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Knowledge and Level of Adherence to Home Exercise Program among Malaysian Caregivers of Children with Cerebral Palsy

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Abstract

Background: Cerebral palsy (CP) is one of the most prevalent disorders that severely affected the motor function in young children worldwide. It is a condition that requires life-long care and the efforts needed depends on the severity & complexity of the children. To deliver proper care to the CP child according to their needs, caregivers must have fundamental and adequate knowledge about CP. A caregiver plays a crucial role in encouraging and providing assistance to CP children to achieve their highest potential. Exercise programs in CP are lifelong activities prescribed for home, and it varies from children to children according to their disabilities.
Objectives: To explore caregivers' knowledge of cerebral palsy and the level of caregivers' adherence to home exercise programs.
Method: A cross-sectional survey was conducted with purposive sampling strategy to include the caregivers of CP children from a Non-Governmental Organization for spastic Cerebral Palsy children. A validated self-administered questionnaire was given to the caregivers after they consented to participate in the study. The results were analyzed using descriptive analysis.
Result: 57 caregivers participated in the study survey voluntarily. There are only 52.6% of caregivers answered the questions on knowledge of CP correctly. 45% of caregivers adhered to the home exercise program that physiotherapist implements.
Conclusion: Caregivers of children with cerebral palsy have a low level of knowledge and low adherence in performing a home exercise program. Empowering the caregivers and creating better awareness of the condition and treatment adherence need to be encouraged.

Keywords

Cerebral Palsy, Caregivers, Home exercises adherence, Knowledge.

Introduction

Cerebral Palsy (CP) describes a group of permanent disorders of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. Beside the motor impairments, sensation, perception, cognition, communication, behavior, epilepsy and musculoskeletal problems are also associated with cerebral palsy (Rosenbaum et al., 2007). According to United Nations Children's Fund (UNICEF)

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Malaysia, the cumulative number of registered children with cerebral palsy between 2011 and 2017 was 5840. The Ministry of Health Malaysia on the other hand, registered 2766 children with special needs in 2012, of whom 215 were children with CP.

According to Gunel (2011), the main aim of physiotherapy is to support the CP children to achieve their potential for physical independence and fitness levels within their community, by minimizing the effect of their physical impairments, and to improve the quality of life (QOL) of the child and especially their family who have major role to play in the process. It is clearly stated that physiotherapy role in CP rehabilitation is undeniable. Although there is a lack of article studies about parental knowledge on CP, but majority of current literatures showed that the parents of CP lack of knowledge regarding the disease (Huang, Kellett, & St John, 2010; Ribeiro, Barbosa, & Porto, 2011). Study demonstrated that lacking of knowledge on diagnosis and prognosis is preventing the parents in accepting and knowing the treatment, education and care available for their children (Ribeiro et al., 2011).

Parents of children with CP have proposed an insightful and enriched definition of home programs from the family perspective: "home programs are a form of guidance and advice, which become a way of life for parents and children. Through particular practice of activities at home, parents maximize their child's potential. Parents use the guidance and support that they gain from home programs to build confidence about how to help their child." (Novak, 2011). A study done by Novak et al., (2014) concluded that home programs are effective when the content of the program is designed upon proven effective interventions, implementation of program following parents' preferences and support and coaching from parents in program planning.

Study done by Lillo-Navarro et al., (2015) showed that some parents would prefer exercises that are simple, enjoyable, without adverse effects (pain & discomfort), improve outcomes and, with least time consumption and less burden. Imposition of a prescribed exercise might decrease adherence to HEP for parents and children who did not enjoy it (Lillo-Navarro et al., 2015). Therefore, knowledge and compliance to HEP by caregivers is important throughout the caring of CP children. This study was conducted to find out the present knowledge on cerebral palsy of caregivers with CP children and their level of adherence on HEP implemented by physiotherapist. Knowledge of caregivers on cerebral palsy is important in chronic care of CP children. Adherence to HEP was defined as how often does the caregivers followed the home program compared with their actual performance.

Methodology

The design of this study used was cross-sectional study. A purposive sampling method strategy was used to recruit caregivers of CP children. A written informed consent was obtained from the caregivers. Validated self-administered questionnaire in English, which consisted of three parts, demographic data, knowledge of caregivers on CP and adherence of HEP was given to the caregivers. Caregivers of aged one to eighteen years old CP children, CP children who currently have received at least three months of physiotherapy rehabilitation, caregivers of CP children who were prescribed with HEP were included. Caregivers presented with communication impairments that are not suitable to participate were excluded. The Faculty Ethical Committee granted ethical

approval. Informed written consent was obtained from the caregivers

Results and Discussion

Fifty-seven participants were recruited after screening for their eligibility. Table 1 demonstrates the demographic data of caregivers.

Table 1. Demographic data of caregivers

		Frequency (n)	Percentage (%)
Gender	Male	8	14
	Female	49	86
Race	Chinese	43	75.4
	Malay	9	15.8
	Indian	5	8.8
Employment	Employed	16	28.1
	Unemployed	41	71.9
Educational level	Primary	4	7
	Secondary	29	50.9
	Tertiary	24	42.1
Relationship with the child	Mother	45	78.9
	Father	7	12.3
	Others	5	8.8

Table 2 demonstrates the knowledge of cerebral palsy among the caregivers. Thirty-four out of 57 of them chosen others for the cause of CP to occur where it mostly mentioned about reduced oxygen level, followed by premature, surgery and some mentioned that they do not know about the cause. Only 22 (38.6%) of them are able to define CP correctly. Majority of the caregivers (93%) are aware of the treatment that is available for CP condition.

Table 2. Knowledge about cerebral palsy among caregivers

		Frequency (%)
Cause of cerebral palsy to occur	Absence of protein	1 (1.8)
	Superstition	0 (0)
	Unknown cause	16 (28.1)
	Genetic	6 (10.5)
	Others	34 (59.6)
	Correct (%)	Incorrect (%)
Define cerebral palsy	22 (38.6)	35 (61.4)
Progressive disorder	33 (57.9)	24 (42.1)
CP can be cured	34 (59.6)	23 (40.4)
CP is preventable	31 (54.4)	26 (45.6)
	Yes (%)	No (%)
Aware of treatment(s) that is available for this condition?	53 (93.0)	4 (7.0)

Table 3 refers to adherence to home exercise program. Fifty (87.7%) of them were instructed by therapist to perform the program more than 6 times per week, but only one third of them are compliance. The rest of 31 of them performed the program for 1-2 times, 3-4 times or 5-6 times per week. More than half of the caregivers performed the exercises for 16-30 minutes per session. Twenty-five of the caregivers performed 3 exercises in one session and only 7 caregivers performed 1 exercise in one session.

Table 3. Adherence to home exercise program

		Frequency (%)
How often were you instructed by the therapist to follow the HEP?	1-2 times per week	3 (5.3)
	3-4 times per week	2 (3.5)
	5-6 times per week	2 (3.5)
	More than 6 times per week	50 (87.7)
How often were you able to carry out the HEP?	1-2 times per week	11 (19.3)
	3-4 times per week	17 (29.8)
	5-6 times per week	10 (17.5)
	More than 6 times per week	19 (33.3)
What is the duration of HEP given for each session?	Less than 15 minutes	13 (22.8)
	16-30 minutes	30 (52.6)
	31-45 minutes	12 (21.1)
	46-60 minutes	2 (3.5)
	More than 60 minutes	0 (0)
How many exercise(s) do you performed in one session?	1	7 (12.3)
	2	9 (15.8)
	3	25 (43.9)
	4	8 (14.0)
	>4	8 (14.0)
Adherence to HEP	Adhere	Non-adhere
	26 (45.6)	29 (54.4)

The purpose of this study is to explore caregivers' knowledge of cerebral palsy and the level of caregivers' adherence to home exercise programs. In this study, there were at least 38.6% caregivers who are able to define cerebral palsy correctly. A similar study was done to investigate parental knowledge of CP showed result that none of the parents could correctly explain the term “cerebral palsy” (Karande et al., 2008). Etiology for CP to occur still remains unknown in most of the cases. However, there are associated risk for CP to occur such as congenital brain formations, maternal infections, complications during labour and delivery, neonatal problems and postnatal conditions such as surgery (Rana et al., 2017). There are quite a number of parents/caregivers who are not aware of the correct definition of CP, it is a non-progressive disorder, and it is not a curable and preventable disease.

Study showed that most parents are having insufficient knowledge regarding the “core basic issues” of cerebral palsy (Karande et al., 2008). The researcher also believed that parents who are empowered with this core knowledge about CP from the time of diagnosis would accept the diagnosis with more open heart and also begin early intervention therapy sooner and continue to carry out the treatment (Karande et al., 2008). Additionally, study has shown that it is important to have more educational activities to improve the parental knowledge which in the otherwise, it

will lead to poor compliance with the treatment and hence further interferes with the process of rehabilitation (Karande et al., 2008). From this study it can be seen that most of the caregivers (n=35) bring their children to the rehabilitation centre once a week. It was found that a high frequency physical therapy (PT) regimen, regardless of the type of intervention, enhances treatment results (Ödman & Öberg, 2005).

54.4% of caregivers in this study does not adhere to HEP. Study done by Basaran et al., (2014) showed that the ratio of poor adherence to HEP was 34.7%. Fifty out of 57 of caregivers claimed that they were instructed to perform HEP more than 6 times per week but only 19 of them are compliance to the frequency. According to American College of Sports medicine (ACSM) guidelines, it is recommended to perform cardiorespiratory training at least three to five sessions per week and at least 20 minutes per session for typically developing children, adolescents and healthy adults (Garber et al., 2011). Study suggested that frequency for cardiorespiratory training for severe CP is possible and advisable to start with one to two sessions per week and progress gradually according to their tolerance and adaptation (Verschuren et al., 2008; Verschuren et al., 2016).

This study has the limitation of small sample size that could not be used to generalize for all caregivers of CP children. Small sample size is also due to no reaching out to the public such as caregivers who bring their children to hospitals, private clinic or other special care centre which also provide physiotherapy treatment. Future study should have included more participants from different centres. As for the adherence on HEP, the results collected are based on statements given by the caregivers, the honesty when answering on the adherence must have been affected as it is difficult for them to justify the frequency and intensity performed in every week. Future studies should have provided logbook to monitor the HEP so that researcher can keep track on their performance. Furthermore, the content of questionnaire developed was not complete enough as there are inadequate questions on the knowledge part which make it is difficult to conclude about their level of knowledge. Further studies need to include more questions on assessing knowledge of the caregivers.

Conclusion

The present study documents that caregivers' knowledge of cerebral palsy condition is insufficient as not many of them can answer the questions correctly. Sufficient information should be provided to the caregivers to empower them in taking care of cerebral palsy children throughout this chronic life-long disorder. This study also demonstrated that there is low adherence of home exercise program in caregivers of cerebral palsy children.

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