

A study on identification and treatment of Clubfoot patients among Rural and Marginal population of Uttar Pradesh

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Abstract

Clubfoot is a congenital birth condition in which the foot (or both feet) of the child is turned inward. Approximately 1,50,000-2,00,000 children are born with clubfoot each year and 80-90% of these children are born in middle- and low-income countries that have inadequate access to treatment for the birth condition and healthcare in general. In India, the incidence rate is 1.2 per 1000 live births (source- CIA factbook) and around 35,000 children are born with clubfoot each year. The success rate of treatment depends upon the age at which child reaches the clinic, the earlier it is the more is the success rate. If the treatment starts right after birth, the success rate is expected to be at 95%. The research mainly focusses upon the major influencers/motivators, hindrances, access to treatment of clubfoot and healthcare facilities. Since the treatment runs for around 5 years, the dropout is quite often observed during the treatment and patients do not complete the full course due to various reasons which were highlighted during the research such as distance of the health facility, opportunity cost of lost wages etc.

Introduction

Clubfoot is a deformity in which an infant's foot is turned inward, often so severely that the bottom of the foot faces sideways or even upward. Approximately one infant in every 1,000 live births will have **clubfoot**, making it one of the more common congenital (present at birth) foot deformities. The condition is immediately visible at birth but can also be detected before birth by ultrasound. Clubfoot is mainly idiopathic which means the cause of it remains unknown, genetic factors are believed to play a major role i.e. it can be passed down from mother or father to the child or if someone in the immediate family have this birth defect, chances are more that other family member also have this congenital birth defect. Gender also plays a major role and males are twice as likely as females to be born with clubfoot. Environmental factors may play a role. Research has found a link between the incidence of clubfoot and maternal age, as well as whether the mother smokes cigarettes, and if she has diabetes.

Uttar Pradesh is the most populous state of the second most populous country in the world and an average of 7000 children are born with clubfoot in the state of Uttar Pradesh. Majority of them belong to the rural areas where there is inadequate access to proper healthcare. Estimates are that 20% of the children born with

clubfoot receives treatment. The most suitable method of treatment is considered to be Ponseti method which is majorly non-surgical apart from a minor tenotomy procedure. Ponseti method tries to manipulate the position of the foot with the help of serial casting and after that through continuous use of foot braces.

The research have tried to find out the key influencers and motivators to the children's parents and the major hindrances in receiving the continuous treatment for clubfoot.

Need for the study

Children who are challenged physically are at a disadvantage in social and economic terms, in low- and middle-income countries. Educational and employment opportunities are reduced for the child and also mothers of these children spend more time looking after them leaving them having less time for other children and for agricultural, domestic and economic activities which ultimately hampers the living standard of such families. The prudent estimate of prevalence of clubfoot is approximately one in every 1000 live births. Some research suggests two in 1000 live births in some countries. Most of these children are receiving little or no treatment for their disorder for number of reasons including the following:

1. The clubfoot deformity is not recognised at birth: Many birth attendants and parents, particularly in the rural areas, are unaware that clubfoot deformity can be treated and the need for early treatment.
2. When recognised, there is no treatment available: Lack of trained local medical or paramedical workers make clubfoot treatment inaccessible for many families.
3. Inadequate treatment: Many medical personnel have not had an opportunity to upgrade their skills over the years.
4. Religious Beliefs: In some part of the rural communities, parents sometimes accept the disease as god's punishment and they don't treat it in medical ways.

Objectives of the Study

- To study the awareness of clubfoot among rural and marginal population of Uttar Pradesh.
- To understand the impact of social, economical and demographical barriers in treatment of the clubfoot.
- To understand the demographic profile of the patients affected by the clubfoot.
- To study the identification and subsequent course of action at the point of delivery for treatment of clubfoot by parents in rural area of Uttar Pradesh.
- To study the factors influencing discontinuation of the treatment of clubfoot among rural population of Uttar Pradesh.
- To study the role of health activists in identification and treatment of clubfoot in rural areas of Uttar Pradesh.

- To study the genealogical medical history of clubfoot among rural and marginal population of Uttar Pradesh.
- To study the impact of media for spreading the awareness of clubfoot among rural areas of Uttar Pradesh.
- To study the technology adaptation among rural and marginal population of Uttar Pradesh.

Research Methodology

Respondents for Parent's survey were selected through non-probability based Random Sampling. Prior to framing the questionnaire for parents of clubfoot affected children, researcher had informal discussions with 30 such parents. A detailed questionnaire was then prepared to conduct in-depth structured interviews of parents of Clubfoot affected children. The questionnaire comprised of sections such as classification, about the child, treatment, community and communication covering all broad aspects related to the study. The survey questionnaire was administered on 50 parents.

Pathways to Identify Clubfoot affected child

There is a possibility that the clubfoot of a child can be diagnosed during pregnancy but there is a 50-50 probability to it as the diagnosis depends on the proficiency of the radiologist/gynaecologist performing the check and also on the ultra-sonography machine they're using. While discussing with doctors about the diagnosis of Clubfoot during pregnancy, most of them told that many parents go for abortion in case it is detected during pregnancy and if abortion is possible at that point in time (usually during 18-20-week scan). Under Pradhan Mantri Surakshit Matritva Yojana, ultrasounds are being provided free of cost at some government health facility in a district at 3rd, 6th and 9th month of pregnancy. On 9th day of every month, mass check-up is being held for high risk pregnancies. Even if the birth defect is diagnosed during pregnancy, the treatment can only begin after birth. Since Clubfoot is a congenital defect i.e. it is present at the time of birth, it is commonly recognised by the doctors and paramedical staff, at the point of delivery, soon after birth just by having a look on the shape and position of the child's foot. At times, the doctor might request for X-rays to confirm the birth defect before starting the treatment or referring it to appropriate point of treatment. At CHCs, screening of new-borns is also undertaken by the two RBSK health teams present at CHC to identify if the child is born with one (or more) of the 31 selected health conditions listed under RBSK. If the identification is missed at the point of birth, during the initial 42 days of birth it can be detected by ASHAs as they visit the home of the new-born for post-natal care of the mother and child at regular intervals during the first six weeks of the baby being born. Also, they are entrusted with the responsibility of immunization and vaccination of children aged from 6 weeks to 5 years

so if the ASHAs are briefed properly to identify the birth defect, it can also be identified at the vaccination points and on the Village Health and Nutrition Day (VHNDs) which is being held every month at village level for immunization and vaccination of children. Apart from ASHAs, the Anganwadi workers can also play a vital role in identification of such children as children go to Anganwadi Centres during the age of 3-6 years, a play school as well as nutrition centre in a village. But Anganwadi workers need to be trained just like ASHAs to identify Clubfoot in children. Nodal teachers have also been appointed in Schools under RBSK who are entrusted with the responsibility to identify children born with those 31 selected health conditions. A brief training is also held for such teachers time-to-time whenever there is introduction of government schemes related to children aged 6-18 so that the health department can leverage the workforce and infrastructure of the Education Department. Also, under School 24 Health Programs of RBSK, Medical check-ups are held for children enrolled in Anganwadi Centres and Schools so that any deficiency, disease, defect or developmental delay including disability can be identified earlier and the child can be treated at an early age. A major limitation in identifying clubfoot at Anganwadi Centres and School is that not all the children are enrolled in the Anganwadis and Schools. Out of the children enrolled in these places, many of them are absent on a regular basis. So, the scope of identification is limited to the Enrolment Ratio and Absenteeism at these places. In a nutshell, following are the broad pathways to identify Clubfoot in a Children:

During Pregnancy

- through ultrasounds (50% probability of detection)*- available free of cost at specific points in a district At the time of birth
- through Gynae/Paediatrician
- through Medical Officers, Gynaecologists, Paediatricians and RBSK teams at CHCs
- through Paramedical staff present at the Point of delivery If identification is missed at the point of birth-
- 0 days to 42 days... through Accredited Social Health Activist (ASHA)
- 6 weeks to 5 years • at Vaccination points through ASHAs (Village Health and Nutrition Days)
- 3 years to 6 years
- in Pre-schools through Anganwadi workers and RBSK team
- School Health Program under RBSK- mobile health team screening children in Schools.

Stages of Identification

Clubfoot can be identified during pregnancy by way of Ultra-sonography (by radiologists and gynaecologists) but the percentage of women going USG during pregnancy in the state of Uttar Pradesh is

30.8%, digging up further the data is even more skewed between urban and rural areas where the percentage of such women in rural areas is mere 26% and in Urban areas is 52.1%. Also, since the probability of identification is ~50%, there is high possibility of false negative results during identification of Clubfoot during pregnancy with more women going for ultrasounds during pregnancy. Also, there is also ethical issues surrounding identification of clubfoot during pregnancy as most of the rural population especially in the state of Uttar Pradesh are not literate enough to understand the risk associated with abortion of pregnancy. Many families may pressurise the girl to get the baby aborted even when the pregnancy is older than 20 weeks (the permissible limit for abortion as per law) without considering the risks associated with it which may further put the mother's life and health on risk. Birth: The birth of a child can occur at the following places in case it is an institutional delivery which is 56.7% of total deliveries in the state: (a) Government Hospitals (b) Private Hospitals (c) Trust Run Hospitals or (d) Home. For (a), (b), and (c)- the birth defect can be identified at the point of birth provided the postnatal check-up of baby is taken up by the doctor and paramedical staff diligently to screen birth conditions if the child is born with any.

For Home Deliveries which is 44.3% of total deliveries, the Skilled Birth Attendants and Unskilled Birth Attendants (Daai) are present at the delivery point so they are also vital in identification of Clubfoot if provided with proper briefing and training.

After Birth: During Post-Natal Care: ASHAs are associated with postnatal care in the rural areas. ASHAs visit the home of new born for initial six weeks for postnatal care of mother as well as the child. Also, apart from the home visits of new born babies, they also visit 3-4 homes on a daily basis as a part of awareness activities. They also motivate the masses for institutional deliveries and attending immunization and vaccination drives in the villages. Their incentives are also decided based on this and they get INRs. 600 for institutional delivery through them and ~Rs.150 for attending vaccination drives in the village.

The period of postnatal care is crucial and the baby and mother is under constant vigil of ASHA workers which becomes an important point at which Clubfoot can be identified early in childhood.

Vaccination: Village and Health and Nutrition Day (VHND) are held every month in the village for the vaccination and immunization of children of age 6 weeks to 5 years. Initially, the frequency of vaccination is more and later in years it becomes less frequent. These vaccination points are also critical as children would be visiting these places so it also becomes an important place to identify early the children born with clubfoot. But the limitation with vaccination point is that not all the children born are fully vaccinated and the full immunization of rate differs place to place depending upon the literacy rate, health facility coverage and other related indicators.

According to WHO guideline, "Complete or full immunization" coverage is defined as a child has received a BCG vaccination against tuberculosis; three doses of DPT vaccine to prevent diphtheria, pertussis and

tetanus (DPT); at least three doses of polio vaccine; and one dose of measles vaccine. The full immunization rate in Uttar Pradesh is 51.1% which means out of 100 children born, ~57 children are getting all the vaccinations mentioned above.

Pre-school (Anganwadi): Under RBSK, the Child Health Screening and Early Intervention Services envisage to cover the 30 listed health conditions in RBSK. Under RBSK, these health conditions are detected, treated and managed (follow ups) for free through the 2 dedicated mobile health teams in every block in the country. The teams screen the children enrolled in Anganwadis at least twice a year. Children who will be diagnosed with any of the 27 to 30 health conditions, clubfoot being one of them, would receive follow up referral support and treatment including surgical interventions at tertiary level free of cost. Micro plan is assigned to the health teams at the beginning of the year for the coverage of Anganwadi Centres village to village. Since Clubfoot is also one the 30 health conditions mentioned under RBSK, it becomes duty of the RBSK team to screen and refer children to the point of treatment. It becomes essential to provide them with proper support through our clubfoot clinic so that more and more patients are referred by the RBSK teams. School: Children from 6 to 18 years of age studying in Government and Government aided schools would also be receiving regular check-ups by the mobile health teams under RBSK.

Technical People to Target

Pregnancy Stage- Gynaecologists and Radiologists

Birth Stage

Public Health Facilities District Hospitals-Gynaecologists, Paediatricians and Paramedical Staff Community Health Centres- Doctors, Gynaecologists, Paramedical Staff and RBSK Mobile Health Teams Primary Health Centres- ASHAs and ANMs Private Facilities- Gynaecologists, Paediatricians and Paramedical Staff Home Delivery- Skilled Birth Attendants, Unskilled Birth Attendants, ASHAs, ANMs After Birth Stage Post-natal care- ASHAs, ANMs Vaccination-ANMs, ASHAs and Anganwadi Workers Pre-school-Anganwadi Workers and RBSK Mobile Health Team.

Gynaecologists/Obstetrician

A gynaecologist is a doctor skilled in the treatment of women's diseases especially those of reproductive organs (of women who aren't pregnant) and Obstetricians also deals with pregnant women and are also associated with prenatal check-ups and also with the deliveries. Since it is the first point where a pregnant woman reaches in case of check-up or in case of complication, it becomes an important first point of detection for any birth defect including clubfoot either during USG during pregnancy or at the time of birth.

Radiologists are the specialist doctors who are also entrusted, along with obstetrician, with prenatal check-ups of Pregnant women through USG. It is also one of the first point of detection of any birth defect including clubfoot by way of USG.

Paediatricians are specialist doctors who specializes in the care of children. So, if a child gets sick, it would be visiting a Paediatricians. It can also be seen in the preliminary findings of the Parent's survey that 12% of the children were identified by paediatricians. Since the immune system of child is not that strong in the early age, there are chances that he may suffer from minor ailments at early age and visits Paediatricians for treatment. So, it becomes necessary to equip the paediatricians with basic knowledge of Clubfoot, it's treatment, advancement in treatment, the free treatment under RBSK

Orthopaedic Surgeons An orthopaedic surgeon is a surgeon who has been educated and trained in the diagnosis and preoperative, operative and post-operative treatment of diseases and injuries of musculoskeletal system. They may be practicing solo or in multi-speciality group or in a super-speciality or multi-speciality hospitals. In big cities, there might be a possibility that one may find paediatric orthopaedic who are specialist orthopaedic surgeon dealing with diagnosis and preoperative, operative and postoperative treatment of diseases and injuries of musculoskeletal system of 29 children. They are the specialist doctors dealing with the birth defect of Clubfoot. Paediatric orthopaedic is a concept of big cities in India. And in tier 2 or tier 3 cities, simple orthopaedic surgeons are treating children also. Orthopaedic surgeons are the specialist doctors who treats clubfoot.

Paramedical Staff General Nurse and Midwife and Auxiliary Nursing Midwife are the general paramedical staff available at Hospitals. Apart from them there can be assistants of doctors and emergency medical technicians in case of Private Hospitals.

Skilled Birth Attendants A skilled birth attendant is a health professional who provides emergency as well as basic care to pregnant women and their new born babies during pregnancy, delivery and are also associated with post-natal care. A skilled birth attendant can be a GNM, ANM, Obstetrician or a Nurse.

Unskilled Birth Attendants or Traditional Birth Attendant The daai, or traditional birth attendant (TBA) is still the primary health care provider during times of pregnancy and childbirth in much of the Rural India and also in Uttar Pradesh. In the preliminary findings of the Survey, 20% of the children were born at Home under supervision 30 of a Traditional Birth Attendant. A TBA is typically an older or widowed woman and draws upon years of experience and generations of traditional knowledge for her delivery practice.

ASHA Accredited Social Health Activists are incentive-based community health workers instituted by the Indian Government's Ministry of Health and family Welfare as a part of National Rural Health Mission. An ASHA is selected from the community itself and is accountable to it. The ASHAs are trained to work as an interface between the public health system and the community. They are primarily entrusted with the

responsibility of motivating the community for institutional childbirth, facilitating other healthcare services, attending immunization camps and building awareness about healthcare entitlements. They are paid on the basis of these two things usually, ~Rs. 600 per institutional delivery through them and ~Rs. 150 for attending immunization drive with a bare minimum of Rs 1000 per month. Under RBSK operational guidelines also, ASHAs will be coordinating with the health teams for early detection and treatment of the 30 selected health conditions. There is 1 ASHA volunteer for every ~1000 of population. For a group of ~20 ASHAs, there is one ASHA Sangini whose main role is to supervise the ~20 ASHAs and conducting a monthly meeting of these ASHAs to discuss the happenings of the month and to fix agenda for the next month. Monthly meetings of ASHAs are also held at block level once a month with Health Education Officer, Medical Superintendent and MO/IC to brief them about new schemes and initiatives and also to monitor their performance.

Anganwadi Worker Anganwadi is a type of rural child care and nutrition centre in rural India. Anganwadi workers have specified responsibilities under the guidelines such as active participation in executing the program (Integrated Child Development Services Program) to combat child hunger and Malnutrition, organizing pre-school activities, providing of health and nutrition education to families esp. pregnant women etc.

Preliminary Findings of the Survey & Significant Hindrances in the Treatment

Profile of Families

The families so interviewed were classified into categories R1, R2, R3A, R3B, R4A, R4B based on the education level of the chief wage earner and type of house (kaccha, pucca and semi-pucca) that they were living in currently. The matrix used here has been developed by to segment rural customer base.

Following is the definition of Pucca, Kaccha and SemiPucca House:

Pucca House: Pucca house is the one of which predominant materials of wall and roof are as given below: a. Wall: Burnt bricks, G.I. Sheets or other metal sheets, stone, cement, concrete etc. b. Roof: Tiles, slate, corrugated iron, zinc or other metal sheets or asbestos, cement sheets, burnt bricks, lime stone RBC/RCC etc,

Kaccha House: A house with mud, thatch walls and thatch roofs, i.e., walls made of grass, leaves, reeds etc., and roof or similar materials.

Semi-Pucca: Houses which do not fall within the pucca/ kutchka category, generally such houses will have either the wall or roof of pucca material. Most families (32%) from the sample were from R2 category

followed by R1, R4A, R3A, R3B and R4B. Telephonic Interviews were also conducted to set off balance between Rural and Urban population and to include diverse set of families in the survey.

Table 1 : Economic Profile of Families (Respondents)

Education of Chief Wage Earner (CWE)	Type of House (Residence)		
	Pakka	Semi-Pakka	Kachha
Illiterate	R4A	R4A	R4B
Below SSC (Std. X)	R3A	R4B	R4A
SSC/HSC	R2	R3A	R3B
Attended College (But not Graduated)	R1	R2	R3B
Graduate / Post-Graduate (General)	R1	R2	R3A
Graduate / Post-Graduate (Professional)	R1	R2	R3A

There were 42% respondents living in urban areas and 58% in Rural area. R1 18% R2 30% R3A 16% R3B 12% R4A 16% R4B 8% Socio Economic Classification of Families

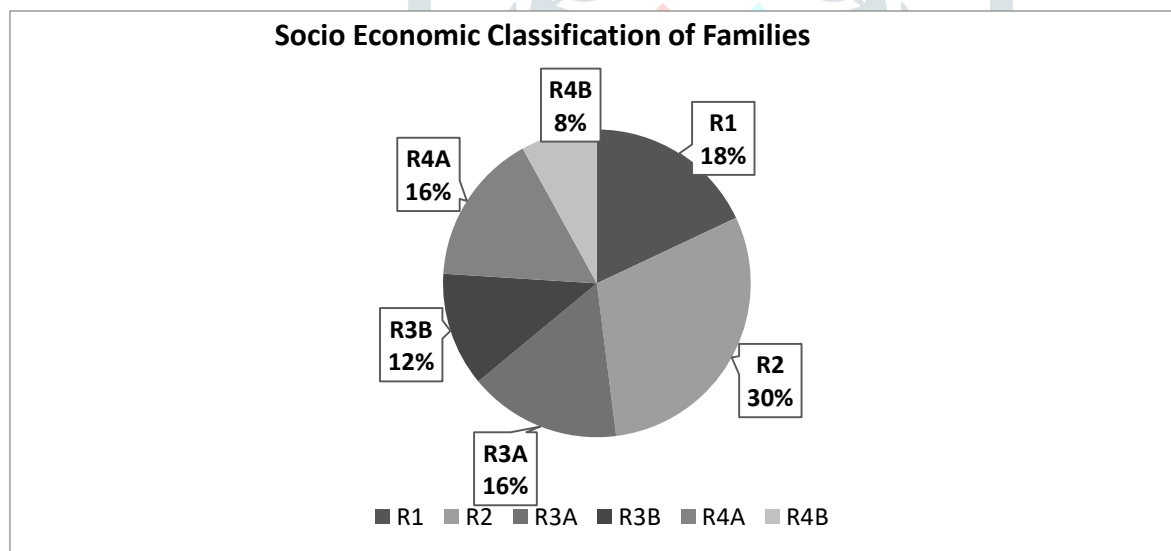


Figure 1: Socio-Economic Classification of Families

Figure shows Socio Economic Classification of Families, Basis of Socio-Economic Classification (Source-MRSI, The New SEC System 2011 34 16.2. Profile of Families)

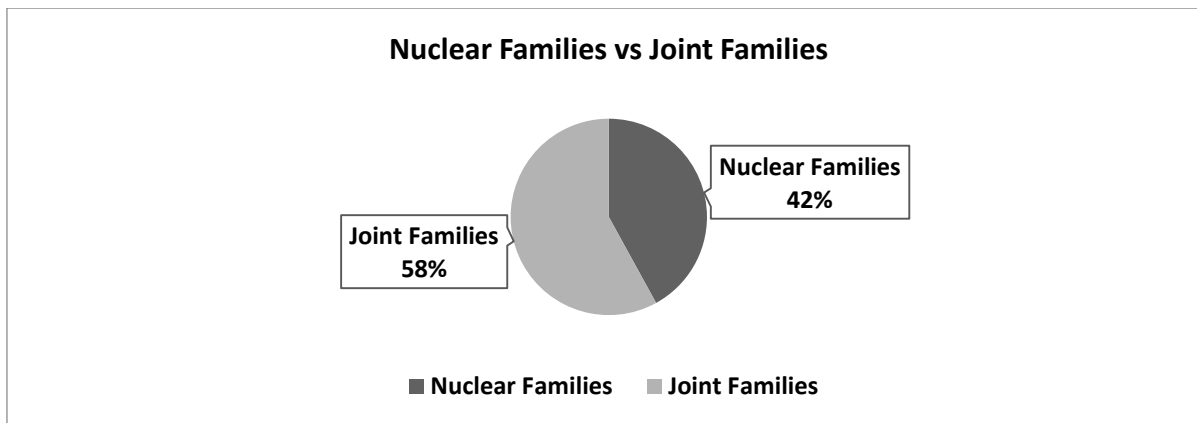


Figure 2: Type of Family

There were 58% joint families and 42% nuclear families which is a good representative of the general population as most of the families in Uttar Pradesh are joint in nature and the family lives together. Families living in the same house and having different kitchen have also been considered joint families by the respondents and also in the survey questionnaire. Having joint families significantly lessen the burden of care of children in case of emergency and also financial help is also available through inside the family which further reduces the risk of borrowing the money for healthcare from outside.

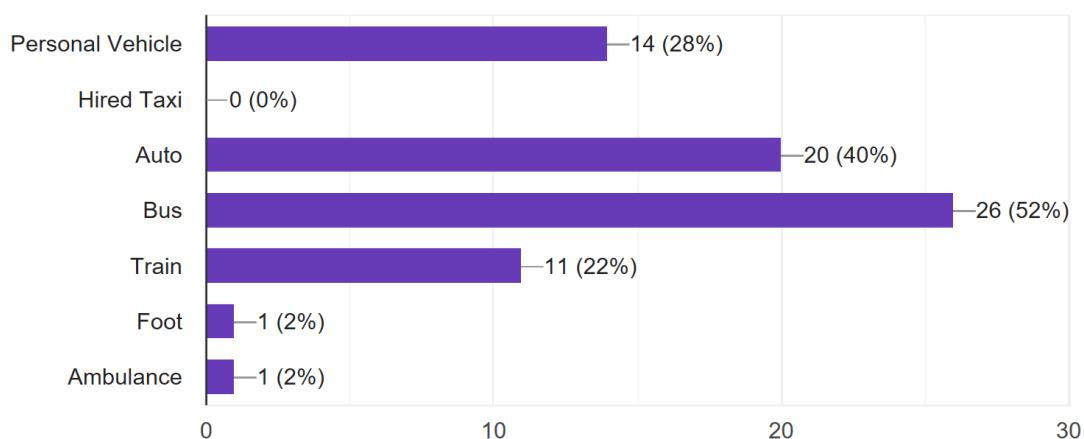


Figure 3: Type of Transportation to commute for treatment

Most of the patients used bus service to come to the clinic, around 52% used it. 40% of the patients used Autos. 28% used personal vehicles and cited that it saved them time. 22% of them used train, one patient used the 108-ambulance service to come to the clinic. In the recent orders of the government, it would now be possible for patients to travel between districts through ambulances for cases listed under RBSK. The questions had multiple responses so the total of percentages might not add up to 100%

Profile of Families-Sources of Income

Most respondents were salaried employees or daily wage labourers (76% of total respondents) and this was one of the main reasons of dropouts and missing appointments in the clinic as 58% of the total population was rural in the sample and also the patients were coming from far off places, it was seen that wages of 1-2 days were lost per week during the active phase of treatment.

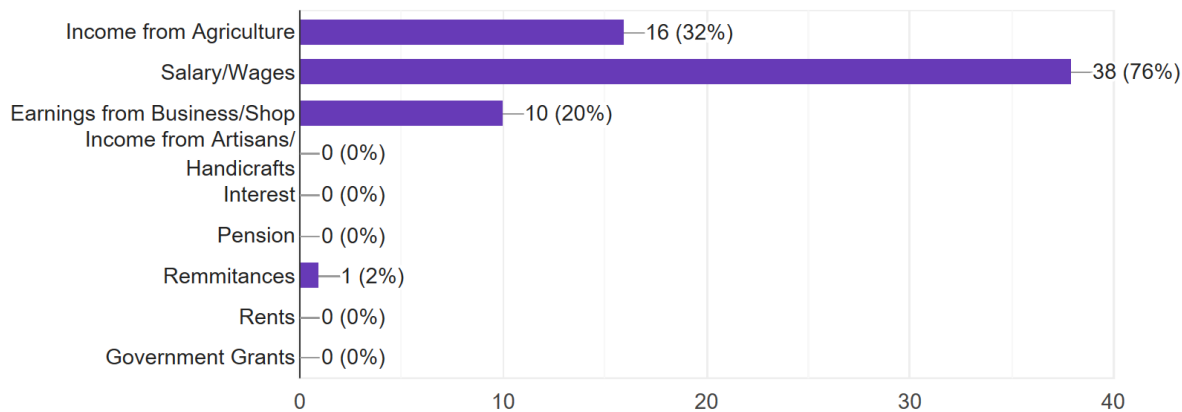


Figure 4: Economic & Earning Profile of Families

The below figure shows profile of Families Borrowings for healthcare in last one year. Since most of the families were joint families and treatment of clubfoot is free under RBSK, not many of the patients borrowed money from outside. Small sum of money borrowed internally from family members are not considered as borrowings and this is the reason most of the respondents did not take loan in last one year for healthcare.

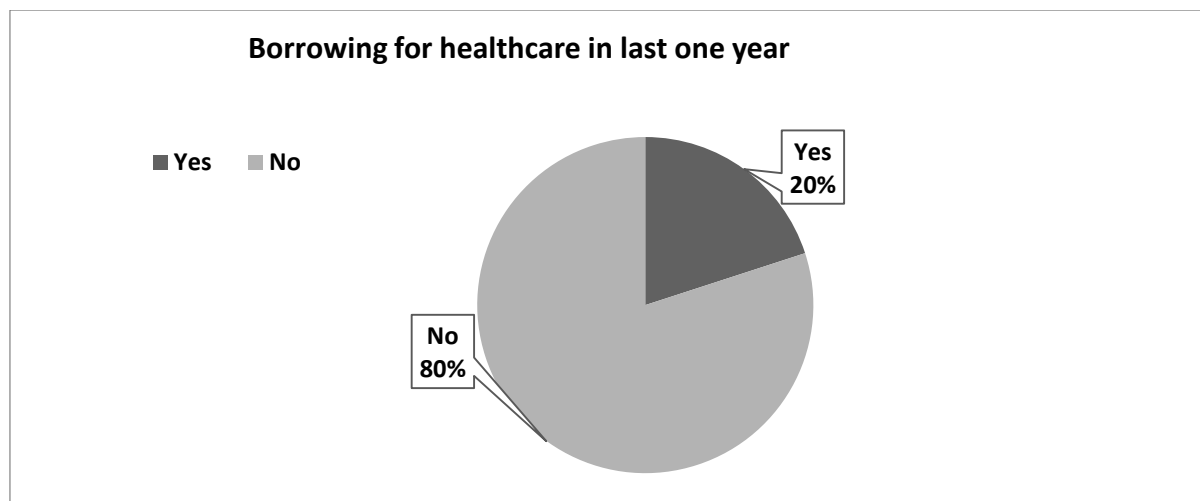


Figure 5: Borrowing for healthcare in last one year

Awareness about both the birth defect Clubfoot and the Government Scheme- Rashtriya Bal Swasthya Karyakram (RBSK) is minimal among the parents of the clubfoot affected children. There were many patients found during the survey who initially thought the deformity to be Polio and thought its untreatable. Also, it was general perception of the people that treatment of Clubfoot is very expensive as most of them first enquired it from a private orthopaedic clinic. Unawareness about the free treatment of Clubfoot under RBSK was major setback that the footfall of the Clinics Knew about RBSK 20% Did not know about RBSK 80% Awareness about RBSK Yes 20% No 80% Borrowing for healthcare in last one year

Awareness about Clubfoot is not as much as expected. Once the information regarding free treatment under the aegis of government is disseminated to the masses of Uttar Pradesh, the clinics will have their footfalls increased.

Family History of Clubfoot

As genetics is one of the causes of clubfoot as indicated by various researches, a question to enquire the same was also included in the questionnaire and only 8% of the total parents surveyed had someone in their family who also had/has clubfoot. One of the children was adopted and not biological. 2 of the 50 children had someone in their immediate family who had clubfoot and 2 had someone in their extended family. No One 90% Adopted Child 2% Extended Family 4% Brother 2% Mother 2% Family History of Clubfoot

Awareness about RBSK Never heard about Clubfoot before 84% Heard about Clubfoot 16% Awareness about Clubfoot Figure 20 Awareness about Clubfoot

Delayed Treatment

Most of the parents (around 76% of all respondents) started the treatment of their children in the initial 3 months only followed by 3 to 6 months (10%), 6 to 9 months (10%) and 12+ months (4%). The first point of treatment is either the nearest health facility, government or private, or a private orthopaedic surgeon where the cost of treatment is much higher than a public health facility.

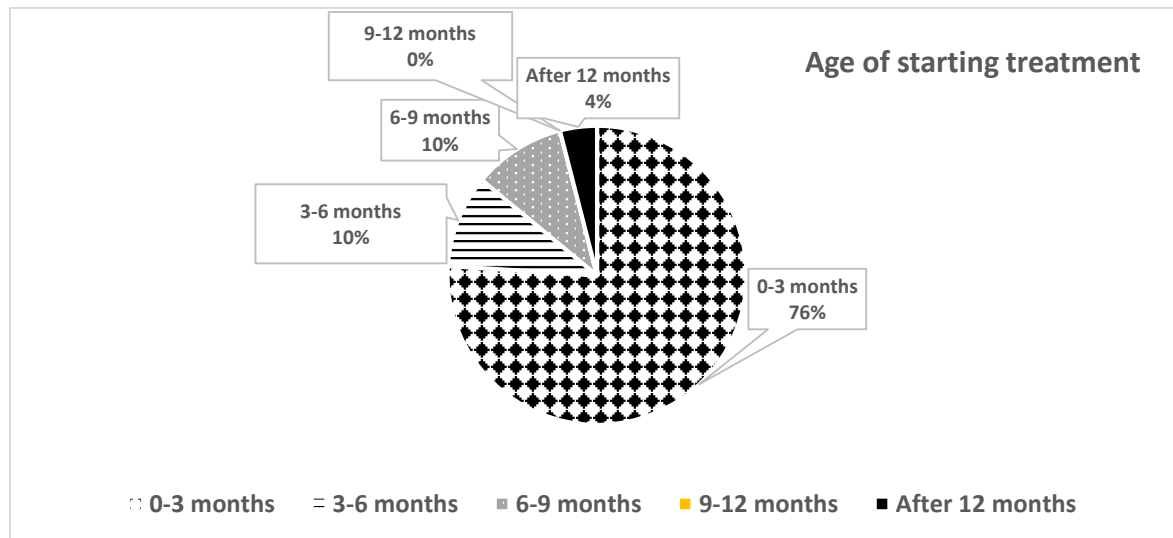


Figure 6: Age of Starting the Clubfoot Treatment

Access to healthcare

Yes 90% No 10% Patients Comfortable contacting clinic with doubts Yes 90% and No 10%. Sufficient information to look after the cast Government Hospital 20% Private Hospital 20% Trust Run Hospital CHC 2% 20% PHC 38% Nearest Health Facility Less than 10 kms 82% 10-20 kms 14% 20-30 kms 2% More than 40 kms 2% Distance of Nearest Health Facility.

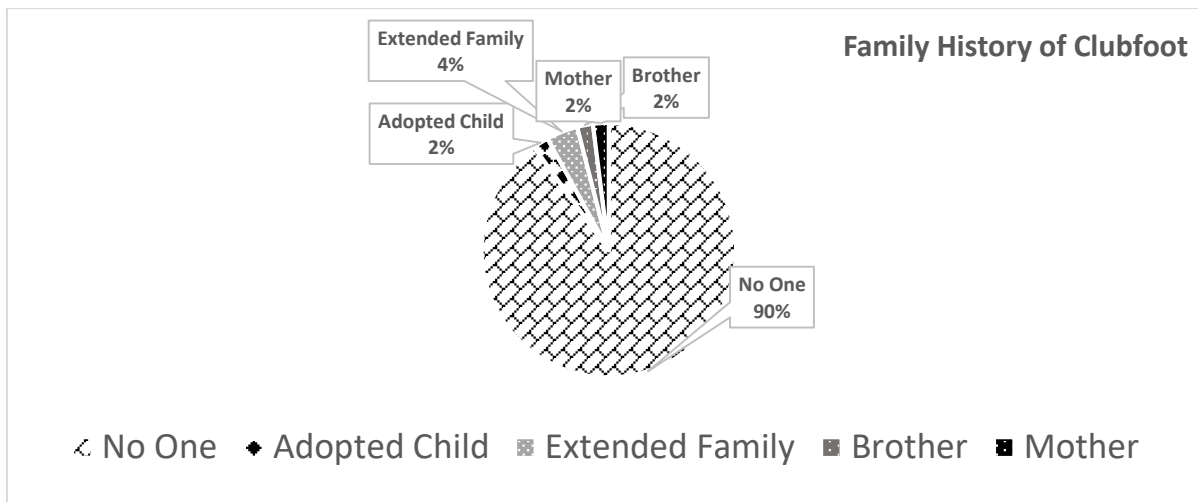


Figure 7: Family History of Clubfoot (Disease)

Most of the children (84% of all respondents) reached Clubfoot Clinic in the initial stage of casting only. Casting in Clubfoot Clinic is free, it works as an incentive for the parents to get enrolled in treatment as early as possible.

Distance of Nearest Health Facility

Since PHC is the most basic unit of healthcare in the 3-tier healthcare system, most of the patients (38% of all respondents) had it nearest to their homes followed by equal proportion (20%) of CHC, Government Hospital (DH) and Private Hospital. One patient also had trust run hospital in the near to his respective residence.

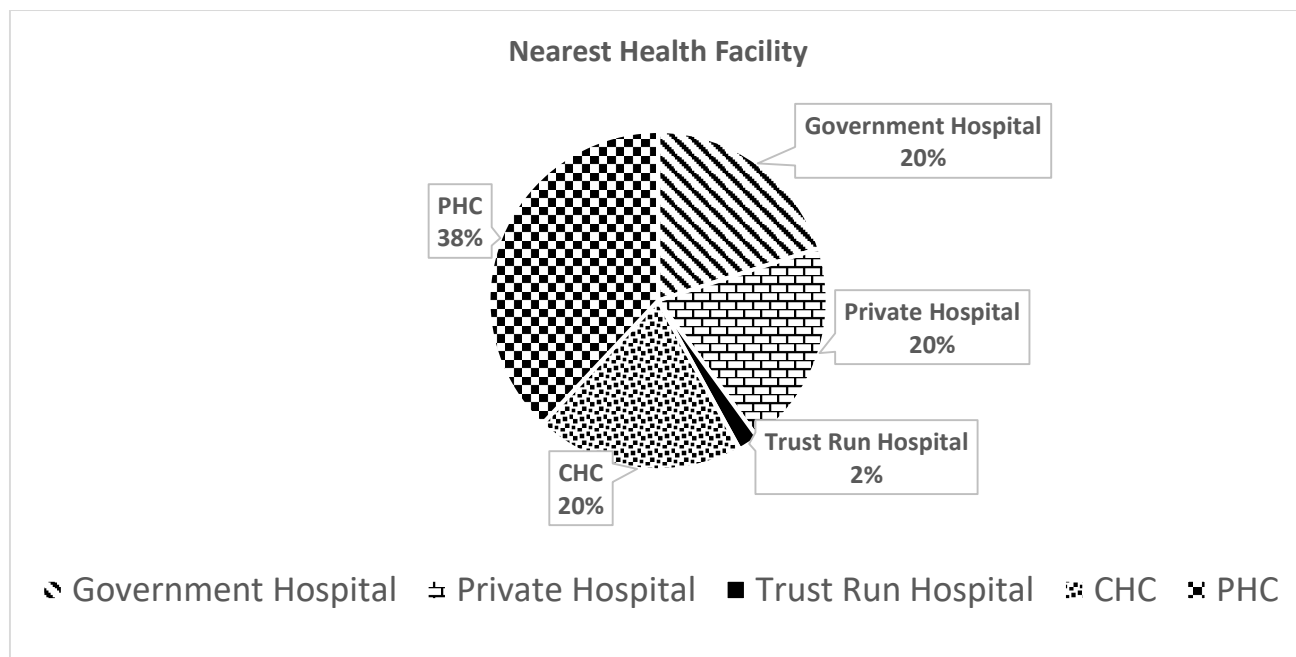


Figure 8: Nearest Health-Care Facility

Currently majority (52% of all respondents) of the patients travelled more than 40 kms to reach the clinic, this also included some patients travelling 250+ kilo meters every week to get the casting done. Near to one-fourth of the patients had the clubfoot clinics less than 10 kms from their home, for 10-20 kms, 20-30 kms and 30-40 kms bracket there were 16%, 8% and 2% respondents respectively. Similarly, time taken to reach the clubfoot clinic, it took more than 3 hours to 18% of the patients to reaching the clinic. It also Less than 1 hour 35% 1-2 hours 25% 2-3 hours 22% More than 3 hours 18%

Time taken to reach Clubfoot Clinic

Distance of Clubfoot Clinic - Time taken to reach Clubfoot Clinic Less than 10 kms 22% 10-20 kms 16% 20-30 kms 8% 30-40 kms 2% More than 40 kms 52%

Distance of Clubfoot Clinic 40 includes patients travelling 7 hours from places as far as Pratapgarh and Allahabad. 35% of the patients travelled one hour or less, 25% travelled between 1 to 2 hours and 22% travelled 2 to 3 hours to reach the clubfoot clinic. With the launch of new clinics, the travel time will also be reduced and positive impact can be expected on the dropout rates.

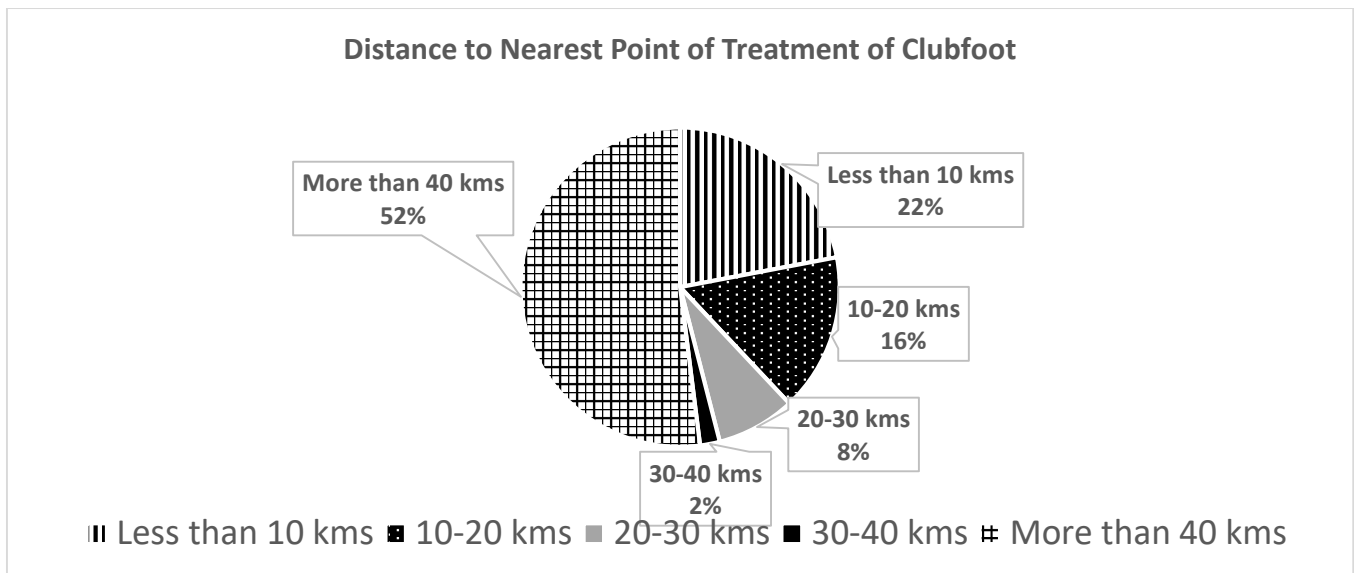


Figure 9: Distance to nearest Point of Treatment of Clubfoot (Disease)

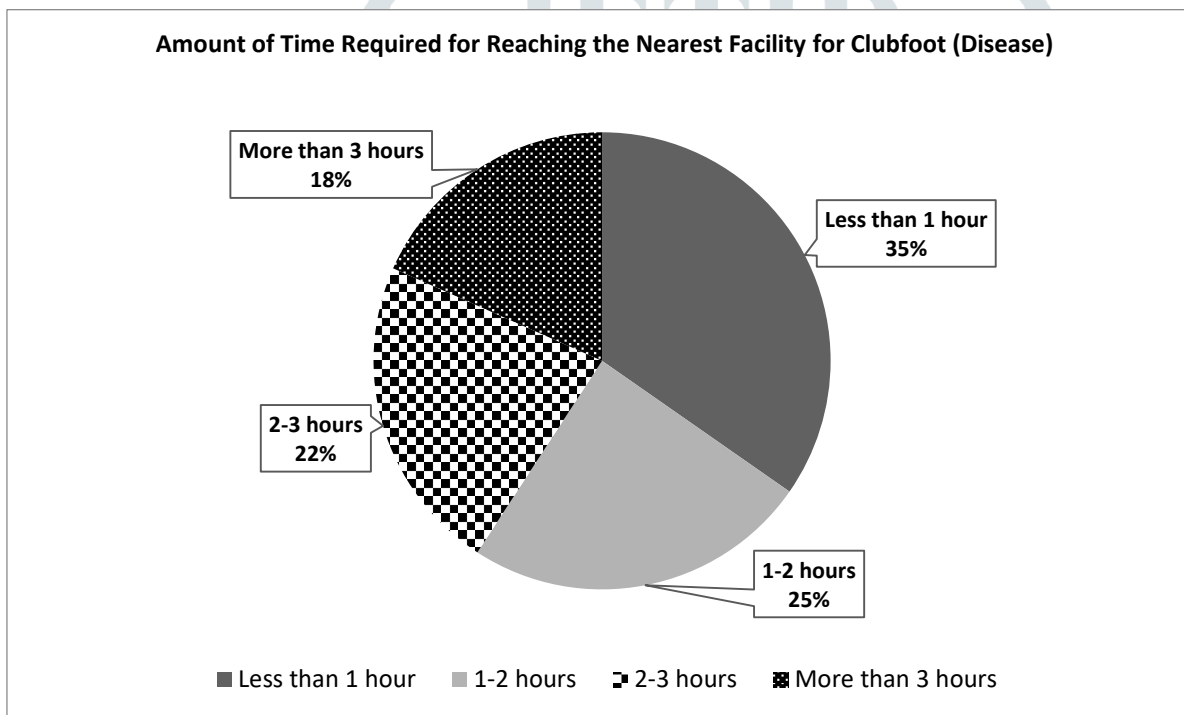


Figure 10: Amount of Time Required for Reaching the Nearest Facility for Clubfoot (Disease) Treatment

Distance of the facility had been cited by two-third of the patients as the major hindrance in the treatment process.

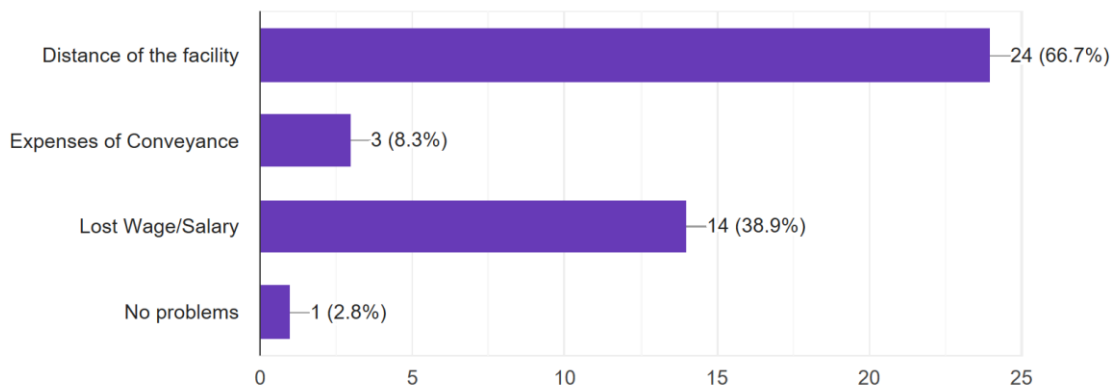


Figure 11: Major Hindrance in the Treatment of the Clubfoot (Disease)

Lost wages and salary came second to it and for 38.9% this was the major hindrance in the treatment.

Three people cited as expense of the conveyance a significant hindrance. To compensate for the lost wages and expense of the conveyance, transport subsidy can be given to motivate patients for continuous treatment and follow up after the active phase.

Parents’ anxiety due to Clubfoot in their Child

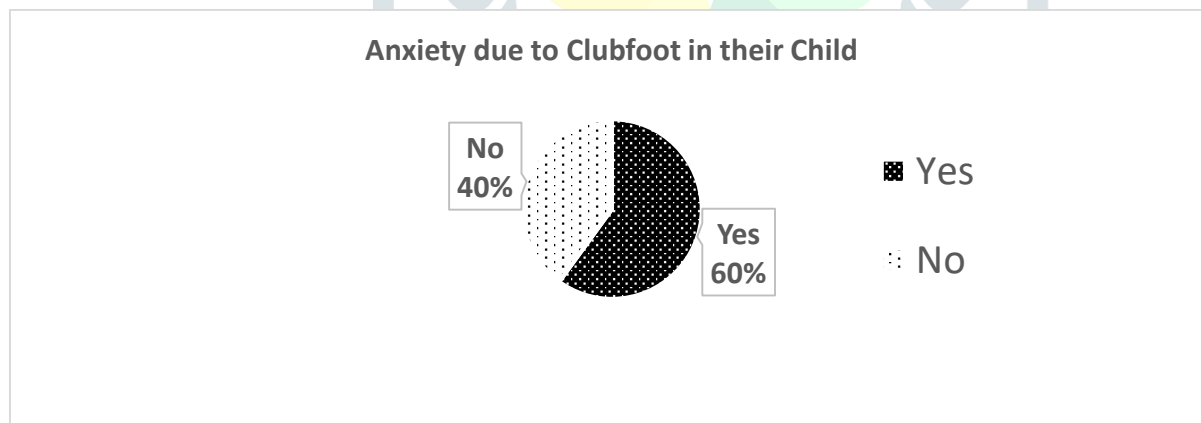


Figure 12: Anxiety due to Clubfoot in their Child

Most of the patients before coming to the clinic were anxious and doubtful about the treatment and its success but now since parents meet other parents of clubfoot patients whose treatment have been successful, they feel less anxious and hopeful regarding the treatment. Seeing successful treatment of other patients without surgical intervention, people are motivated to complete the treatment process diligently. 40% of the total surveyed parents said they fell no more anxious about the clubfoot and are very hopeful about the

treatment process. 60% of the patients were minimally and moderately anxious regarding the treatment patients, most of the patients who were anxious includes most of the parents of newly enrolled children.

Communication- Asset Profile

60% of the parents of the children possess Smartphone with internet connection, 40% of them have feature phone. 77% of them have television- 31.8% with cable connection and 47.7% without cable connection. 36.4% of the parents have subscribed to a newspaper. As per the results of the survey, one way of communication could be through phones and voice advisory phone calls, SMSs can be one medium of reaching out to the general population and health activists.

Recommendations

The awareness and outreach strategy would be leveraging the healthcare machinery of the state, at all levels as GOI has also come up with RBSK programme in which treatment of Clubfoot is free for children in the age of 0 to 18 years. The awareness strategy so designed is effective, achievable and replicable (with some revisions depending upon place it is going to be used). In order to make the strategy effective, the main people, authorities and groups to target are to be identified beforehand. Since the data of institutional delivery, pregnant women undergoing USG, , full immunization rate, enrolment ratio, absenteeism in school is very skewed district to district depending upon literacy, urbanisation, healthcare facility coverage and other related factors, the plan is charted out based on the primary data collected through the survey and the secondary data referred through the government sources such as Annual Health Survey, National Family Health Survey, Census data of village and town amenities, independent reports on education in the state etc. As per the data so collected and studied, different priorities were defined so as to cover the villages and towns of the state of Uttar Pradesh and also to estimate the workforce required in terms of program executives and branch managers. Uttar Pradesh consists of 75 districts 49 divided among 18 divisions. First, the clubfoot clinics will be opened at the Divisional Headquarters and then in the nearby districts. The plan is to be rolled out in phases and the priorities for selecting the towns and villages is devised in such a manner that it covers maximum population by targeting minimum number of villages initially so the results can be seen instantaneously

Internet and Applications

Only 38% of the parents surfed the internet often and applications used by them include WhatsApp (44%) and Facebook (28%) majorly. Patients using mobile applications such as WhatsApp and Facebook can be selectively targeted by way of advertisement reaching out to the target population only. Mobile penetration in the rural areas is not as much as urban areas and also much of the rural population of Uttar Pradesh can't read and write, this can be some of the reasons advertising through these mediums might not give results as much as expected but surely it would be of big help in the urban areas.

Reading Newspaper Daily Only 32% of the parents read newspaper daily and 68% did not. The data will be even more skewed in case of Rural Uttar Pradesh as much of the population is illiterate. Advertising through Newspapers are useful but costs a lot, it might be useful once all the clinics are open throughout Uttar Pradesh. Yes 38% No 62% Surfing internet often Yes 32% No 68% Reading newspaper daily Figure 38 Internet use by Parents Figure 39 Newspaper reading

Newspaper and Cable TV 20% of the total parents had Local Cable TV provider and 12% had satellite TV connections. Video advertisements or educational videos can be broadcasted on local televisions to reach to a greater number of people. 32% of the parents did not have cable connection and 36% did not even have television. Here the cost of advertisement would be significant as the cable TV charges as per slot basis (how many times an advertisement is aired) and also lump sum package are also available for broadcasting advertisement on local cable.

Suggested activities (Rural and Urban) for identification & treatment of clubfoot in marginal population of Uttar Pradesh

Rural

1. Educating ASHAs, school teachers and Anganwadi workers about Clubfoot. The point that most of the people don't know about the free treatment of Clubfoot holds them back to get treatment for it. There is a misconception among people that it costs a lot for the treatment of Clubfoot which is actually true with respect to Private Points of Treatment but not in case of Government Health Facilities. Once they know about RBSK and MF, there is more probability that they reach for treatment in early stages.
2. Attending ASHA meetings with ASHA Sangini(supervisor) at Village Level which is held every month. Program Executive can coordinate with ASHAs and their supervisors to fix a suitable time for meeting and can simultaneously conduct some sort of awareness activities.
3. Pamphlets containing information about Clubfoot in simple Hindi for distribution inside villages through ASHAs during and after meetings.
4. Sensitization activities to be taken up by Program Executives collaborating their efforts with ASHAs and RBSK. PEs can also visit villages along with RBSK teams.

Urban

1. For early identification of Clubfoot or any other birth defect, Pregnant women can avail free Ultra sound services at CHCs and District Hospitals. (Currently available at Kanshiram Hospital, Bilhaur CHC and Ghatampur CHC). → Single Point Change to motivate them for Ultrasound during pregnancy.

2. Health Executives should be trained properly for briefing Medical Officers, Specialist Doctors, ASHAs and Paramedical Staff about Clubfoot.
3. Health executives should conduct awareness activities on 9th of every month, at CHCs and DHs, when there is mass screening and management of women with High Risk Pregnancies (PM Surakshit Matritva Abhiyan).
4. For increasing footfall in clinic a. Prosthetist and Orthotist can be contacted for dropped out patients and seeking referrals from the P&O centre in case the patient can't afford the cost of braces.
b. Awareness activities should be carried out in the private Orthopaedic, Gynaecology and Paediatric clinics for referrals in case the patients cannot afford treatment at private points of treatment.
c. Awareness campaigns in CHCs/PHCs/DHs so that the staff of the hospitals and general public know about MiracleFeet initiative.
5. Continuous Medical Education (CME) conferences can be targeted to reach out to specialists such as Orthopaedicians, Gynaecologists and Paediatricians.

Items to be Developed

- IEC Materials- IEC Material for ASHAs and general public should be developed keeping in mind the average educational levels of them. The material should comprise of Pictures and instructions in simple Hindi for identification of clubfoot and its treatment.
- Materials for Medical Practitioners should also be developed so that it can be given to them in case they want to know more about the initiative further. Details about clubfoot, recent advancement in its treatment,
- Videos and Images- Videos and Images in Hindi can be developed to be shown on Screens in Government Hospitals and as filler during Meetings of Medical Officers. It can be shown on the televisions in the wards and other common areas of the hospital.
- Posters, Pamphlets, Leaflets in simple Hindi should be developed to be distributed among the people attending awareness drives in villages and towns. It can also be used to distribute among the ASHAs, Anganwadi workers etc. Posters should be pasted at visible points in the hospital especially near the Labour Room, Paediatric Wing, New born care unit, Gynaecology Wing, Registration Desk and other important places in the hospital building and outside.

Audio Advisory and Inbound Calling Service Audio advisory service is a medium of information dissemination especially in the rural areas. The literacy rate in the rural areas of Uttar Pradesh is low which makes it a suitable medium for disseminating information to the rural masses. It delivers the message to the target audience via phone calls through 40-60 seconds pre-recorded audio messages. The message will be 55

having an easy to remember toll free phone number (1800-xxx-xxx) in case there are any queries from the receivers' end. These phone calls can be targeted to the personal phone numbers of the program executives so this service won't need any extra manpower to handle the phone calls.

Critical data points such as duration of the call, point at which phone was disconnected, number of successful calls, calls not picked up. This may help us knowing what kind of messages is being accepted more at the receivers' end. So, at the back end, we can also analyse the information seeking behaviour of the people over the time.

There is a total of ~2,20,000 ASHAs in the state of Uttar Pradesh, so if 10 lines are allocated to the given load of phone numbers and calls are being made for 12 hours a day, ideally from morning 9 AM to night 9 PM, then all the ASHAs can be covered in 3.5 months. After covering ASHAs, school teachers, AWW and general population can also be targeted.

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Questionnaire for Parents

1. RESPONDENT ID- _____

INTRODUCTORY QUES

2. Name of the Child- _____

3. Sex of the Child

- a. Male
- b. Female
- c. Other

4. Name of Father- _____

5. Name of Mother- _____

6. Name of Other Primary Caregiver- _____

7. Date of Birth of Child (DD/MM/YYYY)- ____/____/____

8. Address

- a. Line 1 _____
- b. Line 2 _____
- c. Village (if Rural)/Ward (if Urban) _____
- d. Block _____
- e. District _____
- f. State _____

9. Mobile No.- _____ (_____)
_____ (_____)
_____ (_____)

CLASSIFICATION

10. Nearest Health Facility

- a. Sub Centre
- b. PHC
- c. CHC
- d. Government Hospital
- e. Private Hospital

f. Trust-run Hospital

11. How far is the Health facility from your home?

- Less than 10 kms
- 10-20 kms
- 20-30 kms
- 30-40 kms
- More than 40 kms

12. Family Type

- Nuclear
- Joint

(Prompt- Nuclear: living with just wife and children, Joint: living with parents, brother-sisters, wife, children and other family members)

13. Number of Family Members_____

14. Socio-Economic Classification of the household. Please circle the appropriate cell in the grid.

Education of Chief Wage Earner (CWE)	Type of House		
	Pucca	Semi-Pucca	Kaccha
Illiterate	R4A	R4A	R4B
Below SSC (School upto 9 standard)	R3A	R3B	R4A
SSC/HSC	R2	R3A	R3B
Some College, but not Graduate	R1	R2	R3B
Graduate/Post Graduate (General)	R1	R2	R3A
Graduate/Post Graduate (Professional)	R1	R2	R3A

(Pucca House: Pucca house is the one of which predominant materials of wall and roof are as given below:

- Wall: Burnt bricks, G.I. Sheets or other metal sheets, stone, cement, concrete etc.
- Roof: Tiles, slate, corrugated iron, zinc or other metal sheets or asbestos, cement sheets, burnt bricks, lime stone RBC/RCC etc,

Kaccha House: A house with mud, thatch walls and thatch roofs, i.e., walls made of grass, leaves, reeds etc., and roof or similar materials.

Semi-Pucca: Houses which do not fall within the pucca/ kutch category, generally such houses will have either the wall or roof of pucca material.)

15. What would be your approximate family income?

- Per month_____

b. Per Year _____

16. What are the different sources of income of your family? Please circle the appropriate box. (Multiple response possible)

	Y	N
Income from agriculture	1	2
Salary/Wages	1	2
Earnings from Business/Shop	1	2
Income from Artisans/Handicrafts	1	2
Interest	1	2
Pensions	1	2
Remittances	1	2
Rents	1	2
Government grants	1	2
Any Other (Please specify) _____	1	2

17. Have your family borrowed money for health care during last one year?

- a. Yes
- b. No

ABOUT THE CHILD

18. Where was the Child born?

- a. Private Hospital/Nursing Home
- b. Government Hospital/CHC
- c. Trust-run Hospitals
- d. Home

19. Did you ever hear about clubfoot before it occurred to the child?

- a. Yes
- b. No

20. When was the clubfoot first identified in the Child?

- a. During pregnancy
- b. At the time of birth
- c. 0-3 months
- d. 3-6 months
- e. 6-9 months
- f. 9-12 months
- g. After 12 months _____

21. Who identified it?

- a. Father/Mother of the child
- b. Doctors/Staff at the point of delivery
- c. Paediatrician
- d. ASHA/Anganwadi
- e. Family member
- f. Someone from community/Friend
- g. Other, please specify _____

22. Is there anyone in the family who had the same birth defect? If yes, who?

- a. Grand Parents
- b. Father
- c. Mother
- d. Brother
- e. Sister
- f. Extended Family

TREATMENT**23. Has the child already started treatment?**

- a. Yes (Continue to Q.24)
- b. No (Proceed to Q.38)

24. At what age of the child did the treatment started?

- a. 0-3 months
- b. 3-6 months
- c. 6-9 months
- d. 9-12 months
- e. After 12 months _____

25. Was the first point of treatment of Clubfoot different from this (MiracleFeet Clubfoot Clinic)?

- a. Yes (Continue to Q.26)
- b. No (Proceed to Q.29)

26. What was the first point of treatment of Clubfoot?

- a. Quacks/ *Bengali Doctor*/
- b. Pehlwan/ Massager
- c. Private Hospital
- d. Government Hospital
- e. Trust-run Hospital
- f. Other, please specify _____

27. What was the reason of discontinuing first point of Treatment?

- a. High cost of treatment
- b. High cost of transportation
- c. Unsatisfactory Treatment
- d. Advice from family/community
- e. Other, please specify _____

28. Who referred to the first point of treatment?

(only ask if the first point of treatment is different from **MiracleFeet Clubfoot Clinic**)

- a. Parents
- b. Doctors/Staff at the Point of Delivery
- c. Paediatrician
- d. Family Member
- e. Someone from community/ Friend
- f. Other, please specify

29. Who referred to this Clinic (**MiracleFeet**)?

- a. Parents
- b. Doctors, Nurses or Hospital staff at the Point of Delivery
- c. Paediatrician
- d. ASHA/Anganwadi
- e. Family Member
- f. Someone from community/ friend
- g. Posters/radio announcements
- h. Other, please specify

30. How much did you spend on treatment before coming to this clinic (**MiracleFeet**)?

- a. Less than 1000
- b. 1000-5000
- c. 5000-10000
- d. 10000-15000
- e. More than 15000

31. At which stage of Clubfoot did you come to this clinic (**MiracleFeet**)?

- a. Casting _____ # _____
- b. Tenotomy
- c. Bracing

32. How far is **MiracleFeet Clubfoot Clinic** from your Home?

- a. Less than 10 kms
- b. 10-20 kms
- c. 20-30 kms
- d. 30-40 kms
- e. More than 40 kms

33. What mode of Transportation do you use to come to the Clinic? (Multiple Response Possible)

- a. Personal Vehicle
- b. Hired Taxi
- c. Auto
- d. Bus
- e. Train
- f. Foot
- g. Other, please specify

34. How much time does it take you to come to this clinic (**MiracleFeet**) from your home?

- a. Less than 1 hour
- b. 1-2 hours
- c. 2-3 hours
- d. More than 3 hours

35. Do you feel comfortable to contact the clinic with questions?

- a. Yes
- b. No

36. Did you have sufficient information to be able to look after the cast?

- a. Yes
- b. No

37. What are the most significant hinderance in the treatment of the Child?

- a. Distance of the facility
- b. Expenses of Conveyance
- c. Lost Wage/Salary
- d. Other, please specify_____

COMMUNITY

38. Are you aware of any child in your village/town who is presently having clubfoot?

- a. Yes (Continue to Q.39)
- b. No (Proceed to Q.43)
- c. I don't know (Proceed to Q.43)

39. If yes, how many such people are there in your village? _____

40. Are they receiving any medical treatment?

- a. Yes
- b. No
- c. I don't know

41. Are their families satisfied with the services?

- a. Yes
- b. No
- c. I don't know

42. Do the persons/their families get any counselling? If yes, then at what interval?

- a. I don't know
- b. No
- c. More than once a week
- d. Once in two weeks
- e. Once in a month
- f. Once in 2 months
- g. Once in more than 2 months

PARENTS

43. Does Clubfoot in your child makes you anxious or depressed at times?

- a. Yes
- b. No

44. Do you think Society looks down upon people with Clubfoot?

- a. Yes
- b. No

45. Have you delayed treatment/missed appointments because of superstitious reasons?

- a. Yes
- b. No

46. Have family or community members encouraged you to seek medical treatment for your child?

- a. Yes
- b. No

47. Were you advised by anyone to delay treatment/not to take treatment for your Child's Clubfoot?

- a. Yes, then reason? _____
- b. No

48. Have you adhered to any other kind of treatment other than/instead of medical?

- a. Yes, then what? _____
- b. No

COMMUNICATION

49. Are you aware that Government is providing free treatment to Children (aged 0-18 years) for 31 selected health conditions including clubfoot?

- a. Yes
- b. No

50. Which of the following things have you known (related to Clubfoot)?

- a. *Nukkad Natak*- Attended _____ Seen _____ Heard about _____
- b. Special Campaign-Attended _____ Seen _____ Heard about _____
- c. Posters- Seen _____ Heard about _____
- d. Any other Advertisement, please specify _____
Seen _____ Heard About _____

51. Do you have the following in your house? Please circle the appropriate box. (Multiple Response Possible)

- a. TV with Cable/Satellite

1

- b. TV without Cable/Satellite

2

- c. Radio

3

- d. Feature Phone

4

- e. Smartphone with Internet

5

- f. Newspaper Subscription

6

- g. Landline

7

- h. Electricity Connection

8

52. How many times in a month do you visit the following places?

1. Post Office	
2. MFI/Banks	
3. ATMs	
4. Gram Panchayat	
5. Ration Shops/FPS	
6. Fairs	
7. School	
8. College	

9. Bus Stand	
10. Railway Station	

53. Do you use Social Media? If yes, which all sites and applications?

- a. WhatsApp
- b. Facebook
- c. Snapchat
- d. Instagram
- e. Others, please specify _____

54. Do you surf the internet often?

- a. Yes
- b. No

55. Do you read newspaper daily?

- a. Yes
- b. No

56. Which Newspaper have you subscribed to?

- a. I don't have a newspaper subscription
- b. National Newspaper _____
- c. Local Newspaper _____

57. Which DTH have you installed in your TV?

- a. Tata Sky/Dish TV/VideoconD2H etc
- b. Local Cable TV Provider
- c. I don't have a cable connection
- d. I don't have a TV

58. What radio channels do you usually listen to?

- a. _____
- b. _____
- c. _____
- d. _____

Any improvements, changes that you would suggest in the processes of MiracleFeet Clubfoot Clinic

Signature of the Respondent

ANY SPECIFIC OBSERVATION

