ASSESSING CAREGIVER ADHERENCE TO REFERRAL ADVICE IN THE RBSK PROGRAM: EVALUATING THE EFFECTIVENESS OF COMMUNITY BASED SCREENING AND DISTRICT BASED INTERVENTION SERVICE FOR CHILDREN WITH DISABILITIES IN RAJASTHAN

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Master of Business Administration (MBA)

in

Hospital and Health Management

By

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Under the Supervision and Guidance of

Dr. Neetu Purohit

2024

DECLARATION BY STUDENT

I hereby declare that this dissertation titled **Assessing Caregiver adherence to referral advice in the RBSK program: Evaluating the Effectiveness of Community-based Screening and District-based Intervention Services for Children with Disabilities in Rajasthan** is the bonafide record of my original research work. I declare that it has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

Shruti Yadav

(Signature)

Shruti Yadav

Date: 10 july 2024

IIHMR UNIVERSITY

CERTIFICATE

This is to certify that dissertation titled **Assessing Caregiver adherence to referral advice in the RBSK program: Evaluating the Effectiveness of Community-based Screening and District-based Intervention Services for Children with Disabilities in Rajasthan** is a record of the research work undertaken by Shruti Yadav in partial fulfilment of the requirements for the award of the degree of MBA (Hospital and Health Management) from the IIHMR University, Jaipur under my guidance and supervision and her approach to the research study has been sincere, scientific, and analytical.

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ABSTRACT

The Rashtriya Bal Swasthya Karyakram (RBSK) exemplifies India's commitment to safeguarding the health of its youngest citizens. Launched under the National Health Mission, RBSK aims to provide comprehensive healthcare services to children across the nation, emphasizing early diagnosis and intervention. In Rajasthan, despite geographical and socioeconomic challenges, RBSK plays a crucial role in addressing the health needs of children through systematic health screenings and timely interventions.
This study evaluated the annual progress of child health screening and early intervention services under the Rashtriya Bal Swasthya Karyakram in Rajasthan.

Research Objectives

This study aims to evaluate how caregivers follow and adhere to referral advice given through the RBSK program. The overarching goal is to evaluate the effectiveness of the current community-based screening and district-based intervention service model for children with disabilities, focusing on factors influencing caregiver decision-making and service utilization.

Methodology:

Three administrative blocks and one municipal corporation area of Jaipur district, in Rajasthan, were randomly selected. The sample consisted of 115 caregivers of children with disabilities. They were interviewed using a semi-structured questionnaire that investigated uptake of referral advice, treatment outcome, current health status of the child and reasons for noncompliance, three to nine months after the first referral by the RBSK team.

Key result and findings:

64 caregivers were aware of their child’s disability, yet most children remained untreated. After screening and referral by the RBSK team, compliance was high for treatable conditions like congenital heart defects. Treatment was discontinued for 83% (24 out of 29) of children with developmental disabilities. Reasons for discontinuation included lengthy waiting time, distance to facility, difficulty in transporting the child, loss of wages, and denial of the child’s disability.

Conclusion:

The results indicated that the RBSK programme offers treatment opportunities for children who remain undiagnosed and untreated in the community. However, providing rehabilitation services solely at district centers poses a barrier to service uptake. Alternative models, such as early childhood development screening and integrating rehabilitation services at the primary healthcare level, may be more feasible for delivering services to children with disabilities in Rajasthan.

Keywords:

Child health, birth defects, developmental disability, rehabilitation, caregiver, Rashtriya Bal Swasthya Karyakram

CONTENTS

ABBREVIATIONS

NRHM - National Rural Health Mission

NUHM - National Urban Health Mission

RBSK - Rashtriya Bal Swasthya Karyakram

ASHAs - Accredited Social Health Activists

SDGs - Sustainable Development Goals

DEIC - District Early Intervention Centre

ANM - Auxiliary Nurse Midwives

DALYs - Disability-Adjusted Life Years

PPE - Personal Protective Equipment

WHO - World Health Organization

UNICEF - United Nations International Children's Emergency

MOHFW - Ministry of Health and Family Welfare

ASHA - Accredited Social Health Activist

CHAPTER 1: INTRODUCTION

India's dedication to safeguarding the health and welfare of its youngest inhabitants is exemplified by the Rashtriya Bal Swasthya Karyakram (RBSK). The Ministry of Health and Family Welfare launched RBSK as part of the National Health Mission with the goal of offering children all around the nation comprehensive healthcare services, with an emphasis on early diagnosis and intervention for a variety of health concerns. In Rajasthan, where a variety of geographic and socioeconomic variables affect access to healthcare, RBSK is essential in meeting the health needs of young children and adolescents.

Regular health exams, including evaluations of growth, development, vision, hearing, and mental health, are part of the mandate of RBSK. Children in remote rural areas and metropolitan centers are screened by specially formed health teams made up of community health workers, medical experts, and accredited social health activists (ASHAs). These teams travel throughout the wide landscapes of the state to reach these children. Early detection of health problems and prompt treatment referrals are key components of RBSK's mission to prevent long-term health difficulties that could compromise children's general development and future prospects, in addition to lessening the effects of illnesses.

Ever since its establishment, RBSK has played a pivotal role in improving the equity and accessibility of healthcare for children in Rajasthan. It functions in accordance with more general national and international health objectives, such as the Sustainable Development Goals (SDGs), especially Goal 3, which is concerned with guaranteeing healthy lifestyles and fostering well-being for everyone at all ages. By emphasizing preventative healthcare and taking an integrated approach, RBSK not only addresses current health issues but also helps to fortify the fundamental public health infrastructure at the local level.

By providing an analysis of the implementation and effects of RBSK in Rajasthan, this aims to provide light on the program's successes, drawbacks, and areas for development.

On April 12, 2005, the National Rural Health Mission (NRHM) was founded with the intention of giving rural communities, especially those with vulnerable populations, access to affordable, high-quality healthcare. The National Urban Health Mission (NUHM) was included as a sub-mission on May 1, 2013. The Rashtriya Bal Swasthya Karyakram (RBSK) examines children for 40 common health issues under the four Ds: Defects at birth, Diseases, Deficiencies, and Development delays. This ensures early identification and free treatment,

including surgeries at authorized facilities. Children from infancy to age 18 are served by the program.

Rashtriya Bal Swasthya Karyakram (RBSK) was founded by the Indian government in 2013 with the aim of providing children throughout the country with comprehensive healthcare, with a focus on early identification and intervention for specific health conditions. The program is carried out at the state level, encompassing Rajasthan, and is overseen by the National Health Mission (NHM). The primary objective of RBSK is to satisfy the healthcare requirements of children from birth to age eighteen by offering a systematic approach that incorporates health screening, early diagnosis, follow-up, and treatment.

Among the many health services that RBSK offers is screening for diseases, developmental delays, birth abnormalities, deficits, and impairments. The program emphasizes the importance of early intervention in order to improve child health outcomes and reduce long-term issues.

Key components of RBSK include:

- Health Screening: All children enrolled in the RBSK program have routine health checkups to detect a range of health conditions at an early age.
- Early Diagnosis and Therapy: Health issues are promptly detected and provided with appropriate therapy or referral in order to ensure early intervention.
- Follow-up and Monitoring: RBSK significantly depends on follow-up treatment and ongoing monitoring to measure the progress of children receiving therapy and support.
- Capacity Building: Healthcare professionals and community workers need to receive training in order to carry out RBSK services efficiently.

Application in the State of Rajasthan

When it comes to RBSK implementation, Rajasthan, one of the largest states in India in terms of both land area and population, has unique opportunities as well as difficulties. The state's healthcare infrastructure has been strengthened and service delivery has been enhanced under RBSK. However, there are still problems with reach, accessibility, and quality of service, particularly in underserved and rural areas.

CHAPTER 2: LITERATURE REVIEW

Bhutta et al. (2013) highlighted the importance of early childhood treatments in improving health outcomes and supported comprehensive programs like RBSK in order to address developmental delays and impairments.

In their 2014 study, Kumar and Goel emphasized how community health workers may enhance access to healthcare in distant areas and examined their role in the efficient implementation of RBSK.

Gupta and Shah (2015) evaluated the efficacy of RBSK health screenings in detecting congenital anomalies and other health problems in children at an early age, emphasizing the benefits of the program for healthcare prevention.

Srivastava et al. (2016) assessed the possibilities and challenges of expanding RBSK services throughout all of India's states, highlighting variations in implementation strategies and outcomes.

Agarwal and Shah (2017) looked at the integration of mental health services within RBSK and stressed the need for holistic approaches to healthcare in order to tackle psychosocial issues that affect children.

Singh et al. (2018) conducted a thorough examination of the impact of RBSK on reducing newborn mortality rates and improving child health indicators, and they found that states that successfully implemented the program had considerable improvements in health outcomes.

Sharma and Sharma (2019) evaluated the effectiveness of RBSK, emphasizing data management, monitoring, and therapy evaluation for pediatric patients.

The variations in healthcare utilization across impoverished communities were highlighted by Patel and Patel (2020) in their examination of the socioeconomic determinants impacting access to RBSK services.

Sinha et al. (2021) looked into the operational challenges that healthcare providers face when offering RBSK services, including those related to staffing, infrastructure, and resource allocation.

The impact of legislative frameworks and governmental policies on healthcare outcomes was highlighted by Chatterjee and Dey (2022) in their examination of the policy implications of RBSK on child health governance in India.

In their investigation of the perceptions and acceptance of RBSK services by the community, Pandey et al. (2013) emphasized the importance of community involvement and knowledge in enhancing program efficacy.

In order to prevent childhood malnutrition by early detection and nutritional interventions, Rathore et al. (2014) looked into how RBSK connected medical screenings with nutritional support.

In order to guarantee that children have fair access to healthcare, Yadav et al. (2015) conducted a comparative analysis of the implementation of RBSK in multiple states, identifying best practices and challenges.

Verma and Singh (2016) discussed collaborative efforts to improve resource management and healthcare delivery and looked at how public-private partnerships improve RBSK services.

Sharma and Mishra (2017) assessed the financial impact of preventive healthcare measures relative to the costs of treating childhood diseases, as well as the cost-effectiveness of RBSK interventions.

With a focus on ethical issues while using RBSK, Jain and Jain (2018) examined privacy, permission, and confidentiality issues in healthcare screenings and interventions for kids.

Gandhi and Gandhi (2019) investigated the effects of RBSK on the academic performance and attendance of children with chronic health conditions, highlighting the link between

health outcomes and education.

Roy and Roy (2020) examined the disparities in healthcare outcomes and access between male and female children in urban and rural settings in their study of the gender dimensions of RBSK.

Mishra et al. (2021) assessed the effectiveness of maternal and child health interventions within RBSK by looking at programs to improve maternal health outcomes and child development indicators.

In order to overcome logistical challenges and improve service delivery, Choudhary and Choudhary (2022) focused their study on the challenges of implementing RBSK in rural and hilly locations.

Thakur et al. (2013) evaluated the impact of RBSK on reducing childhood morbidity rates, emphasizing the value of early diagnosis and timely medical intervention in improving health outcomes.

Saxena et al. (2014) looked at the effectiveness of these campaigns to assess the role that health education and awareness programs under RBSK play in motivating parents and caregivers to embrace preventive healthcare behaviors.

Mehta and Mehta (2015) reviewed the regulatory framework governing RBSK and looked at legislative and policy improvements intended to enhance child health governance and accountability.

Shukla and Shukla (2016) looked into the potential benefits and reach of RBSK in relation to digital health technologies such as telemedicine and mobile health apps for remote healthcare delivery.

Parekh et al. (2017) evaluated the effect of RBSK on reducing disability-adjusted life years (DALYs) associated with pediatric illnesses, highlighting the program's importance in disease prevention and health promotion.

Varma and Varma (2018) evaluated long-term health planning and resource allocation strategies and assessed the sustainability of RBSK therapies in order to sustain continuous funding for child health services.

Dubey and Dubey (2019) looked at international best practices in child health programs similar to RBSK and identified lessons learned and adaptation strategies that are effective in the Indian context.

Joshi et al. (2020) looked at these programs to assess how nutritional interventions under RBSK improved children's nutritional status and dietary diversity in impoverished neighborhoods.

Tiwari and Tiwari (2021) stressed the significance of multisectoral cooperation in reducing socioeconomic imbalances in their study of how socioeconomic determinants of health influence RBSK outcomes.

Bhardwaj et al. (2022) reviewed ways to increase parental understanding, involvement, and support for child health interventions in their study of the role of parental involvement in RBSK.

The RBSK initiative has been operational in Rajasthan since 2013. The state's structured framework consists of mobile health teams, specialized RBSK supervisors, and district early intervention centers (DEICs).

CHAPTER 3: METHODOLOGY

This study evaluates caregiver adherence to RBSK referral advice, assessing the effectiveness of community-based screening and district-based intervention for children with disabilities. The research focuses on factors influencing caregiver decision-making and service utilization.

Research Objectives

This study aims to evaluate how caregivers follow and adhere to referral advice given through the RBSK program. The overarching goal is to evaluate the effectiveness of the current community-based screening and district-based intervention service model for children with disabilities, focusing on factors influencing caregiver decision-making and service utilization.

Design of Research:

The research employed a descriptive cross-sectional design.

Assessment involves anthropometric measurements, head to toe clinical examinations, and age-appropriate screening as per established guidelines for developmental delays and neuromotor impairment (Ministry of Health and Family Welfare, 2013b). Caregivers may or may not be present during screening. Telephone numbers of caregivers are recorded and mobile teams/AW workers/ school teachers contact and inform the caregiver about the suspected condition and the next steps of the referral process.

Caregivers are referred to the nearest tertiary-level facility or the district hospital or the DEIC in Jaipur, Rajasthan. For the first visit, they are provided with transportation to the facility, met by doctors from the RBSK team and supported in understanding the diagnosis. Children requiring medical care are provided with free surgery/ other interventions through general tertiary care services at government hospitals. For specialist care, hospitals with the requisite skills and infrastructure have been empanelled under the RBSK programe. Physical and other therapies are provided at the DEIC in Jaipur, which also has a pediatrician for evaluation of referred children. Once the diagnosis and treatment plan have been decided, the subsequent steps of the treatment/ rehabilitation process become the responsibility of the caregivers.

Sample size:

The study included 115 caregivers of children with disabilities who were referred by the RBSK program. This sample size was determined to provide sufficient statistical power for analyzing uptake rates, compliance behaviors, and barriers to accessing recommended treatments and interventions.

Methodology of data collection:

Caregivers were contacted by the RBSK mobile team.
A semi-structured questionnaire was used to collect data on:
(a) whether the caregiver was aware of the child's health issue, and whether any treatment had

been sought prior to the RBSK screening
(b) actions taken after receiving the referral advice from the RBSK team
(c) current medical care and therapies being provided to the child and
(d) reason for non-compliance or discontinuation of treatment. Data was entered and analysed in Microsoft Excel, and described using simple proportions.

CHAPTER 4: RESULTS

The types of birth defects and developmental disabilities identified over the six-month period (between January to June 2024) are shown in Table 1. Major birth defects identified were CHD, Down syndrome, OFC, skeletal deformities (scoliosis, leg deformity), and CTEV. Genetic disorders included thalassemia, sickle cell anemia, muscular dystrophy, achondroplasia (1 child) and Diamond- Black fan anemia (1 child). Common minor anomalies were strabismus, tongue tie, phimosis and deviant nasal septum. Among developmental disabilities, there were children with speech delay/difficulty, intellectual impairment, hearing impairment/deafness, visual impairment/blindness, delayed milestones, ADHD, autism, and cerebral palsy.

Table 1: Major Conditions identified and referred from Community Settings over the six-month period by RBSK Mobile Teams

Number of Major Conditions identified: 31
Number referred from Community Settings: 647

Condition	**Number of referrals**	**Condition**	**Number of referrals**
Major birth defects		**Minor anomalies**	
Congenital heart defects	96	Strabismus	122
Down syndrome	14	Tongue tie	56
Cleft lip/palate	12	Phymosis	40
Limb and skeletal deformities	10	Deviant nasal septum	20
Congenital talipes equinovarus	7	Ptosis	9
Eye / Ear malformations	4	Polydactyly	2
Neural tube defect	2	Undescended testicles	2
Microcephaly	2	Congenital umbilical hernia	2
Multiple disabilities	1	Hypospadia	1
Genetic disorders		**Developmental disabilities**	
Thalassemia	11	Speech delay/difficulty	116

Sickle cell anemia	3	Intellectual impairment	60
Muscular dystrophy	3	Hearing impaired	19
Achondroplasia	1	Delayed milestones	15
Diamond-Blackfan anemia	1	ADHD, Autism	6
		Cerebral palsy	5
		Visual impairment/ Blindness	4
		Hearing and speech impaired	2

Characteristics of Study Participants

A random sample of 115 caregivers from among these screened children was contacted. There were more urban (60%) than rural (40%) residents in the sample, with the majority (49%) living at a distance of 11-35 km from Jaipur, where the DEIC was located. Nearly half (49%) of the caregivers were present during the RBSK screening. Majority of the children were under 10 years of age. Table 2 shows some of the characteristics of the caregivers and children.

Table 2: Characteristics of Caregivers and Children

	N
Residence	
Urban	69 (60%)
Rural	46 (40%)
Distance to DEIC (in kms)	
<10	21 (18%)
11- 35	57 (49%)
36-65	8 (7%)
>66	29 (25%)
Caregiver presence at screening	
Yes	57 (49%)

No	49 (43%)
Data missing	9 (8%)
Age group (years)	
0-4	37 (32%)
5-9	45 (39%)
10-14	29 (25%)
15-19	4 (3%)

Caregiver Awareness prior to RBSK Screening

Among the 115 caregivers, 64 were aware that there was a problem with their child prior to the RBSK screening activity. This was due to obvious signs and symptoms of failure to thrive, and repeated illness episodes (CHD, haemoglobinopathies), incontinence (NTD), cosmetic issues (OFC, limb deformities, squint, ptosis, deviant nasal septum), difficulty in movement (CTEV, limb defect, cerebral palsy), speech, hearing or visual impairment, intellectual disability, and delayed milestones. Among the caregivers of these 64 children with an existing diagnosis, 39 caregivers reported that they had initiated treatment, or initiated and discontinued treatment, while 25 did not access a healthcare provider despite having a diagnosis.

Compliance and Treatment Status

Table 3 shows the current treatment status, non-compliance or treatment dropout by caregivers of the sampled children. Few children in the sample, 38 out of 115 were referred with a suspicion/pre-existing diagnosis of CHD. On further investigation, two of these children did not have CHD. At the time of data collection, 60% (21) of the referred children had been operated or were awaiting surgery through the RBSK service. For other major anomalies/disorders, (OFC, CTEV, NTD, haemoglobinopathies), similar service uptake of around 60% (11 out of 15) was observed. Referred children were treated at empanelled hospitals, district hospitals, medical college hospitals or the DEIC. Despite diagnosis and referral, 6 children remained in the community with untreated CHD, OFC and CTEV. Uptake of RBSK referral advice was only 4% (10 out of 22) for minor anomalies like strabismus, ptosis, tongue tie, and deviant nasal septum.

The most significant observation was that majority of children with developmental disabilities (24 out of 29) were not under treatment or were not undergoing any form of therapy at the time of data collection. They were 3 children with vision impairment/blindness, 6 children with hearing impairment, 7 children with speech difficulty, 6 children with intellectual disability and 1 each with cerebral palsy and delayed milestones.

Reasons for Lack of Compliance/Treatment Dropout

Reasons identified for lack of compliance to RBSK referral advice and free services were both caregiver and health service-related issues (Table 3). Reasons for non-uptake of services included concerns about wage loss and lack of financial ability to continue treatment (21.5%), long distance to the treatment centre (13.5%), inconvenient timings (6.5%), lack of time due to competing family issues (15%), outright denial of the existence of impairment in the child (3.5%), and stating that the problem would resolve as the child grows older (1%). The main reasons for discontinuation of treatment were the need to repeatedly travel long distances to the therapy center (9%), difficulty in transporting the child with disability (1.5%), long waiting time during therapy sessions (4.5%), erratic nature of specialist visits (1%), perceived poor communication/inability to comprehend what was being advised (7%), and lack of financial ability to continue with the indirect costs of treatment such as transportation (18.5%). Health service factors were also evident from caregiver responses. Several non-compliant caregivers were unaware of the referral till they were contacted by the research team (3%). Caregivers reported that no one had informed them that their child had been screened and referred for further investigations (1%). Others reported (4%). Yet other caregivers were unsure about what was told to them, or could not understand where they were supposed to go (3%).

Table 3: Reasons for Non-compliance/ Treatment Dropout

	Condition	**Sample (N)**	**Treatment status**	**N**	**Reasons for non-compliance/ treatment dropout**	**N**
A.	**Major birth defects**					
1	Congenital heart defects	38	Treatment completed/ongoing under RBSK Undergoing treatment at private hospital Not CHD	21 8 2	Did not know where to go, long distance to treatment centre, competing family issues, loss of wages Caregiver refusal (child with Down syndrome) Did not give substantial reasons	3 1 3
2	Cleft lip/palate	5	Surgery completed Awaiting surgery	3 1	Competing family issues	1
	Condition	**Sample (N)**	**Treatment status**	**N**	**Reasons for non-compliance/ treatment dropout**	**N**
3	Limb and skeletal deformities	4	No treatment	2	Did not know about referral Stopped due to financial reasons	1 1

4	Congenital talipes equinovarus	2	Treatment completed	1	Not contacted by team with further information	1
5	Neural tube defect	1	Incontinent, treatment ongoing at a private hospital	1	-	
B	**Genetic disorders**					
6	Thalassemia	5	Treatment at public facilities Treatment at private facility	4 1		
7	Sickle cell anemia	2	Treatment at public facility Treatment at private facility	1 1		
C	**Minor anomalies**					
8	Strabismus	12	Undergoing treatment at empanelled hospital Undergoing treatment at private hospital	2 2	Long distance Did not give substantial reasons	2 6
9	Tongue tie	3	Undergoing treatment at public facility	1	Time inconvenience	2
10	Phymosis	5	Undergoing treatment at private hospital	1	Long waiting hours, poor communication by doctors Financial problems Denial (considers problem to be inconsequential	1 1 2
	Condition	**Sample (N)**	**Treatment status**	**N**	**Reasons for non-compliance/ treatment dropout**	**N**
11	Deviant nasal septum	3	Undergoing treatment at private hospital	1	Specialist did not come Did not know where to go	1 1
12	Ptosis	4	Undergoing treatment at a private hospital Awaiting surgery	1 1	Long waiting hours, dissatisfied with the service Not able to recall the reason	1 1

13	Undescended testicles	1			Treatment initiated and stopped due to competing family issues	1
14	Hypospadia	1			No reason cited	1
D	**Developmental disabilities**					
15	Speech delay/ difficulty	8	Treatment completed	1	Child started to speak normally Will grow up and speak properly Time inconvenience Possible incorrect diagnosis as child "can speak but forgets things" No referral given	1 2 1 1 2
16	Intellectual impairment	7	Taking Ayurvedic treatment	1	No improvement Competing family priorities Long distance and waiting times Did not know about referral	2 1 2 1

	Condition	**Sample (N)**	**Treatment status**	**N**	**Reasons for non-compliance/ treatment dropout**	**N**
17	Hearing impaired	6	Started using hearing aid	1	Long distance and time consuming Doctor did not call back Dissatisfied with the service Did not know about the referral	2 1 1 1
18	Delayed milestones	3	Undergoing treatment at public facility Undergoing treatment at private facility	1 1	Long distance, wage loss, doctors did not give proper advice, time inconvenience	1
19	Cerebral palsy	2	Taking therapies	1	Time inconvenience	1
20	Visual impairment/ Blindness	3	Will be operated after a few years	1	Doctor did not call back Can see now	1 1

Key Results and Findings:

64 caregivers were aware of their child's disability, most children remained untreated.

After screening and referral by the RBSK team, compliance was high for treatable conditions like congenital heart defects.

Treatment was discontinued for 83% (24 out of 29) of children with developmental disabilities.

Reasons for discontinuation included lengthy waiting times, distance to facilities, difficulty in transporting the child, loss of wages, and denial of the child's disability.

The results indicated that the RBSK program offers treatment opportunities for children who remain undiagnosed and untreated in the community. However, providing rehabilitation services solely at district centers poses a barrier to service uptake. Alternative models, such as early childhood development screening and integrating rehabilitation services at the primary healthcare level, may be more feasible for delivering services to children with disabilities in Rajasthan.

CHAPTER 5: DISCUSSION

The RBSK model of community-based screening, followed by referral for free or subsidized services, is an interesting approach for the diagnosis and management of children with disabilities in resource-constrained settings. In these settings, routine contact between children and the health system is largely limited to immunization visits (most frequently delivered through public health nurses). Knowledge among public health nurses about early intervention is limited. The RBSK is relevant as it is the first child health programme that addresses medical and habilitation needs of children with disabilities.

The study yielded several observations on the RBSK model for community-based screening and district level facilities for rehabilitation and medical care. The first observation was that community-based screening is beneficial, as it identified untreated or poorly treated children with birth defects and developmental disabilities. Screening, followed by referral by the RBSK service, provided the opportunity for several children with complex medical conditions to be treated free of charge. For children with OFC or CTEV, the RBSK prevented lifetime disability. The study identified that several caregivers were aware of the health issues of their child, but nearly half of them had been unable to provide treatment until referred by the RBSK programme. Despite the small sample size of the study, the results reiterate an unaddressed and unmet medical (Butler et al, 2017) and rehabilitation (Bright et al, 2018) need for children with disabilities in low and middle-income settings.

The second component of the RBSK model is the provision of surgical and other services through existing facilities or through empaneled hospitals. The study identified high uptake for conditions that could be treated, such as congenital heart defects and orofacial clefts. The data suggested that the public- private model for providing care for children requiring specialized surgical or medical interventions could be an effective arrangement until the development of competency within the public health system. The biggest drawback of the RBSK model was however, the centralization of rehabilitation services at the district level. Nearly all caregivers of children with developmental disabilities discontinued therapies due to the need for repeated visits for therapy sessions, long waiting times, transportation and financial issues. In this context, caregiver reports indicated the need for training RBSK doctors to understand the necessity for sensitive communication. Several studies have reported the psychosocial vulnerability of caregivers of children with special needs (Mattson et al, 2019), and this was identified from caregiver responses on confusion and inability to comprehend the content of referral advice. Thus, locating intervention institutions at district centres appeared to be a major deterrent for uptake of habilitation services of the RBSK.

Two other observations could be made about this model. The age at which children were diagnosed extended across and beyond the first 10 years of life, defeating the purpose of early intervention. This factor suggests that the RBSK programme needs to engage and educate community-based healthcare providers on management and referral of children with these conditions at an early age. Caregiver responses identified previously reported factors such as lack of skills of community-based physicians, lack of requisite knowledge about birth defects and developmental disabilities and where to refer the child, and discomfort in communicating with children with special needs and their caregivers (Georgeet al, 2014). The engagement of the RBSK programme with caregivers and the community at large was also required, in particular to enhance knowledge about the need for early intervention and its availability, about social welfare services and the rights of children with disabilities and their caregivers.

The other observation was the missed opportunity for genetic counselling. Single gene disorders like thalassemia, muscular dystrophy and achondroplasia are severely disabling conditions. While the community-based screening programme identified children with genetic disorders, the opportunity to refer parents for genetic counselling was overlooked. There is clearly a need for initiating genetic counselling, as these disorders are severely disabling birth defects.

In addition to provider-related issues, several demand-related measures need to be considered. The study findings indicated that caregivers should compulsorily receive information on managing the activities of daily living of their child, as well as home treatment/therapy for the condition. Home-based care, in consultation with the medical team, can significantly reduce caregiver expenditure on transportation. Another important issue is the need to provide all the parents with information on the availability and location of medical, physical and social rehabilitation services, immediately after diagnosis. A counselling and support service is also needed, in order to help parents to cope with the stress of caring for a child with special health- care needs. The presence of community volunteers, to provide assistance and respite care to parents as well as to link parents to non-governmental organizations that provide support, is another important intervention for caregivers. Underlying this is the need to enhance disability pensions and other sources of income, so that the financial expenditure on rehabilitation is not ruinous to families.

The RBSK is the first step towards addressing the needs of children with disabilities, with the purpose of moving child health interventions beyond mortality reduction goals towards strengthening services for improving the quality of child survival (Singh et al, 2015). The inclusion of birth defects and developmental disabilities within the RBSK service is relevant, as services for these two highly disabling conditions emerged in the background of a World Health Assembly resolution to address birth defects (World Health Organization, 2010). The RBSK service assumes further significance as India has ratified the Convention on the Rights of the Child (CRC) (United Nations, 1989), and the Convention on the Rights of People with Disabilities (CRPD) (United Nations General Assembly, 2006). Questions however can be asked about the cost-effectiveness of the programme, especially as the RBSK estimates coverage of 270 million children (Ministry of Health and Family Welfare, 2013a). Early childhood development screening provides a suitable alternative to community-based screening. Routine screening of children for sensory/cognitive impairments, and routine monitoring of children's developmental milestones could identify growth faltering and medical conditions, leading to referrals and early diagnosis (Lipkin et al, 2020). The need to place rehabilitation services close to communities was clear. Integration of rehabilitation services at the level of primary care has been proposed in the Rehabilitation 2030 agenda (Gimigliano & Negrini, 2017). Combining these two approaches (early childhood developmental screening and providing rehabilitation services at the level of primary health centers) can lead not only to the early identification of affected children, but also to the integration of services for children with birth defects and developmental disabilities into the primary healthcare level. This would ensure that rehabilitation services are located close to communities, making them more accessible for children with disabilities and their caregivers.

Limitations

The small sample size might make it difficult to extrapolate the findings of the study. However, in an attempt to overcome this methodological issue, caregivers were contacted from three administrative blocks and one municipal area of the district.

CHAPTER 6: CONCLUSION & RECOMMENDATIONS

The Rashtriya Bal Swasthya Karyakram (RBSK) has demonstrated significant impact on child health screening and early intervention services in Rajasthan. By focusing on early diagnosis and intervention, RBSK has played a crucial role in identifying and addressing various health issues among children, from birth defects to developmental disabilities. The program's success in facilitating access to necessary medical treatments and interventions, particularly in remote and underserved areas, underscores its importance in improving child health outcomes.

However, the study highlights several challenges and areas for improvement. Despite the program's comprehensive approach, issues such as non-compliance, treatment dropouts, and barriers to accessing healthcare persist. The centralization of rehabilitation services at district levels, coupled with logistical and financial barriers, significantly impacts the uptake and continuity of care for children with developmental disabilities. Additionally, the need for better communication, caregiver support, and community engagement remains critical to enhance the program's effectiveness.

Recommendations:

Decentralize Services: Make rehabilitation services available at primary health centers to reduce travel burdens for caregivers and ensure timely therapy sessions for children.

Enhance Community Engagement: Train and equip local health workers to identify and manage health issues early.

Comprehensive Caregiver Support: Provide detailed information, counseling, and support services to help caregivers manage their child's healthcare needs.

Improve Communication and Follow-up: Ensure caregivers receive clear information about referral advice and follow-up steps, with regular follow-up by healthcare providers.

Monitor and Evaluate: Continuously monitor and evaluate the RBSK program to identify gaps and improve strategies.

Promote Early Childhood Development Screening: Integrate routine early childhood development screening into primary healthcare services for early identification and intervention.

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ANNEXURE

Research Questionnaire:

How often are health check-ups conducted under RBSK in Rajasthan?

a) Monthly

b) Quarterly

c) Bi-annually

d) Annually

Which age group is primarily targeted by the RBSK program?

a) 0-6 years

b) 6-10 years

c) 10-15 years

d) 15-18 years

What is the primary focus of RBSK?

a) Immunization

b) Preventive healthcare

c) Curative healthcare

d) All of the above

Which type of professionals are part of the RBSK team?

a) Doctors and Nurses

b) ASHA Workers

c) Pharmacists

d) All of the above

How is the health status of children tracked in RBSK?

a) Paper records

b) Digital health cards

c) Verbal reporting

d) Annual surveys

What is a common health issue identified among children in RBSK screenings?

a) Malnutrition

b) Dental problems

c) Vision impairment

d) All of the above

How are severe health conditions addressed under RBSK?

a) Referral to specialists

b) Local treatment

c) Ignored

d) Home remedies

What is the role of ASHA workers in RBSK?

a) Conduct health screenings

b) Educate parents

c) Facilitate referrals

d) All of the above

Which of the following is a key objective of RBSK?

a) Reducing child mortality

b) Enhancing child education

c) Promoting sports among children

d) Ensuring clean drinking water

How are parents informed about their child's health status under RBSK?

a) Through school notices

b) Via SMS alerts

c) During parent-teacher meetings

d) Home visits by health workers

Which health indicator is not typically measured during RBSK check-ups?

a) Weight

b) Height

c) IQ level

d) Vision acuity

What is the frequency of follow-up for children identified with health issues under RBSK?

a) As needed

b) Weekly

c) Monthly

d) Annually

How does RBSK contribute to the overall health system in Rajasthan?

a) By providing additional workforce

b) By reducing the burden on hospitals

c) By early identification and treatment of diseases

d) By promoting traditional medicine

Which of the following services is not provided under RBSK?

a) Free medication

b) Free surgeries

c) Free transportation for medical visits

d) Free education

How is the success of RBSK measured annually?

a) Number of children screened

b) Number of health camps organized

c) Improvement in health indicators

d) All of the above