifting where required with mentoring and regular audits to enable delivery of good quality services [15]. Likewise, INAP recognizes the development of a mechanism of supportive supervision through existing systems or through partnerships (with professional organizations, medical colleges, and private hospitals) at the regional and state level as a priority action.

Making Strides Towards Achieving SDGs

The Astana Declaration 2018 is committed to building sustainable primary health care [17]. Emerging evidence through research studies [18] such as this can meaningfully contribute to evidence-based primary health care that is yet to make its mark in Low and Middle Income Countries (LMICs). The Asthana Declaration also marks a shift towards empowerment and health literacy, beyond the conventional understanding of community involvement, public participation, and health education [19]. The SDG paradigm refocuses the direction towards universal health coverage via strengthened primary health care, instead of the prevailing single disease control focus. The four delivery platforms for this purpose include: community-based care, health centers, first-level hospitals, and populationbased interventions [20]. The authors present evidence in this context of the relevance and urgency of strengthening community-based approaches and the primary and/or community health center particularly for early recognition and follow-up services. Further, along with a tiered referral system, authors highlight the critical role played by FHWs like ASHAs and the caregiver/mother in enabling linkage between community and facilities closer to home and ensuring early care seeking. Home based newborn care (HBNC) has been proven as an important measure in improving neonatal as well as maternal health. The HBNC component has been further expanded to allow follow-up of babies discharged from SNCUs and low birth weight (LBW) babies through home visits by ASHAs uptil 12 mo of age. Timely information to ASHAs for follow-up visits post SNCU/facility discharges as well as their adequate



training and supervision can help tackle the problem at hand. In addition, there needs to be provisions for transfer of information from the ASHA to the facilities regarding the follow-up care being provided and child's health. Further, empowering the mother/caregiver for follow-up care can ensure better care-seeking for their babies as per need. Strengthening counseling provided at the time of discharge and during follow-up care by the ASHAs can play a role in improved follow-up rates. Along with ASHAs and mothers, data entry operators appointed within each SNCU can be better leveraged to improve follow-up rates while the routine health information system is leveraged in parallel. Lastly, establishing and/or strengthening the DEICs to deliver the services envisaged can significantly improve follow-care utilization by caregivers.

The current study highlights some of the contextual challenges and highlights, as also previously stated [21], that successful delivery of integrated continuum-of-care services within health systems depend on systematic efforts to address these constraints and to ensure planning of implementation strategies adapts over time to address complexity encountered at the ground level. The need for improved newborn and child survival has been recognized for long and been discussed for long including a special series in this journal more than a decade ago [22]. Over the years, several initiatives within the RMNCH+A as described above has shown government's commitment towards newborn care and prioritization of interventions for both newborn survival and thrive, especially focusing on small and sick babies as highlighted in the INAP [9, 23]. Further, the INAP release and subsequent initiatives under various programs including Ayushman Bharat bring our attention towards primary healthcare (including health and wellness centers) which can and should be leveraged by bringing communities to the forefront and its integration with the facility-based services [24, 25].

Conclusions

Addressing newborn thrive especially in small and sick newborns is critical in bending the curving of neonatal mortality further and expediting our progress in achieving the SDG 3. While the government has shown a renowned focus towards enabling newborn survival and thrive, bringing family and community at the centre of these interventions is critical to make progress (Box 2). With an established system of primary healthcare in the country which is connected through a network of primary health facilities and community health workers, strengthening the facilities and community for care provision, and enabling linkage for early care seeking or follow-up care can significantly help towards achieving the thrive agenda.

Box 2 Key recommendations

Rethink and restructure linkage between facility and community and vice versa Focus on a tiered referral system and institutionalize referral mechanism to ensure to-and-fro transfers; strengthen utilization of SNCUs database system for follow-up [26–28]; enabling ASHAs/ANMs, through a system to link facility and home, for follow-up and care of the discharged babies; better preparedness of mothers for care of babies at the time of discharge and post-discharge at home which would allow linkage to appropriate interventions for babies specifically breastfeeding counseling and improvements in nutritional support etc. [10, 27–29]; holding monthly review meetings at PHC and involving more medical colleges for problem solving and building strong linkages for referral [28].

Health facility strengthening Closing access gaps while ensuring functionality of NBSUs and strengthen capacity of functional newborn units [2]; hiring a mix of contractual and regular physicians and nurses to tackle shortage of Human Resource followed by training [15, 30]; strengthen admission and discharge process (admission and discharge check list/protocol) [2]; strengthening the availability of high quality data.

Systems accountability and strengthening ASHAs for follow-up care Strengthening ASHAs for follow-up care of small and sick babies provides a window of opportunity for early identification of growth faltering, adequate counseling of mothers and linkage to facilities for appropriate intervention. Some possible mechanisms include modification of the training modules and supportive supervision for the ASHAs [15, 28, 31].

ANMs Auxiliary nursing midwife, *ASHAs* Accredited social health activist, *NBSUs* Newborn stabilization unit, *PHC* Primary health centers, *SNCUs* Special newborn care unit

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Authors' Contributions RDG, JJ were involved in conceptualization of the manuscript based on the insights generated from the primary study conducted in the state of Himachal Pradesh; JJ and RJ drafted the manuscript with technical inputs from RDG, HC and MS in finalizing



the manuscript; RDG, SR, HC, RG, RMP, MS, and JJ were involved in the conduct of the primary study under the overall guidance of late Dr. M K Bhan. All the authors have reviewed and approved the final version of the manuscript. RDG will act as guarantor for this manuscript.

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Declarations

Ethical Approval The ethical approval for the primary study was obtained from the Institutional Ethics Committee of Maulana Azad Medical College, New Delhi (F.1/IEC/MAMC/(62/02/2018/No 268 dated 30/3/18)).

Conflict of Interest None.

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