

Continuity of information in nutrition interventions in India: Experiences from Jharkhand



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This work draws on part of the author's doctoral thesis.

Location: *Jharkhand State, India*

What we know: Informational continuity – the availability and utilisation of information that connects healthcare providers and beneficiaries and facilitates consistent care across time and levels – is important to achieve continuity of care for acute malnutrition.

What this article adds: A case study in Jharkhand State, India, explored the continuum of information-sharing between care providers and beneficiaries across different levels of care in India between community (home) and facility-based care. Interviews with mothers/caregivers and nurses at malnutrition treatment centres identified many shortcomings in the nature and timing of information shared between frontline health workers (FHW), facility staff, mothers/caregivers and communities. These impact on prevention (e.g., missed danger signs), treatment (e.g., late or declined referral for severe cases) and rehabilitation (e.g., no community-level support post facility discharge). Actions to improve information continuity around case management of acute malnutrition are identified, including: clear FHW guidance on referral communication, training of facility staff on contextual messaging and post-discharge communication between facility and community services for individual children.

Context

The term 'continuum of care' (CoC) describes a system that guides beneficiaries through health services over time and prevents them from falling out of the care pathway through regular follow-up. CoC covers delivery of a range of healthcare services across different levels that are timely, consistent and appropriate.¹ One of the key drivers of CoC is informational continuity – the availability and utilisation of information that connects healthcare providers and beneficiaries and facilitates consistent care across time and levels. Good information flow also connects different healthcare providers to each other to aid coordination of care and to facilitate early identification, the development of an appropriate care plan, and the provision of consistent care to ensure that a beneficiary does not slip out of the continuum.

Information continuity centres on information-sharing and good communication between healthcare providers and beneficiaries. This goes beyond mere information transfer to the incorporation of processes for the co-creation of appropriate care plans. One of the primary requirements for information continuity is the provision of clear messages that can be correctly understood and acted on by beneficiaries. Community knowledge, belief and practices in child-care and feeding influence mother/caregivers' interpretation of messages, and practicing care advice is influenced by socioeconomic and cultural position of mothers/caregivers (Ramji,

2009). This interpretation in turn governs their practices of care and feeding, which determine actual prevention, treatment and rehabilitation of malnourished children.

This article examines the interplay between information continuity and treatment outcome (high default rate, low cure rate and secondary failure to respond). Drawing on findings from a case study in Jharkhand State, India, it considers the continuum of information-sharing between care providers and beneficiaries across different levels of care in India from home (community-based care) to facility-based care and back to home.

Treatment of acute malnutrition in India

The primary acute malnutrition intervention in India focuses on addressing severe acute malnutrition (SAM) through facility-based management at nutrition rehabilitation centres (NRCs), also known as malnutrition treatment centres (MTCs). This nutrition intervention model has two major care points – facility and community level. At the facility level (NRC/MTC) SAM cases with medical complications are treated with therapeutic food and medical care, modelled on the African experience of SAM management. As malnutrition interventions in India do not have a strong community-based component, community-level or family-centred care is crucial. A fractured continuum in care services (between facility and community-level care points) has been identified as one of the

reasons why SAM management in India exhibits poor treatment outcomes (Dasgupta & Chaand, 2018). Furthermore, India has a high prevalence of stunting and in many states stunting and wasting co-exist in children under five years of age. This has prompted recommendations for an extended treatment regimen to achieve target weight gains (Dasgupta *et al.*, 2014).

Nutrition in the state of Jharkhand

According to the National Family Health Survey-4 (NFHS-4), 2015-16, Jharkhand is in the top five states with the highest prevalence of malnutrition in children under five years old in India. Almost half of children (45.3%) are stunted (higher than the national average of 38.4%) and 29% are wasted. Almost half (47.8%) are underweight.

Jharkhand, as in most states in India, has a three-tier healthcare system comprising of primary health centres (PHC), community health centres (CHC) and district hospitals. The main model for the management of malnutrition is the provision of care for children aged between 3 and 6 years through Anganwadi centres, under Integrated Child Development Services (ICDS). There is no state provision of care and support for children below three years of age. Village health and nutrition days are organised monthly and include screening for severely malnourished children and referral to an MTC for further

¹ See research snapshot in this issue of *Field Exchange*, 'Programmatic approaches for nutritional care in India: Perspectives on continuum of care', which summarises a research paper by the same author.

care. Community-based care in Jharkhand, as in the rest of India, is largely delivered by frontline health workers (FHWs), including Anganwadi workers (AWWs), accredited social health activists (ASHAs) and auxiliary nurse midwives (ANMs). These workers are responsible for health promotion, prevention, referral of complicated SAM cases and community-based rehabilitation of discharged children through additional supplementary nutrition and follow-up.

Research method

This research study adopted a case study method. Six MTCs in Jharkhand were used as case settings. In-depth interviews were carried out across the MTCs with 15 mothers/caregivers accompanying children to the facility for inpatient care and 10 nurses. In addition 20 FHWs (AWWs and ASHAs) were interviewed in the community using semi-structured interview guides. Data was transcribed, coded and analysed. Programme documents, reports (published and unpublished) were also used to extract necessary data.

Results

Prevention

The study indicates that continuity of information between FHWs and beneficiaries is inadequate to support and capacitate mothers/caregivers in preventing malnutrition among children under five years old. Findings indicate that the sharing of information between FHWs and mothers/caregivers is inadequate to capacitate them to identify danger signs, take precautionary measures and/or seek appropriate healthcare for the treatment of their malnourished children. Results also indicate that caregivers do not receive support from the FHWs to provide appropriate care and feeding to children with uncomplicated MAM/SAM or children discharged from MTCs.

The study identified many examples of misinterpretation or misunderstanding of information provided by FHWs to mothers and how this can compromise care. For example, explanation of exclusive breastfeeding revolves around not feeding food or honey to infants; mothers therefore consider that exclusive breastfeeding allows giving water to their infants. There may be ambiguity in information provided; e.g., “feeding at frequent intervals” does not define how long an interval is. FHWs advise mothers to wash hands before feeding ‘food’ (khana) to children. Culturally, khana is understood to mean a meal. It was found that, while mothers washed hands before feeding each meal, they did not practice the same before feeding other items between meals. Such a difference in understanding of terms by FHWs and mothers/caregivers governs the actual behaviours that result around age-appropriate feeding and needs-based care of children.

Sickness and malnutrition are fundamentally interrelated. Appropriate and timely treatment of sickness among children is critical to preventing malnutrition among children (Dasgupta *et al*, 2012). The analysis found that capacity-building of mothers and caregivers to identify danger signs among their children was weak. There was inadequate transfer of knowledge to the community concerning appropriate care providers and care facilities for the provision of different health services for children. Hence, caregivers either do not utilise available services or present to the wrong service level when their child is unwell and are turned away unattended.

Treatment

Sharing the right information at the right time is key to early identification and treatment of malnourished children. One of the primary functions of CoC is to ensure timely care. Lack of ac-

curate and adequate communication to the family about the need for referral is an important driver of delay in accessing and utilising timely, appropriate care.

This study found that FHWs do not routinely inform mothers about the dangers of growth faltering, growth stagnation or dropping off growth curves. Mothers are informed about the growth status of their children only if a child falls into the red band in the growth-monitoring chart or MUAC tape or if the child has visible signs of undernutrition.

Once FHWs identify an ‘at-risk’ child, they inform the mother/caregiver that their child is getting ‘kamzor’ (weak) and mothers are counselled to ‘feed well’ and ‘provide good care’ to children.² None of the mothers interviewed could explain what this means in practice. The FHWs do not follow or find reason for consistent decline in a child’s weight; mothers/caregivers are only informed when there is severe growth faltering warranting treatment referral. On identifying a SAM child, mothers are informed that their child has become ‘bahut kamzor’ (too weak) and is in need of medical care. However, the cause of weakness, possible consequences of delay in seeking medical care, and the value of nutrition rehabilitation is not explained.

FHWs usually counsel mothers for referral. If a mother is unable to convince her husband or family of this need, the FHWs try counselling the family to attend the MTC/NRC. However, the community is not informed on SAM as a condition that requires medical attention. Rather, it is often communicated to the family as a local

² The words kamzor (‘weak’) and kamzori (‘weakness’) are used in the community by community members as well as healthcare providers to denote a child with malnutrition.



disease called 'kamzori' or 'puni/puniya'. The community has its own cultural understanding of the cause and treatment of this disease and so prefers to seek treatment from traditional healers and faith healers. Thus, due to poor knowledge of malnutrition and its management, families refuse referrals, only accepting them if traditional/fait healers fail to provide any relief to the ailing child.

Before referring mothers/caregivers to NRC/MTC, FHWs do not adequately prepare them regarding admission, probable duration of stay, treatment and treatment output at the facility. Mothers/caregivers are not informed that their child is being referred for malnutrition assessment and may be admitted for treatment. Since mothers/caregivers come unprepared for a stay of 14 to 21 days, they must go home to make necessary arrangements and return after a few days. This leads to delay in initiation of care at the facility or declined admission.

If admission is denied at the health facility, health professionals do not then inform parents of SAM children of the reasons for this. Such experiences create mistrust among parents regarding the credibility of FHWs, such that the community refuses to act on referrals made by FHWs in future. There is also no information exchange between FHWs and care providers at the MTC/NRC regarding children who are denied admission to inpatient care; nor are FHWs equipped to provide appropriate care for such children in the community.

FHWs commonly inform parents that malnutrition is a disease that can be treated at the NRC/MTC. This understanding of malnutrition as a disease and therapeutic food as a medicine creates confusion among mothers/caregivers. Before mothers/caregivers bring their children to the NRC/MTC they are informed by FHWs that children will be treated with 'good medicine'. They perceive therapeutic feed as food and not medicine; hence they often become confused and feel deceived that their child is not receiving medical treatment. They also do not understand why some children are subjected to various tests and receive pills and syrups, whereas others do not receive tests or medicines. Mothers report that, when they do ask about the differences in treatment at the health facility, nurses and doctors do not address their queries, leading mothers to feel discriminated, alienated and confused.

Mothers/ caregivers appear to be more satisfied with treatment if doctors screen children before admission, if their children undergo tests and if they are prescribed medicines. Nurses at NRC/MTC play a significant role in motivating mothers to stay at the facility until treatment is completed. Mothers/caregivers were found to be more satisfied at facilities where nurses provided regular health updates of children, gave reasonable answers to their queries, dispelled their doubts and counselled on care and feeding practices (orally and through support in care and feeding).

Rehabilitation

The findings show that, during their prolonged stay, mothers/caregivers are not adequately prepared for care of their child post-discharge. The FHWs and doctors/nurse counsel mothers/caregivers on 'treatment' aspects; however none of them are made aware of their child's 'rehabilitation' needs. During inpatient facility treatment, mothers/caregivers are counselled on appropriate care and feeding. These counselling sessions are, however, challenged by lack of dedicated personnel and separate time for counselling, lack of individual counselling sessions, lack of context-specific advice, and lack of appropriate information education communication material to facilitate learning and retention by mothers/caregivers.

Neither the mothers/caregivers nor the FHWs understand the difference between discharge from facility and discharge from the nutrition programme. Facility discharge is concluded without counselling mothers/caregivers fully on the reason for discharge from inpatient care and the significance of follow-up visits and care and feeding practices post-discharge. Neither are they informed of the need to contact FHWs for assistance for home-based care. Hence, although mothers/caregivers are entitled to reach out to the FHWs for care support, they do not do so. In their understanding, children discharged from the facility are completely cured and therefore they often do not attend follow-up visits and return to routine child care and feeding.

On discharge, the case history of each NRC/MTC beneficiary is not shared with the appropriate FHWs; nor are they assisted in developing an appropriate care plan for the ongoing community-based care of the discharged child. FHWs are unaware of their role in the rehabilitation of SAM children in terms of frequent growth-monitoring, supply of supplemental nutrition, follow-up, support in child care and actions in case of growth faltering. FHWs have very little and sometimes zero involvement in the rehabilitation of discharged cases. Children discharged from inpatient care are managed by mothers/caregivers amidst their usual responsibilities and lack support to mitigate and overcome childcare challenges.

Conclusion and recommendations

This small study identified many opportunities to improve on information continuity around case management of acute malnutrition that should improve outcomes. Successful communication is critical to promote prevention and early identification, effective treatment and rehabilitation of SAM children.

Providers at different levels of care must be capacitated to provide appropriate information and support to help mothers/caregivers to improve health behaviours and overcome barriers to positive health practices. Carefully drafted messages should consider the specific health needs and sociocultural context of the community and individual beneficiaries. The existing health structure

provides space for community-level counselling both in groups, particularly on village health and nutrition days and on a one-to-one basis through home visits. In both cases counselling should focus on assessing feeding and care practices, identification of challenges, information to overcome challenges, provision of feasible care advice, and information on identification of danger signs. Once a referral is needed, both at community and facility levels, counselling must then include information about where the child is being referred and why and what the referral will entail in order to manage expectations and give every chance for the family to access and utilise the appropriate available service. Furthermore, both community and facility-level practitioners must be capacitated to communicate with each other to facilitate effective referral from community to facility and back to community again to ensure continuity of care for each child.

Recommended actions include:

- The provision of clear guidelines to FHWs on the management of malnutrition in children under five years old, including clear referral guidelines with important messages to convey to caregivers at the point of referral.
- Training for healthcare providers at facility and community levels on the social, economic and cultural context of the community, the provision of care appropriate to this context and the drafting of context-specific health messages.
- Appointment of trained nutrition counsellors at MTCs (or training of existing nursing staff) to provide nutrition and health counselling for caregivers during admission and discharge, including appropriate child care and feeding.
- Sharing of information on all cases discharged from MTCs with primary health facilities and FHWs to enable effective monitoring and follow-up in the community.
- Improved coordination between the National Health Mission and ICDS in the early identification of at-risk children, secondary prevention, referral and community-based management of malnourished children.

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