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Korean Cerebral Palsy Registry (KCPR): study rationale and protocol of a multicentre prospective cohort study

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ABSTRACT

Introduction Cerebral palsy (CP) is a leading cause of motor developmental disability in children. Generating epidemiological data on CP could enable early diagnosis, intervention and translational research. We aim to establish a Korean network and online data repository for CP called the Korean Cerebral Palsy Registry (KCPR).

Methods and analysis The KCPR is a nationwide, multicentre, prospective cohort study designed to conduct a 20-year longitudinal follow-up of children with CP. Institution-based surveillance involving 42 institutions across the country will be used for the registration of children with CP aged less than 7 years to participate in KCPR. The data collection form of the KCPR will comprise diagnostic information, risk factors, extent of disability, genetic data, quality of life, socioeconomic status, functional levels according to life cycle stages and patterns of healthcare utilisation, including rehabilitation. The primary goal of KCPR is to establish a national data repository for CP in Korea, providing a platform for continuous monitoring and analysis of CP cases. Based on its role as a registry, KCPR will support various research projects to enhance the understanding and management of CP. The specific objectives of research projects using KCPR data include: (1) identifying the pathological characteristics of CP and their associated medical, social, economic and psychological needs; (2) using data from prospective tracking of CP children's function and quality of life to develop integrated service plans and policies and (3) conducting intervention cohort studies to establish guidelines for standardised rehabilitative medical services.

Ethics and dissemination The study protocol was approved by the ethics committees of all 42 participating hospitals. Findings from this study will be disseminated in peer-reviewed publications.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The Korean Cerebral Palsy Registry is a nationwide, multicentre, prospective cohort study designed for comprehensive tracking of cerebral palsy over 20 years.
- ⇒ A web-based electronic case report form ensures centralised data management, real-time monitoring and quality control across 42 institutions.
- ⇒ The study employs a standardised data collection system, integrating medical records, caregiver interviews and direct assessments to enhance reliability.
- ⇒ Annual follow-up assessments will track functional classifications, rehabilitation status and other health indicators.
- ⇒ Institution-based registration may lead to a risk of selection bias, requiring caution in data interpretation.

INTRODUCTION

Cerebral palsy (CP) is a leading cause of motor disorders in children, with an estimated 2–3 cases per 1000 live births.[1 2] The aetiology of CP is multifaceted, originating from structural or functional brain damage that occurs during brain development, leading to disorders of movement and posture.[3] In addition to motor impairment, individuals with CP may also exhibit symptoms such as communication challenges, cognitive deficits, secondary musculoskeletal issues, sensory impairments and epilepsy.[4] Limitations in activity and participation may persist throughout an individual's lifespan. Consequently, management and medical support are necessary for various issues that may arise during the development process.

Long-term and continuous rehabilitative medical services are required for children with CP, which are intertwined with their growth and development. These services should be complemented by appropriate treatments at various life stages, support for community living and phased education. To enhance the all-encompassing development of children with CP and provide comprehensive services across medical, educational and social domains throughout their lifespan from infancy, certain countries have established CP registry systems or networks, such as the Surveillance of Cerebral Palsy in Europe (SCPE)[5] or Australian Cerebral Palsy Register (ACPR).[2] Over the decades, these registries have systematically collected and analysed data on CP, establishing a foundation for identifying causes and developing policies for prevention, medical care and educational services. Nonetheless, establishing a comprehensive platform for collecting and validating data remains challenging, and a registry that accurately captures the situation in each country is imperative.

The Korea Database of Cerebral Palsy (KDCP), which was established as the first CP register in South Korea, was initiated in 2009 by the Korean Society of Pediatric Rehabilitation and Developmental Medicine (KSPRDM). The KSPRDM is an academic association comprising professionals committed to serving children with disabilities across South Korea. However, the KDCP collected cross-sectional data from 773 individuals, focusing solely on epidemiology and failing to track or report long-term changes.[6] This lack of long-term epidemiological data regarding CP in South Korea is a significant concern. To address this need, the Korean Cerebral Palsy Registry (KCPR) has been established. This initiative will enable the identification of preventable risk factors for CP and facilitate the development of good clinical practice guidelines for children with CP.

Objectives

The primary purpose of the KCPR is to create a national data repository for CP in South Korea, serving as a robust platform for analysing the epidemiological trends of CP in South Korea. In addition to its role as a registry, the KCPR will support a range of research activities aimed at improving the understanding and management of CP. The specific objectives of research using KCPR data are as follows:

i. To identify the pathological characteristics of CP along with their medical, social, economic and psychological needs and challenges.
ii. To develop comprehensive service plans and policies that integrate medical care, special education and welfare based on data accumulated through the prospective tracking of the function and quality of life of children with CP.
iii. To conduct intervention cohort studies to create guidelines for the provision of standardised rehabilitative medical services.

METHODS AND ANALYSIS

Study design

KCPR is a nationwide, multicentre, prospective institution-based cohort study of children with CP. This 20-year longitudinal follow-up study of children with CP is a multicentre project involving 42 institutions (38 general hospitals and four rehabilitation hospitals) across the country (online supplemental additional file 1), and if there are institutions interested in registering with KCPR, their inclusion will be considered through a representative meeting. Regular meetings, shared protocols and centralised data management will ensure consistency and reliability across all sites, facilitating cooperation among the 42 institutions involved. The first participant was enrolled on 23 June 2023, and participant registration is ongoing.

Sample size

The target sample size was determined based on the incidence of CP. Considering that the incidence rate of CP in South Korea is 2–3 per 1000 children (2.5 average) and the current annual birth rate is approximately 250 000, approximately 625 new CP cases are estimated to occur each year. Using the G*Power V.3.1.9 programme with a population size of 625, a confidence level of 90% and a margin of error of 5%, the sample size of the population was estimated to be 189. Factoring in a dropout rate of 6%, the annual target number of participants was set at 200. As the study includes children with CP aged under 7 years, the total number of participants over a 3-year enrolment period was set to be at least 800. This is a longitudinal cohort study that continuously recruits 200 new children with CP annually while maintaining long-term follow-up of enrolled participants.

Participants

Children who meet the following criteria will be considered for enrolment in this cohort study: (1) confirmed diagnosis of CP[7] by a paediatric physiatrist, (2) age 12 months to 6 years 11 months at the time of recruitment and (3) willingness of participants and parents to participate in the study. The exclusion criteria are as follows: (1) children less than 11 months old based on their birth date or older than 7 years (84 months), (2) diagnosis of a progressive neurological disorder, such as neurodegenerative diseases or metabolic disorders, (3) severe hypotonia associated with genetic disorder, including primary neuromuscular involvement, or an unknown cause and (4) unwillingness to participate in the study. Participants will be withdrawn from this study if they (1) cannot be contacted or decline to participate, (2) are later diagnosed with a progressive disorder after an initial clinical diagnosis of CP, (3) demonstrate normal development after initial diagnosis with CP or (5) relocate outside of South Korea during the study period.

Patient and public involvement statement

No participants or their caregivers have been engaged in the planning, execution or development of this study.

Consent

For the consent process to participate in this cohort, written informed consent will be obtained from the primary caregivers prior to registration in KCPR, through face-to-face recruitment at the institutions. During the consent process, participants will be given the option to directly choose the retention period for clinical information and personal identifiers (eg, resident registration number) as either permanent or semipermanent (30 years). Additionally, if clinical information needs to be obtained from KCPR participating institutions other than the registering institution, consent will also be sought for the authority to review such information.

Once the institution that initially decided to participate has obtained the consent form, the registration for KCPR can proceed. If, at a later stage, it becomes necessary to change the institution due to various circumstances, the institution transfer process will be followed to ensure continuity of follow-up observations.

Participants or caregivers have the right to withdraw their consent at any time and for any reason. In the event of withdrawal, researchers will confirm whether the participant agrees to the storage of the information collected up to that point. If they do not wish to retain the collected information, all such information will be deleted.

Procedure

The recruitment process will be institution based, targeting children with CP who have access to outpatient clinics or rehabilitation therapies at hospitals. Participants will be recruited from 38 general hospitals and four rehabilitation hospitals, which comprise outpatient and inpatient facilities located across all areas of South Korea. At each hospital, an experienced paediatric physiatrist and physiotherapist/occupational therapist participated as researchers.

A web-based electronic case report form (eCRF) was developed to record all the collected data. Information will be stored on a secure server of the KCPR as coded non-identifiable data. All information, including hospital records, personal data and research data, will be kept strictly confidential according to the South Korea General Data Protection Regulation. Participants will be assigned a subject identification number (SID). The corresponding data will be kept anonymous and coded with the same assigned SID for consistency. To prevent duplicate registration, the system was designed to compare the participant's name, date of birth, gender and the dates of birth of parents in order to verify the presence of duplicate records among existing registrants. In the case of duplicate information, the registrant will be notified for verification

To ensure the reliability and validity of the data, several measures have been implemented. First, the eCRF has been designed with built-in logic checks and validation rules to minimise data entry errors and ensure consistency. Second, all researchers involved in assessment and data entry will undergo comprehensive training, including standardised procedures for data collection and entry. Third, regular data audits will be conducted throughout the study period to identify and correct any discrepancies or inconsistencies in the data.

Measurements

This 20-year longitudinal follow-up study of children with CP is a prospective multicentre project. The data collection form of the KCPR will comprise diagnostic information, risk factors, extent of disability, genetic data, quality of life, socioeconomic status, functional levels according to life cycle stages and patterns of healthcare utilisation, including rehabilitation. The methods and formats of data collection in this study were informed by the guidelines of SCPE[8] and ACPR,[9] which have been successfully established and stably operated as CP registries or networks for several decades. All data will be collected at the time of registration as the baseline assessment, and follow-up assessments will be performed once per year. There are three methods of data collection, as follows: (1) confirmation of documents, such as medical records or official government documents, such as birth certificates, (2) caregiver interviews relying on their memory and (3) direct measurement and evaluation by researchers. A multidisciplinary team comprising rehabilitation specialists and physiotherapist/occupational therapist researchers will be involved in improving the quality of data collection. To minimise errors such as recall bias, information should be cross-checked among the three methods, if available. The configuration of the collected information, timing and type of collection method are described in table 1, and the detailed categoric organisation and information acquisition methods are described in online supplemental additional file 2.

Baseline assessment

Demographic data

Information about the patient's age, date of birth, sex, current residence and country of birth at the time of registration would be collected. The main method of data collection is the interview of the patient's caregiver; however, confirmation should be performed if official documents such as the Household Register Resident Register and Family Relations Certificate are available.

Family information

Data related to the biological father and mother of the participant, such as age, occupation, marital status and highest level of academic qualification, will be collected in this category. In this category, interviews with patients' parents are the main method of information collection; however, if possible, cross-checking should be performed using their identification card, certificate of employment and certificate of degree.

Pregnancy-related information

Information about the obstetric history of the biological mother, as well as the pregnancy-related history of registered patients, such as a history of multiple gestations, order of birth, amount of amniotic fluid and use of assisted reproductive technology, will be collected. The medical history of biological mothers, such as hypertension and diabetes, will also be collected. The main method of collecting information is by interviewing the caregivers. However, cross-checking should be performed if medical records by an obstetrician or paediatrician where the registered patient was born could be obtained.

Delivery-related history

Delivery-related histories, such as delivery mode and ante/perinatal history, will be included in this category. For items with a low probability of recall bias, such as delivery

Table 1 Baseline structured questionnaires for patients with cerebral palsy in the Korean Cerebral Palsy Registry study

		Time of collection		Collection method		
Category	**Item**	**Initial**	**Follow-up**	**Document**	**Caregiver interview**	**Researcher assessment**
Demographic data	Birth date, age, sex, current residence	▨		▨	■	
Family information	Parent's birth date, parent's age at time of delivery, parent's country of birth, parent's country of origin, parents' highest level of academic qualification at time of delivery, parents' occupation, marital status	▨		▨	■	
Pregnancy-related information	Obstetric history, singleton/multiple gestation, order of birth, amount of amniotic fluid during pregnancy, usage of assisted reproductive technology, maternal history of diabetes, maternal history of hypertension	▨		▨	■	
Delivery-related history	Delivery mode	▨		▨	■	
	Antenatal/perinatal history	▨		■	▨	
Birth-related history	Gestational age, birth weight, place of facility, estimated date of confinement, facility of birth, birth hospital level of care	▨		▨	■	
Neonatal care-related information	Apgar score at 1/5 min, need for initial resuscitation, neonatal history of convulsion, neonatal history of care	▨		■		
	Length of stay in neonatal intensive care unit (days)	▨		▨	■	
	Place of neonatal care	▨		■	▨	
Diagnostic information	Timing of brain injury, aetiological factors of brain injury, congenital malformation, result of genetic study, classification of MRI/ultrasound of the brain (neonatal neuroimaging classification system/MRI classification system)	▨		■		
	Predominant±secondary motor types of cerebral palsy with involved side	▨				■
	Age at which motor disorder was first described as cerebral palsy by clinician, first recommended period of rehabilitation therapy	▨			■	
Descriptions of the functional classification	Gross Motor Function Classification System, Fine Motor Function Scale: Manual Ability Classification System (MACS), mini-MACS, Communication scale: Viking speech scale, Eating Scale: Eating and Drinking Ability Classification System (EDACS), EDACS assistant level, Visuomotor scale: Visual Function Classification System	▨	▨			■
Associated problem	Cognitive impairment	▨	▨	■		▨
	Epilepsy, strabismus, Retinopathy of prematurity, hearing impairment, respiratory/airway management	▨	▨	■	▨	
Musculoskeletal condition	Hip subluxation, scoliosis	▨	▨			■
Nutritional status	Route of nutritional supply	▨	▨		▨	■
	Current height and weight, current head circumference, body mass index	▨	▨			■
Rehabilitation status	Types of rehabilitation services received in the past 3 months, facility of rehabilitation	▨	▨		■	
Management history	Orthosis possession status	▨	▨		▨	■
	History of botulinum toxin injection, history of orthopaedic surgery/neurosurgery	▨	▨	▨	■	

Continued

Table 1 Continued

		Time of collection		Collection method		
Category	**Item**	**Initial**	**Follow-up**	**Document**	**Caregiver interview**	**Researcher assessment**
Socioeconomic status	Medical insurance service in use, gross household annual income	░	░		▓	
Developmental assessment	Gross Motor Function Measure-88, Bayley Scales of Infant and Toddler Development 3rd edition, speech evaluation (Sequenced Language Scale for Infants, Preschool Receptive—Expressive Language Scale, Language Scale for School-Aged Children, Urimal Test of Articulation and Phonation), cognitive function (Social Maturity Scale, Wechsler Preschool and Primary Scale of Intelligence, Wechsler Intelligence Scale for Children, Visuo-Motor Integration), Childhood Autism Rating Scale-2	░	░	▓		

Shading indicates items corresponding to the time of collection or collection method. The darker shading indicates the most reliable information among the data collection methods that were cross-checked. If the information between the collected methods differs, the information corresponding to the darker shading should be collected.

mode, interviewing the parents is the main method of data collection. However, for items related to medical treatment, such as the use of steroids before pregnancy, the data should be collected only if the medical record containing the information is available or if caregivers remember the related information accurately.

Birth-related history

In this category, the patient's birth history, including birth weight, gestational age at the time of birth and facility of birth-related information, will be collected. Data collection should be performed only if the caregivers clearly remember the related information or if the birth certificate is available. In the case of information that is not directly included in the birth certificate, such as the expected date of birth and birth hospital level of care, the researcher calculates the date using the gestational age and date of birth and searches the hospital-related information based on the address of birth recorded in the birth certificate.

Neonatal care-related information

The category of neonatal care includes the Apgar score at 1 and 5 min after birth as well as whether and how to perform initial resuscitation. If there is a history of neonatal intensive care unit (NICU) care, related items such as the presence of neonatal convulsions, length of NICU stay and types of therapeutic modality, including mechanical ventilation and neonatal cooling therapy, would be filled out. This category should be filled out only if there is a medical record from an obstetrician or paediatrician at the hospital where the patient was born.

Diagnostic information

Data in this category would be collected by the timing of brain injury, aetiological factors related to CP, motor subtype classifications based on symptoms, concomitant diseases such as congenital deformities and genetic abnormalities, and information about brain images taken during the neonatal period and/or later. All data should be written by a medical doctor with extensive medical knowledge of CP. Motor types and topographic patterns would be classified according to the SCPE.[10] Classifications of congenital anomalies are based on the International Statistical Classification of Diseases and Related Health Problems 10th Revision and European Concerted Action on Congenital Anomalies and Twins Guide 1.5.[11] Free texts can also be used to describe congenital anomalies. Brain imaging classification is based on the MRI classification system and neonatal neuroimaging classification system (NNICS)[12] according to the period of brain imaging being taken before and after the neonatal period. Only MRI of the brain and cranial ultrasonography should be used for NNICS.[13] Both imaging classifications are based on raw imaging data or official image-reading documents. This information is based on the caregivers' interviews, but cross-checking should be recommended if the medical record is available.

Descriptions of the functional classification

In this category, detailed information on the functional level of enrolled patients would be collected. Based on the time of measurement, the researcher should perform the functional classification of the registered patient. All functional classification tools have been widely used in patients with CP and have been recognised for their reliability and validity.[14–19] In this study, the Gross Motor Function Classification System is used for gross motor function, and the Manual Ability Classification System (MACS) or mini-MACS is used to classify fine motor function depending on age: 1–4 years old for mini-MACS and 4–18 years old for MACS. The Communication Function Classification System is used for communication function, the Viking Speech Scale is used for speech performance, and Eating and Drinking Ability Classification System (EDACS) and EDACS assistance level are used for eating and drinking ability as well as the level of assistance. The Visual Function Classification System is used for visuomotor function. All types of classifications should be evaluated by a physiatrist or physical/occupational therapist with extensive medical knowledge about CP.

Associated problems

In this category, information about common problems associated with CP would be collected, such as strabismus, hearing loss, epilepsy and respiratory problems. If any procedures are undertaken to improve the associated problems, such as tracheal intubation or measuring a hearing aid, information about the type and timing of the procedure should be collected. Data acquisition in this category is based on the caregivers' statements only if they clearly remember the information, but the confirmation of medical records should be recommended if available.

Musculoskeletal condition

The information in this category includes the common musculoskeletal complications of children with CP, such as hip dislocation and scoliosis at the time of measurement. The severity of hip subluxation and dislocation is measured by the migration percentage,[20] and the Cobb angle is used for measuring the severity of scoliosis.[21] The most recent radiograph taken at the time of measurement would be used, and the researcher should calculate the aforementioned indicators directly.

Nutritional status

In this category, information regarding the route of nutritional intake and various indicators that can determine growth status, including height, weight and body mass index (BMI), would be collected. Confirmation of the main route of nutritional intake will be based on caregiver interviews and the researcher's inspection. Moreover, the registered patient's current weight, height and BMI should be measured directly by the researcher. If the patient is unable to maintain a standing position or has severe joint contractures and/or scoliosis, alternative methods such as the division method[22] for height and wheelchair scale for weight should be considered for accurate measurements.

Rehabilitation status

The experience of rehabilitation received in the past 3 months and the type of facility where the rehabilitation treatment was provided based on the caregivers' interviews are obtained. If available, treatment-related documents of the facility could be considered for verification. 11 types of rehabilitation treatment are included in this category, such as conventional physical and occupational therapy as well as augmented reality and virtual reality-based interventions incorporating cutting-edge technology. For the items related to rehabilitation treatment facilities, the status of providing rehabilitation treatment specialised for South Korea is reflected.

Management history

In this category, information related to orthosis, botulinum toxin injection and orthopaedic/neurosurgery history to improve patients' functional status or prevent complications will be obtained through an interview with their caregiver. Confirmation of information in this category is based on caregiver interviews, but the researcher's inspection and co-confirmation of medical records should be considered to verify the information. In addition, to minimise recall bias, the exact name of the surgery and target site of botulinum toxin injection are not included in this category. Only information about the location and time of intervention, as well as the number of injections, will be included.

Socioeconomic status

In this category, information about the current income and insurance status of their caregivers based on the time of registration is collected. The confirmation of this information is based on the caregivers' interview. Current income is divided into several categories to prevent answer avoidance and medical insurance. Information about the status of insurance is based on the types of national insurance covered by all South Korean citizens, including the Medical Care Assistance Service and National Health Insurance Services. Moreover, information on private insurance subscriptions will be obtained.

Developmental assessment

In this category, the most recent assessment results regarding developmental status will be collected. The results of various assessments considering their developmental status are collected as follows: Gross Motor Function Measure-88[23] for gross motor function and Korean Childhood Autism Rating Scale 1st or 2nd edition for socioadaptive function,[24] Korean-Wechsler Preschool and Primary Scale of Intelligence-IV,[25] Korean-Wechsler Intelligence Scale for Children-IV[26] or Korean-Wechsler Intelligence Scale for Children-V,[27] Social Maturity Scale[28] and Visual Motor Integration 6th edition for cognitive function,[29] Sequenced Language Scale for Infants,[30] Preschool Receptive-Expressive Language Scale,[31] and Language Scale for School-aged Children for speech function,[32] Urimal Test of Articulation and Phonation for articulation and phonation function,[33] and Bayley Scales of Infant and Toddler Development Third Edition able to measure various development areas.[34]

Follow-up measurement

Among the information collected at the baseline assessment, the following categories would be regularly collected on a 1-year cycle: 'descriptions of the functional classification', 'associated problem', 'musculoskeletal condition', 'nutritional status', 'rehabilitation status', 'management history', 'socioeconomic status' and 'functional assessment.' The information acquisition method would be the same as that for baseline assessment. For items obtained through caregivers' interviews or evaluation by the researcher, information should be acquired based on the date of follow-up. For items obtained from the document, the most recent information within 1 year from the time of follow-up measurement should be obtained. If follow-up information cannot be obtained for any reason, researchers should describe the relevant reason and check whether it corresponds to one of the three reasons for research termination as follows: follow-up loss due to the death of the participant; the participant and/or their caregivers' willingness to withdraw from this study; violation detection of inclusion criteria such as other aetiologies confirmed that do not satisfy the diagnostic criteria of CP after enrolment.

Statistical analysis

For descriptive statistics, regarding categorical variables, summary tabulations of absolute and relative frequencies for each qualitative variable are presented. In the case of continuous sociodemographic variables, the number of participants, mean, median, SD, minimum and maximum values and IQRs will be presented. The normality of the distributions will be assessed with graphical displays (histogram, box plots and normal plots). For data analysis, multivariate analysis by linear or logistic regression will be performed to determine associations between clinical outcomes such as musculoskeletal problems and associated problems. Group differences based on various parameters, such as functional classification and aetiologies of brain injury, will be analysed across measurement time points using repeated measures analysis of variance in continuous variables. In addition, subgroup analysis based on the variable classification will also be performed. For non-normalised data analysis, corresponding non-parametric tests will be used. Prediction modelling will also be attempted using the new covariates under study. In addition to deriving statistical significance based on clinical indicators, non-clinical indicators such as socioeconomic status, family information and rehabilitation facilities could be analysed to clarify their influence on prognosis. Participants who drop out during the study will be excluded from the analysis.

Ethics and dissemination

The study protocol was approved by the ethics committees of all 42 participating hospitals, and the IRB approval numbers for each hospital are listed in online supplemental additional file 1. The research will be performed in accordance with the Declaration of Helsinki. Findings from this cohort study will be disseminated in peer-reviewed publications.

DISCUSSION

KCPR is the first nationwide prospective cohort study on CP in South Korea. It aims to create a national data repository and analyse epidemiological trends of CP. Beyond its role as a registry, KCPR serves as a research platform, supporting various initiatives to enhance the understanding and management of CP. It also facilitates the development of comprehensive service plans and policies and conducts intervention cohort studies to establish standardised rehabilitation guidelines.

South Korea has a population of approximately 51.5 million, and its total fertility rate, which is the average number of children a woman is expected to have in her lifetime, is around 0.7, one of the lowest in the world. Regardless of the relatively small population of South Korea compared with other cohorts in Europe or the USA, the high quality of data collection is a significant strength of our cohort study. This is due to excellent accessibility to medical institutions and abundant treatment and diagnostic modalities.[35]

Additionally, KCPR has the potential to collaborate with both domestic and international databases and registries, enhancing the scope of research. For instance, integrating data from public healthcare-related big data platforms, such as the Healthcare Big Data Hub of the Health Insurance Review and Assessment Service and the Korean National Network for very low birthweight infants or prematurity, could strengthen its research capabilities. Furthermore, KCPR follows standardised data collection methodologies aligned with global CP registries, enabling future international collaborations and multicountry cohort studies. This alignment will contribute to a deeper understanding of CP epidemiology, intervention effectiveness and long-term outcomes on a global scale.

Moreover, Korea's unique cultural and ethnic characteristics offer distinct advantages compared with other countries. South Korea has a relatively homogeneous population, as it remains largely a single-ethnicity nation. This homogeneity,[36] along with the very low illiteracy rate,[37 38] may reduce confounding variables related to ethnic and educational diversity, thereby potentially increasing the internal validity of our findings. However, it is important to note the growing number of multicultural families in South Korea,[39] which may influence future CP demographics.

A limitation of our study is its institution-based recruitment method, which may introduce selection bias. Although the cohort includes hospitals distributed across the country, children who are not treated in one of the participating hospitals may be under-represented in the cohort, which could affect the generalisability of the findings. This potential bias should be considered when interpreting the results.

In conclusion, the KCPR will serve as a valuable resource for research on the epidemiology of CP in South Korea, contributing to the development of effective prevention, diagnosis and intervention strategies. This study also aims to conduct various intervention cohort studies to establish guidelines for standardised rehabilitative medical service provision. This approach is expected to limit unnecessary medical consumption and reduce unmet medical needs. The findings derived from this research are anticipated to be appropriately integrated into the fields of rehabilitative therapy, health services, special education and healthcare policy.

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Contributors D-wR: Conceptualisation, methodology, project administration, funding acquisition, supervision and writing—review and editing. JH and JC: Conceptualisation, methodology, data acquisition, investigation and writing—original draft. J-YK, Y-BS, S-sY and D-HJ: Data acquisition, project administration and writing—review and editing. All coauthors are involved in this study. All authors have read and approved the manuscript. JH is responsible for the overall content as guarantor.

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