

Profile, Quality of Life and the Client Satisfaction of Beneficiaries Registered under Rashtriya Bal Swasthya Karyakram (RBSK) at an Urban Primary Health Centre, Ahmedabad: A Retrospective Cohort Study

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Abstract

Background: Under Rashtriya Bal Swasthya Karyakram (RBSK), children (0–18 years) are screened for a spectrum of 30 health conditions, categorized under 4D's namely defect (birth), disease (chronic), deficiency disorders, and developmental delay, and referred for treatment at higher centers. The aim of this study is to document demographic, clinical profile of children detected with any of 4D's during 2018–20 at one Urban Primary health center to assess their Quality of Life (QOL) and client satisfaction. **Materials and Methods:** A total of 102 children <18 years were selected as per Probability Proportionate to Size for different 4D's; within each category required participants were selected randomly. Information was gathered on designed semi-structured proforma. For QOL, customized World Health organization Quality of Life Brief (WHO-BREF) Questionnaire tool was used. Client satisfaction about the RBSK was assessed among RBSK users (N = 46) with Likert scale. **Result:** Out of 102 cases, 97 were covered including 8 with more than 1 type of 4Ds. Majority beneficiaries were male (53.1%), from 5 to 10 years age (43.8%), and middle social class (52%). Congenital defects (48.5%) especially heart defects were the most common followed by deficiency disorders (40.2%) mostly severe anemia and/or severe acute malnutrition. Out of 46 who availed RBSK services, 82.6% rated service as very good or good. Most children (81.7%) had good QOL. **Conclusion:** Most detected 4D's belonged to school going age and middle class. They rated program as very good or good. Congenital defects, specifically heart defects were the most common. Overall, most children (81.7%) had good QOL.

Keywords: Client satisfaction, profile of RBSK beneficiaries, quality of life

INTRODUCTION

Sustainable Development Goals were adopted by the United Nations in 2015 of which Goal 3 aims to end preventable deaths of newborns and under-5 children by 2030 with targets of reducing newborn mortality and under-5 mortality to as low as 12 per 1000 live births and 25 per 1000 live births, respectively, in every country. Gradual yet continuous reduction of infant mortality mainly due to exogenous causes (environment related and communicable diseases), congenital defects, and prematurity have assumed importance in further reduction of related morbidities and mortalities. Rashtriya Bal Swasthya Karyakram (RBSK) launched in 2013 is a step in this direction where services of child health screening and early intervention services

are provided for early detection/management of a set of 30 health conditions prevalent in children <18 years of age. These conditions are broadly birth defects, chronic diseases, deficiency conditions, and developmental delays including Disabilities–4 D's. All these 4Ds are manageable through early detection and prompt and appropriate referral. The timely

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treatment can significantly improve QOL so can yield rich dividends in nurturing the health of our children.^[1]

Globally, the prevalence rates of congenital birth defects (per 1000 live births) range between 82 (low-income region) and 39.7 (high-income regions).^[1] Various nutritional deficiencies affect preschool children ranging between 4% and 70%. Developmental delays are also common in early childhood affecting at least 10% of the children.^[2] In India, 6% of children are born with some birth defects (globally largest share of birth defects @26 million births/year) and account for 4% of under-5 mortality and 10% of neonatal mortality.^[3]

With context of RBSK, while most studies either focused on knowledge, attitude, and practice (KAP) of service providers like medical officers^[4] or Accredited Social Health Activist^[5] or evaluated the gaps in infrastructure, equipment, and manpower at the service points (DEIC),^[6] we could not find any study documenting the “gaps in service” and outcome of children with 4Ds registered. This reinforced the need of such a study to identify any lacuna and bridge the gaps in process to have better outcomes.

Considering the magnitude of problems of 4Ds, launch of RBSK, and the context of limited data availability, present study was undertaken with the objectives to document sociodemographic/clinical profile of children detected with any of 4 D's registered during 2018–19 and 2019–20 in the areas of one of the Urban Primary health centers (UPHC) of Ahmedabad city. Additional objectives of the study were to assess (1) Quality of Life (QOL) of child and (2) client satisfaction regarding care received at District Early Intervention Center (DEIC) and suggest remedial measures.

MATERIALS AND METHODS

It was a retrospective cohort study conducted at a UPHC, also the Urban Health Training Center of a government run medical college catering for a population of 154,043.^[7] List of two cohorts of children registered and referred for 4Ds during Apr 18 to Mar 19 (1st cohort N = 171) and Apr 19 to Mar 20 (2nd cohort N = 131) were obtained from the UPHC. Probability Proportionate to size method was used to find out required number of subjects (@51 subjects from each cohort) with proportional representation of each of 4Ds. Cases whose parent/caregiver were willing to participate and gave informed written consent/assent were contacted. It was ensured that the cases selected should have been registered at least 1 year before the data collection and therefore there was no case below the age of 1 year. It was done to gather the information for client satisfaction among those who availed services or not. Home visits with prior appointment (as per convenience of caregiver) were undertaken by trained investigators. To address refusal and non-availability of subjects, at least one repeat visit was conducted.

All the information was gathered on a designed piloted semi-structured proforma. In case where subject expired, caregiver/parent was interviewed by the team of two

investigators. Client satisfaction was obtained from those who availed the services on a Likert scale of 1 to 5, where 1 was poor and 5 was very good.

WHOQOLBREF Questionnaire

For QOL, WHOQOLBREF^[8] Questionnaire was used for children >2 years after customization for different age groups. Tool used for children aged 2 to 6 years had physical, social, and emotional dimensions while for those >6 years of age, a dimension of scholastic performance was added. Maximum score assigned to each dimension was 12 except for physical dimension where it was 24. Based on the scores, cut-off points were identified to put the subjects in different categories of QOL. For 2 to 6 years old, it was 12 to 24 (Bad), 25 to 36 (Average), and 37 to 48 (Good). For rest, it was 15 to 30 (Bad), 31 to 45 (Average), and 45 to 60 (Good). Information was gathered by interviewing the caregivers except for children aged ≥13 years, where it was obtained from the subjects themselves after taking the due permission.

Ethical clearance

Prior approval was taken from Institutional Ethics Committee and local authorities. During the visits, those needing medical assistance were referred to our hospital and the visits were facilitated by the investigators.

RESULTS

Out of the total 102 cases, 97 (95%) were covered (including 1 expired). Maximum registered cases were from 5 to 10 years (43.8%) followed by under-5s (37.5%) and adolescents (18.8%). Mean age of beneficiaries at time of visit was 6.9 ± 4.4 years. Males (53%) outnumbered females. Based on modified Prasad Classification,^[9] most affected children belonged to middle and upper middle social class (58.3) with few either from lower (10%) or upper (7%) social class. Below Poverty Line card was available with only 21.9% children. Out of 97 cases, 47 had birth defects (few with multiple Ds); common were congenital heart disease, club foot, cleft lip/palate, congenital deafness, and Down Syndrome. Deficiency disorders included Severe Acute Malnutrition (SAM) and/or severe anemia. Chronic and debilitating diseases (10) had juvenile diabetes, thalassemia, nephritic syndrome, pulmonary artery hypertension, and chronic myeloid leukemia. There was only one case of developmental delay (adrenal hyperplasia) [Table 1]. As per WHOQOLBREF Questionnaire for QOL, it was good in all age groups ranging from 64.3% in 13 to 18 years to 89.1% in 2 to 6 years [Table 2]. In 2 to 6 years, physical domain was most affected, while social and emotional QOL were minimally affected. Almost similar trend was observed in 7 to 12 years of age, where the scholastic performance was most adversely affected; so much so that two children dropped out from schooling. In 13 to 18 years, the most affected domain was also scholastic followed by emotional.

An assessment of QOL among the beneficiaries who availed services at DEIC (N = 46) or not (N = 50) [Table 3] revealed

Table 1: Type of 4Ds covered under the study (n=97)

Defect (n=47) (some with multiple Ds)	Number (%)
Congenital Heart Disease (CHD)*	20 (20.6)
Cleft lip/palate	6 (6.2)
Club foot**	6 (6.2)
Congenital deafness	3 (3.1)
Downs syndrome	3 (3.1)
Cerebral palsy, Congenital cataract, Tongue tie, Imperforate Anus, B/L hydronephrosis, Microcephaly with absent left kidney, Developmental Dysplasia of Hip (DDH), Spinal dysraphism with lower limb atrophy, MR and Microcephaly: Post Hypoxic Ischemic Encephalopathy (HIE)	9 (1 each)
Deficiency (n=39)	
Severe Acute Malnutrition (SAM)***	36 (37.0)
Severe Anemia	3 (3.1)
Chronic Disease (n=10)	
Diabetes Mellitus Type 1	5 (5.2)
Thalassemia major	1 (1.0)
Nephrotic syndrome	2 (2.1)
Chronic myeloid leukemia	1 (1.0)
Pulmonary Artery disease	1 (1.0)
Developmental Delay (n=1)	
Congenital adrenal hyperplasia	1 (1.0)

*2 children had other abnormalities also along with CHD—scoliosis and SAM. **1 had cerebral palsy along with a club foot. ***3 children had other issues also along with SAM—hernia, kyphoscoliosis, and CHD-epilepsy

Table 2: Distribution of registered RBSK beneficiaries and their QOL (n=93)*

Age (years)	Bad No (%)	Average No (%)	Good No (%)	Total No (%)
2-6	2 (4.4)	3 (6.5)	41 (89.1)	46 (100.0)
7-12	3 (9.1)	4 (12.1)	27 (81.8)	33 (100.0)
13-18	0	5 (35.7)	9 (64.3)	14 (100.0)
Total	5 (5.4)	12 (12.9)	76 (81.7)	93 (100.0)

*In children <2 years (3) and expired (1), assessment was not made

a negligent difference which was statistically also found not significant.

Clients who utilized the service (46) at DEIC were assessed for satisfaction using the Likert scale. Most of them rated the services as very good (50%) or good (32.6%) followed by Okay (8.7%) and bad (2.2%), while others (6.5%) chose not to answer.

DISCUSSION

Birth screening is important as annually four million newborns die during the first 4 weeks of life and globally neonatal mortality makes up 40% of the total child mortality.^[10,11] This is possibly the reason for a focus on the neonatal period among researchers and policymakers calling for action.^[12]

Larger representation from preschool/school-going children is mainly due to more defect detection at delivery points and

later by frontline workers such as Accredited Social Health Activist (ASHA) and Anganwadi Worker (AWW) who can easily identify conditions such as cleft lip, club foot, and so on, also justifying for a higher proportion (48%) of congenital defects. But in later years especially for adolescents, screening system for 4Ds requires more effort as there was only one RBSK team catering to an area with a 1.54-lakh population. It is largely done through school health checkups but is not enough. So, if strengthened, the RBSK team can prevent not only morbidity/mortality but can reduce dropouts as well. Higher male representation may be either due to them being biologically more fragile or gender-specific treatment-seeking preferences. It also highlights the morbidity and mortality of neglected female children. Detection of 4Ds, their referral, and subsequent management at DEIC are important for affected beneficiaries. Treatment-seeking behavior depends upon awareness, especially for govt services/schemes, and this could be the reason for more representation from the middle social class as those from the lower class are unaware of such people-centric welfare schemes and the upper class may directly go to the private sector. More awareness generation in all social classes can increase service utilization. Consequent better utilization (of RSK) can prevent the catastrophic out-of-pocket expenditure (OOPE) which is an economic burden to the people of all social classes. Another heartening aspect of the study was the almost perfect match found by us during our validation of diagnosis (made by RBSK). Out of the 96 cases, there was only one mismatch (one normal child labeled as Down syndrome) and three to four additional 4Ds observed by us in cases with a congenital defect. It can be either due to the following reasons: (1) after detection a child may develop deficiency disorders or (2) negligence of staff after they detect one condition. Hence, the staff should not be complacent after detection of one type of 4Ds and must examine the child for other 4Ds but also the sibling as both share a common genetic and environmental pool. A high proportion of birth defects especially congenital heart disease emphasize the role of early screening as timely interventions not only prevent morbidity, mortality, and disability but also ensure good QOL among survivors. A high number of congenital heart disease detection which cannot be possible without screening by health personnel reflects the impact of various national health programs and actual post-natal visits. The 4Ds profile reported is based on community-based screening and shall be different from the attendee of a DEIC.^[13]

Client satisfaction (post-intervention) depends upon the type of 4Ds and the point of care. It may be very good for congenital defects, such as cleft palate/lip (post-surgery) or congenital deafness (after cochlear implant), than for cerebral palsy or microcephaly (fewer promising results) or the SAM or severe anemia (recurrent nature).

One-third children had no effect on QOL stating that they had no symptoms (39 deficiency cases) before the referral also. Overall, QOL for most (81.7) reflects the efficacy of 4Ds screening. Defects detected at birth have more impact

Table 3: Quality of life for beneficiaries (utilized versus not utilized RBSK services)

QOL	Utilized RBSK services (n=46)	Didn't use RBSK services (n=50)	Total
Good	38 (82.6)	41 (82.0)	79 (82.3)
Average	6 (13.1)	6 (12.0)	12 (12.5)
Bad	2 (4.3)	3 (6.0)	5 (5.2)

Chi square=0.148; Df=2; P=0.92 (Not significant)

on improving the physical domain than on emotional, social, and even the scholastic domain which are better perceived in later years. A couple of individual case studies make good observations with regard to QOL. In the case of a child with congenital cataract, surgery was withheld by parents and as a result, he developed blindness and now needs someone constantly to avoid accidents. A child with a cleft palate had a visible deformity and problems with speech and breastfeeding. All these (except the speech problem) were resolved post-surgery and both the child and his family have very good QOL. A case of clubfoot after surgery can walk now and his QOL has improved but his parents are still worried due to visible deformity. At the same time, there were children where a complete cure was not possible or not obtained; hence their QOL remained adversely affected. Two children with congenital deafness had compromised interactions and daily activities were also affected. Cochlear implantation was done under RBSK but later children could not go for speech therapy (though costly but mandatory for good outcome), and it affected the QOL of children/families.

CONCLUSION AND RECOMMENDATIONS

Birth defects were the most common 4Ds in this study and most children despite the presence of 4Ds had good QOL. More than 80% of the clients who utilized RBSK services rated services as good. However, the program should have an organized built-in system of collecting the client feedback which should be discussed during the review meetings and also be used for the better organization of the program. The program also needs more horizontal integration to ensure its sustainability and for providing holistic care.

Limitations

Due to the logistic constraints, the small sample and inclusion of subjects from a single UPHC limit the validity of observations. Moreover, the list of cases (registered by RBSK) was obtained from UPHC, hence it does not include the cases which have not been detected by the RBSK team. Finally, the corona pandemic affected our work schedule as lockdown prevented client visits to DEIC/health facility/delivery points (schools and AWKs) were closed.

Declaration of patient consent

The authors certify that they have obtained all appropriate

patient consent forms. In the consent forms, patients have given their consent for his/ her/ their clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

One of the authors (DO) was involved with implementation of this program in the study area.

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