Community Awareness Level about Cerebral Palsy, Its Risk Factors, And the Role of Orthopaedic Surgery in the Management, Abha-Saudi Arabia

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Abstract

Background: The term 'cerebral palsy (CP)' refers to a neuropathological event characterized by a group of disorders that primarily target the musculoskeletal system and cause difficulty in movement, maintaining balance, and posture. Which is unfortunately, sits on the top of the most motor disability in children. The community is not aware of this problem. So, improving awareness and spreading education that will fulfil the knowledge gap in the community regards CP and its many risk factors, should be the first step to encountering this disorder before occurring which will decrease its prevalence as the parents will behave cautiously during pregnancy. **Aim:** to assess community awareness level of cerebral palsy and its risk factors and the role of Orthopaedic surgery in management. **Methodology:** A questionnaire-based cross-sectional survey was applied to target all available populations in the Aseer region, southern of Saudi Arabia using an online self-administrated questionnaire. The questionnaire included participant's socio-demographic data, and knowledge questions regarding cerebral palsy with only one / more than one correct answer for each question allowed. The questionnaire was uploaded online using social media platforms by researchers and all eligible persons were invited to fill it out after explaining the purpose and conforming their data confidentiality. **Results:** A total of 364 participants completed the study questionnaire. Participant's ages ranged from 18 to 61 years with a mean age of 34.2 ± 12.9 years old. The exact 232 (63.7%) participants had university-level of education while 109 (29.9%) had secondary level of education. Exact 66.5% of the study participants correctly defined CP as a chronic neurological disease with loss of the ability to normal movement and behavioural cognition. Considering the main symptoms of cerebral palsy, the most reported were the inability to move/walk (78.3%), followed by mental retardation and low IQ (57.1%), and Delayed development and speech (55.8%). Overall awareness level regarding cerebral palsy among study participants, Saudi Arabia. The exact 324 (89%) participants had poor awareness levels for CP while only 40 (11%) had good awareness level. **Conclusions:** In conclusion, the study showed that public awareness regarding cerebral palsy and its related factors was unsatisfactory especially for causes and its related risk factors, besides surgery's role in minimizing disability and complications. Higher knowledge was detected among young aged participants with high educational level.

Keywords: *Cerebral palsy, knowledge, awareness, population, neurological disorders, Saudi Arabia*

Introduction

Cerebral palsy (CP) results from damage that affects the growth of the brain and is featured by motor impairment. (Krigger, 2006). CP was first defined in 1862 by an orthopedic surgeon William Little (Colver and Pharoah, 2014). Newly, it is categorized as a cluster of permanent disorders of the development of movement and posture, with activity limitation, that are due to non-progressive disorders that occurred in the developing fetal or infant brain. CP may be followed by disturbance of sensation, perception, cognition, communication, and behavior, epilepsy, and secondary musculoskeletal disorders. (Rosenbaum et al., 2007)

Physicians think that CP is attributed to either brain malformation or injury during its developmental period ending with a loss of muscle control (CDC(a), 2022). Risk factors of CP are variant including any state that can insult the developing brain (Stavsky et al., 2017). Brain insult during the intrapartum or postnatal period causes what is called congenital CP including prematurity, low birth weight, and infections during pregnancy (Garne et al., 2008). On the other side, if it occurs after 28 days of birth, it is called Acquired CP such as postnatal brain infection or brain injury (Blair and Watson, 2006). There are other risk factors that may stand behind developing CP including cerebral malformation, perinatal hypoxia, birth trauma, chorioamnionitis, electrolyte disturbance, indirect hyperbilirubinemia, parental consanguinity, fetal distress, obstructed labour, meningitis, infection, and trauma after birth (Odding et al., 2006; Yuan et al., 2019; Daher and El-Khairy, 2014; Tseng et al., 2018).

All the known risk factors for CP are reported and can be prohibited if the parents or caregivers are knowledgeable regarding these factors. Internationally, the reported incidence of CP is about 4 per 1,000 children, (CDC(b), 2022) While, locally, CP in Saudi Arabian children is one of the most common neurological disorders. It is reported that the incidence of CP will not decline if the community is ignoring this disorder (Al Salloum et al., 2011). The current study aimed to assess the community awareness level of cerebral palsy and its risk factors and the role of Orthopaedic surgery in management.

Methodology

A questionnaire-based cross-sectional survey was applied to target all available populations in Aseer region, South of Saudi Arabia. Participants with ages 18 years or more living in Aseer region for at least 6 months, Southern of Saudi Arabia were invited to participate in the survey. A total of 520 eligible persons received the study survey. Exact of 364 persons completed the study questionnaire with a response rate of 70%. Data were collected from participants using a pre-structured electronic questionnaire. The study authors initiated the study questionnaire through a comprehensive literature review and expert consultation. The questionnaire was then reviewed using a panel of 3 experts from the college of medicine at King Khalid University to check its applicability and its content validity. Tool reliability was assessed using a pilot study of 25 participants with a reliability coefficient (α-Cronbach's) of 0.75. The questionnaire included the following data: participant's socio-demographic data like age, and education. Also, knowledge questions regarding cerebral palsy with only one/ more than one correct answer for each question were allowed. The questionnaire was uploaded online using social media platforms by researchers and all eligible persons

were invited to fill it out after explaining the purpose and conforming to their data confidentiality.

Data analysis

After data were extracted, it was revised, coded, and fed to statistical software IBM SPSS version 22(SPSS, Inc. Chicago, IL). All statistical analysis was done using two-tailed tests. P value less than 0.05 was statistically significant. For knowledge and awareness items, each correct answer was scored one point and the total summation of the discrete scores of the different items was calculated. A patient with a score less than 60% of the total score was considered to have poor awareness while good awareness was considered if he had a score of 60% or more of the total score. Descriptive analysis based on frequency and percent distribution was done for all variables including participants' personal data, and education level. Also, participant's awareness regarding cerebral palsy was also tabulated and overall awareness was graphed. Cross tabulation was used to assess the distribution of participant's knowledge level according to cerebral palsy by their personal data. Relations were tested using the Pearson chi-square test and exact probability test for small frequency distributions.

Results

A total of 364 participants completed the study questionnaire. Participants ages ranged from 18 to 61 years with a mean age of 34.2 ± 12.9 years old. Exact of 232 (63.7%) participants had a university level of education while 109 (29.9%) had a secondary level of education (table 1).

Table 1. Personal data of study participants, Saudi Arabia

Personal data	No	%
Age in years		
< 20	44	12.1%
20-30	95	26.1%
30-40	74	20.3%
40-50	104	28.6%
50+	47	12.9%
Educational level		
Below secondary	23	6.3%
Secondary	109	29.9%
University / above	232	63.7%

Table 2. Awareness regarding CP among the study population, Saudi Arabia. Exact of 66.5% of the study participants correctly defined CP as chronic neurological disease with a loss of the ability to normal movement and behavioral cognition. As for the cause

of CP, the most known among study participants were genetic causes that appear during pregnancy and before birth (41.2%), followed by causes related to the first days after childbirth (20.6%), Causes related to childbirth and the method of delivery (19.2%), and Family genetic causes (19%). Considering the main symptoms of cerebral palsy, the most reported were inability to move/walk (78.3%), followed by mental retardation and low IQ (57.1%), Delayed development and speech (55.8%), Seizures and convulsions (54.7%), Difficulty swallowing, eye imbalance and hearing impairment (37.1%), and fractures and osteoporosis (7.4%). Regarding risk factors for developing CP, 62.9% of the study participants know about Neonatal asphyxia during birth, followed by family history of CP (58.8%), Parents consanguinity (42%), Maternal bacterial infection during pregnancy (38.2%), and Gestational DM / HTN (34.3%) while low birth weight was the least reported risk factor (19%). With regard to treatment methods, the most known for the study participants were physiotherapy and exercises (51.9%), Psycho-behavioural therapy (50.5%), Medications or injections to relax muscles (35.2%), Speech & hearing therapy (33.8%), and Surgical treatment of bones and joints (25.5%). The most known preventive methods included follow-up of the mother's health condition during pregnancy (75.3%), Avoiding medications that harm the health of the mother and fetus during pregnancy (62.4%), Follow up on the child's periodic health vaccinations (53.8%), and avoid marriage with relatives (47.5%). The exact of 62.6% of the study participants know that there is no possibility to completely curing cerebral palsy. Also, 44.5% reported that orthopedic surgery has a role in the treatment of cerebral palsy which was mainly helping the patient to walk and move

(50%), Reducing pain and facilitating care and cleaning (27.2%), Reducing the risk of

arthritis (16%), and reduce the risk of hip dislocation (6.8%).

Table 2. Awareness regarding cerebral palsy among study population, Saudi Arabia

Awareness items regarding CP		No	%
What is CP disorder?	Chronic neurological diseases with loss the ability to normal movement and behavioural cognition	242	66.5%
	Chronic neurological disease causes abnormal continuous movement of the extremities	64	17.6%
	Inflammation of the membranes surrounding the brain, causing the child to have continuous seizures	41	11.3%
	A mental illness that affects a child that makes him unable to adapt and grow normally	17	4.7%
Causes of CP disorder	Genetic causes that appear during pregnancy and before birth	150	41.2%
	Causes related to first days after child birth	75	20.6%
	Causes related to childbirth and the method of delivery	70	19.2%
	Family genetic causes	69	19.0%
What are the main symptoms of cerebral palsy?	Inability to move / walk	285	78.3%
	Mental retardation and low IQ	208	57.1%
	Delayed development and speech	203	55.8%
	Seizures and convulsions	199	54.7%
	Difficulty swallowing, eye imbalance and hearing impairment	135	37.1%
	Fractures and osteoporosis	27	7.4%
Risk factors of developing CP	Neonatal asphyxia during birth	229	62.9%
	Family history of CP	214	58.8%
	Parents consanguinity	153	42.0%
	Maternal bacterial infection during pregnancy	139	38.2%
	Gestational DM / HTN	125	34.3%
	Pre-mature labour	101	27.7%
	Post-natal infection	76	20.9%
	Low birth weight	69	19.0%
Treatment methods for CP	There is no cure completely, but symptoms can be controlled	216	59.3%
	Physiotherapy and exercises	189	51.9%
	Psycho-behavioural therapy	184	50.5%
	Medications or injections to relax muscles	128	35.2%
	Speech & hearing therapy	123	33.8%
	Surgical treatment of bones and joints	93	25.5%
Preventive methods for CP	Follow-up of the mother's health condition during pregnancy	274	75.3%
	Avoid medications that harm the health of the mother and fetus during pregnancy	227	62.4%
	Follow up on the child's periodic health vaccinations	196	53.8%

	Avoid marriage with relatives	173	47.5%
	There is no method or intervention that can prevent the disease	63	17.3%
Do you think it is possible to completely cure cerebral palsy?	Yes	136	37.4%
	No	228	62.6%
Do you think that orthopaedic surgery has a role in the treatment of cerebral palsy?	Yes	162	44.5%
	No	202	55.5%
How can an orthopaedic surgeon help a child with cerebral palsy?	Helps the patient to walk and move	81	50.0%
	Reducing pain and facilitating care and cleaning	44	27.2%
	Reduce the risk of arthritis	26	16.0%
	Reduce the risk of hip dislocation	11	6.8%

Figure 1. Overall awareness level regarding cerebral palsy among study participants, Saudi Arabia. Exact of 324 (89%) participants had poor awareness level for CP while only 40 (11%) had good awareness level.
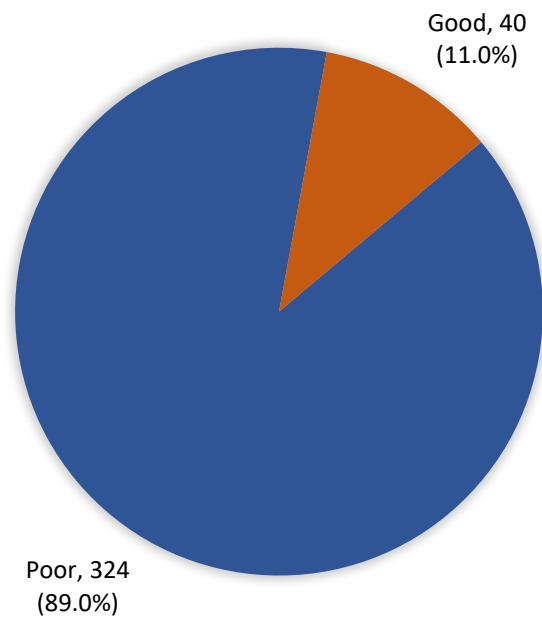

Figure 1. Overall awareness level regarding cerebral palsy among study participants, Saudi Arabia

Table 3. Distribution of study participant's overall awareness level regarding cerebral palsy by their personal data. Good awareness level was detected among 23.2% of participants aged 20-30 years compared to 2.1% of those aged 50 years or more with recorded statistical significance (P=.001). Also, 14.2% of participants with a university level of education had a good awareness level versus 4.3% of those with a low level of education (P=.032).

Table 3. Distribution of study participants' overall awareness level regarding cerebral palsy by their personal data

| Personal data | Overall awareness level | | | | p-value |
| | Poor | | Good | | |
	No	%	No	%	
Age in years					
< 20	40	90.9%	4	9.1%	
20-30	73	76.8%	22	23.2%	
30-40	66	89.2%	8	10.8%	.001*
40-50	99	95.2%	5	4.8%	
50+	46	97.9%	1	2.1%	
Educational level					
Below secondary	22	95.7%	1	4.3%	
Secondary	103	94.5%	6	5.5%	.032*$
University / above	199	85.8%	33	14.2%	

*P: Pearson X^2 test $: Exact probability test   * P < 0.05 (Significant)*

Discussion

Cerebral palsy (CP) is considered as a medical and social problem. In Europe, the Surveillance of Cerebral describes it as "a group of permanent, but not static, disorders of movement and/or posture with motor function, which are due to a non-progressive interference, lesion, or abnormality of the developing/immature brain" (Johnson., 2002). Children with cerebral palsy experience many abnormalities and disabilities that limit their daily life activities and growth (Fritz and Sewell-Roberts 2020). Management for CP depends mainly on medical rehabilitation to minimize the associated limitations and to improve their quality of life (Verschuren et al., 2012; Aran et al., 2007)

The current study aimed to assess the general population awareness regrading CP and its risk factors, and the role of an orthopaedic surgery in the management. The study revealed that about 1 out of each 10 participants had good knowledge regarding CP and its related risk factors. in more details, about two-thirds of the study participants correctly defined CP as chronic neurological diseases with loss the ability to normal movement and behavioural cognition. As for cause of CP, the most known among study participants were Genetic causes that appear during pregnancy and before birth, followed by causes related to first days after child birth (20.6%), Causes related to childbirth and the method of delivery (19.2%), and Family genetic causes (19%). As for the main symptoms of cerebral palsy, the most reported were inability to move / walk (three-quarters of the participants), followed by mental retardation and low IQ which was known for more than half of the study participants, with delayed development and speech, seizures and convulsions, while only one-third know about

difficulty swallowing, eye imbalance and hearing impairment. Garfinkle et al. (2020) assessed that the most reported features of CP were early hand preference on clinical history, delayed or absent motor developmental milestones on developmental screening, and lasting primitive reflexes on neurological examination. Dakovic et al. (2014) detected clinical features of cerebral palsy in children with symptomatic congenital cytomegalovirus infection. Authors found that most of children (85.7%) had bilateral spastic cerebral palsy, and 71.4% lost walking ability while fine motor function was highly affected among 62.8%. Most of the children with severe CP had severe associated impairments. 11.4% of children had severe visual and 42.8% had severe hearing impairment, 77.1% complained of epilepsy, where intellectual impairment was detected among 77% of the cases, and delayed speech in 71%.

As for risk factors of developing CP, nearly two-thirds of the study participants mentioned neonatal asphyxia during birth, followed by Family history of CP (58.8%), Parents consanguinity (42%), Maternal bacterial infection during pregnancy (38.2%), and Gestational DM / HTN (34.3%) while low birth weight was the least reported risk factor (19%). Kułak et al. (2009) conducted studies to assess cerebral palsy risk factors among babies. In a retrospective study, the clinicians compared CP risk factors developing before labour and delivery, and in the neonatal period among babies with CP. These studies established a statistically significant association between placental abruption, premature rupture of membranes, and spontaneous abortion during the antenatal period, and the development of CP. Additionally, an association between premature birth, Caesarean section, and birth weight of a baby with CP was reported. Also, Liveness et al. (2005) found that premature rupture of membranes and premature

birth were significantly associated with the occurrence of CP. Thorngren-Jerneck and Herbst, (2006) noted an association between CP and being first delivery, multiple birth, premature rupture of membranes, preeclampsia, old age of mother (>40 years), cigarette smoking, and low Apgar score. Additionally, Polak et al. (2008) reported that the major CP risk factors included gestational age, multiple pregnancies, and infections, especially infection of the amniotic sac and membranes (chorioamnionitis).

With regard to treatment methods, the most known for the study participants were Physiotherapy and exercises (51.9%), Psycho-behavioural therapy (50.5%), Medications or injections to relax muscles (35.2%), Speech & hearing therapy (33.8%), and Surgical treatment of bones and joints (25.5%). The most known preventive methods included Follow-up of the mother's health condition during pregnancy (75.3%), Avoid medications that harm the health of the mother and fetus during pregnancy (62.4%), Follow up on the child's periodic health vaccinations (53.8%), and avoid marriage with relatives (47.5%). Exact of 62.6% of the study participants know that there is no possibility to completely cure cerebral palsy. Also, 44.5% reported that orthopaedic surgery has a role in the treatment of cerebral palsy which was mainly helping the patient to walk and move (50%), Reducing pain and facilitating care and cleaning (27.2%), Reduce the risk of arthritis (16%), and reduce the risk of hip dislocation (6.8%).

Conclusions and Recommendations

In conclusion, the study showed that public awareness regarding cerebral palsy and its related factors was unsatisfactory especially for causes and its related risk factors, besides surgery role in minimizing disability and complications. Higher knowledge was detected among young aged participants with high educational level. Increased awareness regarding preventable CP is vital because it can help parents or caregivers in understanding what happened to their child, how they can take action, and perhaps most important, what options may be available for their child's care, including the possibility of Lifetime Benefits. Periodic health education programs should be initiated for CP patients' parents / caregivers to improve their awareness level regarding the disease nature and how to deal with any complication besides providing social support to improve their quality of life.

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