Community-Based Screening and Early Intervention for Birth Defects and Developmental Disabilities: Lessons from the RBSK Programme in India

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ABSTRACT

Purpose: *The Rashtriya Bal Swasthya Karyakram (RBSK) is an ongoing screening and early intervention programme for children in India. Children with birth defects and developmental disabilities from rural and urban communities are referred for treatment and therapies to early intervention centres located in urban areas. This study primarily aimed at determining caregiver uptake and compliance to referral advice of the RBSK, with the larger goal of determining the utility of the community-based screening and district-based intervention service model for caregivers of children with disabilities.*

Method: *Three administrative blocks and one municipal corporation area of Pune district, in Maharashtra, 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.*

Results: *Sixty-four caregivers were aware of their child's disability, but 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 and Implications: *The results indicated that the RBSK programme provides treatment opportunities for children who are left undiagnosed and*

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untreated in the community. Providing rehabilitation services at district centres is a barrier for service uptake. Alternative models such as early childhood development screening and integrating rehabilitation services at the primary healthcare level may be more feasible to provide services for children with disabilities in India.

Key words: *India, child health, birth defects, developmental disability, rehabilitation, caregiver, Rashtriya Bal Swasthya Karyakram*

INTRODUCTION

Birth defects are abnormalities of structure, function, or metabolism that are present at birth and that result in physical or mental disability or are fatal (Boyle et al, 2005). Developmental disabilities cause social, emotional, behavioural, cognitive and motor impairments in children (Boyle et al, 2005). Common birth defects like congenital heart defects (CHD), neural tube defects (NTD), orofacial clefts (OFC), and club foot (CTEV), and developmental disabilities like cerebral palsy, hearing, visual, cognitive and communication impairments, autism and attention deficit hyperactivity disorders (ADHD) are common clinical causes of early childhood disability. Birth defects and developmental disabilities challenge public health and social welfare systems of low and middle-income countries (LMICs), as affected children have special healthcare needs.

Service requirements include high cost and specialised surgery such as paediatric cardiac surgery for CHD, oral and maxillofacial surgery for OFC, lifelong medical needs (for example, management of epilepsy or treatment of thalassemia), rehabilitation services like physiotherapy, speech/auditory and occupational therapy for children with cerebral palsy, muscular dystrophy or Down syndrome. Additionally, affected children need special education and vocational training to facilitate independence and ensure their social inclusion. The multidisciplinary and resource- intensive nature of services are among several factors that explain the low prioritisation of services for birth defects and developmental disabilities among all maternal and child health conditions in LMICs (Christianson et al, 2006). However, a number of epidemiological and demographic factors portend the need to develop strategies to address these conditions in LMICs. These include large annual birth cohorts and evidence of transition in causes of child mortality with the emergence of non-communicable conditions among children in these settings (Were et al, 2015).

The Rashtriya Bal Swasthya Karyakram (RBSK) was launched by the Government of India in 2013, by revising an existing school health programme (Ministry of Health and Family Welfare, 2013a).The RBSK is a community-based programme that includes services for birth defects and developmental disabilities in addition to common childhood diseases and nutritional deficiencies. The programme model has three significant components. The first component is community-based screening. Under the screening programme, children between 2 and 18 years of age are screened at government pre-schools (*anganwadis* or AWs) and public schools in rural and urban areas for a list of pre-defined conditions. The second component is referral for further investigations, and treatment/management. Screened children are referred to the nearest tertiary care facility, where free-of-cost surgical and other hospital services are provided (Ministry of Health and Family Welfare, 2013b). As specialised skills (such as paediatric cardiac surgery) and infrastructure are limited in government health services, private hospitals have been empanelled to provide the service at predetermined costs. The third component of the model is the provision of habilitation services through early intervention centres located in different districts (District Early Intervention Centre or DEIC). The success of the RBSK programme investment is however based on the assumption that after screening, children will be taken to the DEIC and treated, namely, that there will be caregivers' compliance to treatment/habilitation advice. Studies however indicate that adherence to medical/habilitation advice for childhood chronic ailments is complex and dependent on a host of factors, including financial considerations, access to treatment, caregiver understanding and acceptance of the complexity of treatment, the rigours of regularity of adherence, and social support (Santer et al, 2014).

Keeping these complexities in mind, the purpose of this study was to determine caregiver compliance to RBSK referral advice, the reasons for non-compliance, and the health status of children with birth defects and developmental disabilities who have been users of the RBSK service. The larger goal of the study was to comment on the RBSK model for addressing birth defects and developmental disabilities, specifically the uptake of treatment at the DEIC by caregivers of children with disabilities.

METHOD

Study Setting

This cross-sectional study was set in Pune district of Maharashtra state, India. Pune district is subdivided into 11 rural and 2 urban administrative areas (or

blocks). Three rural and one municipal administrative block were randomly selected. Secondary data on beneficiaries of the RBSK programme for a period of 7 months (between April and October 2018) was shared by the RBSK office, Pune.

Study Design

As per the RBSK microplan, mobile teams consisting of two Ayurvedic doctors, a nurse and a pharmacist, conducted screening at 501 *anganwad*i centres (for children in the age group of 2-5 years) and 595 government and government-supported schools (for children in the age group of 6-18 years) in these four areas. 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 Pune. 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 programme. Physical and other therapies are provided at the DEIC in Pune, which also has a paediatrician 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.

Study Sample

Contact information was available for 819 (85%) of the 967 caregivers of children with a birth defect or a developmental disability. A sample of 204 caregivers (25%) was randomly selected from this list. Only 115 of these caregivers could be contacted as 32 contact numbers were incorrect, 45 phones were switched off, one caregiver refused consent, and 11 were contact numbers of AW workers or school teachers who were unable to provide a contact number for the caregiver. The purpose of the study was explained to the caregivers and data was collected after receiving their verbal consent.

Data Collection and Analysis

Caregivers were contacted around three to nine months after the screening 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.

Ethics Approval

The study was initiated after institutional ethics approval. Verbal consent of the caregivers was taken prior to conducting the interviews. During the interview, the research team provided contact numbers and directions to the District Early Intervention Centre, Pune, for caregivers seeking information on care and treatment of their child.

RESULTS

Types of Birth Defects and Developmental Disabilities Identified through Screening

The types of birth defects and developmental disabilities identified over the seven-month period (between April and October 2018) 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-Blackfan anemia (1 child). Common minor anomalies were strabismus, tongue tie, phymosis 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 seven- month period by RBSK Mobile Teams

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 kms from Pune 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, long distance to the treatment centre, inconvenient timings, lack of time due to competing family issues, outright denial of the existence of impairment in the child, and stating that the problem would resolve as the child grows older. The main reasons for discontinuation of treatment were the need to repeatedly travel long distances to the therapy centre, difficulty in transporting the child with disability, long waiting time during therapy sessions, erratic nature of visit by specialists, perceived poor communication/inability to comprehend what was being advised, and lack of financial ability to continue with the indirect costs of treatment such as transportation. 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. Caregivers reported that no one had informed them that their child had been screened and referred for further investigations. Others reported that despite assurances, the RBSK team had failed to contact the caregiver with details. Yet other caregivers were unsure about what was told to them, or could not understand where they were supposed to go.

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	21	Did not know where to go, long distance to treatment centre, competing family issues, loss of wages	3
			Undergoing treatment at private hospital	8	Caregiver refusal (child with Down syndrome)	1
			Not CHD	2	Did not give substantial reasons	3
2	Cleft lip/palate	5	Surgery completed	3	Competing family issues	1
			Awaiting surgery	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

DISCUSSION

The RBSK model of community-based screening, followed by referral for free or subsidised 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 immunisation 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 empanelled 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 specialised 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 centralisation 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 (George et 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 organisations 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 Organisation, 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 centres) 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, a random sample of caregivers was drawn from three administrative blocks and one municipal area of the district.

CONCLUSION

Community-based screening facilitates access to medical and rehabilitation care for children with birth defects and developmental disabilities who remain undiagnosed and untreated in the community. Centralised district level medical care and public-private partnership for specialist care provide an opportunity for expanding the scope of public health services. The policy recommendations of this study are that rehabilitation services for developmental disabilities need to be decentralised and incorporated at the level of primary healthcare, close to communities, in order to ensure their uptake. Routine monitoring of early child growth and development might be an alternative approach for early identification of birth defects and developmental disabilities.

ACKNOWLEDGEMENT

The authors are grateful to the RBSK Pune unit, the Civil Surgeon, Aundh District Hospital Pune, and the Doctors and staff at the District Early Intervention Centre Pune, for their assistance.

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