Enhancing Follow-Up and Rehabilitation Adherence in Congenital Heart Disease Patients 0-5 years old: Challenges and Interventions

Organization History, Vision & Mission

History

National Health Mission(NHM) was launched by the GoI in 2013 after integrating the NRHM(2005) and the NUHM(2013).It's main aim is to enhance the overall quality of healthcare delivery in rural and urban areas and strengthen the primary healthcare infrastructure.The Rashtriya Bal Swasthya Karyakram(2013) is an initiative under NHM that aims to improve the quality of life of children aged 0-18 years by providing a wide range of comprehensive healthcare services, and a strong focus on early detection of the 4Ds- Birth Defects, Diseases, Deficiencies and Developmental delays including disabilities.

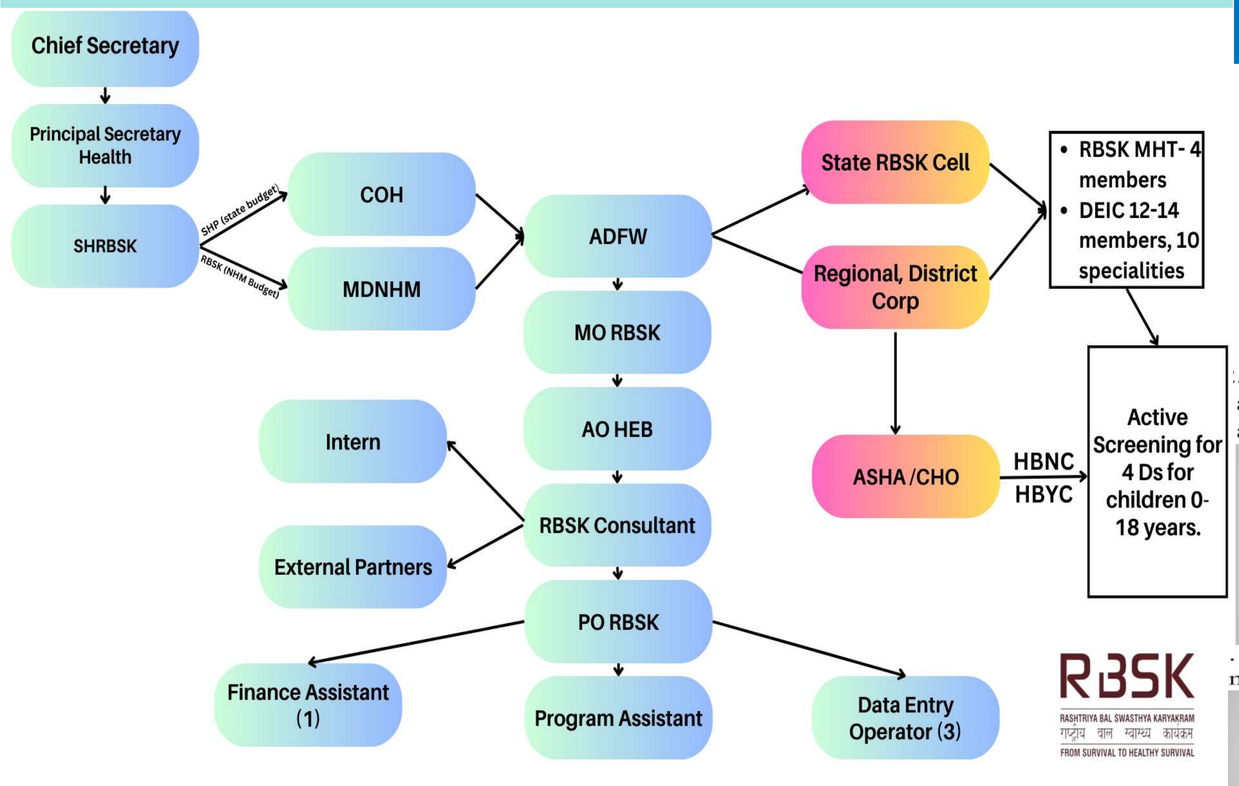
Vision

To provide equitable, affordable, high quality healthcare services that are accessible by all and focused on addressing the diverse health needs in the population grounded in accountability and responsiveness.

Mission

To ensure that the public health delivery system is accountable and fully functional to the community through decentralization, community involvement, effective HR management, infrastructural strengthening, rigorous monitoring and evaluation against the set standards from the most peripheral levels upwards through innovations, flexible financing and appropriate health interventions

ORGANIZATION STRUCTURE



SWOT Analysis

STRENGTHS

- Extensive interdepartmental coordination and good intradepartmental communication
- Continuous and extensive monitoring done to identify gaps and come up with appropriate solutions
- Extensive screening by MHTs to ensure early detection
- Strong referral system to DEICs and tertiary centres to provide timely interventions
- Supportive services to ensure compliance on the patient's part

WEAKNESS

- Lack of awareness among the parents of children about the benefits of early interventions
- Low adherence to treatment modalities due to myths/superstitions or lack of knowledge
- Lack of HR and infrastructure in certain DEICs and MHTs affecting the quality of care
- IEC materials are information extensive
- Lack of attention given to social capital of beneficiaries
- Insufficient focus on the problem of undernutrition in CHD cases causing delay in treatment

OPPORTUNITIES

- Develop IEC/BCC to increase awareness about the benefits of early interventions
- Utilization of IT platforms to make up for the lack of HR or non-adherence due to travel/distance
- Strengthen CHCs for pre/post op rehabilitation services
- Approaches to improve social capital of patients
- Nutritional rehabilitation under RBSK

THREATS

- Delay of entry or incorrect entry into HMIS/TeCHO platforms
- Misreporting about HR and infrastructure in districts
- Scarce literature regarding importance of follow-ups and cardiac rehabilitation
- Lack of linguistic inclusivity in the organization

LEARNING AND VALUE ADDITIONS

Difference between practical exposure at SIP organisation and theoretical understanding from IIHMR University

IIHMR-U	NHM Gujarat
• Theoretical understanding of the program's functioning, targets, beneficiaries, implementation and monitoring • Theory of conducting primary research • Theoretical learning about developing IEC and SOPs • Theoretical learning about MIS and its importance as a source of data for monitoring and analysis	• Practical exposure of the logistics of mobilising such a vast program across the state, its challenges and gaps at the field level • Understanding of the practicalities of primary research and suggesting interventions • Developing IECs and SOPs • Hands-on experience of data analysis

Challenges

- Insufficient linguistic inclusivity
- Myths & Superstitions

Usefulness

- Gained first hand knowledge of program functioning, implementation, monitoring, gap evaluation, and improvement opportunities
- Building connections; skill development

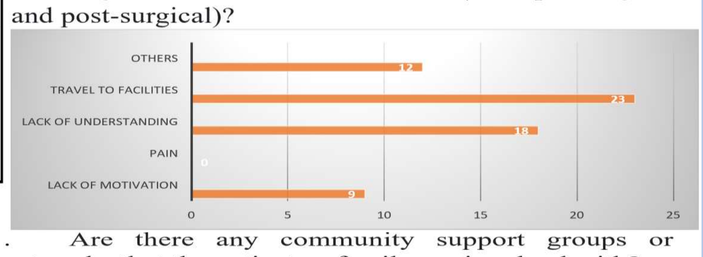
Learnings

• Functioning and staffing of RBSK • HMIS and TeCHO • Developing SOPs and IEC material • Field level observation/ monitoring and evaluation • Interdepartmental collaboration	• Data analysis and triangulation • Data representation • Summarising proposals by external partners • Conducting primary research • Functioning of public health system and refferals

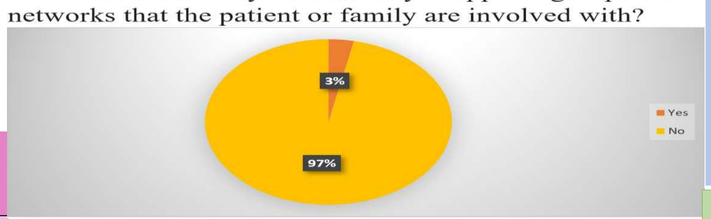
KEY OBSERVATIONS

. What barriers, if any, prevent the patient from attending follow-up appointments (both pre-surgical and post-surgical)?

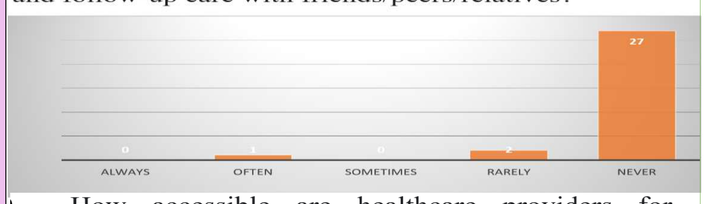
. What barriers, if any, prevent the patient from adhering to rehabilitation exercises (both pre-surgical and post-surgical)?



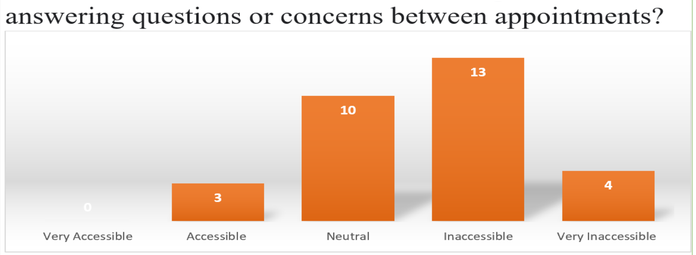
. Are there any community support groups or networks that the patient or family are involved with?



How often does the parents of patient discuss their health and follow-up care with friends/peers/relatives?



. How accessible are healthcare providers for answering questions or concerns between appointments?



Aim: To assess the adherence to pre-surgical and post-surgical follow-up and rehabilitation regime in identified CHD cases in children

Objectives –

- To identify potential barriers to adherence to follow-up
- To elicit the social capital of patients diagnosed with CHDs
- To assess the factors affecting patient and caregiver's satisfaction
- To suggest potential interventions

Study Design: Observational study with cross-sectional design

Sample size taken for study: 30

Sampling: Convenience sampling/Purposive sampling at UNMICRC, Ahmedabad

- Inclusion : Children aged 0-5 with CHDs visiting UNMICRC from Gujarat.
- Exclusion: Children above 5 years of age which CHDs, children not from Gujarat, parents of children who were not willing to participate for the interview

Limitation: Maternal factors and health institutes/hospitals visited prior to UN Mehta were not considered

OTHER FINDINGS

- Unnecessary delay of surgery/treatment due to undernutrition in children
- 67% of families bore additional expenses due to travel, medications or diagnostic tests
- Lack of education and financial freedom in the mother of the child despite being the primary caretaker and having to rely on the father for major treatment decisions
- 17% had post-op chronic conditions
- Only 5 out of 30 patients visited all follow-ups
- 18 out of 30 children felt unhappy/very unhappy and 20 patients showed distress/changed behaviour following visits

SUGGESTIONS

- Increase linguistic inclusivity in the organization for better understanding and input of ideas
- Ensure proper availability of HR/Infrastructure at DEICs and the MHTs; along with accurate and timely reporting of HR gaps
- Provide standardized guidelines to all organizations functioning as tertiary centers of RBSK
- Use of IT to enhance follow-ups, strengthen CHCs to improve care and
- Introduction of support groups through PRA via NGOs for better adherence to treatment regimen and emotional support and to make up for the lack of social capital
- Utilisation of CMAM platform and mandate visits to CMTC/NRC when required for CHD patients
- Conduct proper training and upskilling to ensure accurate and timely entry into HMIS and TeCHO from all districts.

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