# Childhood Cataract: A Socio-Clinical Study at a Public Sector Tertiary Eye Care Centre in India

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#### Abstract:-

Purpose: To study the demographic, sociological and clinical profile of the children presented for childhood cataract at a public sector tertiary eye care centre in India.

Methodology: The design of the study is retrospective and hospital-based. Data available with the Central Registration Department of the PGIMER, Chandigarh was used. The majority of the childhood cataract cases are being reported in this hospital, yet not each and every case of childhood cataract approaches PGI, Chandigarh. Nevertheless, this study is going to be pioneering research in India covering five-year data of the childhood cataract patients who visited the Advanced Eye Centre, PGIMER, Chandigarh from 1.1.2015 to 31.12.2019. The SPSS version 23 was used for all statistical calculations.

Results: 354 children were presented for childhood cataract screening and treatment from 1.1.2015 to 31.12.2019. Of 354 children, 248 (70%) were male, and 106 (30%) were female. Further, out of these 354 children registered in the special clinics, 42 were incorrectly registered for childhood cataract. Therefore, the final number children registered in 5 yearswas 312. Despite two flagship programmes by the Govt. of India, namely the National Programme for Control of Blindness (NPCB) and Aayushman Bharat (PM-JAY), for eradicating cataract-related blindness, only nine children received financial assistance from the Govt of India and only 1 from Avushman Bharat (PM-JAY). Out of 312 patients, 99 children (31.73%) reached late at the hospital, and 39 children did not continue their treatment, mainly due to poverty and transport-related issues. A whopping 99% of these children belong to lowincome families. Out of 39 children who discontinued their treatment, 24 were male, and 15 were female. In most of these families, the mothers were housewives and did not work anywhere. We intend to convey these results to the Govt. of India to evolve a suitable mechanism to address pertinent issues hindering the treatment of children suffering from childhood cataract. Further, the disproportionate ratio of male and female children in this study is an area of concern as it is difficult to assess whether the prevalence of childhood cataract is lower in female children or they are not being presented on time in the hospital by the families.

Conclusion: The World Health Organization (WHO) has categorized Childhood blindness resulting from cataract as a priority area and urged all member countries to develop institutionalized mechanisms for its early detection, diagnosis and management. The childhood cataract is an emerging and major cause of preventable and avoidable childhood blindness, especially in low and middle-income countries. In the formative years, the children require a sound physical, mental and emotional state and in the absence of either one of them, it can severely dent their future growth. The recent estimate suggests that India could suffer an economic loss of US\$12 billion (Rs. 88,000 Crores) due to blindness and almost 35% of cases of blindness are preventable and avoidable if detected at an early age. Besides reporting these results to the policy makers, synchronized efforts are also needed for early detection and management of avoidable causes of childhood blindness such as childhood cataract.

*Keywords:-* childhood cataract, WHO, blindness, NPCB, Ayushman Bharat.

#### I. INTRODUCTION

The visual system is one of the most important sensory organs of the human body.<sup>1</sup> As per the estimates; almost 1.4 million children are blind in the world, with a majority living with socio-economic deprivation and inaccessibility to proper nutritional and medical care. As a result, they are more likely to have infectious diseases and malnutrition, leading to delayed cognitive development, frequent hospitalization and death within the first year of their birth.<sup>2</sup> Nearly 20% of the childhood blindness is caused by childhood cataract, with almost 60% of blind children dying within the first year of their birth and the rest of them live a miserable 40 years without vision.<sup>3,4</sup> Cataract is one of the major causes of childhood blindness and causes more disability in children, compared to any other form of preventable blindness. Blindness in children can have devastating effects on their quality of life and on the socioeconomic condition of the family and society. Childhood cataract, if left untreated, can result in severe visual impairment, including blindness.5

World Health Organization (WHO) has prioritized childhood blindness from cataract as a priority area and has urged all the countries to develop institutionalized mechanisms to tackle this menace threatening the sight of the children, especially in the low and middle-income countries.<sup>6</sup> In developed countries, institutional mechanisms are in place for infantile screening for the detection of congenital diseases that include childhood cataract and retinopathy of prematurity (ROP). All over the world, midwives, primary health care workers and pediatricians remain the first contact with the child, but due to limited number of ophthalmologists in developing countries, the reporting and presentation of childhood cataract often gets delayed. Since the detection and surgical management of childhood cataract is difficult and requires specialization, therefore, there is an urgent need to develop artificial intelligence-based systems for paramedical staff, primary health care physicians and midwives to look for childhood cataract in their routine screening of children after birth. It is, therefore, important for us to sensitize parents, primary care physicians, community health care workers, anesthesiologists, ophthalmic technicians and low vision rehabilitation technicians to closely coordinate with all stakeholders to minimize the extent of childhood blindness leading from pediatric cataracts.

#### II. CLASSIFICATION OF CHILDHOOD CATARACTS

The lens in the human eye has unique properties as the addition of new cells is continuous throughout the life-time of an individual. The growth of the human lens takes place in two phases; the asymptotic phase and linear growth phase. The asymptotic growth starts during the gestational period and lasts up to 3 months after birth and the linear growth phase starts soon after. Due to this biphasic lens growth, two different and distinct compartments are formed within the lens. The lens nucleus is formed during the prenatal period followed by an ever-expanding cortex with unique physical and biochemical properties during the linear growth phase.<sup>5</sup>

The classification and pattern of childhood cataract can provide better insights for management and surgical plan. It is, therefore, desirable to describe the location, layer, density and pattern of the lens opacities. Once the morphology is decided, then ophthalmologists can describe its etiology and associations. Broadly, the childhood cataract can be classified using three categories; based on age, etiology and morphology (Table 1).<sup>6</sup>

Classification of childhood cataracts						
Age of onset	Etiology	Morphology Diffuse/Total Cataract				
Congenital Cataract	Genetic/hereditary					
Secondary cataract	Secondary - Inflammation/ Uveitis - Traumatic - Intrauterine - Iatrogenic	Nuclear Cataract				
		<ul><li>Polar Cataract</li><li>Anterior polar cataract</li><li>Posterior polar cataract</li></ul>				
		Lamellar Cataract				
		Nuclear Combined with cortical - Coral like - Dust like - Blue dot				
		Cortical Cataract Y-suture Cataract				

Table 1: Classification of childhood cataract based on Age of Onset, Etiology and Morphology

#### A. Age of Onset

As per the definition, a cataract present at birth, or developing after birth but before 16 years of age is termed as a childhood cataract.<sup>5</sup> The lens in the human eye is composed of avascular transplant tissue with unique protein composition and cellular structure. The function of this lens, in combination with the cornea, is to focus the image on the retina. Its ability to change the shape and transparency are the key factors in the production of a clear and focused image on the retina. It can further be divided into two categories based on age.

#### a) Congenital cataract

The presence of lens opacity at the time of birth indicates its congenital onset. However, its diagnosis even at a later stage does not rule out its congenital onset. The detailed examination of the lens opacity, its etiology and systemic associations may prove beneficial before the cataract extraction. Anterior polar, persistent hyperplastic primary vitreous (PHPV), central nuclear and posterior polar cataract suggest a congenital onset.<sup>7</sup>

b) Developmental cataract

These cataracts are mostly acquired after birth. All cataracts with onset in childhood, after infancy, irrespective of their underlying etiology can be classified as 'developmental cataract'.<sup>8</sup>

#### B. Etiology

The transparent fibres in the lens are known as crystallin and the nucleus of the lens is layered with fibres, resembling the layers around the onion. As a result of continuous expansion during the lifetime of an individual, the lens becomes rigid and loses its innate ability to change shape, causing visual problems.

a) Genetic/hereditary

In the majority of the cases, etiology of the cataract is not known and is classified as "idiopathic".<sup>5</sup> However, congenital cataract has also been linked to mutation in genes linked with lens development. While most of these genes are dominantly inherited, but cases with autosomal recessive or x-linked inheritance have also been reported.<sup>7</sup> With recent advancements such as next-generation sequencing, researchers are trying to find out the exact cause of congenital cataracts, but it is still in its preliminary stages and will require more time and validation before it can be used for diagnostic purposes.

b) Secondary

The opacity in different parts of the lens depends on the etiology of the cataract and compared to congenital cataracts, the etiology of secondary cataracts are mostly known, including:

c) Inflammation or Uveitis

Due to persistent inflammation and steroids used in the treatment of uveitis, children may develop cataract, most commonly posterior sub-capsular cataract. Hence, ruling out active inflammation is essential before surgical intervention in these Many patients may also develop a children. pupillary membrane, making the surgery challenging. Juvenile idiopathic arthritis is one of the major causes of uveitis with cataract in children. In recent years, the use of systemic antimetabolites has helped to control the inflammation in these.8.9

# d) Traumatic Cataract

Traumatic cataract remains a major challenge in low and middle-income countries (Figure 1). The traumatic cataracts are not uncommon in boys due to their exposure to hazardous working condition, unhygienic living conditions, playing unconventional games, cracker burning and fights with fellow friends.

#### e) Intrauterine infections

Among many reasons, intrauterine infections such as toxoplasmosis, rubella, cytomegalovirus and herpes (TORCH) is some of the major causes in low and middle-income countries due to their high prevalence and require strict vaccination programmes for mother and child.<sup>10</sup>

f) Iatrogenic

In the last few years, we have seen an increased prevalence of cataract after laser treatment of ROP and other intraocular diseases requiring prolonged use of steroid therapy.<sup>3</sup>

C. Morphology

The lens opacities in childhood cataract can have multiple phenotypes and it is perhaps the most challenging task for ophthalmologists to list the precise morphology of the childhood cataract. Diagnosis of cataract can be made by an ophthalmologist under torch light examination or slit-lamp examination (Figure 2). The morphology can guide the ophthalmologists to link its etiology, systemic association, and surgical plan. Based on morphology, childhood cataract can be classified based on the opacity of lens structure (Table 2).<sup>7,8,11</sup>

Whole lens	Total	Congenital	Morganian	Membranous	Partially	
Central	Lamellar	Zonular	Nuclear	Central	Sutural	Cortical
Anterior	Anterior polar	Anterior	Anterior			
	Dot like	subcapsular	lenticonus			
	Plaque like					
	Anterior					
	pyramidal					
Posterior	Posterior polar	Posterior	Posterior			
		subcapsular	lenticonous			
Misc.	Linear opacities	Wedge-shaped/	Coralliform	Dandelion	Reduplicated	Barbed fence-
	_	Crystalline	/Floriform	like/Starry sky	cataract/	like/
		-		cataract/Stud	Nodular stem	Oil droplet
				button	of cactus	-

Table 2: Childhood cataract classification based on morphology

#### III. MATERNAL MALNUTRITION AND INTRAUTERINE INFECTIONS

The role of micronutrients for a pregnant mother is essential for balanced fetal growth and ample studies have established the link between maternal malnutrition and intrauterine growth retardation, increased perinatal morbidity and even mortality.<sup>5</sup>

# A. Maternal malnutrition

The incidence of idiopathic cataract is highest in lowand middle-income countries suggesting the role of low birth weight, malnutrition and infectious causes in the development of idiopathic cataract. Also, the low birth weight indicates poor fetal growth and maternal malnutrition can be one of the factors causing altered physiology of the fetal lens. A possible link has been suggested between maternal malnutrition, low birth weight and the development of childhood cataract.<sup>11</sup> While exploring the existing literature on pathways delivering nutrients to the adult lens, authors presented a cellular mechanism by which oxidative stress caused due to maternal malnutrition can impact the development of antioxidant defence pathways in the embryonic lens, thus accelerating the onset of nuclear cataract in childhood.<sup>5</sup>

# B. Intrauterine infections

In the developing world, intrauterine infections are major causes of childhood blindness.8 The mnemonic TORCH symbolizes the most common congenital intrauterine infections which include; Toxoplasma gondii, others, rubella, cytomegalovirus and herpes. The "others" include varicella-zoster, treponema pallidum, Epstein-Barr, HIV, lymphocytic choriomeningitis and West Nile virus. Though they manifest relatively mild symptoms and illness in the mother, they can severely impact the fetus growth. The more virulent forms of these viruses may also result in abortion, stillbirth and can have direct toxic effects on the fetus. In cases, the fetus is unable to eliminate these viruses; it can lead to chronic infections and elevated levels of IgM In 1941, Sir, Norman Mcalister Gregg, an and IgA. ophthalmologist from Australia described the association of rubella with congenital cataract, congenital heart disease and It was the first-ever demonstration of deafness. teratogenicity secondary to a virus.<sup>10</sup> Rubella is still a major cause of congenital cataracts and blindness across developing countries.

# IV. SYMPTOMS, DIAGNOSIS AND TREATMENT

#### A. Symptoms & Diagnosis

The ultimate goal of diagnosis and treatment of childhood cataractis successful visual rehabilitation. At present, ophthalmologists use a slit lamp examination to diagnose childhood cataract. The decision to operate depends upon the density of lens opacity, evaluated with the help of a red-reflex test, retinoscopy and EUA (Examination under anaesthesia). Decreased vision, leukocoria, and strabismus are the most common symptoms seen in pediatric cataract.<sup>7,8,12</sup>

In general, ophthalmologists look for the following features to confirm the presence of cataract:

- White reflex in the eye (Leukocoria)
- Misaligned eyes.
- Rhythmic and uncontrolled movements of the eye (nystagmus).
- Cloudy or blurry vision.
- Glare in the eye on the application of light (photophobia).

Besides, the diagnosis of childhood cataract is also done using a visual acuity test. In a visual acuity test, ophthalmologists check the vision of the child from different distances whereas the pupil is dilated to get a closer view of the lens, retina and optic nerve.

#### B. Treatment for Childhood Cataract

The treatment of childhood cataract depends on the density of the cataract. Generally, if the lens opacity is central and more than 3 mm in diameter, it should be removed. The ideal time to perform surgery is as early as possible, after the first 4 weeks of life. Primary intraocular lens implantation is favoured by most ophthalmologists in childhood cataract in developing countries, as aphakia required the use of glasses and contact lens for visual rehabilitation, which becomes difficult in low and middleincome countries. The childhood cataract without the risk of amblyopia is generally avoided for surgery. However. ophthalmologists may continue to prescribe spectacles or contact lens. But, there are certain categories of cataracts such as dense and total cataracts, which require immediate surgical intervention to avoid visual impairment. Posterior capsular opacification (PCO) is the most common complication in childhood cataract surgery.8

#### V. PREVALENCE AND EPIDEMIOLOGY OF CHILDHOOD CATARACT

Despite significant improvements in health services over the last century, health inequalities persist among various population groups. The socio-economically disadvantaged areas of the world experience higher morbidity, mortality and disability rates. In addition, even within the developed and developing countries, inequalities exist based on the socio-economic status of the population. The definition of "Health inequalities" refers to the health status of how worse off is the disadvantaged group from the privileged group. India, China and Africa share almost 75% of the global burden of blindness. The data also indicate a disproportionate burden of blindness in developing countries compared to developed countries.<sup>13,14</sup>

The epidemiology of childhood blindness due to cataract corresponds to socio-economic development, demographic change, public health intervention for childcare, accessibility and the availability of eye care services within a geographical area. Though there is a decline in the absolute number of blind children from 1.4 million in the 1990s to 1.14 million in 2014, it attributes primarily due to the improved performance of the developed countries. In the past two decades, blindness due to corneal scarring has also reduced in low-income countries and cataract has emerged as the most common cause of avoidable blindness.

In a major systematic review, the ratio of girls accessing bilateral cataract surgery was found lower especially in the Asian countries. The possible reason for this may be a gender difference in birth rates reported from China and India. In 2015, the United Nations Population Division reported 12.1 and 13.4 million fewer girls than boys (0-9 years) in China and India respectively.<sup>15</sup> The gender bias was reported in almost all categories of child health care including rates of immunization and nutritional values.

The studies further suggest huge variations in the causes of vision loss across different parts of the world. While low-income countries still face a shortage of health care infrastructure, malnourishment and infectious diseases (rubella, measles), the causes in middle-income countries include congenital cataract and retinopathy of prematurity (ROP) as major causes of childhood blindness. However, in developed countries, hereditary or genetic causes are the primary causes of childhood blindness.<sup>16</sup> Almost 75% of the world's blind children live in Asia and Africa. In these countries, a majority of them live in extreme poverty and childhood cataracts and corneal diseases are the major causes of childhood blindness.

However, in one of the major systemic review published in 2016, the findings did not agree with the earlier reported results and suggested higher prevalence even in high-income countries. Overall, there is a substantial gap in the epidemiological knowledge of childhood cataract and the yearly figure and is reflected in the yearly figure for new childhood cataract cases which varies from 1,91,000 cases to 3,14,000.<sup>16</sup> The prevalence of childhood cataract was also reported with a wide range from 1-15/10000. One possible reason for this huge variation is different methodologies, age group and case definitions being used by the researchers in the past. In one of the studies, reports suggest that with a 2% birth in developed countries, the prevalence of bilateral cataract could be 4 children/million, however, the same may increase to 10 children/million in developing countries due to higher birth rate.17

# VI. RESULTS

The design of the study was retrospective and hospitalbased. Data available with the Central Registration Department of the PGIMER, Chandigarh was used. The majority of the childhood cataract cases are being reported in this hospital, yet not each and every case of childhood cataract approaches PGI, Chandigarh. Nevertheless, this study is going to be pioneering research in India covering five-year data of the childhood cataract patients who visited the Advanced Eye Centre, PGIMER, Chandigarh from 1.1.2015 to 31.12.2019.

354 children were presented for childhood cataract screening and treatment from 1.1.2015 to 31.12.2019. Of 354 children, 248 (70%) were male, and 106 (30%) were female. Further, out of these 354 children registered in the special clinics, 42 were wrongly registered for childhood cataract. Therefore, the final number was 312 children registered in 5 years. Despite two flagship programmes by the Govt. of India, namely the National Programme for Control of Blindness (NPCB) and Aayushman Bharat (PM-JAY), for eradicating cataract-related blindness, only nine children received financial assistance from the Govt of India. Out of 312 patients, 99 children (31.73%) reached late at the hospital, and 39 children did not continue their treatment, mainly due to poverty and transport-related issues. A whopping 99% of these children belong to lowincome families. Out of 39 children who discontinued their treatment, 24 were male, and 15 were female. In most of these families, the mothers were housewives and did not work anywhere. We intend to convey these results to the Govt. of India to evolve a suitable mechanism to address pertinent issues hindering the treatment of children suffering from childhood cataract. Further, the disproportionate ratio of male and female children in this study is an area of concern as it is difficult to assess whether the prevalence of childhood cataract is lower in female children or they are not being presented on time in the hospital by the families.

# VII. DISCUSSION

#### A. Social factors affecting health-seeking behaviour:

The cultural, economical and social conditions of the individual and family can have a substantial influence on the health-seeking behaviour of the individual and family; and remain the most significant determinants of the healthseeking behaviour in low and middle-income countries.<sup>15</sup> Besides, lower educational level of mother and gender disparities were also reported as major reasons in accessing health care services. In low- and middle-income countries, girls from families with higher socioeconomic status are more likely to undergo treatment than girls from lower socioeconomic status. There is a fear of surgeries in parents from lower socio-economic.In the studies conducted in Asia and Africa, the parents of a girl child from a lower socioeconomic background are more likely to delay the presentation of their ailing girl child to hospitals, as they believe that it would be detrimental to her marriage prospects. Besides, the lack of understanding of medical treatment and surgery and fear of visiting urban cities for treatment was also reported as one of the major reasons for delayed presentation.<sup>15</sup>

#### B. Economic Burden of Childhood blindness

As per global estimates, childhood blindness contributes to an enormous loss in earning capacity of US\$ 6000-27000 million. With extrapolation, if we assume a 3% growth rate in the global population, the economic loss over a period of 10 years resulting from childhood cataract varies from US\$ 1000-6000 million. The Indian estimates suggest, a loss of US\$ 3500 million in earning capacity, considering an average of 33 years of blind years due to cataract.<sup>18,19</sup> The latest estimates from Orbis India show that India can incur an economic loss of Rs. 88,000 crore in 2020 with almost 35% of cases of blindness are preventable and curable. It has been reported that with this trend, the country can incur a loss of Rs. 3,31,000 crore in national GDP considering 40 lost working years.<sup>19</sup>

# C. Psychosocial Impact on children & family:

Unlike the cataract in adults, where the results are highly encouraging after surgery, cataracts in children can have detrimental effects on their overall psychology and their families.<sup>20</sup> In childhood cataract, parents play a crucial role in the care of the child and it has been reported in two inductive studies that uncertainty can become a major barrier in self-efficacy. However, to balance the ability or inability of a child, parents generally use a process comprising of four main categories; mastering, collaborating, facilitating and adapting.<sup>20</sup> Their painful journey starts from birth and continues for years with frequent visits to the eye clinics. The parents are also expected to be vigilant in reporting the complications. It has been seen that strict compliance during the treatment such as administering eye drops, handling contact lens, patching and motivating the child for treatment and visiting the hospital can be extremely challenging.<sup>21</sup> Fatigue, physical and mental exhaustion can become barriers for parents as fatigue contributes significantly among parents with children having bilateral cataract. Fatigue can also diminish the meaningfulness and can negatively impact the willingness of the parents to handle contact lenses, eye drops and patching.<sup>21</sup> It has been observed that the mothers are more likely to be affected than fathers during the care of the child; with mental fatigue and lack of motivation jointly contributing as significant barriers for loss in follow up.

During the treatment, most of the children began to feel self-conscious, embarrassed and ashamed. In cases of amblyopia, children experience felt and enacted stigma. Felt stigma refers to the emotions of shame during one's illness. The children also feel that they drew adverse attention from others during and after the treatment. They felt interrogated and being stared at; with these concerns particularly dominant in children with an eye patch and glasses. However, few children responded positively as they thought they look "smarter" and "faster" with glasses. Most children also adopted secrecy to minimize feelings of stigma, prevent breakdown and maintain positively. They often conceal treatment details from their friends and peers. Though the psychosocial impact may differ for each child and family; the level of perceived stigma and social support plays a significant role during and after the treatment.<sup>22</sup>

#### VIII. CONCLUSION

It is difficult to imagine life without vision as it provides rich and immediate details about the objects and facilitates communication in combination with the neurological network. Without vision gathering, information becomes instinctive with conscious attention and is based on the information received by other senses. Psychosocial development in children may also get compromised in the absence of social input that vision offers. Visual impairments often leave the child in a state where they experience the world differently from their sighted peers and often relegate them to live in hopelessness and dependence.<sup>23</sup>

Over the years, the history of science has reflected the tremendous progress achieved by medical sciences and rehabilitation, including advances in the field of optics and technology. Over the past century, rapid strides were made in untraded areas of preventable and avoidable blindness. These advances not only minimized the impact of childhood blindness but also gave newer insights for research to look into the emerging causes of avoidable and preventable With change in time and environment, blindness. demographic centric strategies are required to maximize the efforts for sensitization of pregnant mothers to adopt a healthier lifestyle, with emphasis on the role of nutrition and intrauterine infections like rubella and measles. In addition, synchronized efforts are needed for early detection and management of avoidable causes of childhood blindness such as childhood cataract.

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