

ORIGINAL ARTICLE

Challenges faced by clients of RBSK: A mixed method study from Uttarakhand, India

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ABSTRACT

Background- Rashtriya Bal Swasthya Karyakram was launched in 2013, to reduce mortality and morbidity in children due to prevalent birth defects, diseases, deficiencies, and developmental delays. The strategy employed is early detection and management of health conditions. Mobile health teams (MHTs) and District early intervention centers (DEIC) are set up for screening, management, and referral of beneficiaries.

Methodology – A concurrent mixed method study was conducted in Uttarakhand for exploring challenges faced by clients and to assess client satisfaction regarding services provided under the program. Caregivers of beneficiaries were interviewed telephonically about the challenges they faced while availing the facilities.

Result- It was found that out of 41 caregivers of beneficiaries, 13 (31.7%) faced challenges while availing the services, and 2 (4.87%) were dissatisfied with the services. Challenges faced by caregivers were out-of-pocket expenditure on transportation, food and stay, long time in referral and unavailability of beds, unavailability of medicines, and failed treatment. **Conclusion-** The majority of the caregivers were satisfied with the referral and treatment provided. RBSK provides free-of-cost treatment to children but the indirect cost that the caregivers have to pay for travel, stay and multiple visits pose a challenge for utilization of the services.

Keywords- Child Health, Challenges, RBSK, Uttarakhand

Introduction

Rashtriya Bal Swasthya Karyakram (RBSK) or 'Child Health Screening and Early Intervention Services' was launched in 2013 for reducing mortality and morbidity rate among children. It aims to cover 27 crore children in a phased manner for early identification of 4Ds - Defects at birth, Diseases, Deficiencies, and Developmental delays, including Disabilities prevalent in children aged 0 to 18 years.¹ This program ensures free treatment and management of health conditions, including surgical interventions at tertiary care centers.¹

Screening of children for 4Ds is done at the time of birth, during home visits by ASHAs, by Mobile health teams during their visits to Anganwadi centers, and Government and Government aided schools.¹

District Early Intervention Centers (DEIC) are established at the district level and acts as a first referral point for further investigation, management or referral to tertiary level hospitals. Empanelled tertiary care centers are involved in providing high-end medical care for surgical interventions.² Under RBSK, surgical packages include the cost of all preoperative and postoperative investigations.³

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The state of Uttarakhand has four functional DEICs (Dehradun, Haridwar, Nainital, and Almora) in the state. There are four empanelled hospitals in the state, centralized in the Dehradun district, catering to the needs of 13 districts. Feedback from the beneficiaries reflects on the status of program implementation.⁴ Feedback also sheds light on the difficulties faced by beneficiaries while availing the benefits of the program. The present study explored the perceived challenges faced by the beneficiaries and assessed the beneficiary satisfaction regarding services received from the point of referral till the treatment was received.

Methodology

A concurrent mixed method study was conducted in Uttarakhand to assess the Client Satisfaction for RBSK services at the Empanelled hospitals present in the state in October 2020. Out of the four empanelled hospitals, one private hospital and one government tertiary care hospital were selected based on convenience. A list of beneficiaries with contact details, who visited the hospital for treatment from January 2020 to July 2020 was obtained from the empanelled hospitals. Parents of beneficiaries were contacted telephonically as per the list. If the parent was not available on the day of contact, a second phone call was arranged after confirming their availability on later dates. If the parent was still not available on the second phone call, then the next beneficiary was contacted. If the phone number was not reachable or switched off on the day of contact, an attempt was made twice on subsequent days and if then also contact was not established next beneficiary on the list was contacted. The interview schedule was prepared to know about the challenges faced by the beneficiaries. The interview schedule contained questions regarding socio-demographic profile, awareness about the condition of the child, source from where they got to know about the RBSK program, challenges faced while availing the services from the referral to the treatment facility, and were they satisfied with the treatment provided. The parents who faced challenges were further probe into nature of the challenges. Profile of birth defect of the beneficiaries was obtained from hospital records. Interviews for nature of challenges were conducted till the point of saturation i.e., till no new information emerged. Data were entered into MS Excel 2007, and descriptive statistical analysis was done. Qualitative data analysis was done by conventional content analysis using the deductive approach. The information collected and the audio recordings were transcribed into written text. This text was read and re-read line by line to identify themes and categories. Categories were identified a priori, and any text which could not be categorized with the a priori categories was given a new code. Two independent investigators (AM and MK) analyzed data separately, and discordance was settled with discussion. Ethical approval from the Institutional ethics committee was taken before conducting the study.

Results

We tried to contact 70 caregivers based on the treatment records, out of which 41 caregivers were interviewed. We couldn't establish contact with 29 caregivers as their phones were either switched off or out of the network coverage area. Out of these 41, 20 children got treated at the tertiary care government hospital and 21 at a private hospital.

Table-1: Profile of beneficiaries of RBSK according to age and gender (N=41)

| Age | Male | Female | Total | |
|-----------------|-------------------|-------------------|-----------|------------|
| | | | No. | % |
| 0-28 days | -- | 1 | 1 | 2.4 |
| 29 days -1 year | 11 | 7 | 18 | 43.9 |
| 1-3 years | 6 | 7 | 13 | 31.7 |
| 3-6 years | 4 | 1 | 5 | 12.2 |
| 6-12 years | 2 | 2 | 4 | 9.8 |
| Total | 23 (56.1%) | 18 (43.9%) | 41 | 100 |

According to the Modified Kuppuswamy scale, 2019⁵ 30 (73.1%) families of the beneficiaries belonged to lower and upper lower class and only 11 (26.8%) families belonged to the middle socioeconomic class, 11 (26.8%) beneficiaries were from the Kumaon region and 30(73.2%) from the Garhwal region.

In Table 1 it can be observed that the majority of the beneficiaries (46.3%) were infants (≤ 1 year), 31.7% were of the age group 1- 3 years and 9.8% were above the age of 6. Out of all the beneficiaries who got treated, 56.1% were males and 43.9% were females.

Table -2: Distribution of time taken for referral, Profile of birth defects, and source of Primary information for the treatment under RBSK (N=41)

| Particulars | | No. | % | |
|---|-----------------------|--------------------------------------|------|------|
| Time taken from referral to hospital | Duration | ≤ 1 month | 36 | 87.8 |
| | | 2-6 months | 2 | 4.9 |
| | | ≥ 6 months | 3 | 7.3 |
| Profile of birth defects for treatment was undertaken | Birth defect | Neural tube defect | 15 | 36.6 |
| | | Congenital Heart disease | 14 | 34.1 |
| | | Congenital cataract | 5 | 12.2 |
| | | Cleft lip and palate | 9 | 22.0 |
| | | Club foot | 1 | 2.44 |
| Primary source of information about RBSK | Sources | Frontline workers(ASHAs, AWWs) | 6 | 14.6 |
| | | Private Hospital | 7 | 17.1 |
| | | Gram Panchayat | 3 | 7.3 |
| | | Mobile Health Team | 6 | 14.6 |
| | | Primary level Healthcare referral | 1 | 2.4 |
| | | Secondary level Health care referral | 9 | 21.9 |
| | | Tertiary level Healthcare referral | 5 | 12.2 |
| | Friends and relatives | 5 | 12.2 | |

At the time of birth 22 of the beneficiaries were screened for birth defects at the healthcare facilities and were referred for treatment. ASHA and Anganwadi workers identified 6 beneficiaries who required treatment for birth defects and referred them. Few (14.6%) of the caregivers reported that their children were screened by Mobile Health teams at Anganwadi centers and schools. It was found that at some places even Gram Panchayat and local leaders were creating awareness regarding the program and were helping in the mobilization of parents. Doctors at private hospitals and clinics also gave information about the program to parents who couldn't afford the treatment. Out of 41 parents, 40 parents were aware of the diagnosis. On average it took the caregivers 31.8 days (SD= 10.4 days) after the first point of referral to reach the treatment facility. The treatment was sought for birth defects that were mainly neural tube defects and congenital heart disease. They didn't know the medical terms for the health condition. They referred to conditions in the local language. Out of 41 caregivers, 13 (31.7%) reported that they faced challenges while availing RBSK services and 2 (4.9%) were unsatisfied with the services and treatment outcome (Table-2).

Verbatim of the parents who faced challenges while availing RBSK services

Out of pocket expenditure- “We spent 15 – 20 thousand rupees on travelling and food. Some medicines were available at the hospital but we had to buy few medicines on our own.” Father of 6 years female suffering from congenital cataract resident of Rudraprayag

Challenges at the hospital- “Already we bear the cost of travelling, food, and medicines, I was ready to pay for my daughter’s treatment even if I had to sell my house or my land. But when the government is providing free treatment why should I pay for it”. - Father of a 3-year-old girl diagnosed with cleft lip and palate, congenital cataract, and congenital heart disease spoke about the financial challenges. He was asked for money by an empanelled private hospital for treatment despite having all the paperwork

Challenges related to referral process- “.....we spent a lot on travelling, how we can say it is a free facility. We had to visit 4-5 times. The issue is that the child is not comfortable even after the operation; he is having the same problems. - Mother of a 3-year-old boy suffering from neural tube defect

Most of the caregivers reported that they faced financial challenges. (Figure 1)

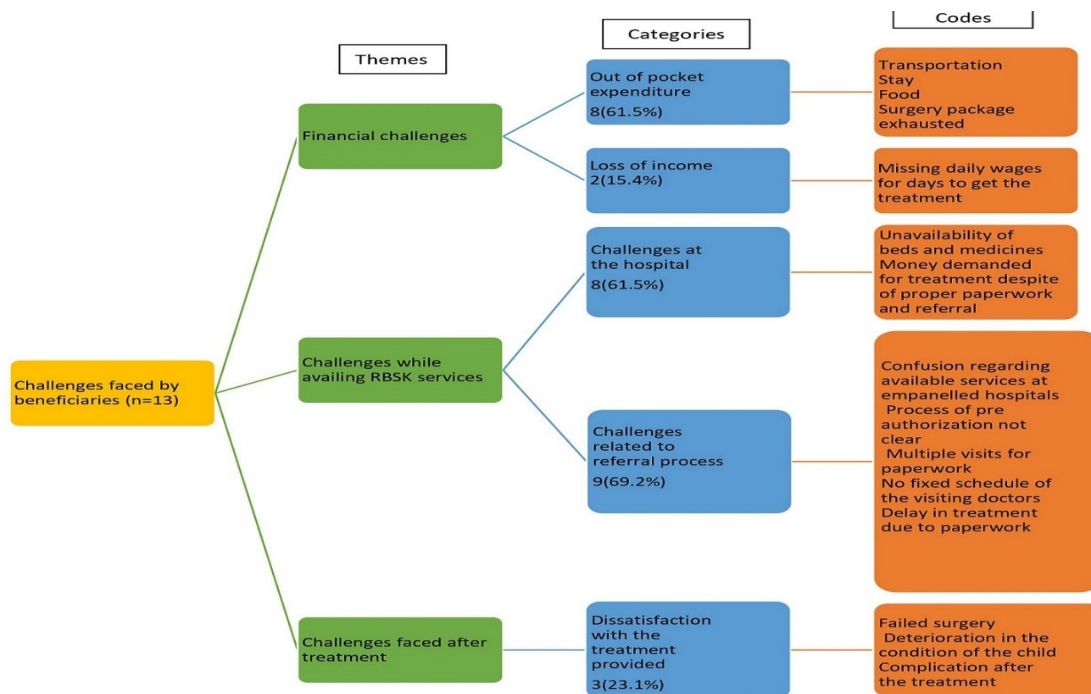


Figure 1- Perceived challenges faced by the caregivers of beneficiaries while availing benefits of RBSK

Discussion

This study was conducted to obtain feedback from the beneficiaries of RBSK regarding services received. Among the participants, only 4.9% were dissatisfied with the services due to unfavourable treatment outcomes. The caregivers (31.7%) who faced challenges were satisfied that their children got the treatment through RBSK which they couldn’t afford otherwise. The majority of the caregivers (68.3%) were satisfied with the referral and treatment provided. These participants were majorly from Dehradun and Haridwar area so they didn’t have to travel far to avail the benefits. Out of all the surgery packages provided under RBSK, treatment was mainly sought for Neural tube defects and Congenital Heart Disease (CHD). These birth defects are identified within a few days of birth and put the child in life-threatening situations. The financial challenges reported by the caregivers are mainly due to transportation costs as all the empanelled hospitals are concentrated in state capital; many had to travel long distance. The empanelled hospitals were not fully equipped to cater to all the diseases and services covered under RBSK. This further increased the challenges for the caregivers. Even after travelling to the state capital, if the beneficiaries don't get the treatment, they feel dissatisfied.

Prabhu SA et al assessed beneficiary satisfaction in Chhattisgarh regarding their experience at DEIC. They reported that 53.0% of beneficiaries were satisfied with the services at DEIC. Too much paperwork, Unavailability of specialized treatment, and loss of wages were the reported reasons for the dissatisfaction. (6). Anita Kar et al also reported that wage loss, distance to the treatment facility, inconvenient timings, transportation, and long waiting time were the reasons for dissatisfaction and treatment dropout.⁷ Evaluation study done in Madhya Pradesh reported 75% and 70 % of caregivers were satisfied in Indore and Ujjain respectively.⁸ Formative Evaluation study of RBSK in conducted 5 states reported that main barriers for caregivers were financial challenges and transportation.⁹ Similar challenges were reported by the caregivers in the present study. Transportation was the biggest challenge in the present study as people from remote hilly areas were spending a large sum of money to reach Dehradun for treatment. The absence of DEIC in each district as recommended by the guidelines and insufficient number of empanelled hospitals is the main cause of the problem. Parmar et al found that the caregivers were dissatisfied with the expenses, behaviour, and availability of DEIC staff.⁹ Unavailability of doctors was reported in our study which leads to multiple visits by the beneficiaries. RBSK was launched to decrease the out-of-pocket expenditure of the caregivers so that early management of the health conditions can be provided but the indirect cost that the caregivers have to pay is a deterrent for utilization of the services.

There is a need for operational research on RBSK related to assessment of the out-of-pocket expenditure of the beneficiaries and development of an innovative service delivery model for the geographically diverse state of Uttarakhand.

Recommendations

To reduce out-of-pocket expenditure - Once a week Mobile Health Teams should be used for the transportation of children and their parents from respective blocks to DEICs. Mapping of the secondary and tertiary care facilities for the provision of services should be done in all the districts.

For challenges related to the referral process and at hospitals- A certain number of beds should be kept reserved for the beneficiaries and it should be reflected on the portal so that the referral from District Early Intervention centre (DEIC) is made accordingly. The Schedule of visiting doctors at DEIC should be circulated to doctors of MHTs so that they can guide the caregivers for visits accordingly. A portal for RBSK should be set up, in which each child referred at DEIC should have a profile with all the diagnostic reports which can be updated by the empanelled hospital where the beneficiary gets treatment.

Conclusion

All the four Empanelled hospitals under RBSK are centralized in the Dehradun district, so beneficiaries from all over the state had to travel to Dehradun for surgeries. Some caregivers (Parents/Relatives of the beneficiary) faced challenges while availing the services which mainly included out-of-pocket expenditure on travel, food, stay, multiple visits, confusion regarding the referral process, delay in treatment due to paperwork unavailability of medicines at the empanelled hospitals.

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