



Assessment of Quality of Life of Children at Risk of Developmental Delays During Covid 19 Pandemic Through Telephonic Follow-Up

¹Aarti Nair, ²Corresponding Author- Prof. (Dr.) Niraj Kumar, ³Dr. Anchit Gugnani

¹PhD Scholar, National Institute of Medical Science University Jaipur, Rajasthan.

²Ph. D (Physiotherapy), MPT, MHA, BPT, Professor, Shri Guru Ram Rai Institute of Medical & Health Sciences, Shri Guru Ram Rai University,

³Associate Professor NIMS College of Physiotherapy and Occupational Therapy, Jaipur, Rajasthan . India

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ABSTRACT:

Introduction: As the world grappled with the Covid-19 pandemic, families of High-risk infants were left unsupported. Tertiary care was not a priority when the healthcare system was in crisis. Therefore, high-risk infants and their families were not provided the services they needed.

Objectives: To assess the quality of life of children at risk of developmental delays through telephonic follow-up during Covid 19 Pandemic.

Methods: We used creative ways of managing and nurturing 899 children at home through online follow-up over a period of 12 weeks. The assessment was done using an evaluation tool namely "Health-Related Quality of Life". This tool was used to evaluate the overall quality of life along with a range of child's developmental characteristics. Information was collected through 25-item questionnaires, which were parent administered.

Results: This study has contributed to championing the role of the family in child development during Covid 19 Pandemic and identifies families as having a critical role in the child's development.

Conclusions: The Report acknowledges that family-centred, early intervention programs are complex to implement besides requiring a fine understanding of the diverse needs of children and their families across different contexts.

1. Introduction

Medical institutions and healthcare facilities were grappling with challenges in primary care facilities during the lockdown. Covid 19 pandemic posed a huge danger to children who were at high risk at birth. Families of children at high risk of developmental delays were suddenly left unattended and unsupported (3). The caregivers had to gather their strengths and act in fortitude to optimize the development for their children.

Many infants born with a high level of risks, lag in their developmental potential. Infants who receive early intervention demonstrate improved neurodevelopmental outcomes. The early years of infants are crucial as brain

development takes place at a fast pace. With care, nurture, and stimulation, brain cells develop to inherent potential (1).

Assessing the quality of life is part of the process of identifying children at risk of poor development outcomes (2). To thrive, children, need food, shelter, and a healthy environment. Parents dealing with the stress of poverty find it hard to establish crucial bonds with their babies, bonds that lay the foundation for learning, emotional regulation, and relationship. Poor families are focused on survival and health care takes second priority. Earning a living is a priority so they have no time to play with their children (4).



Capacity building for parents and caregivers of special needs children was the only way to enable them as part of tertiary care. The first step was to follow up with all families who had registered at LRF whose children were under the age group of 4 years in September 2020. Early intervention and providing support to families was a priority. Enabling families to provide the required stimulation and care is a key strategy for improving outcomes for high-risk infants (5).

Brain development does not simply unfold with neurological maturation. Neurological development is shaped, positively or negatively, by the interactions between biological and environmental influences. Understanding these interactions is the key to improving children's developmental outcomes. Research has proved that the period of birth to 4 years are the most critical years for all children. This is especially true for children with delays in development. Therefore, it stands that early intervention programs can significantly improve the quality of their lives and the lives of their families (5). Thus, programs that help in early intervention help children achieve their maximum potential to bring about improved outcomes and improved quality of life.

2. Objectives

The aim of this study was to assess the quality of life of children at high risk of developmental delay, during Covid-19 pandemic.

3. Methods

This is a prospective cohort study where we followed up on a cohort of 899 children from 1st June 2020 -31st August 2020 who were identified to be at high risk of developmental delay during infancy. All children born in the Government Doon Hospital, Dehradun, Uttarakhand having a Neonatal Intensive Care Unit (NICU) stay of ≥ 5 days were considered to be at high risk of developmental delay.

Six health professionals from Latika Roy Foundation, Dehradun, including, two physiotherapists, one special educator, and three child development aids were recruited and made phone calls to 899 families over a period of 5 weeks, from July 2020 - August 2020. The Professional Qualifications of the team are as follows: Physiotherapist 1 - Masters in Physiotherapy with 12 years of work experience. Physiotherapist 2 - Masters in Physiotherapy with 8 years of work experience. Special Educator- Master in Special Education with 20 years of work experience, Child developmental aide-1, Bachelor in Arts, 5 years work experience, Child developmental aide-2, Bachelor in

Arts, 15 years work experience, Child developmental aide-3, Diploma in special education, 5 years work experience.

Support was provided to 899 families whose children were at high-risk of developmental delays by telephone conversations during Covid 19 Pandemic.

The conversation with families started with an introduction, followed by the general well-being of the babies and how the family was coping during the time of lockdown. Parents were then introduced to the "Health Related Quality of Life" (HRQoL) questionnaire and their responses were recorded manually. Instrumentation

The instrument used in this study was a questionnaire, 'Health-Related Quality of Life Tool' (see Table 5).

This tool examined the quality of life of the children while they were in lockdown and unable to attend in-person therapy sessions due to Covid 19 Pandemic. Information on a range of child's characteristics was collected through the 25 items generic questionnaires. A parent-administered questionnaire was used to assess the quality of life of participants. For each item, 5 options are provided to closely examine the child's health on his/her quality of life. HRQoL is a parent-administered questionnaire which through its 25 items helps collect information on a range of child's characteristics. For each item, 5 options on a scale of 1 – 5 are provided to closely assess the child's health on his/her quality of life. Option 1 corresponds to No problem in the domain of QOL being studied and option 5 corresponds to an extreme problem in the domain.

Recruitment Criteria: Families of Infants who were at high-risk at birth, born in the Government Doon Hospital, Dehradun, Uttarakhand, admitted in NICU for ≥ 5 days, due to complications during birth.

HRQoL is considered a reliable [8] and useful indicator when assessing one's health status. This tool helps in providing an overall review of health across domains such as temperament, cognitive development, feeding, communication, movement, etc. Together, these measures provide a comprehensive assessment of the quality of life of the children who were at risk of developmental delays.

4. Results

In this study, the follow-up of the quality of life of children was featured by the staff at Latika Roy Foundation (LRF) during the Covid 19 pandemic. Age group of 6 months-4 years. The data is based on markers mentioned in the HRQoL tool, it provides a more flexible approach to the optimization of family-centered care by parents. (Table/Fig-5).



Most respondents (87%) were from 2 parent families,

Age distribution	Birth-lyrs	>1-2 yrs	>2-3yrs	>3-4yrs
No of participants	149	320	279	151

considered Hindi to be their first language (97%)

and lived in urban settings. The majority (64%) had a family income between Rs10,000-Rs 20,000 and

mothers (63%) had education up to high school, and fathers (76%) had education up to high school.

(Table/fig-1).

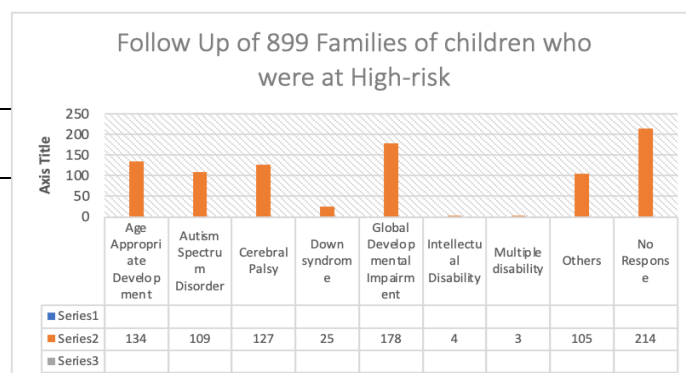
Table 1- Description of families

Categories	Demographics	
Location	Rural 566(63%)	Urban 333(37%)
Family Structure	782(87%) Two-parent families	117(13%) single parent family
Mother tongue	872(97%) Hindi speaking	27(3%) other languages
Family Income	569(64%) Low Income Rs10,000- Rs 20,000	330 (36%) Middle-income Rs21,000-Rs 50,000(6)
Mothers' Education	566(63%) Mothers educated to high school and more	333(37%) Mother less than high school
Fathers' Education	683(76%) Father educated to high school and above	216(24%) Father less than high

Age distribution- There were 149 families whose children were less than a year old. 320 families whose children were in the age group of >1-2 years. 279 families with children in the age group of >2-3 years and 151 families with children of >3-4 years. (Table/fig 2)

Table/fig 2- Age Distribution

The table (Fig-3), depicts the follow-up of children with various types of disorders and typical development. Out of the 899 families that followed up, 134 children had age-appropriate development. 109 children had autism spectrum disorder, 127 had cerebral palsy and 178 had global developmental impairment, constituting the major chunk of our sample.



Table/Fig-3

Out of the 899 registered, 463 phone numbers were no longer in use. 223 phone numbers that did not reply even after being called repeatedly. 68 children were doing well and had age-appropriate development according to the parents. 5 children had died and 140 children who had concerns in development, participated in the study.

We identified 17 key findings from the list of 25 questions in the HRQOL questionnaire reported in the study. We did not have high confidence in any of the findings. We had moderate confidence in 6 findings and low confidence in 11 findings. We are moderately confident in stating that lack of training to work on online methods and telephonic conversations was a barrier to determining the quality of life during Covid 19 pandemic for children at risk of developmental delays. We are moderately confident that with more training and frequent follow-up, families would be supported and have improved quality of life after the initial few months of lockdown. We are moderately confident that familiarity with families and improvement in network and technical knowledge can facilitate the implementation of the intervention. (Table-4)



Families were able to provide information on 6 of the given 25 questions. The information provided

Table-4

	Question 1	Question 3	Question 5	Question 9	Question 14	Question 25
Category	Not at all-63(45%)	Not at all-55(39%)	Not at all-85(61%)	Not at all-3(3%)	Not at all-3(3%)	Not at all-3(2%)
	Slight-56(40%)	Slight-63(45%)	Slight-85(61%)	Slight-18(12%)	Slight-19(14%)	Slight-90(64%)
	Very-18(13%)	Moderately-8(6%)	Slight-55(39%)	Moderately-90(65%)	Moderately-85(61%)	Moderately-35(25%)
	Extremely-3(2%)	Very-10(9%)	Extremely-2(2%)	Very-27(20%)	Very-29(20%)	Very-11(8%)
		Extremely-4(1%)		Extremely-5(2%)	Extremely-5(2%)	Extremely-1(1%)

Thinking about the last 7 days, has there been a problem with —	Not at all	Slightly	Moderately	Very	Extremely
1 — your child's health and fitness?	0	0	0	0	0
2 — your child becoming physically lethargic and tired?	0	0	0	0	0
3 — your child's feeding/eating or drinking?	0	0	0	0	0
4 — your child's sleeping?	0	0	0	0	0
5 — your child's movements or walking?	0	0	0	0	0
6 — your child being in pain?	0	0	0	0	0
7 — your child being happy?	0	0	0	0	0
8 — your child being sad?	0	0	0	0	0
9 — your child behaving in an angry way?	0	0	0	0	0
10 — your child's ability to pay attention to toys or other objects?	0	0	0	0	0
11 — your child's ability to pay attention to people and activities?	0	0	0	0	0
12 — your child's progress in learning or remembering?	0	0	0	0	0
13 — your child using his/her hands to do what is expected?	0	0	0	0	0
14 — your child playing with toys as expected?	0	0	0	0	0
15 — your child using day to day things as expected?	0	0	0	0	0
16 — your child's understanding of what you say to him/her?	0	0	0	0	0
17 — your child communicating his/her needs to you?	0	0	0	0	0
18 — your child sharing interests or other information with you or others?	0	0	0	0	0
19 — your child having fun playing and interacting with others?	0	0	0	0	0
20 — your child's treatment making him feel unwell or unhappy?	0	0	0	0	0
21 — your child because of not getting the treatment needed?	0	0	0	0	0
22 — your family being able to provide for your child's needs?	0	0	0	0	0
23 — your child receiving good attention and engagement from the family?	0	0	0	0	0
24 — other people ignoring your child or your family because of his/her condition?	0	0	0	0	0
25 Overall how is your child's current quality of life?	Excellent	Very good	Good	Fair	Poor

Table/Fig- 5

5. Discussion

This study explores the quality of life of children who were at risk of developmental delays through family empowerment programs and adjustments made by parents during the Covid-19 pandemic. This study has contributed to championing the role of the family in child development during Covid 19 Pandemic. If validated results point to the importance of support and guidance to parents. It facilitates a potential pathway to improving the development outcomes of children at high-risk of developmental delays.

Parents' understanding of their child's needs, capacities, and potential is more than any other person's. With this philosophy in mind the family-centered approach is considered more advantageous than any other model when it comes to optimizing outcomes for the children (7). This approach helps in building parent understanding of their child's condition and ways of supporting his/her development. It strengthens parent-child bonding and

teaches parents how to play and engage with their children in meaningful ways. Most importantly it reduces the stress on parents and thereby leads to a happy environment, improving development levels through stimulation, play, and routine activities. Professionals support and empower the parents with their skilled approaches and this has the potential to enhance their child's and family's outcomes. Family-centred care(5) underlines many models of service delivery and acknowledges the interrelatedness of caregivers and the importance of recognizing the needs of all caregivers and not just children with disabilities. There are four essential beliefs that drive the implementation of family-centered care. Firstly, the family and not the professional is constant in a child's life. Secondly, parents are in the best position to determine the needs and well-being of their children. The best reward for the child is achieved by helping the family. Finally, family choice and decision-making in the provision of services, showing respect and affirming the family's strengths, enhancing family control over the services they receive, and partnership and collaboration with family are emphasized. Thus, effective EI services when facilitated in a family-centred manner can change the child's development trajectory and improve outcomes for the child and the family (8). However, for the field to reach its full potential, there needs to be ongoing testing of family-centred practices and the important outcomes believed to derive from this practice.

The lockdown was a time of significant opportunity to test the family centred approach when tertiary care health systems were inaccessible.

6. Limitations

Health-related quality of life (HRQOL), is a multi-dimensional tool, it provides outcomes that reflect a family's priorities when determining the quality of life of their children, though it is rarely considered the primary endpoint in clinical trials. Since this tool is dependent on parental perceptions it is difficult to assess development in children by this method. Online surveys and telephonic conversations do not give a complete picture of the children's developmental levels. This tool had to be modified and a number of items listed did not give correct information due to the isolation of families during Covid 19 pandemic.

7. Conclusion

The pandemic led to a shift from regular services to online mode of service and displayed clearly that necessity is the mother of invention. When accessibility to essential services was difficult, children with disabilities and their parents were the high-risk groups for various physical and mental health issues. As the world navigated the pandemic



the Latika Roy Foundation staff set up a follow-up program to determine how the families were managing and provide guidance telephonically and through video call wherever possible.

This follow-up was aimed to support parents and guide them during the crisis of Covid 19 Pandemic so that children at risk of developmental delays can have early intervention and stimulation at home during their crucial early years.

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