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ORIGINAL ARTICLE

Development of a Cerebral Palsy Follow-up Registry in Jordan (CPUP-Jordan)

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Abstract

Aims: This study aims to describe the development of a Cerebral Palsy Follow-up Registry in Jordan (CPUP-Jordan) and to provide a baseline child and parent demographic information, birth history of the child participants, and distribution of the participants based on topographical distribution of cerebral palsy (CP) and functional classification systems.

Methods: The CPUP-Jordan was developed using a similar framework of a follow-up surveillance programme for persons with CP in Sweden (CPUP). Standard assessment forms were utilized to collect data related to child and family demographics, child birth history, and functional classifications and physiotherapy and occupational therapy assessments and interventions. Research assistants were trained to conduct the assessments. A secured web-based system was developed to store data and disseminate knowledge maintained in the registry. Children with CP were included in the registry if they have confirmed diagnosis of CP. The ascertainment age of inclusion and the minimum age of survival required are 4 years.

Results: One hundred sixty-seven children were registered between 2013 and 2015 (mean age is 3.6 ± 3.0 years). Forty-two percent were born premature, and 48% were less than the normal birthweight. Perinatal causes were reported for 54% of the participants. The most common type of CP based on tone disturbance was spastic type, and the most common topographical distributions of motor dysfunction were quadriplegia followed by diplegia. Fifty-six percent of the participants had severe limitation in ambulation; 48% had restricted manual abilities, and 47% had limited communication abilities even with familiar family members and partners.

Conclusions: The development of CPUP-Jordan registry for children with CP proved to be both feasible and informative. The registry baseline descriptive data were similar to those reported in previous research in Jordan supporting validity of the data. The implementation of CPUP-Jordan at national level is expected to have a positive impact on children with CP, clinicians, policymakers, and researchers.

KEYWORDS

cerebral palsy, CPUP-Jordan, developing countries, Jordan, registry

1 | INTRODUCTION

Cerebral palsy (CP) is an umbrella term that describes a group of disorders of motor dysfunction due to permanent and nonprogressive lesion in a developing brain (Hurley et al., 2015; Rosenbaum et al., 2007). The motor dysfunction of children with CP is further complicated by development of secondary impairments such as joint deformities, muscle contractures, hip dislocation, and scoliosis (Murphy, Molnar, & Lankasky, 1995; Persson-Bunke, Hägglund, Lauge-Pedersen, Wagner, & Westbom, 2012). Secondary impairments have significant impact on restricting participation of children with CP in activities of daily living (Elkamil et al., 2011).

CP is the most common neurodevelopmental disability in childhood with a global estimated incidence of 2–3 per 1,000 live births (Evans P., Elliott, Alberman, & Evans S., 1985; Hurley et al., 2011; Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). Although the incidence of CP is estimated to be 5–10 times more common in developing countries (Cruz, Jenkins, & Silberberg, 2006),

epidemiological data in these countries are limited. Furthermore, research on causes and patterns of CP in developing countries is limited (Lagunju & Fatunde, 2009; Singhi & Saini, 2013; Nafi, 2012; Al-Ajlouni, Aqrabawi, Oweis, & Daoud, 2006). Knowledge of trends of causality and sequela would provide a foundation for developing policies and programmes to optimize quality of life of children with CP and their families.

Registers of CP are defined as "population [based] databases issuing from multiple sources, relying on a clear definition and inclusion and exclusion criteria of CP, and requiring a mix of skills with the collaboration of obstetricians, pediatricians, and epidemiologists" (Cans et al., 2004, p.18). Forty registry programmes worldwide have been described in the literature with the first population-based registry started in Denmark in 1950 (Hurley et al., 2015). CP registries have been informative in providing population-based data on incidence, prevalence, causes, and risk factors for CP in developed countries (Hurley et al., 2011). Moreover, follow-up registries have played an important role in preventing secondary impairments and for improving healthcare systems. Research registries provide a platform for population-based research because they include huge amounts of data for informing the conduct of intervention trials and service delivery (Hurley et al., 2015; Westbom, Bergstrand, Wagner, & Nordmark, 2011; Westbom, Hagglund, & Nordmark, 2007).

Although the utility of CP registries have been demonstrated in Europe and Australia, no registry has been established in developing countries. Jordan is a developing country with a population of 9.5 million; where almost half of the population lives in the capital Amman (UNICEF, 2015). According to the international incidence of CP, there are approximately ~20,000–30,000 children with CP in Jordan. Few studies, however, have examined the patterns, causes, and needs of children with CP in Jordan (Saleh & Almasri, 2017; Almasri & Saleh, 2015; Nafi, 2012; Al-Ajlouni et al., 2006). One possible reason is the existence of a fragmented healthcare system together with a traditional model of service delivery (Saleh & Almasri, 2017). A follow-up registry for children with CP in Jordan is expected to provide a population-based database that can enhance both epidemiological research and intervention. Outcomes of such research could guide service planning and allocation of limited resources to areas of most needs for children with CP. In addition, registries may enhance collaboration and communication among healthcare professionals who are involved in service delivery for children with CP.

This study, therefore, aims (a) to describe the development of a Cerebral Palsy Follow-up Registry in Jordan (CPUP-Jordan) and (b) to provide baseline child and parent demographic information, birth history of the child participants, and distribution of the participants based on topographical distribution of CP and functional classification systems.

1.1 | Guiding research questions

The following research questions guided the conduct of this study.

- Is it feasible to implement a CPUP-Jordan?
- Do the data collected through the CPUP-Jordan enable estimation of epidemiological characteristics such as prevalence, incidence, risk factors, and survival rate upon implementation of the registry at a national level?
- Does the CPUP-Jordan allow description of profiles of gross motor, manual ability, and communication functions based for children with CP in Jordan?

Key Messages

Development of a follow-up cerebral palsy registry in Jordan is feasible.

- The CPUP-Jordan will contribute to knowledge related to cerebral palsy in developing countries.
- Challenges faced during development are similar to challenges reported by developed countries registries.
- Baseline data related to participants during the development phase have similar trends to previous research from Jordan.

2 | METHODS

2.1 | Development of CPUP-Jordan

In 1994, a programme for follow-up and healthcare for children with CP was established in southern Sweden as a joint project between orthopaedic departments and child rehabilitation units and was named Cerebral Palsy Follow-up Program (CPUP). The CPUP was initially established to prevent hip dislocation and severe contractures by continual and long-term examination of joint range of motion. Other aims were to increase knowledge related to CP, examine current interventions, and to improve communication among healthcare professionals involved in providing services for children with CP. Since 2005, CPUP has served both as a multidisciplinary longitudinal follow-up programme and a national quality registry. The CPUP programme is a population-based registry that is implemented in habilitation clinics throughout Sweden. Most children (95%) who were born in 2000 or later with CP were enrolled in the registry. CPUP registries have also been implemented in Norway, Denmark, Iceland, Scotland, and parts of Australia (Hurley et al., 2015).

In 2013, a proposal to develop a cerebral palsy follow-up registry programme for children with CP in Jordan was funded by the Scientific Research Support Fund, a governmental funding agency in Jordan. The long-term goals of this project were to (a) provide foundations of a national cerebral palsy registry in Jordan utilizing similar framework of the CPUP in developed countries, (b) describe epidemiological trends of CP in Jordan, (c) monitor changes in child function and activity levels, (d) evaluate approaches of treatments and interventions, (e) provide a common language for communication among healthcare professionals, and (f) provide population-based data for international research.

2.2 | Assessment forms

A permission to adapt the assessment forms used in the Swedish CPUP was obtained. A committee of four researchers (two physiotherapists and two occupational therapists) prepared the forms for use in Jordon using the World Health Organization International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY; WHO, 2011) while at the same time considering cultural differences. The assessment forms were field tested in 10 children with CP, and modifications were made on the basis of the participants' feedback.

The assessment forms included four major sections: (a) demographic information which includes identifiable data such as child name, gender, address, parents' age, parents' education levels, and occupations; (b) child birth history including birthweight, birth length, gestational age, and birth defects; (c) physiotherapy and occupational therapy assessments of body functions, activity, and participation outcomes; and (d) medical and rehabilitation services. Demographics and birth history sections were completed using parent-report. A total of 63 variables were collected during each assessment session, of which 22 were identifiable data to allow for participant contact for follow-up assessments.

2.3 | Training research assistants

During the development of the CPUP-Jordan, data were collected by research assistants trained to criteria. The research assistants were physiotherapists and occupational therapists with an average of 5 years clinical experience. Prior to data collection, research assistants completed comprehensive training on the procedural protocol of the CPUP-Jordan. Training included instructions on how to conduct parent interviews and administer clinical tests and measures. Upon completing the training, research assistants were required to complete three assessment sessions with one of the investigators to confirm accuracy and reliability of collected data. Following these checks, research assistants were evaluated by one of the investigators before independently commencing the assessments. Biweekly meetings with the research assistants were held to answer any questions raised during the assessment sessions.

2.4 | Recruitment of participant sites and families

The developed CPUP-Jordan was piloted in the capital city of Amman. Participants were recruited from five sites, two hospital-based settings, two rehabilitation centres for children with disabilities, and one school for children with CP. Institutional Review Board approvals were obtained from the boards of review of the five sites. In January 2013, the CPUP-Jordan research team received its first institutional review board approval and began recruiting participants and obtaining informed consent. Four research assistants were appointed to work with the research team. One who was responsible for recruitment of participants and scheduling appointments; two were responsible for conducting assessment sessions; and one was responsible for data entry.

In hospital-based settings, participants were recruited through neuropaediatrician, physiotherapy and occupational therapy clinics. In the two centres for children with disabilities, participants were recruited after a medical diagnosis of CP was confirmed by reviewing participants' medical records. In school-based setting, all children were diagnosed with CP before school entry by a neuropaediatrician. Participating parents were approached directly by healthcare professionals who treated the children or by research assistants. A study brochure was provided to each family with contact information. Upon parents' approval, a research assistant provided details and answered any questions and scheduled a time that was convenient for conducting first assessment.

2.5 | Inclusion and exclusion criteria of the registry

Children were registered if they have a confirmed diagnosis of CP by a neuropaediatrician and met the criteria of the CP definition approved by the Surveillance of Cerebral Palsy in Europe: "(1) CP is an umbrella term for a group of disorders, (2) is a condition that is permanent but not unchanging, (3) involves a disorder of movement and/or posture and of motor function, (4) is due to a non-progressive interference, lesion, or abnormality, and (5) the interference, lesion, or abnormality originates in the immature brain" (Cans, 2000, p.819). In children aged less than 4 years, their inclusion in the CPUP-Jordan will be reviewed every 6 months, and inclusion in the registry will be ascertained at 4 years. The minimum age of survival required for inclusion as a case in the registry is the age of data ascertainment (4 years).

2.6 | Types of CP and functional classifications

In order to provide a reliable method to assign children with CP to homogeneous groups allowing for better understanding of profiles of CP in Jordan and improving abilities for international comparisons, children were classified according to topographical type of CP and level of function. Children were classified on the basis of type and distribution of motor impairment into spastic diplegia, spastic quadriplegia, spastic hemiplegia, dyskinesia, ataxia, and unknown type of CP. Children were, also, classified on the basis of function-based classifications to shift attention away from body function and structure to activity and participation outcomes as stressed by the ICF model. The following function-based classification systems were used for the child assessments made as part of the registry:

1. *The Gross Motor Function Classification System-Expanded and Revised* (GMFCS-E&R; Palisano et al., 1997, Palisano, Rosenbaum, Bartlett, & Livingston, 2008) is a five-level classification system for children with CP based on their current performance in gross motor function. Level I describes children with CP who can walk without limitation whereas Level V describes children with CP who need a wheelchair to be transported. The GMFCS-E&R has been found to be reliable and valid for classifying children from birth up until 18 years of age (Palisano et al., 2008).
2. *The Manual Abilities Classification System* (MACS; Eliasson et al., 2006) is a five-level classification system that describes the abilities of children with CP to use their hands in manipulating objects and their need for assistance or adaptation to perform manual activities in daily life. Level I describes children with CP who

handle objects easily and successfully whereas Level V describes children with CP who cannot handle objects and have severely limited ability to perform even simple actions. The MACS has been found to be reliable and valid for classifying children with CP from age 4 to 18 years (Eliasson et al., 2006).

3. *The Communication Function Classification System* (CFCS; Hidecker et al., 2011) is a five-level classification system for children with CP that classifies children with CP on the basis of the effectiveness of everyday communications. Level I describes children with CP who independently and effectively alternates between being a sender and receiver of information with most people in most environments whereas Level V describes children with CP who seldom are able to communicate effectively even with familiar persons. The CFCS has been found to be reliable and valid for classifying children with CP aged 2 to 18 years (Hidecker et al., 2011).

2.7 | Data collection during first assessment session

All families who agreed to participate provided written consent. The assessment has two parts. Part one was completed through a parent interview which included questions related to demographic information, birth history, functional mobility, gross motor and fine motor activities, medical treatments, physical and occupational therapy services, and associated health problems. Part two was completed by a research assistant and included evaluation of type of CP, range of motion, test of spasticity, GMFCS-E&R, MACS, CFCS, scoliosis screening, and manual abilities assessment. Assessment sessions ranged between 90 and 120 min based on the children level of function. At the end of each session, participant families were provided with a brief report about the assessment results and schedule time after 6 months for follow-up assessment.

2.8 | Developing a web-based data collection system

A web-based data collection system was developed for direct data entry. A web-based system has many advantages, among which are decreasing time needed for data entry, decreasing errors during data entry, improving accessibility of the registry at different participant clinical sites, and allowing for secure access to data through the main server at the University of Jordan. The web-based site also includes information about the registry, annual reports, and contact information for families of children with CP who agreed to participate in the registry.

The database itself is accessible by only the principal investigator (PI). Other database users will have different accessibility privileges based on their role in the registry. Data are stored on a secure server in the University of Jordan computer centre where regular backups are performed on a predetermined schedule.

2.9 | Data management

Data collected were documented first in paper booklets which along with the consent forms were stored in a locked cabinet at the Department of Physiotherapy at the University of Jordan. At the end of each assessment session, a checklist was completed by the research assistants to ensure accuracy and completeness of data collection. The data were checked for accuracy and completeness by both a research assistant who did not conduct the assessment and by a researcher. Once these data checks were completed, data were entered to the web-based system.

3 | DATA ANALYSES

The baseline data were analysed using SPSS version 21. First, descriptive analyses were performed to provide a baseline description of CP in Jordan. Frequencies were calculated for (a) participant children and parents demographic characteristics including children's age and gender, and parents' age and educational level; (b) children's birth history including birthweight, gestation age, birth defects, causes of CP, age of diagnosis, receiving intensive care after birth, and parents' consanguinity; and (c) children's distribution of functioning across the GMFCS-E&R, MACS, and CFCS levels. Second, cross tabulations were performed to describe the distribution of participant children according to the GMFCS-E&R, MACS, and CFCS levels based on children's age groups: infants (0–2 years), toddlers (2.1–4 years), preschoolers (4.1–6 years), school-age children (6.1–12 years), and adolescents (12.1–18 years).

4 | RESULTS

4.1 | Child and family background characteristics

Children and parents' demographic information are presented in Table 1. One hundred sixty-seven children were registered in the CPUP-Jordan between January 2013 and December 2015. Around 25% of the participant children were less than 2 years of age whereas 35% were between 2 and 4 years. Three quarters of mothers were 21 to 34 years of age, and 40% had less than high school level of education at the time of child's birth.

4.2 | Birth history and causes of CP

Birth history information as reported by the children's parents are presented in Table 2. Forty-two percent of the participant children were born premature (<37 week), and 48% were below normal birthweight (<251 gm). Eighty percent of the parents reported a cause for their children's CP, with 67% of the parents reported pre/perinatal causes (before 27 days of delivery). The majority of the parents indicated that their children's condition was due to perinatal causes such as hypoxia during delivery (54%); 16% mentioned prenatal causes such as exposure of pregnant mothers to viruses or x-rays, and 17% reported postnatal causes such as head trauma after the first month of age. The mean age of children when they were diagnosed with CP was 9.4 ± 9.7 months.

TABLE 1 Child and parent demographic information

Background measures	*N*	*N* (%)
Child age (years)	167	
0–2		43 (25.6)
2.1–4		59 (35.3)
4.1–6		28 (16.8)
6.1–12		34 (20.4)
12.1–18		3(1.8)
Child gender	167	
Male		98 (58.3)
Female		70 (41.7)
Fathers' age at time of child's birth (years)	164	
≤20		2 (1.2)
21–34		101(61.6)
≥35		61(37.2)
Fathers' educational level at time of child's birth	165	
Less than high school		76 (45.2)
High school		39 (23.2)
Diploma		20 (11.9)
Bachelor		27 (16.1)
Postgraduate		3 (1.8)
Mothers' age at time of child's birth (years)	163	
≤20		21(12.9)
21–34		123 (75.5)
≥35		19 (11.3)
Mothers' educational level at time of child's birth	165	
Less than high school		67 (39.9)
High school		50 (29.8)
Diploma		27 (16.1)
Bachelor		19 (11.3)
Postgraduate		2 (1.2)

TABLE 2 Birth history of the child participants

	N	*N* (%)
Child's birthweight (kg)	164	
ELBW ≤1.00		9 (5.5)
VLBW 1.10–1.50		26 (15.9)
LBW 1.51–2.50		43 (26.2)
NBW 2.51–3.99		80 (48.8)
HBW ≥4		6 (3.7)
Child's gestation age, (week)	165	
<37		70 (42.4)
≥37		95 (57.6)
Number of previous live births	165	
0		45 (26.8)
1–3		92 (55.7)
≥4		28 (17.9)
Number of previous still births (>20 weeks of gestation)	165	
0		138 (82.1)
1		22 (13.1)
>1		5 (3.0)
Number of previous miscarriages (<20 weeks of gestation)	165	
0		118 (70.2)
1		27 (16.1)
>1		20 (12.1)
Any birth defects	165	
Yes		19 (11.3)
No		146 (86.9)
The child is one of multiple births	165	
No		142 (48.5)
Twins		21 (12.5)
Triplets		2 (1.2)
The cause of CP occurred after 27 days of delivery	159	
Yes		23 (13.7)
No		113 (67.3)
I do not know		23 (13.7)
Age of child when diagnosed with CP (month)	165	
Mean (*SD*)		
Range		1–72
Parent's consanguinity	141	
Yes (%)		63 (37.5)
No (%)		78 (46.4)
Received intensive care following birth (NICU)	165	
Yes (%)		86 (51.2)
No (%)		79 (47.0)

Note. ELBW = extremely low birthweight; VLBW = very low birthweight; LBW = low birthweight; NBW = normal birthweight; HBW = high birth weight; CP = cerebral palsy; NICU = neonatal intensive care unit.

4.3 | Types of CP and function-based classifications distributions across age groups

Table 3 shows topographical types of CP and the functional classification levels of participant children based on the GMFCS-E&R, MACS, and CFCS levels. Seventy-three percent of the participants have a spastic type of CP. Quadriplegia followed by diplegia were the most common topographical distributions of motor dysfunction. Only 3% of the participants have athetosis; 3.6% have ataxic type of CP, and 15.5% were categorized as unknown type of CP.

Overall, 57% of the participants were classified in Levels IV and V of the GMFCS-E&R indicating severe limitation in ambulation; 52% were classified in Levels I and II of the MACS indicating better manual abilities, and 47% were at Levels IV and V indicating limited communication abilities even with familiar partners.

Figure 1 shows the distribution of children according to the five GMFCS-E&R levels by age groups. Half of the children less than 2 years of age were classified in Level V indicating limited gross motor abilities. Among the participant toddlers between 2 to 4 years of age, 70% were in Level I indicating better gross motor function abilities. Level III and Level IV were observed more frequently in preschoolers and school-age children, respectively. The adolescent (12–18 years) participants were only in Levels IV and V of the GMFCS-E&R.

Figure 2 shows the distribution of children according to the five MACS levels by age groups. The MACS was used to describe the manual abilities of children aged 4 to 18 years (Eliasson et al., 2006);

TABLE 3 Distribution of participant children and adolescents based on topographical distribution and functional classification systems

Topographical type of CP (*n* = 167)	*N* (%)
Spastic/ quadriplegia	52 (31.0)
Spastic/diplegia	47 (28.0)
Spastic/ hemiplegia	23 (13.6)
Spastic/monoplegia	1 (0.6)
Dyskinetic/athetosis	5 (3.0)
Ataxia	6 (3.6)
Hypotonia	5 (3.0)
Mixed	2 (1.2)
Unknown	26 (15.5)
Gross motor function classification system (GMFCS-E&R; *n* = 165)	
Level I	18 (10.7)
Level II	33 (19.6)
Level III	19 (11.3)
Level IV	51 (30.4)
Level V	44 (26.2)
Manual ability classification system (MACS; *n* = 163)	
Level I	41 (24.4)
Level II	47 (28.0)
Level III	21 (12.5)
Level IV	15 (8.9)
Level V	39 (23.2)
Communication function classification system (CFCS; *n* = 166)	
Level I	17 (10.1)
Level II	36 (21.4)
Level III	33 (19.6)
Level IV	36 (21.4)
Level V	44 (26.2)

Note. CP = cerebral palsy.

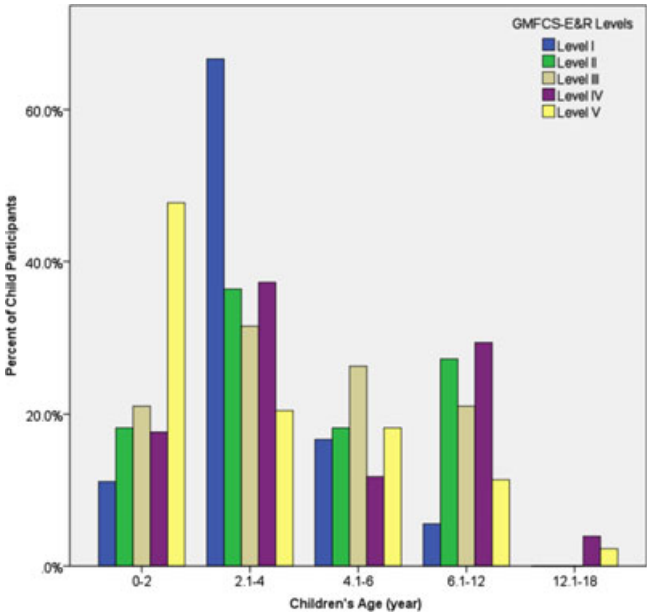

FIGURE 1 Percentage of child participants across the Gross Motor Function Classification System-Expanded and Revised (GMFCS-E&R) levels by age groups [Colour figure can be viewed at wileyonlinelibrary.com]

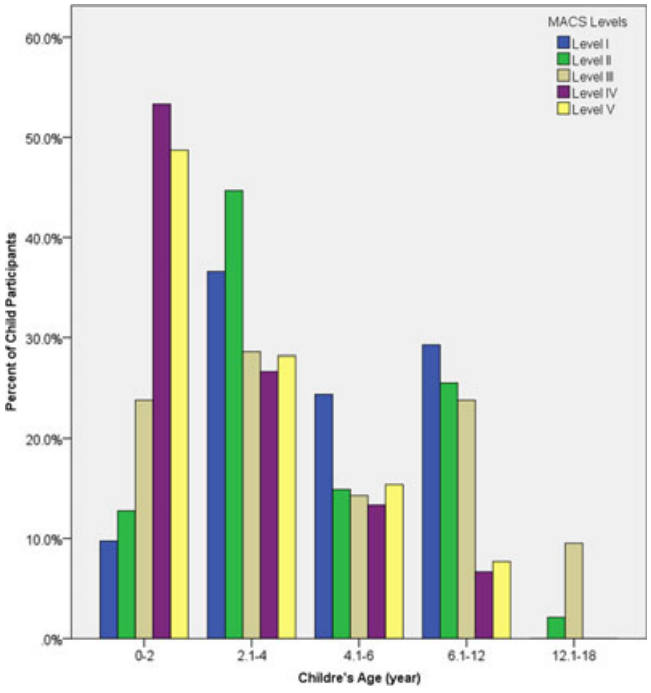

FIGURE 2 Percentage of child participants across the Manual Abilities Classification System (MACS) levels by age groups [Colour figure can be viewed at wileyonlinelibrary.com]

therefore, we examined the frequency of children across MACS levels for the preschool, school age, and adolescent groups of participants. Levels I and III in the MACS were observed more frequently in children aged 4 to 12 years whereas in adolescents group only Levels II and III were observed.

Figure 3 shows the distribution of children across the CFCS levels by age groups. The CFCS was used to describe the communication performance of children as young as 2 years old (Hidecker et al., 2011). Level IV was observed more frequently in children aged 2 to 4 years indicating inconsistent communication even with familiar people, whereas Levels I and II were observed more in children aged 4 to 12 years indicating abilities to communicate with familiar and unfamiliar people.

5 | DISCUSSION

The development of a Cerebral Palsy Follow-up registry for children and adolescents with CP in Jordan constitutes a first step toward a population-based registry for persons with CP in Jordan. To the best of our knowledge, the CPUP-Jordan is the first registry of people with CP in developing countries and particularly in the Middle East. CPUP-Jordan was found to be feasible for compiling information that covers child and adolescent body function and structure, activity, participation, and contextual (environmental, personal) domains of the ICF model. The information and knowledge obtained through CPUP-

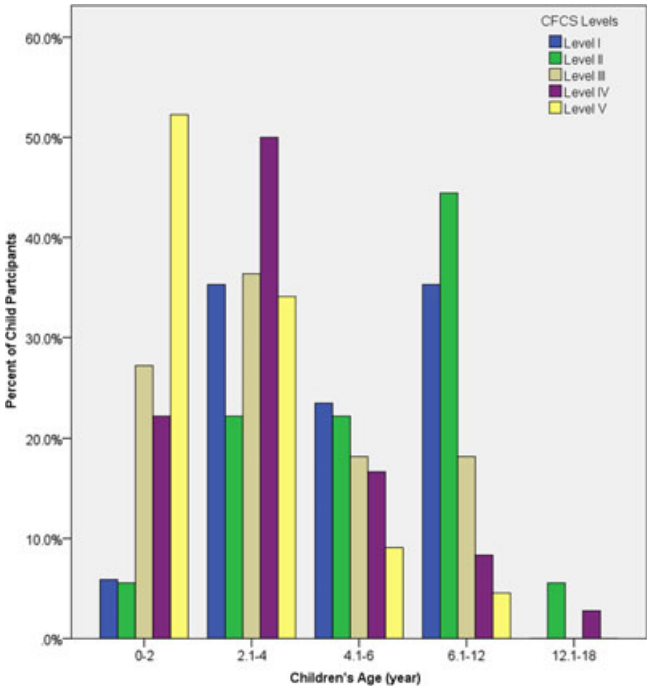

FIGURE 3 Percentage of child participants across the Communication Function Classification System (CFCS) levels by age groups [Colour figure can be viewed at wileyonlinelibrary.com]

Jordan related to demographics, birth history, and profiles of participants based on types and function-classifications during the piloting phase was consistent with available literature. Upon implementation of the registry at national level, these information are expected to guide planning of affordable and effective services for people with CP in Jordan.

5.1 | Challenges in developing the CPUP-Jordan

Major challenges during registry development were related to recruitment of clinical sites and availability of therapists to conduct assessments. The healthcare system in Jordan is divided into public and private sectors with no inter-institutional collaboration. During registry development, the public sector was targeted in order to obtain a more heterogeneous sample from different socio-economic, educational, and geographical backgrounds. The largest public hospital in Amman (Albasheer hospital) was the first site to participate in piloting the registry. Most of the therapists in public hospitals deal with heavy caseloads and frequent rotations among physiotherapy units and therefore were not able to actively participate in the piloting the registry. During the pilot phase, this issue was addressed by training research assistants to conduct the assessments. However, during implementation of the registry at a national-level, therapists in the participant clinical sites will be trained to conduct assessment and formally assigned by the clinical site managers to register children with CP in the registry. The implementation of the registry will include many capacity-building activities for health professionals who are involved in management of CP cases to guarantee continuity of the project.

Although recent guidelines recommend confirming CP diagnosis at 4 or 5 years (SCPE, 2000), 25% of the registered children were found to be less than 2 years of age. Seventy-one percent of the young age children demonstrated server limitation in gross motor functions (Levels IV & V in the GMFCS-E&R) which can explain the diagnosis of CP at young age. We noted that parents usually use other terms to describe the diagnosis of their children such as motor delay, hypertonicity, or developmental delay. This is most likely attributed to the social stigma related to using CP term. An advantage of implementing the CPUP-Jordan registry will be to adopt a clear definition of CP and to set an age of diagnosis ascertainment for children with CP in Jordan.

During implementation of the registry, additional clinical sites from public and private sectors will be recruited in order to expand the base of the registry to involve as many people as possible. The research team will be expanded to include project manager to coordinate the activities among clinical sites, data manger to check for accuracy and completeness of data entry into the web-based system, and a recruiter to conduct awareness activities aiming to increase the number of participant clinical sites. In addition, orthotic and prosthetic specialist, speech language pathologist, and social worker assessments can be added allowing for comprehensive assessment and eventually coordinated services to be delivered to participants.

5.2 | Baseline descriptive profiles

The preliminary results reported in this paper may be skewed because the recruitment for the registry is still in the piloting phase, and the sample is not yet representative of the Jordanian population of children with CP. Birth history information proved helpful in identifying risk factors of CP including prenatal, perinatal, and postnatal causes. Similar to previous studies in Jordan and other developing countries, perinatal causes including birth asphyxia were the most common causes reported by participants (Nafi, 2012; Al-Ajlouni Alagrabawi, Al-Balas, Alawneh, & Daoud, 2008; Singhi, Ray, & Suri, 2002). Premature delivery was reported by 40% of the participants which is more than the percentages reported in previous studies in Jordan (Nafi, 2012; Al-Ajlouni et al., 2008) and suggest prematurity as a main risk factor for CP in Jordan. The CPUP-Jordan should prove informative in providing epidemiological descriptive data related to causality which will allow better service planning and comparisons with international registries to highlight differences in epidemiology of CP between developing and developed countries.

Our preliminary results inform inclusion of children with CP from different age groups and levels of function in the registry. Our baseline results indicated that children in certain age groups and functional levels may be less represented in our registry including adolescents and school-age children particularly children with better gross motor functions, limited fine motor abilities, and limited communication abilities. This might be due to nature of recruitment sites which were mainly physiotherapy clinics where children with limited fine motor abilities and communication skills are less treated. Another reason is the limited access to services for adolescents due to transferring from childhood to adulthood healthcare systems. In developing countries, limited financial resources and accessibility to services might increase families' burden in getting services for their children especially during adolescents and adulthood. These limitation can be addressed during implementation phase through

enlarging the base of recruitment to include rehabilitation clinics, schools and centres that provide services for children and adolescents with disabilities in Jordan. In addition to using the social media and internet to recruit families of people with CP and to improve public awareness.

5.3 | Future directions

The CPUP-Jordan was developed as a precursor of a national-based registry in Jordan. Next step will be to implement the registry at a national level; the expected outcomes will be to provide surveillance of prevalence and survival trends for people with CP in Jordan, prevent CP by identifying aetiological pathways and identifying prevention plans, and provide information for policymakers and administrative managers to plan for services for people with CP considering the limited resources of Jordan. In the future, CPUP-Jordan can provide a platform for clinical research and allow evaluation of interventions and outcomes among clinical sites for quality improvement.

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CONFLICT OF INTERESTS

The authors declare no conflict of interest.

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