COMMENTARY

Building on an Ad Hoc Covid-19 Response to Enhance Community-based Care for Vulnerable Children in Kerala, India

Geeta Madathil Govindaraj, MD, Padinharath Krishnakumar, MD, Vinod Scaria, MBBS, PhD, Edavazhippurath Athulya, MSc, V.T. Ajithkumar, MD, Amol R. Dongre, MD

Vol. No. | November 4, 2020
DOI: 10.1056/CAT.20.0543

The Covid-19–related lockdowns resulted in disruptions of care for children with inborn errors of immunity, who, without access to travel, would be unable to continue immunoglobulin replacement. We initiated a community-based care program through pediatricians in state-run peripheral hospitals. The police network, which was already actively involved in Covid-19 prevention, helped transport essential medicines from the tertiary care center. Two months later, we conducted virtual focus group discussions with the mothers to understand their experiences, identify possible gaps in care, and explore suggestions for improvement. Although the community-based care and subsequent virtual focus group discussions were instituted as a temporary measure to ensure continuity of care, we found that it is effective, feasible, and acceptable. Hence, we decided to continue the program even beyond the pandemic. This model of care can be extended to other chronic illnesses as well as to rare diseases in resource-constrained settings.

Inborn errors of immunity (IEIs) or primary immune deficiency disorders (PIDDs) are rare inherited defects of the immune system that are being increasingly recognized. The most common among these disorders is X-linked agammaglobulinemia (XLA), characterized by a severe deficiency of circulating antibodies due to genetic variants in the BTK gene. Affected children require lifelong immunoglobulin replacement to prevent recurrent infections.

The pivotal role of primary health care systems in managing primary immunodeficiency disorders and the need for professional improvement has been highlighted. A patient-centric model for
care has also been put forward. There is a paucity of information on community-based health care models for primary immunodeficiency disorders in low- and middle-income countries.

**Context and Rationale for Change**

Over the past five years, the Government Medical College, Kozhikode, one of the largest referral hospitals in the region, and the Council of Scientific and Industrial Research (CSIR) – Institute of Genomics and Integrative Biology, Delhi, an institute with a focus on rare disorders, have been working on a collaborative program on inborn errors of immunity. The genetically characterized cohort includes 104 children from the northern districts of Kerala, India, hailing from poor socioeconomic backgrounds and dependent on free treatment at our hospital, a tertiary care center.

Children requiring immunoglobulin replacement travel from 10 km to 180 km (approximately 6 to 112 miles) using public transport (buses or trains) for up to 4 hours to reach our hospital and receive intravenous immunoglobulin (IVIG) infusions every 4 weeks. They usually stay overnight at the hospital and return home the next day. They live mainly in rural areas spread over five districts. The Covid-19–related lockdowns had made travel impossible, and parents were apprehensive because their children are immunocompromised.

The state of Kerala, which has a population of about 35 million, has public health system with accessible primary/community health centers in every village. We developed a community-centered clinical service delivery model involving the public health system and the police network to ensure continuity of care for children with inborn errors of immunity.

As the Covid-19 pandemic evolved and complete lockdown was in effect from March 25, 2020, through May 31, 2020, we began receiving distress calls from parents regarding difficulties getting to care centers to maintain continuing treatment for their children. In response, the clinician in charge of the Immune Deficiency clinic at the Government Medical College, Kozhikode, [GMG] convened an administrative-level meeting with the head of the Department of Pediatrics and the superintendent of the hospital to discuss the problem and to work out solutions. They decided to seek the help of the police department to supply medicines, including IVIG, so that the medicine could be administered at the local community hospitals.

There are complicated administrative procedures to receive, store, and administer costly drugs in the peripheral government hospitals. It would require a government order to that effect, which was not possible to obtain during the lockdown. The solution was for police to deliver the drugs either to the patients’ homes or to the nearest police station for patients to pick up before heading to the hospital for treatment.

The police officers were already involved in many humanitarian activities: delivering emergency medicines to the needy, providing food packets to destitute people and migrant workers, providing essential commodities to tribal hamlets, and conducting blood donation drives, all in addition to law enforcement activities. A system was developed to deliver IVIG to the patients’ homes through the police network. The pediatrician at the peripheral community hospital, which is part of the state-run health services infrastructure, was contacted by tertiary facility specialists and the
technique of administering IVIG, including possible complications and methods to manage them, were discussed. Information was sent to the doctors regarding management of PIDDs. IVIG was collected by the local police from our center and delivered to individual parents. Children were taken by parents to the local hospital, where the drugs were administered under supervision of the doctor in charge of the hospital. The doctor also gave the follow-up care and the consultant in the tertiary care center was contacted over phone when necessary.

“We were able to provide continued care to 15 children with PIDDs on regular prophylaxis with IVIG during the 12-week period of travel restrictions through this ad hoc program with the police. The beneficiaries included 11 children with XLA, 3 children with hyper-IgM syndrome, and 1 child with Wiskott–Aldrich Syndrome from widely dispersed geographic localities in five districts of Kerala (Kasargode, Kannur, Malappuram, Palakkad, and Kozhikode). Twelve pediatricians working at peripheral district hospitals and community health centers were involved in the program. There were no major adverse events and all children received IVIG every four weeks or as per their schedule.

**Evaluation of the Patient/Family Experience**

Two months after initiation of the program, in the last week of May 2020, we conducted a virtual focus group discussion (V-FGD) with mothers of 10 children with XLA to understand their experience, identify gaps in services, and explore suggestions for improvement. The V-FGD was conducted with the help of an expert in qualitative research [AD] and a child psychiatrist [PK]. The study was approved by the Institutional Ethics Committee.

Two V–FGDs were conducted using the Zoom platform version 5.0 to ensure synchronous interaction with five mothers in each group. The interview was conducted by the treating pediatrician [GMG], who is trained in qualitative methods. Each interview lasted 40 minutes. All participants were able to join the V-FGD through their smartphones. The mothers discussed their own and their children’s emotional reactions, health problems of children, and financial problems (Table 1). The mothers also offered insights on how well the program functioned regarding access to care, gaps in care, and how we could improve (Table 2). The experience of the mothers during the lockdown period was considered based on an analysis of transcripts. Manual thematic analysis was done in which similar statements were brought together to form categories.
Challenges Faced

It was sometimes difficult to convince the doctors at the peripheral hospitals that it is safe to provide IVIG infusions at the community facility. Having some of our former students working in the periphery was a bonus, because they were willing to go out of their way to help. Several discussions with the administration were often needed before the doctors would agree to take on the responsibility. Poor awareness about PIDDs among peripheral doctors is a challenge to overcome for continuation of the program beyond the lockdown period.

The police often found it difficult to locate the houses of the patients because telephone connectivity was generally poor. In such situations, the medication was delivered to the closest police station, from which the parents would pick it up. Those who did not own a refrigerator had to rely on their neighbors to provide theirs.

| Emotional reactions of mothers |
|-------------------------------|
| 1. Happiness due to the whole family being together at home |
| 2. Husband at home with no job |
| 3. Worried about immune deficiency of child in the face of Covid-19 pandemic |
| 4. Fear that someone is in quarantine near their home |
| 5. Worried about children being unable to attend school, and their approaching examinations |
| 6. Children not obeying parents, e.g., instructions to stay indoors |

| Emotional reactions of children (described by mothers) |
|-------------------------------------------------------|
| 1. Being confined to the home |
| 2. Unable to see their friends |
| 3. Children very irritable, disobedient, temper tantrums |
| 4. Questions regarding end of lockdown due to uncertainty about the future |
| 5. Increased use of mobile phones, TV |

Table 1. Experience of Mothers of Children with PIDDs during the Covid-19 Lockdown

| Health problems in children in issues in seeking treatment |
|----------------------------------------------------------|
| 1. Children having symptoms; e.g., cough, fever, wheeze |
| 2. Inability to visit usual hospital |
| 3. Interrupted treatment; e.g., delay in IVIG infusion (early in the program) |
| 4. Worry about availability of other medicines; e.g., antimicrobials |
| 5. Difficult to adjust to new medical team, lack of familiarity |
| 6. Inability of parents to access health care for themselves; e.g., arthritis for mother of one child |

| Financial problems of family |
|------------------------------|
| 1. Day-to-day expenses, arranging transportation |
| 2. Loss of job, need to take loans from family members, difficulties in paying electricity and cable connection bills |

Source: The authors

Table 2. Gaps in Services Identified by the Mothers and Suggestions for Improvement

| Gaps |
|------|
| 1. Initial inability to procure IVIG and delay in administering it (due to transportation issues; the supply itself was not affected) |
| 2. Health care providers unfamiliar with treatment and difficulty in obtaining intravenous access |
| 3. Lack of usual level of care; e.g., children and adults in same ward, some usual specialized investigations could not be done at the local center |
| 4. Unable to access care for minor illnesses |
| 5. Difficulties in accessing care for other health problems; e.g., unable to program child’s hearing aid or test for hearing problems |

| Suggestions for improvement |
|-----------------------------|
| 1. Frequent health checkups apart from visits for IVIG |
| 2. Special facilities; e.g., a dedicated ward for IVIG infusion |
| 3. Reduce duration of hospital admission; e.g., discharge on same day after IVIG infusion |
| 4. Regular supply of IVIG so that treatment could be continued in the local hospital until lockdown ended and continue thereafter |

Source: The authors
Post-lockdown Assessments

Once the lockdowns were lifted, a patient’s parent or relative was entrusted with collection of IVIG and other drugs to be delivered to the local hospital. Because the police personnel were overburdened by the various responsibilities as the pandemic progressed, it was a relief to them to hand off that task. We decided to continue the community-based access feature of the program, in part to reduce the risk of infection of immunocompromised children.

In addition, there is growing concern about the secondary impact of the Covid-19 pandemic on children with chronic illnesses due to the restrictions on mobility and access to care, as well as financial constraints among affected families. Infants, immunocompromised children, and those with other comorbidities constitute high-risk groups.

This model of community-based care will benefit children with other chronic illnesses, such as leukemia and other childhood malignancies, rheumatological disorders, and endocrine disorders. Along with the program for PIDD, our hospital had initiated a program to provide community-based treatment for childhood leukemia. Experience from other countries has shown that collaboration between the central hospital and peripheral community hospitals is mutually beneficial and could be applicable to many chronic illnesses, improving access to patients from rural areas.

We realized that community-based follow-up care for chronic childhood illnesses like PIDDs is possible with a robust and well-functioning public health system. Diagnosis and care plans can be formulated by the nodal or tertiary institution and peripheral pediatricians can be trained in continued care. We found that provision of community-based care by empowering local doctors, after the initial work-up, is effective, saves time and resources, and results in easily accessible care. The crisis taught us an important lesson and enabled us to develop this system of care, which can be continued even after the Covid-19 situation abates.

We found that provision of community-based care by empowering local doctors, after the initial work-up, is effective, saves time and resources, and results in easily accessible care. The crisis taught us an important lesson and enabled us to develop this system of care, which can be continued even after the Covid-19 situation abates."

We also realized that Virtual Focus Group Discussion is an effective tool to obtain feedback from stakeholders from distant places when community-based care is initiated. In the beginning, we had doubts about the feasibility and effectiveness of V-FGDs for obtaining parent feedback, because they were unfamiliar with the technology and we anticipated problems with Internet connectivity. But we found that it is feasible and effective with appropriate guidance, even when mothers have limited technological know-how. Although V-FGD has been used before during unforeseen disruptions in care, experience with its use in rare diseases is limited.
Looking Forward to Refinement of the Strategy

As we look ahead, we would like to improve the system. Among the considerations:

1. Inclusion of the entire cohort of children with PIDDs.

2. Improvement in awareness of peripheral pediatricians regarding management of PIDDs.

3. Regulatory changes to extend the provision of delivery of IVIG, free of cost to patients, to include peripheral hospitals.

4. Training of more health care providers in peripheral hospitals to administer IVIG.

5. Better facilities for investigations and treatment at peripheral hospitals.

6. Periodic evaluation through V-FGDs including parents and medical personnel.

7. Provision of multidisciplinary care with the support of social workers and psychologists.

The World Health Organization recommends planning Covid-19 interventions with a long-term perspective, attempting to turn the crisis into an opportunity.17 We initiated the community-based care program for children with PIDDs and chose V-FGDs as a method to get parental feedback as an interim measure during the Covid-19 pandemic when travel restrictions were in place. We found that it is effective, feasible, and acceptable to parents and, hence, decided to continue with this model of care, which can be extended to other chronic illnesses, especially in resource-constrained settings.

Geeta Madathil Govindaraj, MD
Professor, Government Medical College Kozhikode, Pediatrics, Chevarambalam, Kozhikode, Kerala, India

Padinharath Krishnakumar, MD
Director, Institute of Mental Health and Neurosciences, Government Medical College, Kozhikode, Kerala, India

Vinod Scaria, MBBS, PhD
Principal Scientist, Council of Scientific and Industrial Research (CSIR), Institute of Genomics & Integrative Biology, New Delhi, Delhi, India Adjunct Professor, Academy of Scientific and Innovative Research, New Delhi, Delhi, India Adjunct Professor, Indraprastha Institute of Information Technology, New Delhi, India

Edavazhippurath Athulya, MSc
Junior Research Fellow, Government Medical College Kozhikode, Kozhikode, Kerala, India

V.T. Ajithkumar, MD
Professor, Government Medical College Calicut, Pediatrics, Kozhikode, Kerala, India
Amol R. Dongre, MD
Professor, Sri Manakula Vinayagar Medical College and Hospital, Community Medicine, Puducherry, India

Acknowledgments

We acknowledge funding from and the Science and Engineering Research Board, Delhi, for the Primary Immune Deficiency Project (SERB No: EMR/2016/006828) and from the Foundation for Primary Immune Deficiency Diseases (FPID), USA, for supporting the program. We are grateful to the parents for their participation in the study. We acknowledge the help of Dr. C. Sreekumar, Superintendent, Institute of Maternal and Child Health, Government Medical College, Kozhikode, in organizing the program. We also place on the record our gratitude to Abhinav Jain for help with the genetic workup and Mrs. Kavitha for logistic support.

Disclosures: Geeta Madathil Govindaraj, Padinharath Krishnakumar, Vinod Scaria, Edavazhippurath Athulya, V.T. Ajithkumar, and Amol R. Dongre have nothing to disclose.

References

1. Subbarayan A, Colarusso G, Hughes SM. Clinical features that identify children with primary immunodeficiency diseases. Pediatrics. 2011;127(6):810-6

2. Plebani A, Soresina A, Rondelli R. Clinical, immunological, and molecular analysis in a large cohort of patients with X-linked agammaglobulinemia: an Italian multicenter study. Clin Immunol. 2002;104(6):221-30

3. O'Keefe AW, Halbrich M, Ben-Shoshan M, McCusker C. Primary immunodeficiency for the primary care provider. Paediatr Child Health. 2016;21(6):e10-4

4. Orange JS, Seeborg FO, Boyle M, Scalchunes C, Hernandez-Trujillo V. Family Physician Perspectives on Primary Immunodeficiency Diseases. Front Med (Lausanne).

5. Hartog NL, Williams KW, Abraham RS. “The State of the Union”: Current and Future Perspectives on Patient-Centric Care for Primary Immunodeficiencies and Immune Dysregulatory Diseases. Front Immunol.

6. Kerala Population. 2020. World Population Review. Accessed October 5, 2020. https://worldpopulationreview.com/territories/kerala-population

7. List of modern medicine institutions 2017-18. Directorate of Health Services. Government of Kerala. Accessed October 5, 2020. https://dhs.kerala.gov.in/list-of-modern-medicine-institutions-2017-18/.

8. General Administration Department. General Orders, Government of Kerala. Accessed October 5, 2020. https://gad.kerala.gov.in/gos

9. Kerala Police. Covid-19 webpage. Accessed October 5, 2020. https://keralapolice.gov.in/covid-portal.
10. Turney L, Pocknee C. Virtual Focus Groups: New Frontiers in Research. Int J Qual Methods.

11. Saldaña J. The coding manual for the qualitative researchers. SAGE Publication. 2016; London: 3rd Ed.

12. Ashton JJ, Batra A, Coelho TAF, Afzal NA, Beattie RM. Challenges in chronic paediatric disease during the COVID-19 pandemic: diagnosis and management of inflammatory bowel disease in children. Arch Dis Child.

13. Klein JD, Koletzko B, El-Shabrawi MH, Hadjipanayis A, Thacker N, Bhutta Z. Promoting and supporting children’s health and healthcare during COVID-19 - International Paediatric Association Position Statement. Arch Dis Child. 2020; 105(6): 620-4

14. Hamline MY, Forman K, TranViet K-N, McKnight H, Lakshminrusimha S, Lubarsky, DA. Constructive Self-Cannibalism: Pediatric Affiliation Between an Academic University and a Community Hospital. NEJM Catalyst.

15. Ranieri V, Kennedy E, Walmsley M, Thorburn D, McKay K. Rare but heard: using asynchronous virtual focus groups, interviews and roundtable discussions to create a personalised psychological intervention for primary sclerosing cholangitis: a protocol. BMJ Open.

16. Mayer DK, Tighiouart H, Terrin N. A brief report of caregiver needs and resource utilization during pediatric hematopoietic stem cell transplantation. J Pediatr Oncol Nurs. 2009; 26(6): 223-9

17. World Health Organization. Investing in and building longer-term health emergency preparedness during the COVID-19 pandemic: Interim guidance for WHO Member States. July 6, 2020. Geneva: World Health Organization; https://www.who.int/publications/i/item/investing-in-and-building-longer-term-health-emergency-preparedness-during-the-covid-19-pandemic