

Review Article

A global review of cerebral palsy in children: family caregiver burden, risk factors, prevalence and the evolution of technology and policy

Gaurav Chauhan^{1*}, Mamta Verma², Rajratan Gupta³

¹Department of Pediatrics, AIIMS, Bhopal, Madhya Pradesh, India

²Department of Child Health Nursing, College of Nursing, AIIMS, Bhopal, Madhya Pradesh, India

³Department of Mental Health Nursing, College of Nursing, AIIMS, Bhopal, Madhya Pradesh, India

Received: 05 May 2026

Revised: 10 June 2026

Accepted: 03 July 2026

*Correspondence:

Gaurav Chauhan,

E-mail: gaurav123c@gmail.com

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ABSTRACT

Cerebral palsy (CP) is a group of permanent disorders affecting movement and posture resulting from non-progressive disturbances in the developing foetal or infant brain and remains the most common physical disability in childhood. Despite advances in neonatal care and public health measures, CP continues to impose substantial clinical, social, and economic burdens worldwide. This narrative review aimed to examine the global prevalence of CP, associated clinical and social risk factors, family impacts, and contemporary government policies influencing its management. A comprehensive literature search was conducted using electronic databases, national CP registers, published epidemiological studies, and healthcare policy reports from both high-income and low- and middle-income countries. The review identified significant variations in CP prevalence across regions, with approximately 8.1 million children under five years of age living with CP globally. Birth prevalence has declined to approximately 1.6 per 1,000 live births in high-income countries but remains higher in low-income settings, reaching 3.4 per 1,000 live births, while the estimated prevalence in India is approximately 3 per 1,000 live births. Prematurity, low birth weight, neonatal jaundice, and perinatal complications were identified as major risk factors. Families of children with CP frequently experience increased healthcare expenditures, psychosocial stress, and caregiver burden. Recent technological advances, including machine learning-based screening and diagnostic approaches, have enabled earlier identification of CP between 9 and 18 weeks of age. The review highlights a global shift toward family-centered and technology-supported care; however, substantial disparities in access to advanced interventions persist across different socioeconomic settings. Strengthening affordable early detection strategies, rehabilitation services, and supportive national health policies is essential to reduce inequities and improve outcomes for children with CP and their families.

Keywords: Cerebral palsy, Global prevalence, Risk factors, Caregiver burden, Healthcare policy, Pediatric rehabilitation, Machine learning

INTRODUCTION

The field of pediatric disability is currently seeing significant changes in cerebral palsy, which remains the most common physical disability among children worldwide.^{1,2} In the mid-2020s, our understanding of CP

has shifted from a simple neurological diagnosis to a complex life experience shaped by social status, health policy, and technology. In 2019, an estimated 8.1 million children under age 5 lived with CP globally, with over 98% in low- and middle-income countries (LMICs).³ If intellectual disability is included, the number rises to 16.1 million.³ These figures show deep global health

inequalities. This review explores global prevalence, risk factors, family consequences, and government strategies to manage this lifelong condition across different economic settings.

Cerebral palsy is not a single disease entity but rather a heterogeneous group of disorders affecting movement and posture.¹ These disorders are permanent and non-progressive, resulting from disturbances that occur in the developing fetal or infant brain.⁴ While the primary clinical manifestation is motor impairment, the clinical picture is frequently complicated by a "constellation" of comorbidities. These include, but are not limited to, epilepsy, sensory impairments, cognitive and behavioural disturbances, and secondary musculoskeletal problems like muscle contractures and hip displacement.⁵

For decades, the standard epidemiological claim was that CP prevalence remained "stationary" at approximately 2 per 1,000 live births.² However, modern registers, such as those in Western Sweden and Western Australia, have debunked this myth, revealing significant fluctuations between 1.4 and 2.5 per 1,000 live births over decades and, more recently, a downward trend in both prevalence and severity in high-income countries.² A systematic analysis confirms the current birth prevalence of pre-/perinatal CP at 1.6 per 1,000 live births in HICs, contrasting with markedly higher rates of 3.4 per 1,000 in LMICs.^{4,6} Post-2010 meta-analyses report 0.2% in HICs and 0.3% in LMICs for children up to 18 years. However, global estimates vary by motor impairment severity.⁷ This shift in HICs is attributed to advances in obstetric care, neonatal intensive care, and public health awareness regarding healthy pregnancies.² Conversely, in LMICs, prevalence remains alarmingly high, reflecting persistent challenges like limited surveillance and higher rates of preventable causes.^{6,8} Sociodemographic factors exacerbate CP risk. Lower socioeconomic status shows a linear association with CP incidence, linked to higher preterm birth and asphyxia rates.⁹ Rural residence increases risk, with an attributable fraction of 64% in Moldova.¹⁰ Clinical risks include preterm birth, low birth weight, birth asphyxia, neonatal jaundice, hyperbilirubinemia, and kernicterus—pathways largely eliminated in HICs but prevalent in LMICs.^{2,11,12}

The management of CP has also undergone a paradigm shift. There is now a move toward "person-centred care" and "family-centred approaches," as emphasised by United Nations directives and implemented in national schemes like Australia's NDIS.^{13,14} This recognises that child well-being is linked to caregivers' health-related quality of life.¹⁴ However, families face substantial burdens: caregivers experience anxiety, depression, stress, financial strain, and reduced quality of life, intensified by child severity and lack of support.¹⁴⁻¹⁶

Amid evolving epidemiology and management paradigms, gaps persist in synthesising sociodemographic disparities, family impacts, and policy responses across

HICs and LMICs.^{2,6} Given that 98% of CP cases occur in LMICs, this narrative review addresses these gaps, informing equitable interventions and policies to mitigate global inequalities.³

METHODS

To conduct this comprehensive review, we comprehensively searched PubMed/MEDLINE, Embase, Scopus, Web of Science, Cochrane Library, PsycINFO, CINAHL, and Google Scholar from January 2000 to October 2024 using Boolean combinations of MeSH terms and keywords such as ("cerebral palsy" OR "CP") AND ("prevalence" OR "incidence" OR "epidemiology") AND ("child*" OR "pediatric*" OR "infant*") for global prevalence; ("risk factor*" OR "sociodemographic" OR "clinical factor*" OR "maternal" OR "perinatal" OR "prematurity") AND "cerebral palsy" AND "child*" for sociodemographic and clinical factors; ("family" OR "caregiver*" OR "burden" OR "consequence*") AND "cerebral palsy" AND "child*" for family impacts; and ("policy" OR "government*" OR "intervention*" OR "NDIS" OR "support") AND "cerebral palsy" AND "child*" for governmental policies, with no language restrictions but prioritizing English-language peer-reviewed articles on children under 18 years.^{6,17,18}

GLOBAL PREVALENCE AND EPIDEMIOLOGICAL SHIFTS

The global burden in numbers

In 2019, a collaborative study by the Global burden of disease and the World Health Organisation estimated that 8.1 million children under the age of 5 worldwide were living with CP.³ This represents approximately 1.2% of the global under-five population.³ When intellectual disabilities are included as a comorbidity, the number of affected children rises to 16.1 million (2.4%).³

The geographic distribution of this burden is highly skewed. Over 98% of children with CP reside in LMICs.³ The African region records the highest prevalence at 1.6%, while South-East Asia faces the highest prevalence of associated intellectual disabilities.³ In terms of disability-adjusted metrics, CP and intellectual disability account for a significant portion of "years lived with disability" globally.³

Trends in high-income vs. Low-income countries

A systematic analysis reveals that the birth prevalence of pre- and perinatal CP in HICs is currently around 1.6 per 1,000 live births.⁶ In contrast, the reported prevalence in LMICs is significantly higher, at 3.4 per 1,000 live births.⁴ Some meta-analyses focusing on children born after 2010 suggest birth prevalence rates of 0.2% for HICs and 0.3% for LMICs, though these figures vary depending on whether moderate to severe motor impairment is the primary inclusion criterion.⁷

The "continually changing" nature of CP epidemiology is best exemplified by the 60-year data from Western Australian and Swedish registers.² These data show that prevalence has ranged from 1.4 to 2.5 per 1,000 live births over the decades, never truly plateauing.² Notably, severe subtypes—such as dyskinetic CP and tetraplegia—are decreasing in Sweden as clinical practices improve.² A major victory in HICs has been the near-elimination of CP following kernicterus, a pathway that once accounted for significant morbidity.² However, this same pathway remains a major cause of CP in LMICs, where thousands of children continue to suffer from this preventable condition due to a lack of inexpensive, scalable screening and treatment for neonatal jaundice.²

Prevalence in India

While global estimates indicate a prevalence of 2-2.5 cases per 1000 live births, specific data from India suggest a rate of approximately three cases per 1000 live births. However, the actual incidence may be higher.¹⁹ This elevated prevalence within India may reflect a confluence of factors, including heterogeneous healthcare infrastructure, varied access to perinatal care, and diverse socioeconomic conditions across its vast population.²⁰

SOCIODEMOGRAPHIC AND CLINICAL RISK FACTORS

The etiological landscape of CP is a complex tapestry of biological vulnerability and environmental disadvantage.

Socioeconomic status and regionality

Socioeconomic status is a potent predictor of CP risk. Retrospective cohort studies in the United Kingdom and Sweden have consistently found a linear association between lower SES and increased risk of CP.^{9,21} In Sweden, the incidence of unspecified CP was highest among families with the lowest SES, a trend partially explained by higher rates of preterm birth, low Apgar scores, and asphyxia in these populations.⁹ Regionality also plays a critical role. In Moldova, a low- to middle-income country, children born in rural areas had a significantly higher risk of CP (OR 1.6). Multivariable analysis in this population showed that rural residence accounted for an attributable fraction of 64% for CP cases. This is often linked to poorer access to maternity care and higher rates of home births.¹⁰

Maternal and prenatal factors

Maternal health before and during pregnancy sets the foundation for neurodevelopment. Key risk factors identified in the literature include:

Maternal health conditions

Hypertension (OR 2.0) and epilepsy (OR 4.3) are significant indicators of risk.¹⁰

Substance use

Maternal alcohol consumption during pregnancy increases the risk of CP (OR 1.7).¹⁰

Demographics

Advanced maternal age (≥ 35 years) was surprisingly noted as a protective factor in some cohorts (OR 0.6), possibly due to higher SES or better health literacy in older mothers in specific contexts.¹⁰

Education and income

In a Turkish study, 41.9% of mothers of children with CP were illiterate, and 73.3% lived in low-income households.²² Furthermore, 51% of these parents were related, highlighting consanguinity as a notable etiological factor in certain cultural regions.²²

Perinatal and neonatal clinical factors

The perinatal period remains the most critical window for CP prevention.

Prematurity and birth weight

Prematurity is a dominant clinical factor, with 73.3% of children in some CP cohorts being born preterm.²² Low birth weight (<2500 g) affected 48.1% of these children.²²

Delivery complications

Breech delivery (OR 3.1), home births (OR 6.3-7.6), and umbilical cord complications (OR 2.2) are major contributors, especially in settings where emergency obstetric care is unavailable.¹⁰

Neonatal illness

Hyperbilirubinemia (jaundice) carries a massive risk (OR 4.5-5.4, AF 81%) in LMICs.¹⁰ Additionally, neonatal hypoxia increases the risk of not just CP, but also secondary neurodevelopmental disorders like epilepsy.⁵

Clinical classification and functional assessment

Historically, CP was described through the "Minear seven axes," which included physiological, topographic, and etiologic classifications.²³ However, modern practice has shifted toward standardised functional systems that focus on a child's performance in daily life.¹

The functional classification systems

To classify the various functions of children with CP in a simple, standardised, and inexpensive way, clinicians now utilise several reliable scales.²⁴

Gross motor function classification system

This is the gold standard for classifying functional mobility in children with cerebral palsy. Level I indicates children who walk without limitations, while level II includes those who walk with limitations.

Level III describes children who walk using a hand-held mobility device. Level IV refers to individuals with self-mobility but significant limitations, who may use powered mobility. Level V represents children who are transported in a manual wheelchair due to severe limitations in independent mobility.

Manual ability classification system

The Manual ability classification system describes how children handle objects. Level I indicates children who handle objects easily and successfully. Level III refers to those who handle objects with difficulty and require assistance to prepare activities.

Level V describes children who are unable to handle objects and have severely limited ability even for simple actions. The Communication function classification system evaluates the effectiveness of a child as a sender and receiver of information. Level I represents children who are effective communicators with both familiar and unfamiliar partners, while level V includes those who are rarely effective as a sender or receiver even with familiar partners.

Eating and drinking ability classification system

The eating and drinking ability classification system assesses the safety and efficiency of eating and drinking. Level I indicates children who eat and drink safely and efficiently, while level V describes those who are unable to eat or drink safely and may require tube feeding.

Correlation between functions

Research has shown strong correlations between these systems, particularly in children with severe forms of CP (quadriplegia).²⁴ For instance, GMFCS levels are often highly correlated with MACS levels.²⁴

However, the correlation between gross motor function and communication is often only moderate, reminding clinicians that a child with significant physical limitations may still possess high communicative potential, or vice versa.²⁴

CONSEQUENCES FOR FAMILIES AND CAREGIVERS

The impact of CP extends far beyond the individual child, creating a "ripple effect" that affects the entire family ecosystem.

Psychological burden and "chronic sorrow"

Caregivers of children with CP experience significantly higher rates of anxiety, depression, stress, and burnout.^{14,26,27} These parents often face "chronic sorrow"—a lingering grief that resurfaces as the child misses developmental milestones.²⁷ Isolation and "experiential avoidance" are common, as families may withdraw from social participation due to the demands of care or the stigma attached to disability.^{27,28}

Studies have shown that as the child's functional impairment (GMFCS/MACS level) increases, so does the level of caregiver burnout and mental health deterioration.²⁶ This is compounded by the fact that caregiver burden often increases as the child grows older and heavier, making physical care more taxing.¹⁴

Economic strain

The financial burden of CP is "staggering" and often exceeds family expectations.²⁹ In South Korea, the mean total lifetime healthcare cost for a child with CP is \$26,383, which is 1.8 times the cost for the general population (\$14,579).²⁹ In other settings, children with CP may require medical services at rates 13 times higher than typical children.²⁹ These costs are not merely medical; they include assistive technology, home modifications, and the loss of income when a parent must quit their job to become a full-time caregiver.³⁰

Cultural and social contexts

The caregiving experience is deeply influenced by cultural context. Comparisons between English-speaking and Korean-speaking caregivers using the CPCHILD tool revealed significant differences in responses, despite similar child characteristics.³¹ This suggests that cultural perceptions of disability and the availability of community support significantly alter how parents perceive their quality of life.³¹ In LMICs like Mexico and Zimbabwe, social stigma and limited access to professional rehabilitation force families to rely on traditional beliefs or non-governmental support.^{28,30}

GOVERNMENTAL POLICIES AND HEALTHCARE SYSTEMS

National policies dictate the level of support a family receives, and the global landscape reveals profound inequities.

The Australian national disability insurance scheme

Australia's NDIS, legislated in 2013, represents a major policy shift toward "choice and control".^{13,32} Funded through taxation, the NDIS provides individualised funding packages that allow participants to purchase the supports they need to meet their life goals and participate in society.^{32,33} However, the implementation has received

mixed reviews. While it brings the principles of the UN CRPD into domestic law, critics argue that the policy is "fragmented" and "coercive".^{34,35} Families often find themselves navigating a complex "pathological categorisation" system rather than receiving integrated support.³⁵ Furthermore, there are tensions regarding how the NDIS supports access to education, with some arguing it creates a distance between the policy and other vital service systems.³⁴

New Zealand: a dual pathway

Aotearoa New Zealand operates a unique disability support system with two distinct pathways: the accident compensation corporation and the health districts.³⁶ This dual system has been critiqued for creating significant inequities; children supported by the ACC (for injury-related disability) often receive more comprehensive support than those supported through health districts.³⁶ These inequities particularly impact Māori and Pacific people, prompting calls for a system-wide review following the establishment of the Ministry for disabled people.³⁶

European and global disparities

In Europe, access to advanced treatments like intrathecal Baclofen pumps—a critical intervention for severe spasticity—is directly tied to a country's GDP.³⁷ Countries with higher health spending offer significantly better access to these "advanced care" indicators.³⁷

In LMICs, the situation is more dire. In Ghana, healthcare providers express frustration with national health insurance policies that do not cover specialised pharmaceuticals and infrastructure needs for CP care.³⁸ In Mexico, the government healthcare system often lacks the resources for early diagnosis and rehabilitation, leaving non-governmental organisations like the Mexican academy of cerebral palsy to provide essential services.²⁸ These NGOs are "pivotal" in filling the gaps, providing evidence-based medicine and assistive technology that the state cannot.²⁸

Indian context

The Indian context presents its own challenges, where fragmented policies and a lack of standardized care pathways exacerbate existing disparities in accessing comprehensive support services for children with cerebral palsy.^{39,40} Despite governmental policies and guidelines advocating for early support, the capacity and availability of services, regional differences in provision—particularly stark between urban and rural areas—and delays in assessment processes remain significant barriers to accessing timely intervention or, in some instances, primary health care systems struggle with inadequate staffing, limited resources, and low community engagement in rural settings, prompting calls for integrated outreach centers.^{39,40,42} This often results in a significant number of

children failing to receive appropriate and integrated therapeutic care, with studies in Maharashtra reporting low rates of visual/hearing assessments and rehabilitation initiation.⁴³⁻⁴⁵ Cross-sectional data from Gujarat further underscore the burden, with most children classified at Gross motor function classification system levels III-IV and parents facing financial strain, social isolation, and shortages of trained physiotherapists.⁴⁶⁻⁴⁷ Experts advocate for infrastructural reforms, increased numbers of skilled professionals, a national CP registry, and family-centred approaches incorporating ICF principles to bridge these gaps.^{41,45,48}

TECHNOLOGICAL ADVANCEMENTS IN REHABILITATION

The future of CP care is being rewritten by digital innovation and high-precision technology.

Artificial intelligence and machine learning

Machine learning is revolutionising pediatric neurorehabilitation by providing objective, high-speed assessment tools.⁴⁹

Early detection

Deep learning models can now predict CP in high-risk infants as early as 9 to 18 weeks of age by analysing a single video of their spontaneous movements. This allows for intervention during the "critical window of neuroplasticity".⁴⁹

Gait analysis

ML algorithms can interpret complex 3D gait data and automatically generate high-quality analysis results, identifying sagittal gait patterns in children with diplegic CP.⁴⁹

Robotic interaction

ML allows rehabilitation robots to perceive a child's "affective state" and movement intentions, adaptively adjusting the difficulty level to keep the child engaged and motivated.⁴⁹

Robotics and virtual reality

Conventional therapy often suffers from a "lack of engagement" and limited personalisation.⁵⁰ Digital therapeutic platforms are addressing this through gamification and VR.⁵⁰

VR rehabilitation

Immersive virtual environments allow children to perform reaching, grasping, and gait training in scenarios that mimic the real world but are safe and controllable.⁴

These systems provide immediate, accurate biofeedback, which is essential for motor learning.⁴

Robotic-assisted training

High-precision robots provide the repetitive, intensive training required for neuroplastic changes.⁴⁹ Portable robots can now be integrated into home-based programs, yielding outcomes similar to those of laboratory-based therapy.⁵¹

Telerehabilitation

The COVID-19 pandemic accelerated the adoption of telerehabilitation.⁵² Research during the lockdowns showed that TR—using computer games, robots, and wearable haptic devices—is a "significant means" of maintaining functional gains when in-person therapy is inhibited.⁵² TR is considered a viable "alternative to routine therapy" for families who lack daily access to clinical centres due to geography or financial constraints.⁵²

SYNTHESIS AND THE "EQUITY GAP"

The literature presented in this review reveals a profound "equity gap" in the global management of Cerebral palsy. While high-income nations are debating the finer points of "choice and control" within individualised funding schemes and testing deep-learning models for early detection, low-income nations are still grappling with a "staggering number" of severe CP cases caused by preventable neonatal jaundice (kernicterus).^{2,33,49} The "changing panorama" of CP epidemiology is a testament to the power of medical advancement, but it also highlights the urgent need for "inexpensive, scalable treatments" in LMICs.² The fact that birth prevalence can range from 1.4/1000 in Sweden to 3.4/1000 globally indicates that a significant portion of the global CP burden is entirely avoidable.²⁻⁴

Furthermore, the review emphasises that CP is a family-level disability. The consensus across global literature—from Zimbabwe to Korea—is that the caregiver's mental and physical health is a critical predictor of the child's functional success.^{14,30,31} Policies like the NDIS in Australia and the dual pathway in New Zealand must be continuously critiqued to ensure they don't add an "administrative burden" to families already facing "chronic sorrow" and "financial strain".^{27,35,36} Finally, technology offers a path forward, but only if it is accessible. Machine learning for early screening could be a "low-cost, swift" solution for LMICs if implemented via mobile applications, bypassing the need for hours of certified clinician time.⁴⁹

CONCLUSION

Cerebral palsy remains the most prevalent motor disability in childhood; however, contemporary evidence

demonstrates that its epidemiology is dynamic and strongly influenced by medical, social, and economic factors. This review highlights substantial disparities in prevalence between high-income and low- and middle-income countries, with preventable perinatal conditions continuing to contribute significantly to the burden of disease in resource-limited settings.

Sociodemographic factors, particularly low socioeconomic status and rural residence, play a critical role in determining risk and access to healthcare services, emphasizing the need for strengthened public health and maternal care programs. The widespread adoption of standardized functional classification systems has improved the assessment of abilities and participation, facilitating more consistent clinical management and research. In addition, the growing emphasis on family-centered care recognizes caregiver well-being as an essential component of successful rehabilitation and long-term outcomes. Emerging technologies, including artificial intelligence, robotics, and telerehabilitation, offer promising opportunities for earlier diagnosis, enhanced engagement in therapy, and improved functional outcomes.

By synthesizing current evidence on epidemiological trends, risk factors, functional assessment, caregiver impact, and technological innovations, this review advances understanding of the multifaceted nature of cerebral palsy and underscores the importance of equitable access to early intervention, rehabilitation services, and supportive health policies. Addressing the clinical, social, and economic barriers identified in this review is essential to reducing disparities and ensuring improved quality of life and opportunities for all children with cerebral palsy, regardless of their geographic or socioeconomic background.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: Not required

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Cite this article as: Chauhan G, Verma M, Gupta R. A global review of cerebral palsy in children: family caregiver burden, risk factors, prevalence and the evolution of technology and policy. *Int J Contemp Pediatr* 2026;13:1566-73.