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Original Article

Establishing a cerebral palsy registry in Kuwait: An exploratory study

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Abstract

Background: Cerebral palsy (CP), the most common motor disability in childhood, comprises a group of permanent non-progressive disorders affecting the antenatal, neonatal, or early postnatal development of areas in the brain responsible for posture and movement. Registries for children with CP, or surveillance programs, have been a source of consistently increasing research productivity; 38 related articles were published in 2013. In Kuwait, a CP registry would provide baseline information on children with CP and their parents. The registry could include demographic information obtained through parental interviews, or review of the mothers' and the children's medical charts.

Objective: This study was aimed at exploring the establishment of a pediatric CP registry in Kuwait.

Methods: In this exploratory study, caregivers of children with CP were recruited from rehabilitation clinics around Kuwait. The inclusion criteria were 1) boys or girls with a documented diagnosis of CP made between 6 months and 18 years of age, 2) caregivers with permanent residency in Kuwait, and 4) caregivers speaking Arabic and/or English fluently. The variables collected comprised registry and feasibility variables. Registry-associated variables comprised demographic and medical information about the children, and caregivers' willingness to be contacted for a follow-up or participation in other research projects. Feasibility variables were the percentage of information gathered, and the willingness of caregivers to participate in, and of therapists to recruit for, the registry.

Results: Fifty-three caregivers of children with CP participated in this study. The mean age of the recruited children with CP was 5 years and 5 months (SD = 3 y 4 m, range = 11 m to 16 y 8 m/female n = 25). GMFCS level V was reported by half of the sample (n = 29/55.77%). Of the 112 caregivers screened, fewer than half (n = 53 of 112/47.32%) participated in the study. Most caregivers (n = 48/90.56%) used the Arabic version of the form.

Conclusion: The establishment of a pediatric CP registry in Kuwait is feasible, on the basis of our data.

Keywords: Cerebral palsy; Feasibility; Pediatrics; Registry; Surveillance

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الملخص

أهداف البحثيصف الشلل الدماغي ، وهو أكثر الإعاقة الحركية شيوعا في مرحلة الطفولة ، مجموعة من الاضطرابات الدائمة غير التقدمية في تطور الموقف والحركة التي تحدث أثناء فترة ما قبل الولادة أو حديثي الولادة أو بعد الولادة المبكرة لدماغ الجنين أو الرضيع. سجل الأطفال المصابين بالشلل الدماغي، أو برامج المراقبة، كان مصدر إنتاجية ثابتة في السنوات الماضية

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ويتجه نحو الأعلى، حيث أظهر 38 مقالة في عام 2013 في الكويت، سيوفر سجل الشلل الدماغي معلومات أساسية عن الأطفال المصابين بالشلل الدماغي و والديهم، والتي يمكن أن تكون معلومات ديموغرافية تم الحصول عليها من خلال مقابلة الوالدين أو مراجعة المخططات الطبية للأم والطفل. استكشاف إمكانية إنشاء سجل للأطفال في الكويت.

طريقة البحثفي هذه الدراسة الاستكشافية، تم توظيف مقدمي الرعاية للأطفال المصابين بالشلل الدماغي من عيادات إعادة التأهيل في جميع أنحاء الكويت. كانت معايير الاشتمال هي: 1) تشخيص موثق للشلل الدماغي ، بين 6 أشهر و 18 سنة ، بنين أو بنات ، 2) مقيم دائم في الكويت ، و 4) يتحدث العربية و / أو الإنجليزية بطلاقة. كانت المتغيرات التي تم جمعها هي متغيرات التسجيل والجدوى. كانت المتغيرات المتعلقة بالسجل عبارة عن معلومات ديموغرافية وطبية عن الطفل، والاستعداد للاتصال من أجل المتابعة أو المشاركة في مشاريع بحثية أخرى. كانت متغيرات الجدوى هي النسبة المئوية للمعلومات التي تم جمعها ، واستعداد مقدمي الرعاية للمشاركة ، والمعالجين لتعيينهم في السجل.

النتائج: شارك في هذه الدراسة 53 من مقدمي الرعاية للأطفال المصابين بالشلل الدماغي. كان متوسط عمر الأطفال المستقطبين للدراسة المصابين بالشلل الدماغي 5 سنوات و 5 أشهر. تم الإبلاغ عن المستوى الخامس من مستويات كرسي متحرك بالتحريك اليدوي الذاتي بنصف العينة (ن = 29 / 55.77٪). من بين 112 مقدم رعاية تم فحصهم ، شارك أقل من النصف (العدد = 53 من أصل 112 / 47.32٪) في الدراسة. استخدم معظم مقدمي الرعاية (العدد = 48 / 90.56٪) النسخة العربية من النموذج.

الاستنتاجات: يمكن إنشاء سجل الشلل الدماغي للأطفال في الكويت بناء على هذه البيانات.

الكلمات المفتاحية: الشلل الدماغي؛ الجدوى؛ طب الأطفال؛ التسجيل؛ المراقبة

Introduction

Cerebral palsy (CP), the most common motor disability in childhood, comprises a group of permanent non-progressive disorders that affect the development of posture and movement, and develop in the brain during the antenatal, neonatal, or early postnatal period.[1,2] Population-based studies worldwide have shown that the prevalence of CP ranges from 1.5 to more than 4 cases per 1000 live births.[3] The overall birth prevalence of CP is approximately 2 per 1000 live births, and CP is 1.4 times more frequent in boys than girls.[4] CP usually affects premature infants and in many cases is associated with comorbidities such as epilepsy, communication disorders, cognitive disabilities, hearing and vision disorders, feeding and bladder incontinence disorders.

These children are known to develop limitations in activities and participation restrictions.[2] Depending on the extent of damage, children may lack independence in daily activities such as self-hygiene, play, and schooling. The ability to lead independent lives as adults is also affected.[5] Owing to the heterogeneity of CP, many classification systems have been developed to better classify this population (e.g., the Gross Motor Function Classification System (GMFCS) and Communication Function Classification System (CFCS)).[6–8]

In healthcare, a registry is a collection of information on individuals that is focused on a specific diagnosis or condition, and aids in comprehensive understanding of individuals with certain diseases.[9] Registries can be sponsored by a government agency, nonprofit organization, health care facility, or private company. One of the first population-based CP registries was established in Denmark in 1950, followed by Sweden in 1954, and England and Ireland in 1966.[10] The establishment of these registries faced several issues, such as the variables collected, data sources, collection methods, inclusion/exclusion criteria, and registry/surveillance program aim.[9,10]

Registries of children with CP, or surveillance programs, have been a source of consistently increasing research productivity, and 38 related articles were published in 2013.[9] A research registry could help children with CP by promoting understanding of the disorder and identification of barriers to leading an optimal life. The main goal is to increase children's functioning and the involvement of families and individuals with CP. Other types of registries can have aims such as public health surveillance or outcome tracking. Knowledge regarding the frequency, cause, occurrence, and severity of CP has been documented by CP registries worldwide. These registries have aided in the development of effective interventions for CP and overall improvement in quality of life.[10] Having accessible databases for children with CP that include medical records, early intervention records, and other helpful information, would enable a systemic approach for health care providers, including extended follow up of cases. Such databases would also help children's families, through providing a better understanding of the children's abilities, as well as information on therapeutic interventions (e.g., drug therapy, treatment programs, or intervention equipment). Registries for children with CP have provided informative population-based data on CP incidence, prevalence, causes, and risk factors. Other studies have shown that follow-up registries have played important roles in preventing secondary impairment and improving healthcare systems. Registries provide opportunities for collaboration and communication among healthcare professionals who are involved in service delivery for children with CP. Moreover, registries help form a framework for collaborative research.

In Kuwait, a CP registry would provide baseline information on children with CP and their parents, which could include demographic information obtained through a parental interview or a review of the mothers' and children's medical charts. This database would provide valuable information to potentially improve survival rates for infants not at particular risk of neurological damage and to decrease the prevalence of CP in full-term infants.[11] In addition, it would provide information to guide future directions in perinatal and neonatal care.[12] A registry for children with CP in Kuwait is expected to provide a population-based database that could enhance both epidemiological research and interventions. Therefore, the aim of this study was to examine the possibility of establishing a CP registry in Kuwait. We hypothesized that the establishment of the registry would be feasible, but we anticipated some challenges, such as an inability to complete data collection at a single time point and the lack of a clear CP diagnosis in a large percentage of the affected population in Kuwait.

Materials and Methods

Study design

This was a cross-sectional, exploratory study of the establishment of a pediatric CP registry in Kuwait. This study was conducted between August 6, 2020 and January 31, 2021.

Participants

Caregivers of boys and girls with CP between the ages of 6 months and 18 years were recruited. This age range was chosen according to a review of the literature on previously established registries worldwide.[9] The lower age limit for inclusion was chosen to include children with CP who receive an early diagnosis (e.g., extremely premature babies and babies born with extremely low birth weight).[2] The inclusion criterion for children was a documented diagnosis of CP by a physician, whereas the inclusion criteria for caregivers included permanent residency in Kuwait, and speaking Arabic and/or English fluently. The documentation of a CP diagnosis was based on the definition stated by Rosenbaum and colleagues in 2007.[1]

Procedure

Seven rehabilitation clinics (e.g., physical therapy, occupational therapy, and speech therapy) in five governmental hospitals in Kuwait were contacted as potential recruitment sites. Snowball sampling was used through flyers and word of mouth. Flyers advertising the study (Arabic and English versions) were sent to clients from sites that agreed to participate in the study. Therapists in these sites were also approached to inform their clients about the study.

Outcomes

A data extraction form was established by a group of experts (pediatric physical therapy researcher and two pediatric physical therapy clinicians); variables were included on the basis of medical records used in the clinical practice and a review of the literature of established CP registries.[9,12] Participants who agreed to participate were sent an online form (in Arabic or English, according to their preference), from which variables were extracted Table 1. Parents were asked to complete the form to the best of their knowledge regarding their child's case. The GMFCS family report questionnaires (age-appropriate versions) were included in the form in both English and Arabic. The reliability and validity for these questionnaires in both languages have been established.[6,8] Manual Ability Classification System (MACS) and CFCS were presented in only the English form,[7] because they are not valid nor reliable in Arabic. Collection of written consent preceded the questionnaire.

The feasibility of the establishment of the registry was examined with the following indices: 1) number of recruitment sites/total sites contacted, 2) number of therapists who agreed to inform their clients about the study/total number of therapists contacted, 3) number of families who agreed to participate in the study/number of participants approached, and 4) number of caregivers consenting to be contacted for follow-up and informed about future research projects/total number of participants agreeing to participate in the study.

Statistical analysis

Registry and feasibility variables were summarized with measures of central tendency (e.g., sample means and medians) and variation (e.g., standard deviation and range). Categorical data (e.g., gender and GMFCS level) are presented as frequencies and percentages, along with cross tabulation. Feasibility indices are defined as the number of participants agreeing to participate (e.g., caregivers or therapists) divided by the total number of participants invited to participate (e.g., number of families who agreed to participate in the study/number of participants approached $\times$ 100). Statistical Package for the Social Sciences (SPSS v26, IBM, Armonk, NY) was used for all data analysis procedures. Cross tabulation was performed for certain variables for children with CP who could walk (e.g., GMFCS levels I, II, and III; walkers) versus those who were unable to walk (e.g., GMFCS levels IV and V; non-walkers).

Results

Registry variables

Fifty-three caregivers (n = 53) of children with CP participated in this study. The mean age of the children with

Table 1: Variables of the pediatric CP registry.

- Age and date of birth of the child
- Gender of the child (i.e., girl or boy)
- Birth procedure (i.e., vaginal or cesarian section)
- Presence of any complications during delivery (if yes, indicate them)
- Gestational age at birth (i.e., <26 weeks, 26–32 weeks, or >32 weeks)
- Birth weight (i.e., <1 kg, 1–1.4 kg, or 1.5–2.5 kg)
- Maternal age at birth (years)
- Presence of any auditory, visual, or communication problems
- Presence of epilepsy
- Surgical history of the child
- Current medication history of the child
- Whether the child is independent in feeding and dressing (i.e., completely dependent, partially dependent, or completely independent)
- Current use of any assistive devices (e.g., orthotics or walkers)
- Rehabilitation services that the child is currently receiving (e.g., PT, OT, ST, or RT)
- Child's topographic type of CP (i.e., spastic quadriplegia, spastic diplegia, spastic hemiplegia (right or left), or unknown)
- Child's GMFCS level (Arabic and English versions)
- Child's MACS level (English versions).
- Child's CFCS level (English versions).

CP: cerebral palsy; kg: kilogram; PT: physical therapy; OT: occupational therapy; ST: speech therapy; RT: respiratory therapy; GMFCS: Gross Motor Function Classification System; MACS: Manual Abilities Classification System; CFCS: Communication Function Classification System.

CP who were registered was 5 years and 5 months (SD = 3 y 4 m, range = 11 m to 16 y 8 m). Twenty-five (47.1%) of the children were girls. Twenty-seven children (50.94%) were born vaginally. Regarding gestational age, only 5 (9.43%) were born at less than 26 weeks of gestation, whereas 21 (39.62%) were born after 26–32 weeks of gestation. More than half (n = 32/60.38%) of the children with CP included in this study had a birth weight between 1.5 kg and 2.5 kg. The mean maternal age when these children were born was 29 years (SD = 6.28 y/range = 19–43 y). GMFCS level V was reported by half of the sample (n = 27/55.10%), and level II was the second most reported (n = 10/20.40%). Regarding MACS, of the eligible children evaluated with this scale (n = 2), one child had level II, and the other was in level III. Similarly, the children eligible for CFCS examination (n = 2) had levels III and IV. More than half the caregivers reported not knowing their children's topographic type (n = 32/60.37%). Of those who reported this variable, nine (16.98%) reported the topography as spastic diplegia. Twenty-three (44.23%) caregivers reported that their children had at least one surgery, and 19 (35.85%) caregivers reported that their child took least one medication. Anti-spastic agents were the most common medications reported (n = 10/18.86%; e.g., Baclofen) and were followed by anti-epileptics (n = 6/11.32%; e.g., Levetiracetam). Most children were reported to use orthotics (n = 43/81.13%). Detailed descriptions of the response of the registry variables are provided in Tables 2 and 3. The cross tabulation between children who were ambulatory (e.g., GMFCS levels I, II, and III/n = 16) and non-ambulatory (e.g., GMFCS levels IV and V/n = 33) showed that fewer ambulatory than non-ambulatory children with CP reported having at least one surgery (n = 3/18.75% and n = 19/57.57%, respectively). Similarly, fewer ambulatory than non-ambulatory children took at least one medication (n = 1 (6.25%) and n = 17 (51.51%), respectively; Table 4).

Table 2: Demographic characteristics of the participants.

	N (%) or mean (SD)	% or range
Age (n = 52)		
Mean ± SD	5 y 5 m (3 y 4 m)	11 m–16 y 8m
Gender [girls] (n = 53)	25	47.17%
Birth procedure [VDP] (n = 53)	27	50.94%
Complications during delivery (n = 53)	25	47.17%
Gestational age (n = 53)		
<26 weeks	5	9.43%
26–32 weeks	21	39.62%
>32 weeks	27	50.94%
Birth weight (n = 51)		
<1 kg	9	16.98%
1–1.4 kg	10	18.87%
1.5–2.5 kg	32	60.38%
Maternal age at birth (n = 53)		
Mean ± SD	29 y (6.28 y)	19–43 y
GMFCS (n = 49)		
I	2	4.08%
II	10	20.40%
III	4	8.16%
IV	6	12.24%
V	27	55.10%
Topographic type (n = 53)		
Quadriplegia	6	11.32%
Right hemiplegia	5	9.43%
Left hemiplegia	1	1.88%
Diplegia	9	16.98%
Unknown	32	60.37%

SD: standard deviation; F: female; VDN: vaginal delivery procedure; kg: kilogram; GMFCS: gross motor function classification system.

Table 3: General health and functional level variables of the participants.

	N (%)
Auditory problems (n = 53)	3 (5.66)
Visual problems (n = 53)	33 (62.26)
Epilepsy (n = 52)	7 (13.46)
Communication problems (n = 47)	23 (48.94)
At least one previous surgery (n = 52)	23 (44.23)
On at least one medication (n = 53)	19 (35.85)
Feeding (n = 53)	
Completely independent	14 (26.42)
Partially independent	21 (39.62)
Completely dependent	18 (33.96)
Dressing (n = 53)	
Completely independent	1 (1.89)
Partially independent	13 (24.53)
Completely dependent	39 (73.58)
Using orthotics (n = 53)	43 (81.13)
Using a walker (n = 53)	16 (30.19)
Rehabilitation services received (n = 49)	
PT	49 (100)
OT	23 (46.94)
ST	19 (38.78)
RT	1 (2.04)

PT: physical therapy; OT: occupational therapy; ST: speech therapy; RT: respiratory therapy.

Table 4: Cross tabulation of GMFCS levels of participants.

	GMFCS levels I, II, and III (ambulatory, n = 16) N (%)	GMFCS levels IV and V (non-ambulatory, n = 33) N (%)
Gestational age (n = 52)		
<26 weeks	1 (6.25%)	4 (12.12%)
26–32 weeks	7 (43.75%)	12 (36.36%)
>32 weeks	8 (50%)	17 (51.51%)
Birth weight (n = 51)		
<1 kg	2 (12.5%)	7 (21.21%)
1–1.4 kg	2 (12.5%)	7 (21.21%)
1.5–2.5 kg	11 (68.75%)	19 (57.57%)
At least one previous surgery (n = 51)	3 (18.75%)	19 (57.57%)
On at least one medication (n = 52)	1 (6.25%)	17 (51.51%)
Communication problems (n = 47)	7 (43.75%)	15 (45.45%)

Feasibility variables

Seven rehabilitation departments in five hospitals were contacted to participate in the study. Only five of seven (71.43%) departments agreed to participate, in which 85 therapists who were known to address pediatric population daily were identified and invited to participate. Of those, 18 (21.18%) therapists agreed to participate. Less than half (n = 53 of 112/47.32%) of the caregivers of children who were requested to participate in the study agreed to participate (Figure 1). The time spent to complete the electronic form ranged between 12 and 17 min. Most caregivers (n = 48/90.56%) used the Arabic version of the form. The response rate to the questions included in the form ranged between 90.90% and 100% (n = 33 questions). Finally, 43 of the participating caregivers (81.13%) agreed to be contacted to be informed of future research projects (Table 5). The project was completed between August 2020 and February 2021.

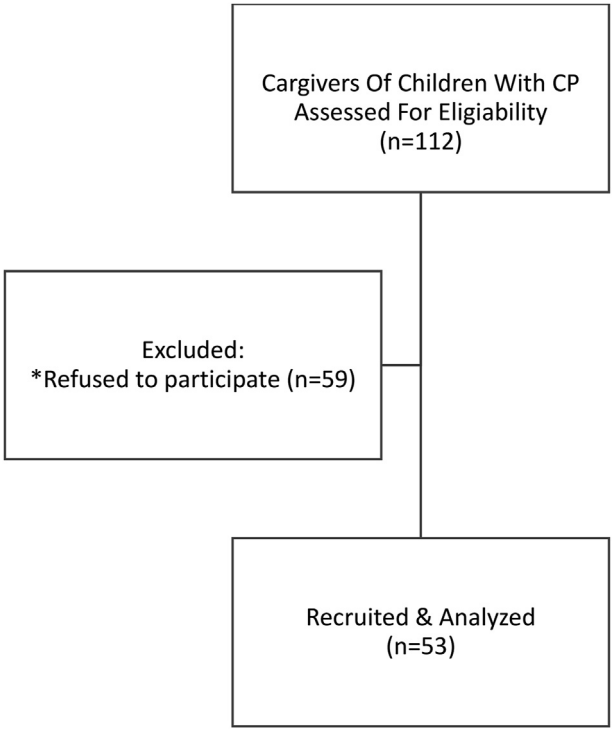

Figure 1: CONSORT flow diagram of the recruitment of the participants.

Table 5: Feasibility variables of the CP registry.

	Agreed to participate N (%)
Participants contacted (n = 112)	53 (47.32%)
Therapists contacted (n = 85)	18 (21.18%)
Departments contacted (n = 7)	5 (71.43%)

Discussion

To our knowledge, this is the first attempt at examining the feasibility of establishing a CP registry in the state of Kuwait. The results showed that establishing such a registry in the state of Kuwait would be feasible and achievable. Although almost 47% of the caregivers who were approached agreed to participate, the data collection process coincided with the spread of the SARS-CoV-2 virus, after the first case was documented in Kuwait on February 23rd, 2020.[13] The pandemic might have affected the participation rate in this study. Therefore, because of the exploratory nature of the study, the results were not representative of the population of children with CP in the state of Kuwait. The low percentage (21.18%) of therapists who agreed to participate in the study might have been due to the high demand of their profession, particularly in the field of neurological pediatric physical therapy. This aspect could be rectified in future studies by allocating special personnel to collect the needed information from the caregivers.

Examination of the data notably indicated that GMFCS level V was the most reported level among the sample, possibly because the recruitment occurred in a hospital/clinic setting. Consequently, the sample was limited to caregivers of children who needed constant attention because of many primary and secondary impairments (e.g., low functional level).[3] In contrast, many caregivers did not know the topographic type of their child's CP, possibly because of a lack of communication between primary physicians and caregivers. This aspect should be examined in detail in future studies.

Further exploration of individuals with CP in Kuwait and other developing countries would provide crucial information about their characteristics and progress, thereby expanding understanding of the disorder, and the ethnic and cultural differences experienced by these individuals, to ultimately improve management. Future attempts in establishing a registry should focus on establishing a centralized database, into which all information would be incorporated, to aid in maintenance of the registry. Dedicated personnel should also be involved in future efforts to establish a registry in Kuwait for children with CP. The establishment of such a registry should be adapted nationwide to enable capturing the full extent of the experience of children with CP in our culture. Programs to raise awareness of the importance of registries should be implemented among healthcare professionals and the general population, to help increase participation in CP registries and future registries.

Other developing countries have made similar efforts in establishing pediatric CP registries in their regions. One successful attempt has been reported by Khandaker et al. in Bangladesh.[14,15] Their latest published report indicates that their registry, established in 2015, now includes 2852 children with CP; the registry was a population-based surveillance program in which children with disabilities were identified in each community by local volunteers.[16] In the Middle East, the CP follow-up registry in Jordan (CPUP-Jordan) was one of the first CP registries established.[7] In the capital city of Amman, between 2013 and 2015, 167 children with CP were included in the registry.[12] In Egypt, Altonoby and colleagues have examined the feasibility of a registry in a

major city and identified 224 children with CP among more than 600,000 children registered as living in the city. Their study was a clinic-based registry. However, despite the study aim, feasibility variables were not reported.[17]

Limitation

Although a CP registry was constructed for the first time in the State of Kuwait on a large population of children, this study has many limitations. A major limitation is the small sample size recruited. Future studies should focus on generating a larger sample size. The restricted amount of information gathered from the caregivers was another limitation. Because most residents of Kuwait are Arabic speakers, the lack of availability of validated Arabic versions of MACS and CFCS hindered the amount of information extracted from the participants. Another limitation of this study was the focus on rehabilitation therapists' participation in the recruitment process, which added to their daily burdens and hindered their ability to help patients. Therefore, other personnel should be explored as recruiters for the registry establishment.

Developing a validated Arabic version of MACS and CFCS should be a priority of upcoming research projects. Finally, although participation among therapists was limited, a pediatric CP registry throughout the State of Kuwait should be established. The adaptation of a parent-reported based registration in registry would relieve therapists from performing this task and encourage them to participate in the recruitment process to expand the registry. The registry should also include outcome measure scores of the children, to provide a broader understanding of children with CP in Kuwait.

Conclusion

The establishment of a pediatric CP registry in the State of Kuwait is feasible on the basis of this initial effort. Caregivers' willingness to participate exceeded that of clinicians. Future attempts to expand this registry should focus on parent-reported registration, and the inclusion of subjective and objective outcome scores as variables in the registry.

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Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

The protocol was approved by the research ethical committee at Kuwait University (#624).

Authors' contribution

ABA conceived and designed the study, conducted research, provided research materials, collected and organized the data, and wrote the initial and final drafts of article. AEA provided research materials, collected and organized the data analyzed, and interpreted the data. AA collected and organized the data analyzed, interpreted the data, and provided logistic support. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

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