

Exploring What Happens to Children Identified with AFP under the Pulse Polio Programme in Uttar Pradesh, India

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INTRODUCTION

Poliomyelitis, or polio, is a paralytic disease of virus aetiology in children transmitted faecal-orally. It causes Acute Flaccid Paralysis (AFP) in less than 1 percent, but once this occurs, can lead to lifelong paralysis, or residual paralysis. Prevention by vaccines is essential because there is no curative treatment. Those infected, irrespective of severity, shed the virus in their stools for weeks, potentially infecting others.

In 1988, the Global Polio Eradication Initiative was launched to eradicate polio from the world, and much effort was put in. Now, there are only four countries endemic in polio: India, Nigeria, Pakistan, and Afghanistan. Among the four, India is in the worst situation, in spite of its intensive Pulse Polio Programme. Under this programme, polio vaccines are given to children under 5 years almost every month, house-to-house, and children with polio are detected through its surveillance system. There were 559 polio cases, and over 45,000 non-polio AFP cases reported in 2008.¹ Another issue has been currently brought up regarding

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newly reported polio cases. It is estimated around 85 per cent of children who are affected have received more than three doses of polio vaccines earlier, and among these children, one-third had received ten doses or more, but still are affected by polio.^{2,3}

Regardless of this high number of children with polio and AFP, little is known about what kind of healthcare they are receiving; if they are getting any treatments, care, and support after identification. Even though there is no definite treatment for polio, several measures can be taken to ease their symptoms including supportive and symptomatic medicines, physiotherapy and mobility aids. Likewise, there are treatments and care for other diseases that cause AFP. Despite rigorous search, there was no literature exploring what were the experiences of children after they were diagnosed with polio or AFP, and what were the perceptions of their families. One research by Kishore⁴ interviewed 10 families of children with polio in Uttar Pradesh, but the study's focus was on determining the reasons for occurrence of the disease. Yet, the study has found that none of the parents were aware of the importance of physiotherapy and were feeling burdened by the expenses of their treatment. All cases belonged to the poor socio-economic group with only one case with literate parents. Some researches were found exploring perceptions of older patients with childhood-onset polio in industrialized countries, and they all described how quality of life decreased for these patients.^{5,6}

To examine the above question, children identified with AFP and/or with residual paralysis are explored in this study with respect to their difficulties, health needs, and healthcare services provided. Healthcare providers and key informants from the community were approached to explore around the same issues. The results were used to devise strategic options for improvement of the programme and to enhance quality of life of these children.

METHODOLOGY

The study was conducted from April to June 2008 in Uttar Pradesh (UP), India. Seven villages (three urban and four rural) in Muzaffarnagar, a high-risk district for polio in UP, were visited to represent the diversity of the district. Focus group discussions (FGDs) with mothers and key informant interviews with healthcare providers were conducted in each village. We also interviewed families of children with residual paralysis found in the same villages. We searched children diagnosed with polio from April 2005 to March 2008 from the AFP Surveillance list provided to us by the courtesy of the district government and undertook interviews with parents of these children. Interviews with policy influentials and individuals from civil society were conducted at national and district levels.

Study Design

This was a qualitative study using FGDs and in-depth interviews. Interview guides were semi-structured, open-ended, and probing. Questions for the FGDs focused on participants' experiences and perceptions around the status of health-care provision of the area. The same were explored among the parents of children with AFP and/or residual paralysis together with their experiences due to their children's disease, their needs, and suggestions for improvement. Questions for the key informant interviews focused on the interviewee's knowledge, beliefs, and concerns in looking after children with AFP and/or residual paralysis, and further explored issues around service delivery.

Interview guides and consent forms were piloted to check for their validity and language appropriateness. Researchers trained and experienced in qualitative research conducted the FGDs and interviews. FGDs and interviews were digitally recorded, transcribed verbatim, and if it was performed in

Hindi, translated into English. Written consent was obtained in principle, but with those who were non-literate, it was verbal consent.

Data Collection

Focus group discussions: A total of seven FGDs were held. Mothers with children aged under 5 years were selected purposively with assistance from village leaders (*'Pradhans'*) and the local NGO. Six to nine mothers participated in each FGD, adding up to 56 mothers altogether. Their median age was 30.6 years (range 22–45), average number of children were 3.5 (range 1–9), and four were literate. FGDs were stratified according to their religious background because (1) villages were mono-religious society (Hindu or Muslim) and (2) it provided a better environment for the participants to voice their opinions among people with the same religion. All focus groups were conducted in Hindi and lasted 60–90 minutes.

In-depth interviews: A total of 95 key informant interviews were conducted. Of the total, 28 key informant interviews were held with frontline healthcare workers (ANMs, ASHAs, AWWs), primary health centre (PHC) doctors, and private clinic doctors: those with firsthand experience regarding immunization. 23 interviews were held with national and district policy influentials, including government officials and managers of non-governmental organizations (both international and national). The study also recruited individuals who potentially had a role in influencing immunization programmes from the civil society such as academics, religious leaders, community leaders (*'Pradhans'*), and journalists, for a total of 15 interviews. We were able to contact and interview a total of 17 parents with children diagnosed with polio, nine parents with children diagnosed with non-polio AFP, and 18 parents with children with residual paralysis.

A total of 74 interviews were conducted in Hindi, and the remaining 21 were in English. One respondent from the families of children with polio and three respondents from the healthcare providers did not agree to recording, but otherwise all the respondents gave consent on voice-recording their interviews. Duration of interviews varied from 30 minutes to some with over one hour according to their knowledge and interest.

Data Analysis

Data analysis was performed using systematic approach. Common key themes that emerged within and across respondent groups were drawn from raw data, and a coding framework was developed according to topic area by three researchers. To ensure validity and reliability, three key informant interviews and two FGDs were randomly selected and were independently translated and coded by two researchers. The percent agreement with the translation and coding was 88 percent and 82 percent respectively. Several meetings were held to discuss the differences until consensus was reached, and the framework was revised. All the raw data was then coded and analyzed using the MAXqda software, a qualitative data analysis programme.

Limitations

Generalizing the findings to other settings is limited because the study was conducted just in one district. Language was a big constraint and made limitations to the findings of the study because the main researcher was not able to speak the local dialect. Most of the interviews were conducted in Hindi, and it was difficult for her to have control over the kind of information being generated from time to time. Also, much informal information was missed out from talk before and after the interviews. Furthermore, some essence

of the interviews was lost because many Hindi words did not have corresponding words in English; but also the dialect of Hindi spoken in the study area was very local and even the co-researchers fluent in the language sometimes had difficulties in understanding. This, and also non-literacy of families made many interviews very difficult to understand which had little information. This created the necessity to conduct many interviews to fit in all the puzzles together into one piece (e.g., sometimes it needed 6–8 interviews to understand one piece of information).

Still, focus of this study on healthcare for children with AFP is a theme which has never been looked at before, and the study was able to highlight their experiences around what kind of healthcare they received and the reasons for their experiences.

Findings

Experience and Perceptions of the Families of Children with AFP

This section uncovers experiences of families whose children suffered from AFP and the kind of feelings that were associated with these experiences. It is presented in a chronological manner following their experiences step by step; from the first moment they detected paralysis in their children to when they got the final diagnosis.

Early Stages of Paralysis

Onset of paralysis: For most people in the local community, paralysis was equal to polio though there are various other diseases that cause paralysis; because prevalence of polio was very high in the area. Therefore, when families noticed that their children were “falling down on the ground” or “air was coming out of the legs,” as they often described paralysis, the first thing they suspected was polio. One mother explained:

“He got up in the morning and he turned on his stomach. He tried to move towards me, but he could not move. I was kneading flour, and I wondered as to what happened. He used to get up and walk, but why isn’t he moving now. It suddenly struck me that he’s got polio. I immediately took him down and left him with another boy of his age. I thought let me see if he plays. He used to run by holding on to the cot. But he could not move. I thought to myself that seems like his leg has got polio. I thought what has happened.” (mother of 2 yr. old child with polio (P3), identified 10 m. before)

People believed that once affected by polio, a child’s whole life would be “wasted.” From this fear, most of the families sought for an immediate care after seeing their child with the symptom.

First access to health facilities: When asked about families’ experiences around accessing hospitals at onset of their children’s diseases, a range of experiences was heard. Some families accessed government hospitals, but by and large, many families had approached private hospitals or their village doctors first rather than the government hospitals. The same health-seeking behaviour was seen among the respondents of the FGDs.

However, under the system of AFP Surveillance, whoever was suspected of AFP had to be reported to the District Hospital, the top government hospital of the district, and stool test had to be performed for diagnosis. This rule was understood universally among practitioners in the area, which was also confirmed through interviews with them. Therefore, even in the case of families that made access to private practices in the beginning, with just a few exceptions with some village doctors, referrals or phone-calls were made to the government hospitals and the families were either made to go to the government hospitals or were visited at their homes by the government doctors.

“No Peace of Mind” at Government Hospitals

Given this system, all families had experiences around using government hospitals or seen by government doctors at their homes. The doctors examined children and stool samples were taken for all cases. However, most families did not continue their visits and went on with treatments from private doctors because they did not get “peace of mind” going to government hospitals. Many families were highly dissatisfied with the services and attitudes they experienced there. One of the main reasons behind this was unavailability of medicines. Many families complained that they did not get any medicine from the hospital, but instead, got a box for storing stool samples. This father expressed his anger:

“The government doctors refused. They didn’t give any medicine. They didn’t give injection nor did they give any tonic for strength. They said that his prevention is the only cure for this. They just did stool checking...Hospital provided no help.” (father of 3 yr. old child with polio (P3), identified 10 m. before)

However, it became clear that in some cases the families were describing their situation as they were given “no medicine” even though they were given a prescription. Prescription meant little to them, and moreover, they did not consider this as treatment received from the government hospitals as they had to buy the medicines out of their pockets.

Furthermore, at Primary Health Centre (PHC) levels, families were told that their children cannot be treated there because it was beyond their “capacity.” This is revealed in one mother’s response:

“They (The PHC doctors) said she could not be treated here. You may go and show her some place else.” (mother of 3.5 yr. old child (P3), identified 10 m. before)

However, for few cases among the families who received similar responses from the PHC doctors, it became apparent during the course of the interviews that they were told to go to the District Hospital (e.g., it is PHC doctors' duty to report cases of AFP to the District Hospital), which the families had taken to mean that they should go and seek treatment somewhere else.

Also, many had a feeling that no attention was paid for their children. There was minimal interaction between the doctors and the families, and most families mentioned that they were only told about their children's status, that their children had polio, otherwise no further information was given.

Visits made by Healthcare Providers to their Houses

Stool test and follow-up: Many visits were made by government healthcare providers to the children's houses after they were identified with AFP. Families gave a list of people who visited them, and among those were doctors from the District Hospital, PHC doctors, and Auxiliary Nurse Midwives (ANMs). There were also some occasions when they were visited by people from outside the district.

Nonetheless, many families did not understand why they were visited because neither medicines, prescriptions, nor anything were provided for them. Excluding the first few visits which were for stool collection and the purpose for which was also obvious for them, for other visits, families typically described these visits as "doctors come, just glance at the child, and go."

"Teams of doctors came many times in cars, sometimes four, sometimes two, sometimes six for checking. They checked. They all came to see our child. But nothing at all was given. They would come and see, check his leg, take measurement and go back." (father of 3 yr. old child with polio (P3), identified 10 m. before)

There were just two cases where some kind of medicine was given to the children. One mother shared her experience:

“Many big big doctors had come to see my child. One of the big doctors, I forgot his name, gave a bottle of medicine and my child got much relief with that medicine.” (mother of 2.5 yr. old child with polio (P3), identified 7 m. before)

After confirmation of diagnosis: Two families said that they did not receive the report, but otherwise all families were visited at their homes with the stool test results on “paper.” Some remembered what they were told at that time and shared their experiences.

“They said it’s your child and you can show him where ever you like. He doesn’t have dangerous polio*. It’s still in limits and the child will be cured. He will be all right. After that they didn’t give any medicine to anything...They said you can show him where ever you like. And there is nothing specific. He may or may not be cured.” (mother of 2 yr. old child with polio (P3), identified 10 m. before)

*Type P3 is considered to be less severe.

After this visit, the frequent visits by the doctors stopped for many families.

Financial Burden

Financial burden was a common theme that emerged from every interview. This was a cost incurred by the families because they preferred going to private hospitals. Most of the families were poor with their income being usually around Rs.50 to 100 per day, while they were paying more

than Rs.500 per visit for doctors. It is not difficult to imagine how much of burden the cost of treatment for children with AFP was to the families.

Sometimes, the families had to manage either by taking debt or stopping treatment for their children, or by selecting which treatment they would give to their children according to cost.

“We stopped since we can’t afford it anymore. Either we can eat or give her medicine. We have not been able to pay off money we had taken earlier for her treatment. Now you can see what happens in 50 rupees earning.” (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)

Some families were using government hospitals, but nevertheless they often had to pay for medicines and for transportation, which still was a burden for such families. One father commented:

“We haven’t got any help from anybody. Whatever we are spending, we are spending it from our own pocket. Everybody wants to take money. Those who are sitting in government hospital, they also gave 700 rupees medicine in a week!” (father of 6.5 yr. old child with polio (P3), identified 5m. before)

As this father mentioned, there was no financial help provided for families with these children; at least among those who were interviewed in the study.

Why Did Our Children get Affected?

One of the biggest concerns with the children who were affected by polio virus is the fact that they all had received over 10 to 20 doses of polio vaccines and still were affected.

This of course was the big question in the families' mind which they wanted somebody to answer.

"I asked them how can she have polio? She has been taking drops and she had vaccinations. Her name was written down when she was born. When she was born, lady doctor (ANM) had come to the house and gave her drops and also wrote her name. So I asked then how can she have polio, you tell me? If we are not giving drops and child gets affected we can't do anything. They said it's type 3. I don't know what that is. We are illiterate people. We don't know anything." (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)

In fact, many families were not able to obtain satisfactory answers. Sometimes no answer was given, and sometimes blame was put on them. These included the possibility of mothers missing out on polio drops, which they were sure they had not, and possibility of their children not having swallowed polio drops properly. However, the most common answer was that it was in "God's hands" or it was their "destiny:"

"They said: 'what can we do?' The doctors here said its god's will what we can do. They said there will be no complaints from this side as all your children had taken medicine (polio drops)." (father of 2.5 yr. old child with polio (P3), identified 8 m. before)

"They just said it was his destiny. Now we can't do anything and you can't do anything. They would just say that and leave." (mother of 3.5 yr. old child with polio (P1), identified 1 yr. 11 m. before)

Perceptions of the Healthcare Providers and Key Informants on "AFP Cases"

In contrast to the previous section, perceptions of the healthcare providers, the providing side of the AFP Surveillance, are explored here. Also, information obtained from key informants is used to help complement the findings.

Importance of AFP Surveillance

All healthcare providers were aware of their role in the AFP Surveillance and how the system worked. They were generally feeling confident about the system. This was especially strong among doctors regardless of public or private background or their position, and described the system as a “well-established” and “very much systematized” data collection system.

Every doctor interviewed at the periphery level believed it was their duty to be alert not to miss any children with AFP. One doctor stated:

“If there is any child and even if — because it is also in the WHO guidelines — even if you are thinking it’s not an AFP case, you have to send, to minimize the risk of the polio.” (PHC)

Also, they indicated the importance of informing the District Hospital and the NPSP-WHO office in the district as described by this doctor:

“Once it is clear that it is a fresh case of AFP, same day same time, we inform WHO and our district level, DIO (District Immunization Officer).” (PHC)

Furthermore, all doctors and international organization members, those who were involved in the diagnostic process of AFP, stressed the importance of stool samples, called them a “must,” and explained how they had to be done in a timely manner according to guidelines. This is well expressed in the comments given by this doctor:

“When a case is classified as AFP on the clinical ground, stool sample is done in ‘each and every’ case of AFP within 48 hours...We have to collect the stool as early as possible. Guideline says, we should collect the stool within 48 hours of the notification of the case.” (District-level provider)

On the other hand, when ANMs were asked about the AFP Surveillance, they explained that their role was to inform their nearby PHC “first and foremost” if there was any case suspicious of AFP. However, besides this, the work was not in their level, and did not have much idea around diagnosis and treatment of children with AFP.

The work of the AFP Surveillance is completed in the 60-day follow-up visit to children’s houses as explained by this doctor:

“Final follow-up is done, on 60th day of all sorts of AFP. All sort of symptoms, rather. In last follow-up, that is on 60th day, all the motor powers, sensory powers, or atrophy, either the circumference of the arms or circumference of the thighs, is done, so we have to see that patient has developed atrophy or not, or going to develop atrophy or not. So, last follow-up is done on the 60th day.” (District-level provider)

Benefits of AFP Surveillance for Children with AFP

Many health providers perceived AFP Surveillance as beneficial to children who were identified with the symptom. One district-level provider mentioned:

“In both cases, whether it is polio or whether it is AFP, non-polio AFP, the benefit goes to the programme as well as in favour of a child.” (District-level provider)

Common reason behind this perception was that the providers believed children identified were able to receive services which they could not have if they did not come under this system. These services included diagnosis being done free-of-cost, but also certain things such as attention of doctors.

“And meanwhile, we are giving them some extra medicines and sympathies, and all sorts of other things to this family and that family, all things.” (PHC)

“As you know, AFP cases are very important for us. We are giving more and more attention to that child, so I think there is no lacking or there is no gap from the health point view of that child.” (PHC)

Who is Providing Treatment? Whose Responsibility is it?

It is natural to have this question come up into one’s mind when someone is diagnosed with a disease. When this issue was explored, though doctors at PHC were giving treatment also, it became apparent through interviews with private doctors and other key informants that more children with AFP were looked after at private hospitals. One private doctor revealed:

“Government doctors diagnose and they send the children back home, that’s all. In the case of most of the patients, which we have been referring to hospitals, they will take samples of stools, they will diagnose whether it is a case of polio or not, and they ask them to go back to their doctor. Most of the time, they are not giving any treatment to that patient, or patient may not be following...that may be the reason. But most of the time, I have seen that patients come back to us only without any treatment.”

Hence, despite these children’s diagnostic processes were taken up under the AFP Surveillance, many children identified with AFP seemed not to have benefited in terms of treatment. This is because the AFP Surveillance is purely for identifying AFP cases to avoid spread of polio viruses. One academic described the AFP Surveillance as:

“Their sole concern is this: whether they find the virus or not.”

The role of the WHO, which is the main organization running AFP Surveillance, was clarified by one of its members:

“The WHO has no supportive role in treatment or care. Families can seek for treatment in either private or public sector depending on what is available to them.”

Collecting all the information together, it may be said in conclusion that there was no defined route, rule, or system through which children identified with AFP could seek necessary treatment following their diagnosis under the AFP Surveillance.

Difficulties in Treating Children with AFP

In addition to paralytic polio, there are mainly three other conditions present with AFP, and these are Guillain-Barre syndrome, traumatic neuritis, and transverse myelitis. In addition, AFP sometimes manifest as side effects of drugs, and sometimes no definite diagnosis can be made. The research found that often AFP patients were treated according to symptoms they presented with.

As there is no specific “anti-viral drug” to cure paralytic polio, a diagnosis that confirmed polio was a challenge shared by every doctor in treating each child and interacting with their families. Supportive and symptomatic treatments were given including antibiotics, analgesics, and nutritional supplement in the form of calcium and additional protein. Added to these were vitamin B1, B6, and B12 to support normal neuro-development and sometimes zinc to enhance auto-immunity, though these treatments are not well evidenced.^{7,8} Only one traditional healer who was called the “polio expert” by people mentioned about the importance of physiotherapy, which is one of the key treatments for polio. Few families

mentioned about being told of doing exercises at their homes, but were not told how.

Support and Care for Families of Children with AFP and Residual Paralysis

It was a general perception among families of children with AFP and residual paralysis that there was no help for their children, and they had to manage everything on their own. This perception was stronger among families of children with residual paralysis, and in fact, all families believed so. Also, they often did not know where they can go and seek for help or what kind of help existed. Sometimes, they tried to seek for help but ended up in vain, as the experience of this mother with ANMs show:

“We also asked ANMs for suggestions but they said that they were sent from there for giving drops and that is what they do.” (Mother of 10 yr. old with residual paralysis, onset at 5 yr. old)

Moreover, even when they did have some information or have accessed services somewhere, things did not work rightly for them. There was an instance where low education level of the family hindered their action of going forth with what they were told.

“They said, write application. Now, who has skills to do all that? They had asked to write application but then who will write...” (Grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)

Also, some things did not happen as they were expected. One family said, they were told they would get some financial help after the stool test, which they never got. Two families had experience of having their photos and names taken, but nothing happened afterwards.

"I got my picture clicked; sent them to Pradhans; gave it in block office as well but nothing has happened so far...We went to Muzaffarnagar with her and we came back at 12-1 am at night, after all these hardships." (Father of 9 yr. old child with residual paralysis, onset at 1 m. after birth)

There was just one case where they were provided crutches when they went to city. Otherwise, parents made crutches from wood and bought tricycle for their children on their own.

"We bought him a cycle for Rs.2,500. I used to cry and think when I had to carry him for nine months (to school); why should I wait for the government; I will buy it from my own money." (Mother of 15 yr. old child with residual paralysis, onset at 1 yr. old)

When asked around support and care available for children with AFP and residual paralysis, many individuals including ANMs, Pradhans, international organization members, and journalists, were unaware of these services and were incapable of providing information.

Needs of Children with Polio and Non-Polio AFP

This section displays themes around needs of children with AFP which emerged from all interviews. Focus was put on the needs of polio-affected children, for they were the ones who were more in need of help.

"The fact of matter is that, I don't have much idea about this subject. We are not provided information." (Worker for International Organization)

Need of Education

Many families expressed eagerly the need of education for their children with residual paralysis because they

were unable to work as labourers just like their parents or their siblings. Their desire was to have their children educated so that he or she would “not be dependent on anybody,” “do something in life,” and “survive.” One mother stated:

“That is must; only education will help him. If he can’t do anything but if he will be educated, he may be successful in life.” (Mother of 3.5 yr. old child with polio (P1), identified 1 yr. 11m. before)

Healthcare providers and key informants also suggested the need of education for these children, called it their “basic need.”

Transportation Difficulties: Regardless of their strong feeling towards the need of education, most children with residual paralysis were not attending school solely due to difficulties in transportation. Among the few who were attending, a lot of effort was needed in doing so; sometimes their mothers carried them to school or the child skidded along on his or her knees. On the other hand, even those who could stand on their own feet but were still limping, their parents avoided sending them to school because they “fall down” from time to time. Many were unable to go out of their homes going to places, even to their relatives’ house. This father pleaded for his daughter:

“I just want that by whatever way she is just able to walk on her own. I don’t need money. I just want her to walk on her own.” (Father of 10 yr. old child with residual paralysis, onset at 5–6 yr. old))

Need for some kind of transportation arrangements to school also was a theme that emerged with healthcare providers and key informants. District-level providers suggested that more NGOs should come forward to distribute mobility aids.

Medicine and Nutrition

The need for sufficient medicine for these children was another common theme that emerged among families.

“Not even money, but at least medicines should have been provided. It’s government hospital, at least they should have given medicines.” (Mother of 1.5 yr. old child with polio (P3), identified 6 m. before)

Several PHC doctors and ANMs made a similar suggestion. In addition, some noted a need for improvement in the children’s nutrition status.

Expectations from the Government

Expectations from the government were heard from many places. A number of families held a perception that the government should offer more help and pay more attention to the problems of children and their families when the children were affected by polio. One father made a statement on what the government’s role should be:

“If somebody is affected by polio, government should act as a shield. In case people are not capable of managing on their own, then they should be supported by the government.” (Father of 12 yr. old child with residual paralysis, onset at 3 yr. old)

Another father gave a reason behind to why they should be helped:

“Government should help; when government is spending so much money for polio. Gives drops to so many children, going in villages, gives vehicles for it; government should work more rigorously. Something must be done or show them to a good government hospital. Then only one knows whether polio is getting cured or not.” (Father of 3.5 yr. old child with residual paralysis, onset at 2 yr. old)

Expectations from healthcare providers and key informants were also given to the government in helping polio-affected children by taking measures in fulfilling their needs in education, transportation, and healthcare. Moreover, some key informants indicated a necessity of looking into children who were classified as non-polio AFP, but if they were still classified as AFP under the system, they should be taken care of. One academic suggested:

“See, for them, any paralysis is polio. As ordinary people, why should I make the difference that this is due to poliovirus, and this is not. My child is affected. I feel that if I have given that dose, those two drops, why should my child get polio? ...Every child with AFP needed to be suitably compensated as well as rehabilitated, irrespective of polio cases or non-polio cases. That should be the government’s responsibility.”

No expectation

On the other hand, some families expressed no expectation not only from the government, but more generally from anywhere due to their previous experiences of not getting any help. This made them indifferent, and they were unable to come up with their own needs or suggestions. Underneath was this belief that they were poor and poor people never get any help.

DISCUSSION

Gap between the Perceptions of Families and Healthcare Providers

This study found experiences of families of children with AFP in using government hospitals were similar to those of other mothers from the community. The treatments and care they received were inadequate with all of them having to buy medicines from outside many times, sometimes being asked to seek care from other hospitals, and little attention was

paid for their affected children. Many complained that only stool tests were done, and reports were given to them which stated whether it was type P1 or P3 polio; whereas what all mattered to them was their children's illness. Most families were seeking treatments from private hospitals which imposed a considerable financial burden on them.

On the other hand, healthcare providers interviewed in the study believed the AFP Surveillance was beneficial to children, and many considered they were delivering a good service to them and their families. Doctors were sending stool samples according to guidelines, ANMs were reporting paralytic cases foremost to the nearest PHC, and reports were delivered to families at their houses. They were all performing and fulfilling their roles according to their positions.

The probable reasons behind for this gap relate to the nature of the AFP Surveillance and the poor quality of the health system in the area. AFP Surveillance is part of the Pulse Polio Programme which aims at global polio eradication, and its role is to detect children with WPV; so there will be no spread of the virus.⁹ Given this role under the programme, it has no responsibilities over treatment, care or support. This was also clarified by one of its members through the study's interview.

It is also important to recognize how Uttar Pradesh is still experiencing its early transition stage in terms of health system as indicated by Peters.¹⁰ Ramani et al.¹¹ have pointed out public health infrastructure is far from satisfactory in poorer states as the availability of services is constrained by "(1) non-availability of staff, (2) weak referral system, (3) recurrent funding shortfalls, (4) lack of accountability for quality of care, and (5) poor logistics management of supply of medicines and drugs." Access to services is an equally important determinant in meeting the healthcare needs of people especially in rural areas, but as echoed by the people in this study. they are not being met due to minimal or no

public transport between PHCs/CHCs and the district hospitals.¹² Many also mentioned how “poor” do not get anything. This also was a particular concern made by Peters¹³ that “pro-rich” distribution of public resources is exercised in Uttar Pradesh. Due to these factors, health status of the state is below average compared to many others.

In places with adequate health infrastructure, just identifying children with AFP will not cause so many problems because subsequent treatment and care will most likely be taken up by the health system of the area. However, in a place like Uttar Pradesh where the quality of health system is poor, problem arises for the families of children with AFP because they do not have adequate places to seek treatment and care afterwards. This results in an unbalanced provision of healthcare where on one side they are getting services for diagnosis from the AFP Surveillance, but on the other side, they are left without any treatment or care.

Needs of Children

The study identified the following needs of children with AFP through interviews with their families, families of children with residual paralysis, healthcare providers, and key informants.

Medicine and nutritious diet: Though medicines are symptomatic and supportive, there is a need for these medicines for children with polio. Secondary infections can be treated, and muscle pain in the affected-limbs can be relieved.¹⁴ Families in the study talked about their needs for medicines free-of-cost. They were substantially burdened with cost of medicines for their children, and this expectation for support with medicine can well be understood.

Need of nutritious diet was suggested by several doctors in the study, and good nutrition is indeed vital for a competent clinical management in poliomyelitis. Boines¹⁵

has drawn attention to the importance of nutrition status of poliomyelitis patients and stated that “two dietary essentials, proteins and calories, are mutually indispensable.” Proteins are especially important in polio patients for two reasons: for development of immunity against the infection and also for effective tissue synthesis for preventing muscle atrophy.¹⁶ Though the study dates back several decades ago, what he stated stands as of now. Recent studies refer to the role of protein in immunity as an already established fact.¹⁷

Rehabilitation therapy: Rehabilitation therapy for poliomyelitis includes physiotherapy, braces, corrective shoes and corrective surgeries. Free corrective surgeries were organized mostly by social organizations. Some doctors in the study area mentioned about a new scheme by the government for corrective surgeries for polio-disabled children and that they have sent a list of eligible patients. However, we could not find any documents concerning this scheme, and therefore, were not able to evaluate its accomplishment. What we were able to find from a government document which was accessible and from newspaper articles was a scheme introduced in 2006 whereby the government had allotted Rs.20 million for corrective surgeries for the polio-affected children in Delhi (i.e., city).^{18,19,20} Nonetheless, corrective surgeries are only needed when a child reaches to a point when he or she develops deformity in later life.

In contrast, physiotherapy is a core treatment for polio-affected patients, and early ambulation is suggested by many physicians.²¹ However, most families in this study were unaware of physiotherapy despite a few that were told to do exercises at their homes but never were told how. This unawareness for physiotherapy was also found in Kishore’s study.²² This study also found lack of awareness among healthcare providers. When they were asked about treatment for polio patients, very few mentioned physiotherapy.

Transportation facilities and mobility aids: The study found many children with residual paralysis suffered from transportation difficulties, and many were unable to go out of their houses because of not having any transportation means. This also hindered their access to education.

According to the government's policy, provision of access for people living with locomotor disabilities is ensured under the Persons with Disabilities Act, 1995.²³ Under this Act, mobility aids including tricycles, wheelchairs, and crutches are provided by the government. However, it is documented by World Bank²⁴ that this government's scheme is not reaching those in need especially in the rural areas and amongst the poor. The barriers to access to this public policy that this study was able to identify were: (1) lack of awareness of the provision among families as well as healthcare providers, and (2) poor education level of the families because the procedure for obtaining this certificate is complex, also requiring many written application forms.^{25,26}

Presently, distribution of mobility aids are done through "health camps"²⁷ by the government or by social organizations (e.g., Rotary Club, local NGOs, etc.), sometimes in collaboration between the two, and not through the Persons with Disabilities Act. This had its limitations in the number of patients and the area it could cover. Many families in rural areas were not aware of these camps.

Education: Education was mentioned by many families in the study as their needs for the children to be independent in the future despite their paralysis. This importance of education was also stated in the World's Bank document²⁸: "education is critical to expanding the life prospects of people with disabilities." Also, free access to education for the disabled is ensured by the Government of India under the Persons with Disabilities Act, 1995. However, in spite of families' strong desire and universal standard principle, very

few were attending school. The study found transportation difficulties as the biggest barrier to education for these children.

Awareness and sufficient information: As stated earlier, the study found awareness of both the families and the healthcare providers were lacking in what kind of treatments and services there were for children with AFP. There is a need for raising awareness and making information available for everyone in order to improve clinical management of AFP and to promote available services for these children.

Strategic Options for a Better Healthcare

The Pulse Polio Programme is currently the biggest public health programme in India. The government allocated Rs.10.4 billion into this programme for the year 2008–09, but this was solely for polio vaccines and logistics needed for its provision.²⁹ While the programme is conceived as a viable technological solution for reducing child mortality and improving social equity, ignorance in the aftercare for those diagnosed with AFP can be perceived as a shortfall in the programme. Hence, the programme needs to incorporate a scheme whereby it will be more responsible for these children. Several strategic options which can be added to the programme to overcome this shortfall can be drawn from this study's findings.

First, medicines including antibiotics and analgesics should be provided free-of-cost for all children diagnosed with AFP according to their conditions. This should also include nutrition supplements for as long as paralysis persists, for both polio and non-polio, and till then they have grown old enough to be in no need of such aids. Taking into account these children's low socio-economic status, supporting their nutritional needs should be considered as one of the priorities in their treatment.

Second, it is essential to raise awareness of both the healthcare providers and the families on the importance of physiotherapy and moderate exercise for polio-affected children. Awareness raising among the healthcare providers including PHC doctors and ANMs can be done within the monthly training sessions for the Pulse Polio Programme.

Third, information for available benefits and social welfare services (e.g., existence of government policy, health camps) should be provided adequately to the families. Individuals who are in good position to inform and help the families would be: ANMs, ASHAs, Anganwadis, Block monitors of the National Polio Surveillance Project (NPSP),³⁰ Block supervisors of the Pulse Polio Programme,³¹ private doctors, religious leaders and *Pradhans*. Using the network established through the Pulse Polio Programme, especially the Social Mobilization network, these groups should be made aware of available services for paralytic children and provide the families with the information.

Fourth, action should be taken to ensure that children suffering with residual paralysis are able to obtain a physically handicapped certificate under the Persons with Disabilities Act. This will help them obtain transportation means and education. A person or organization, for example Block supervisors of the Pulse Polio Programme, ANMs, or *Pradhans*, should be given the responsibility in facilitating the process of certification including writing applications on behalf of them. Also, simplifying procedures for certificates should be considered, and one measure may be taken by accrediting qualified private doctors for certification.

CONCLUSION

This study was able to uncover the realities faced by the children identified with AFP under the Pulse Polio Programme, a programme set up to achieve the goal of eradicating polio from India and from the world. The realities were: the chil-

dren were the most vulnerable in society, confronted with overwhelming poverty. Poverty made them susceptible to polio and other diseases, as well as to the poor healthcare provision they received after onset of their disease.

Qualitative methods used in this study helped elucidate these valuable findings, and no other methods could have achieved the same. They enabled the researcher to look into the issue from all kinds of angles, from the angle of families, from the angle of healthcare providers, and from the angle of key informants from the community, to develop a holistic picture to what had happened to these children.

For improvement, it is necessary to pay attention to these children who are identified with AFP, who they are, and enhance their quality of life by providing them adequate healthcare. This is important not just for the benefit of these children, but also for the programme itself in moving toward eradication of polio. Improvements in general living conditions, healthcare, education, all are needed to have the disease eradicated, and these needs can be met more if there is better understanding of these children. Thus, integrated approach is needed, both from the government and from the international powers, if ever this disease is going to be eradicated from the world.

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 30. Block monitors of NPSP: Most peripheral workers of NPSP who are involved in coordination across various sectors and monitors SIAs at block level.
 31. Block supervisors of the Pulse Polio Programme: people selected from the community to supervise the programme; for example, teachers.