Knowledge and attitude of caregivers of cerebral palsy children in Riyadh city

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ABSTRACT

Background: The diagnosis of a child with a life-long disability, such as cerebral palsy (CP), can be catastrophic to parents. The aim of this study was to evaluate the level of Saudi caregivers’ knowledge about cerebral palsy and the possible association to socioeconomic status or educational status of the parents.

Methodology: This cross-sectional survey included 30 caregivers of children with cerebral palsy who attended the neuropediatric clinic, King Saud Medical City, Riyadh, Saudi Arabia. The knowledge of cerebral palsy questionnaire was administered to assess the caregivers’ knowledge about cerebral palsy.

Results: This study explored inadequate Saudi caregivers’ level of knowledge and awareness about CP. There was substantial lack of knowledge about the etiology and the prognosis of CP. The total knowledge score of the study participants was calculated, it ranged from 8.0-19.0 with a median score of 15.50. According to this score, 50% of the studied caregivers had good level of knowledge about CP. Moreover, there was no statistically significant association between level of the guardian’s knowledge and their educational or financial level.

Conclusion: Based on the findings, the parental knowledge of CP is substantially lacking. There is an urgent need to conduct a prospective research project to better assess the level of awareness and develop actions that contribute to parents being better informed and more secure about their children’s health care.

Keywords: Cerebral palsy, knowledge, caregiver, child, Saudi Arabia.

Introduction

Cerebral palsy (CP) is a motor impairment syndrome resulting from a lesion that affects the development of the brain. This disorder was first described in 1862 by the orthopedic surgeon William Little [1]. Different definitions and classifications of cerebral palsy have been carried out. Recently, it is described as a group of permanent disorders of development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain, and are often accompanied by disturbance of sensation, perception, cognition, communication and behavior, by epilepsy, and by secondary musculoskeletal problems [2].

The complexity of cerebral palsy is evident from its different classifications, where the syndrome can be classified according to: the site of the brain lesion (cortical, pyramidal, extrapyramidal, or cerebellar); clinical manifestations (spastic, dyskinetic, or ataxic); site involved (diplegic, quadriplegic, or hemiplegic); timings of the supposed insult (prepartum, intrapartum, or post-neonatal); and degree of muscle tone (isotonic, hypotonic, or hypertonic) [3].

Prevalence of cerebral palsy range from 2 to 3.5 per 1,000 livebirths. This prevalence is inversely related to gestational age and birthweight, with a prevalence ranging from 90 cases per 1,000 neonatal survivors weighing less than 1 kg to 1.5 cases per 1,000 for those born weighing 2.5 kg or more [4–7].

Genetic factors are increasingly implicated in cerebral palsy and most cases result from an interference in brain development in utero. Several risk factors do exist, including low birth weight, congenital malformation, asphyxia, multiple gestation, intrauterine exposure to...
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infection, neonatal stroke, hyperbilirubinemia, and maternal infections, such as rubella and cytomegalovirus [8–11].

The usual complaint of cerebral palsy is delayed development of motor milestones of the child. However, the deficit is static and not progressive. This history, combined with a neurologic examination usually establishes the diagnosis. The motor disorders of cerebral palsy are often associated with epilepsy as well as problems with feeding, swallowing, and bowel motility, poor nutrition and growth, high rates of infection, and poor hearing and vision [2,12].

Cerebral palsy is a lifelong disorder and patients with cerebral palsy have primarily a disorder of movement. However, many individuals with this disorder have other impairments which may affect their quality of life and life expectancy; children are more prone to psychological difficulties, whereas fatigue, pain, and depressive symptoms are common in adults [13–16].

As cerebral palsy has a crucial effect on quality of life, life expectancy, health care cost, and the resources required by the families of affected children, maximum efforts should be directed toward prevention of this disorder. Preventive strategies may include such measures to enhance protection (e.g., antenatal treatment of the mother with glucocorticoids) or reduce damage (e.g., caffeine and vitamin A supplementation to prevent bronchopulmonary dysplasia) [17,18].

Data regarding Saudi caregivers’ level of the knowledge about cerebral palsy was limited. Hence, the aim of this study was to explore knowledge about cerebral palsy among caregivers of children with cerebral palsy, who were visiting Neuropediatric Clinic of King Saud Medical City, Riyadh, Saudi Arabia.

Subjects and Methods

This was a questionnaire-based, cross sectional pilot study, conducted on caregivers of cerebral palsy children who were visiting Neuropediatric Clinic of King Saud Medical City (Riyadh, Saudi Arabia), during the period from 1-4-2017 to 5-6-2017. The convenience sampling technique was used to recruit 30 participants who were fulfilling the pre-defined eligibility criteria, regardless of their nationalities, ages, genders, or marital status. However, caregivers who were healthcare workers and those with incomplete data were excluded from the study.

Participants were requested to fill an Arabic questionnaire that consisted of two parts: (1) socio-demographic information (such as age, nationality, gender, marital status, level of education, and residency of the caregiver, as well as age and gender of the child with cerebral palsy) and (2) knowledge about cerebral palsy (risk factors, causes, manifestations, complications, and management).

Data were represented and statistically analyzed by using Statistical Package for the Social Sciences v 20.0. Descriptive statistics were represented as numbers, percentages were used for categorical data, and median and interquartile range were used for continuous data.

For calculation of the total knowledge score, each correct answer was given a score of one and incorrect answer a score of 0. Then, the level of a caregiver’s knowledge was assessed as good or poor in relation to the median total knowledge score. Fisher’s exact test was used to estimate the association between the level of knowledge and socio-demographic characteristics of caregivers. p value < 0.05 was considered as statistically significant.

Results

This pilot study was carried out on 30 caregivers of cerebral palsy children. The median age of the children was 4.50 years (IQR = 4.0–6.0), with equal sex distribution. Among the caregivers, mothers were 56.7%, married were 90%, and unemployed were 60%. Additionally, all caregivers were literate and high percentage of them had reached tertiary and after high school education (33.3% and 37.0%, respectively). Moderate level of income was most frequently (79.3%) reported by them (Table 1).

Low frequency of correct responses of the study participants were observed about the possibility of complete cure from CP (30.0%), and the relationship between the development of jaundice soon after birth and likelihood of CP (33.3%). Likewise, there was substantial lack of knowledge about etiology of CP, (Table 1).

Table 1. Socio-demographic characteristics of caregivers and children.

<table>
<thead>
<tr>
<th>Age of children (years)</th>
<th>Range: 0.6–10.0</th>
<th>Median: 4.50</th>
<th>Interquartile range: 4.0–6.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Sex of children</td>
<td>Boy</td>
<td>13</td>
<td>50.0</td>
</tr>
<tr>
<td>Residence</td>
<td>Apartment</td>
<td>15</td>
<td>50.0</td>
</tr>
<tr>
<td>Caregiver’s relationship to child</td>
<td>Father</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>Caregiver’s marital status</td>
<td>Divorced</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Caregiver employment status</td>
<td>Unemployed</td>
<td>18</td>
<td>60.0</td>
</tr>
<tr>
<td>Caregiver’s highest educational level</td>
<td>Primary</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td>Caregiver’s Level of income</td>
<td>High</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>Limited</td>
<td>5</td>
<td>17.2</td>
</tr>
</tbody>
</table>
only 14 participants (46.7%) responded correctly that CP is not an inherited disease and 17 participants (58.6%) recognized that lack of breathing soon after birth is a risk factor for this disorder. Moreover, about two-thirds (60%) correctly identified that CP results from injury to the developing brain. Unfortunately, 70% believed that CP might be caused by witchcraft. Knowledge about clinical presentations of CP were generally satisfactory; most of them correctly identified that CP in children was presented with stiff limbs and muscles, and in some cases might have floppy limbs (93.1% and 70%, respectively). Moreover, it has been known that CP children may have difficulties in learning, and chewing and feeding (96.7% and 82.8%, respectively). All caregivers reported the importance of exercise in the management of a child with CP. In addition, great awareness was found about the role of assistive devices (96.7%), participation in self-help groups to share ideas and experiences (93.3%), and the importance of early treatment for getting better prognosis (90.0%) (Table 2).

The total knowledge score of the study participants was calculated, it ranged from 8.0 to 19.0 with a median score of 15.50. According to this score, 50% of the studied caregivers had good level of knowledge about CP. The absence of statistically significant association between guardian’s level of knowledge, and their educational and financial level as shown Table 3. The marital and the employment status, and whether the participant was the mother or the father were not significantly associated with one’s level of knowledge ($p > 0.05$).

**Discussion**

This pilot study explored Saudi caregiver level of knowledge and awareness about CP. In this study, there was substantial lack of knowledge about the etiology of CP. Lower frequencies of correct responses regarding the exact cause of CP and its common risk factors like lack of breathing soon after birth or the early development of neonatal jaundice were observed. Unfortunately, some myths about what causes CP were prevalent among the study participants. More than two-thirds of them believed that CP can result from witchcraft. Furthermore, the study detected poor knowledge of the guardians about the prognosis of CP. High percent of them believed that CP could be completely cured. Similar to the present findings, the majority of Indian parents of CP children were unaware of basic knowledge of CP like the correct name of the illness, its cause, the aspect of development involved, progression, curability, and treatment modalities [19,20]. This observed lack of

| Table 2. Frequency of correct responses of the caregivers on the knowledge of cerebral palsy questionnaire. |
|---|---|---|
| 1- Cerebral palsy is caused by injury to the developing brain | 18 | 60.0 |
| 2- Children with cerebral palsy are at high risk of suffering from seizures/epilepsy | 22 | 73.3 |
| 3- Children with cerebral palsy may attain developmental milestones, such as rolling, sitting, at a late stage when compared | 30 | 100.0 |
| 4- Difficulties during child birth process, such as prolonged labor, may predispose the child to acquiring cerebral palsy | 22 | 73.3 |
| 5- A child may develop if they do not cry soon after birth | 17 | 58.6 |
| 6- Cerebral palsy may be result of witchcraft | 21 | 70.0 |
| 7- Cerebral palsy is contagious | 28 | 93.3 |
| 8- Cerebral palsy is inherited | 14 | 46.7 |
| 9- If a child suffers from jaundice soon after birth , they may have high chance of acquiring cerebral palsy | 10 | 33.3 |
| 10- Most children with CP present with stiff limbs and muscles | 27 | 93.1 |
| 11- Most children with CP may have floppy limbs | 21 | 70.0 |
| 12- Children with CP may have difficulties in learning | 29 | 96.7 |
| 13- Some children with severe CP may have difficulties with chewing and feeding | 24 | 82.8 |
| 14- Saliva drooling can persist in children with CP | 20 | 66.7 |
| 15- CP can be cured | 9 | 30.0 |
| 16- Exercises are important in the management of a child with CP | 30 | 100.0 |
| 17- Assistive devices such as corner site may be recommended in the management of a child with CP | 29 | 96.7 |
| 18- Integration with children with the same disease may help treat cerebral palsy | 19 | 63.3 |
| 19- Participation in self-help groups to share ideas and experiences with caregivers of children with CP is essential | 28 | 93.3 |
| 20- If a child with CP gets early treatment; they are likely to improve more | 27 | 90.0 |
knowledge might be attributed to very little information received by the parents from the treating physicians, nurses, and therapists, and have many queries about the disease which tend to remain unanswered [21]. This makes it very difficult for the parents to assist in the treatment of their children, as well as participating in educational practices and decision-making. In contrast, a recent study by Dambi et al. [22], reported higher level of knowledge about the cause, risk factors, and prognosis of CP among Zimbabwean caregivers. They also detected positive impact of an educational workshop on such level of knowledge.

The knowledge about clinical presentations of CP was generally satisfactory; most of them correctly identified that CP children present with stiff limbs and muscles and in some cases may have floppy limbs. Moreover, it has been known that CP children may have difficulties in learning, chewing, and feeding. It is known that children with CP present in different ways, depending on the area of the brain that is affected [23].

All caregivers realized the importance of exercise in the management of a child with CP. In addition, great awareness about the role of assistive devices, participation in self-help groups to share ideas and experiences and the importance of early treatment for getting better prognosis were observed. Although CP has no cure, early rehabilitation has been demonstrated to be of tremendous benefit [24]. Group therapy sessions where caregivers are required to demonstrate to other attendants the prescribed home exercise programs reinforce their learning, so as to improve the efficacy of the execution of the exercises [22]. Furthermore, such social support is essential in alleviating caregiver burden [25].

The current study showed absence of statistically significant association between level of the guardian’s knowledge and their educational or financial level. The marital and the employment status and whether the participant was the mother or the father were not significantly associated with the detected level of knowledge. In agreement with this finding, Arora et al. [19] reported lack of significant relation between socioeconomic status or educational status of the parents and the change in parental knowledge of CP caused by educational interventions.

**Conclusion**

Based on the findings of this pilot study, it was concluded that parental knowledge of CP is substantially lacking. This reflects poor educational activities to improve the parental knowledge. So, there is an urgent need to conduct a prospective research project to better assess the level of awareness and develop actions that contribute to parents being better informed and more secure about their children's health care. Raising awareness would help parents to make better decisions about their children and alleviate the stress that arises from ignorance and uncertainty.

**List of Abbreviations**

CP Cerebral palsy

**Conflict of interests**

The authors declared that there is no conflict of interest regarding the publication of this article.

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None.
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Consent for publication
Informed consent was obtained from all participants.

Ethical approval
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