East African Medical Journal Vol. 93 No. 11 November 2016
CARE OF CHILDREN WITH CEREBRAL PALSY AMONG GUARDIANS ATTENDING OCCUPATIONAL THERAPY CLINIC AT KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY, KENYA.

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ABSTRACT

Background: **Among the chronic conditions that arise in childhood, cerebral palsy (CP) is the most common cause of disability. According to CDC, recent prevalence of CP in children aged three years and above is estimated at 3.6 per 1000 children globally. Children with CP tend to have multiple disabilities and caring for them can mean a great deal of extra work and expense for the parents.**
Objective: **To determine level of knowledge of cerebral Palsy(CP) among guardians, the psycho-social experiences and challenges among guardians of children with cerebral palsy.**
Design: **A cross sectional study**
Setting: **Occupational Therapy Clinic at Kenyatta National Hospital (KNH) a teaching and referral hospital in Nairobi city county, Kenya.**
Subjects: **Two hundred and eighty five(285) guardians of children with cerebral palsy**
Results: **The study findings indicated that; the knowledge level of CP among guardians was not significantly associated with functionality of CP children: functional mobility (p=0.691) and ADLs performance (p=0.639). Stigma experienced by respondents was significantly associated with functionality of CP child; functional mobility (p=0.003) and ADLs performance (0.037), and stress level was significantly associated with functional mobility of CP children (p=0.01). Other challenges experienced by respondents included fatigue and financial problems. Fatigue level was significantly associated with functional mobility of CP children (p=0.002). Financial challenge was experienced by a majority (93.3%) of respondents. Catering for healthcare related costs presented a difficulty among 87.6% o respondents. 49.1% of participants stated that they felt they needed support with meeting healthcare related expenses. None of the socio-demographic characteristics of guardians were significantly associated with functionality of CP children.**
Conclusion: **There is need for public education on cerebral palsy in order to protect families of affected children from negative experiences like stigma and stress, and to offer financial support to families of affected children in order to enable them get the essential healthcare services.**

INTRODUCTION

Cerebral palsy (CP) is a disorder of movement and posture that appears during infancy or early childhood. It is caused by non-progressive damage to the part of the brain which controls muscle co-ordination. This damage can occur before, during or shortly after birth. The damage to the brain is permanent and cannot be cured but consequences can be minimized. Any non-progressive central nervous system (CNS) injury occurring during the first 2 years of life is considered to be CP (1). The problems which it causes depend on the extent of the damage and they range from mild stiffness of one arm and leg to severe problems in all four limbs together (2). Among the chronic conditions that arise in childhood, cerebral palsy is the most common cause of disability (3).

In many children, the cause of CP is unknown.

Known risk factors include low birth weight and prematurity, for example, infants of very low birth weight are 20–80 times more likely to have CP than infants of a birth weight of more than 2500 grams. Known causes include prenatal events responsible for approximately 75% of all cases of CP, Perinatal causes responsible for 10-15% cases and postnatal causes responsible for around 10% of all cases (4). Estimates of prevalence of CP throughout the world vary depending on the methodology of count, percentage ascertained and variations in selection criteria. However, an average of the figure range between 3-4/1000 live births (5).

A child with CP suffers from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual impairment, and gastrointestinal and feeding problems. Cerebral palsy children also have several limitations in self-care functions such as feeding, dressing, bathing, and mobility. These limitations can result in requirements for long-term care that far exceed the usual needs of normal children (6). Most children with special needs are cared for at home by their families and the presence a child with a disability in a family can mean a great deal of extra work and expense for the parents (2).

In traditional African society, the birth of a child with any form of disability brings a lot of emotional stress to family members as a result of the stigma attached to such a condition. Another important emerging issue is that children with cerebral palsy (CP) require a lot of financial support for their rehabilitation thus causing a lot of financial strain in the families (7).Children with cerebral palsy (CP) suffer from several problems, the family especially the mothers undertake a lot of social and emotional difficulties. Parents of mentally retarded children also have limited leisure time and social interaction (8).

A majority of children with disabilities are more likely to experience debilitating forms of criminal neglect due to dependence. Cases of near-starvation, extreme deprivation, highly unhygienic living conditions and total abandonment are among those that have been realized by studies in Kenya, Uganda, and Tanzania. Cases of children with disabilities being killed or dying as a result of violence have also been recorded. The most important obstacle is negative thinking about people with disabilities, and to believe that they are not deserving of positive attention, care or a dignified life (9)

MATERIALS AND METHODS

Design: This study utilised a cross sectional descriptive design with both quantitative and qualitative techniques. Descriptive design entails fact-finding enquiries of different kinds with the aim reporting the state of affairs as it exists at present. The study was cross-sectional because data were only collected at one particular point in time. The research design was appropriate for this study because it is good for descriptive analysis without any manipulation of variables. It was also a more practical option because it provided results at a relatively low cost and in a shorter period.

Variables: A concept which can take on different quantitative values is called a variable. Qualitative attributes are quantified on the basis of the presence or absence of the concerning attribute(s). A dependent variable is one which depends upon or is a consequence of another variable and the variable that is antecedent to the dependent variable is termed as an independent variable.

Independent Variables: Independent variables in this study included; knowledge level of guardians of children with CP. This was assessed in terms of knowledge on causes, management and prognosis of the condition. Psycho-social experiences of guardians as a variable was assessed in terms of stress level, stigma associated with caregiving. Socio-demographic characteristics of guardians of CP children that were considered included: age, marital status, educational level and income status of guardians.

Dependent Variable: Dependent variable in this study was functionality of a cerebral palsied child.

Location of the Study: The study took place in Kenyatta National Hospital (KNH) at the Occupational Therapy Clinic (OTC) in Nairobi City County, Kenya. KNH is the main referral and teaching hospital in Nairobi City County and in Kenya. KNH was selected because it serves a large population thus the likelihood of finding a large number of study subjects with desired characteristics.

Target Population: Target population refers to the population which the researcher wants to generalize the results of a study (Mugenda, 2003). The target population for this study was the guardians of registered children with CP obtaining occupational therapy and physiotherapy services at KNH.

Inclusion Criteria: Biological parents of children with cerebral palsy aged 2-18 years and/or legal guardians of children with CP in the absence of biological parent.

Exclusion Criteria: Guardians of children with cerebral palsy who refuse to give consent to participate and/or guardians who have been responsible for care of a cerebral palsied child over a period of less than three months.

Sampling Technique: Systematic random sampling was used in the selection of study participants. Averages of 50 clients with different diagnoses attend KHN Occupational Therapy Clinic (OTC) each day out of which averages of 35 have a diagnosis of CP. The researcher visited the facility (KNH) before actual data collection process began to check on the clinic appointments of clients and their diagnosis according to medical records. This facilitated the identification of study subjects in regard to those that met the inclusion criteria. The first study subject was selected randomly using coin tossing technique then systematic random sampling was used to select the subsequent respondents whereby every second (2nd) study subject in the list attending each day was selected to participate in the study each day until the desired sample size was achieved. The structured questionnaires were then administered to respondents who had children with cerebral palsy and met study inclusion criteria that gave consent to participate in the study. Respondents were required to respond by answering provided in questionnaires. The principal researcher was available to clarify any issue to respondents in regard to questionnaire filling. Data collection exercise took nine weeks which enabled the researcher to obtain full sample size.

Sample Size: Sample size was determined by Fisher's formula.
Determination of sample size (n)

$$n=\frac{2^2pq}{d^2}$$

Where:
z = standard normal deviation set at 1.96 z-score corresponding to 95% confidence level
p = the proportion in the target population estimated to have characteristics being measured (taken as 0.5 if exact probability is not well known).
q = represents the total probability minus p i.e. 1-P, 1-0.5=0.5
d = level of statistical significance set (normally 0.05 if 95% confidence level is desired).
Therefore

$$n=\frac{1.96^2 \times 0.5 \times 0.5}{0.05^2} = 384.3 \approx 384 \text{ guardians of children with cerebral palsy}$$

However, the population (1082) from which the sample was selected was below 10, 000, thus the following formula by Fisher further applied in getting nf (exact sample size)
Correctional formula for a population of less than 10,000 was then be used

$$n_1=\frac{n}{1+\frac{n}{N}}=\frac{384}{1+\frac{384}{1082}} = 284.4 \approx 285 \text{ guardians}$$

Therefore n_f = 285 guardians of children with cerebral palsy

Data Collection and Quality control: Collection of data from the guardians of children with CP attending OTC at KNH involved visiting the clinic premises earlier in order to obtain information on clients with CP according to their diagnosis as per medical records and their clinic appointment dates and time. This facilitated accurate systematic random selection of study subjects. The researcher avoided collection of data from any particular study subject more than once during the entire period of the study by assigning serial numbers to attendance cards of children whose guardians had already participated in filling questionnaires. Each potential study subject was approached by researcher and informed of the study and voluntary informed consent to participate obtained before administration of questionnaire. After administration, questionnaires from respondents were checked for completeness by the researcher at the end of each data collection day. These measures focused on ensuring data quality.

FGD was conducted by the researcher in order to collect qualitative data. This was accomplished by the help of a research assistant who was recording the discussion and was also taking notes on the same. The respondents and researcher were seated in circular order to ensure engagement of each participant. The researcher led the discussion by conducting introduction and helping to set the norms of the session.

Ethical Considerations

Relevant research and ethical review boards were consulted and permission obtained before conducting the actual study by sending applications. These included; Kenyatta University Ethics Committee, Kenyatta National Hospital and University of Nairobi Research and Ethics committee, National Commission for Science, Technology and Innovation (NACOSTI), and the Departmental Head and In Charge of the Occupational Therapy Clinic at KNH. Voluntary informed consent was obtained from all guardians of children with CP attending KNH at the OTC who were involved in the study.

RESULTS

The researcher obtained 100% (285) of the sample size in this study and all respondents were female. A similar observation was made during FGD where all participants were female. A total of four demographic variables were investigated and these included: age, marital status, education level and income. A majority 59.6 % (170) of these were aged between 25 and 30 years. Nearly half 46.7% (133) of the respondents had attained college education or above while 54% (154) of them were currently engaged in some form of employment. Majority of 80% (228) of the respondents were married with over a third (37.5%) earning an average monthly income of between Kshs 10,000 and 19,999(USD 98.81-197.62) (Table 1)

Table 1
Socio-demographic Characteristics of the respondents

Characteristic	Categories	Frequency	Percentage (%)
Age	18-24	93	32.6
	25-30	170	59.6
	31-36	17	6.0
	37-42	3	1.1
	43 years and above	2	0.7
Total		285	100
Highest level of education attained	College level and above	133	46.7
	Secondary school level	126	44.2
	Primary school level	26	9.1
Total		285	100
Employed	Yes	154	54.0
	No	131	46.0
Total		285	100
Nature of employment	Self/casual employment	125	43.86
	Formal employment	29	10.18
	Unemployed	131	45.96
Total		285	100
Marital status	Married	228	80.0
	Single parent	47	16.5
	Separated	10	3.5
Total		285	100
Monthly average income	Ksh 0-9,999(USD 0-97.84)	92	32.3
	Ksh 10,000-19,999(USD 98.81-197.62)	107	37.5
	Ksh 20,000-29,999(USD 197.63-296.43)	61	21.4
	Ksh 30,000-39,999(USD296.44-395.25)	20	7.0
	Ksh 40,000 and above(USD 395.26 and above)	5	1.8
Total		285	100

Functionality of CP children of respondents: A majority; 91.2%(260) of the children with CP whose guardians participated in the study were aged between 2 to 4 years with a majority of guardians 98.6%(260) stating that their children had started attending occupational therapy sessions before the age of 2 years (Table 2). Functionality of cerebral palsied children of respondents was assessed in terms of functional mobility and ability to perform ADLs. The GMFCS- Expanded and Revised scale was used to assess the level of functional mobility of the children with CP. Those belonging to level I & II were categorized as having mild limitation, those in level III were categorized as having moderate limitation while those in level IV & V were categorized as having severe limitation. Majority 82.8%(236) of the children with CP had severe limitation in functional mobility, 10.2%(29) had moderate limitation while only 7.0%(20) had mild limitation in functional mobility (Table 2).

Assessment of the child's performance of activities of daily living(ADLs) was done using the Katz index of independence through the report of the respondents on whether their children were able to perform a list of basic activities including ability to feed, getting to bed, control of urination and defecation, ability to go to toilet, ability to bathe and clothe. A child who was able to perform five to six tasks was considered fully functional, a child who was able to perform three to four tasks was considered moderately functional while a child who was able to perform two or less tasks was considered to have severe functional impairment. Majority 95.4%(272) of the children had severe functional impairment while only 0.7%(2) were classified as fully functional or independent (Table 2).

Table 2

Characteristics of CP children of respondents

Characteristic	Categories	Frequency	Percentage (%)
Age of the child	2-4 years	260	91.2
	4-6 years	24	8.4
	6-12 years	1	0.4
Total		285	100
Age child started attending physiotherapy sessions	Before 2 years	281	98.6
	At 2 years	2	0.7
	At 3 years	1	0.4
	At 4 years and above	1	0.4
Total		285	100
ADL performance	Severe impairment	272	95.4
	Moderate functional impairment	11	3.9
	Fully functional/independent	2	0.7
Total		285	100
Functional mobility	Mild limitation	20	7.0
	Moderate limitation	29	10.2
	Severe limitation	236	82.8
Total		285	100

Knowledge level about CP among the respondents: To assess the level of knowledge about CP among respondents, a group of seven questions were included in the questionnaire regarding cause of CP, management, and prognosis among others. Respondents who answered three (3) or less questions correctly were classified as having low knowledge; those who answered four or five questions correctly were classified as having moderate knowledge, while respondents that answered more than five (5) questions correctly were classified as having high knowledge about cerebral palsy. A majority of 66.3%, that is, 189 out of the 285 respondents were classified as having high knowledge about cerebral palsy (Figure 1). A similar observation was made in the FGD session whereby a majority of respondents gave correct answers as they contributed to the discussion. Knowledge level about cerebral palsy was noted to be high among respondents with children of low functionality both in terms of functional mobility and ADLs performance (Table 3). However, there was no significant association between knowledge levels and CP child functionality.

Figure 1

Knowledge level about CP among respondents

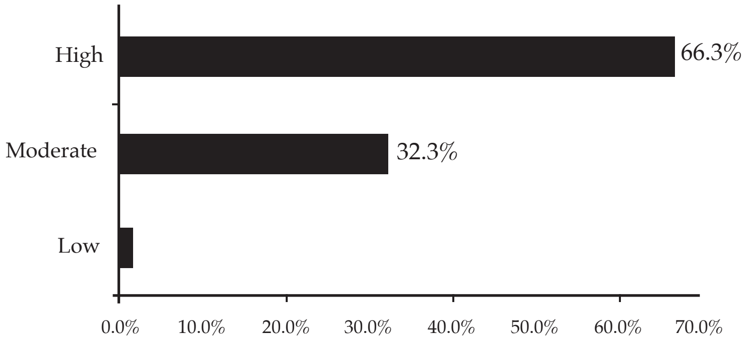

Table 3

Relationship between Knowledge level about CP of respondents and Functionality of CP Child

Functionality of CP children		Knowledge level of respondents			Chi-square* p-value
		Low	Moderate	High	
Functional mobility	Mild limitation	.0(0)	3.2(9)	3.9(11)	0.691
	Moderate limitation	.0(0)	3.5(10)	6.7(19)	
	Severe limitation	1.4(4)	25.6(73)	55.8(159)	
ADL performance	Severe impairment	1.4(4)	30.5(87)	63.5(181)	0.639
	Moderately functional	.0(0)	1.8(5)	2.1(6)	
	Fully functional	.0(0)	.0(0)	.7(2)	

* *Fisher's Exact*

Psycho-social experiences associated with CP of respondents : A majority; 97%(276)of respondents reported that their lives had changed since having a CP child (Table 4).

Stigma: A majority of 81.1%(231) of the respondents reported having little time for social activities due to the demands of their cerebral palsied children while 15.4%(44) reported that friends and family had withdrawn as a result of them having a CP child (Table 4). A majority 67.0%(191) of the respondents reported having people in their social circle having a view that CP was a medical condition while the rest14.0%(40) were blamed as being the cause of the condition. 19% of respondents had those around them with the view that CP was either as a result of witchcraft or bad omen (Table 4).

A majority 61.4% (175) of respondents reported to have experienced stigma from other people as a result of having a child with CP while only 38.6%(110) of the respondents reported to have experienced acceptance. A majority 64% (182) of respondents reported to be experiencing self-stigmatization while only 36%(103) of the respondents reported to have a feeling of acceptance towards themselves as a result of having a child with CP (Table 4).

Table 4

Social and self-opinions of respondents related to having a CP child

Change in personal social patterns of respondents	Frequency	Percent (%)
Little time for social activities due to childcare demands	231	81.1
Friends and family have withdrawal & isolation	44	15.4
No change in life	8	2.8
Others	2	0.7
Total	285	100

People's views about causes of CP according to respondents	Frequency	Percent
It is a medical condition	191	67.0
It is caused by bad omen	40	14.0
It is caused by factors related to parent (blame)	40	14.0
It occurs as a result of witchcraft	14	5.0
Total	285	100

Reactions towards respondents from society due to having CP children	Frequency	Percent
Isolation	113	39.6
Acceptance	110	38.6
Rejection	32	11.9
Blame	28	9.5
Others	2	0.4
Total	285	100

Feelings of respondents as a result of having CP children	Frequency	Percent
Acceptance	103	36
Anxiety	91	32
Depression	48	17
Self-pity	43	15
Total	285	100

The findings were in agreement with those of FGD where respondents expressed feelings such as; *"Relatives also blame me for having such a child, they keep telling me to take the child home so that he gets treated with traditional medicine which is not a working option for me. They are a source of stress to me. My husband blames me for having such a child because he had told me not to have more children. Now that I had this one and he has cerebral palsy he makes unpleasant comments that hurt me."(FGD8, 2015)*

"I have been affected psychologically because this is my first child and she is affected by cerebral palsy, I have undergone so many challenges with her and so am scared of having another child who may have the same problem. In my whole extended family, all people have normal children except me. I keep asking myself why I am the only one with this problem."(FGD2, 2015)

"People would not like to talk to me either here or in my rural home, they think am the cause of the problem in my child and they think if they talk to me, I will start telling them my problems and you may bring same problem to their families."(FGD1, 2015)

However there were cases of acceptance as expressed by another FGD respondent that;*"I have accepted my situation even if sometimes other younger children than mine can walk and call mine the baby, I know all will be well. I feel encouraged by my neighbor who has a child with cerebral palsy too that is doing well even if she attends special school." (FGD5, 2015)*

A stigma scale was developed such that a person who reported having been stigmatized by self and other society members was considered to be highly stigmatized. Those who experienced stigma from either self or others was considered moderately stigmatized while those who experienced self-acceptance and acceptance by others were considered not stigmatized. Stigmatization level was significantly associated with child functional mobility (p-value = .003) and ADL performance (p-value = .037). This shows that guardians of children with severe CP were more stigmatized (Table 5).

Stress: Stress level was evaluated by self-rating of the respondent's perceived level of stress on a 5-point likert scale. Slightly over a third (34.1%) of the respondents were feeling moderately stressed for the past fourteen days preceding the data collection while only 3.6% reported not to have felt stress.Stress level in respondents was significantly associated with child's functional mobility (Fisher's Exact Chi-square p-value = 0.010) and not significantly associated with ADL performance(Fisher's Exact Chi-square p-value = 0.425). This shows that guardians of CP children with severe functional mobility were more stressed (Table 6).

These findings were in agreement with those from the FGD whereby a respondent said; "The child gives me stress. He had improved and then slowed down again and so I feel frustrated."(FGD7, 2015).

Table 5

Child Functionality by stigma in respondents

Functionality of CP children	Stigmatization level (N = 285)			Chi-Square P-value*
	Not stigmatized %(n)	Moderately stigmatized %(n)	Highly stigmatized %(n)	
Functional mobility				
Mild limitation	1.1(3)	4.6(13)	1.4(4)	.003
Moderate limitation	3.5(10)	3.5(10)	3.2(9)	
Severe limitation	11.2(32)	30.5(87)	41.1(117)	
ADL performance				
Severely impaired	15.1(43)	35.1(100)	45.3(129)	.037
Moderately impaired	.7(2)	2.8(8)	.4(1)	
Fully functional	.0(0)	.7(2)	.0(0)	

Table 6
Child Functionality by Stress levels in respondents

Stress level	Functional mobility			ADL performance		
	Mild limitation	Moderate limitation	Severe limitation	Severe limitation	Moderate limitation	Mild limitation
Not stressed	.0(0)	.4(1)	3.2(9)	3.5(10)	.0(0)	.0(0)
Somewhat stressed	3.2(9)	5.3(15)	20.0(57)	26.0(74)	1.8(5)	.72 ()
Moderately stressed	2.5(7)	2.1(6)	29.5(84)	32.3(92)	1.8(5)	.0(0)
Fairly stressed	1.1(3)	2.5(7)	18.2(52)	21.4(61)	.4(1)	.0(0)
Very high	.4(1)	.0(0)	11.9(34)	12.3(35)	.0(0)	.0(0)
Chi-Square P-value*		.010			.425	

** Fisher's Exact*

Challenges associated with care of children with CP

Fatigue: Fatigue level was evaluated by self-rating of the respondents' perceived level of tiredness on a 5-point Likert scale. Slightly over a third 35.4%(101) of the respondents reported having felt moderately tired for the previous fourteen days preceding the study (Table 7). Fatigue level in respondents was significantly associated with child's functional mobility (Fisher's Exact Chi-square p-value = 0.002) and not significantly associated with ADL performance (Fisher's Exact Chi-square p-value = 0.194). This shows that guardians of CP children with severe limitation in functional mobility had more fatigue (Table 7).

Nearly half of the respondents, 49.5%, reported to spend 9 hours or more daily to care of their cerebral palsy children and a minority of 1.1%(3) only reported to spend three hours or less daily towards caring for their children with cerebral palsy (Table 9). Daily hours spent by respondents to care for the CP child was significantly associated with child's functional mobility (Fisher's Exact Chi-square p-value = 0.002) and ADL performance (Fisher's Exact Chi-square p-value = 0.018). This shows that guardians of CP children with severe functional mobility spent more time caring for children with CP (Table 8).

These findings are in concurrence with those of FGD discussion whereby one respondent reported that "It is also difficult to find someone who understands the child with cerebral palsy as well as his/her mother in the case of finding a house help to care for the baby." (FGD7, 2015).

Table 7
Child Functionality by Fatigue levels in respondents

Fatigue level	Functional mobility			ADL performance		
	Mild limitation	Moderate limitation	Severe limitation	Severe limitation	Moderate limitation	Mild limitation
Not tired	.7(2)	.4(1)	3.5(10)	4.2(12)	.4(1)	.0(0)
Somewhat tired	2.5(7)	5.3(15)	18.2(52)	23.9(68)	1.8(5)	.4(1)
Moderately tired	3.5(10)	2.8(8)	29.1(83)	33.3(95)	1.8(5)	.4(1)
Fairly tired	.0(0)	1.4(4)	24.6(70)	26.0(74)	.0(0)	.0(0)
Very tired	.4(1)	.4(1)	7.4(21)	8.1(23)	.0(0)	.0(0)
Chi-Square P-value*		.002			.194	

** Fisher's Exact*

Table 8

Time per day spent by respondents caring for CP children by functionality

Hours spent caring for CP child	Functional mobility			ADL performance		
	Mild limitation	Moderate limitation	Severe limitation	Severely functional	Moderately functional	Fully functional
≤3	.0(0)	.4(1)	.7(2)	.7(2)	.0(0)	.4(1)
3-6	2.8(8)	4.2(12)	20.4(58)	25.6(73)	1.4(4)	.4(1)
6-9	1.8(5)	3.9(11)	16.5(47)	20.7(59)	1.4(4)	.0(0)
>9	2.5(7)	1.8(5)	45.3(129)	48.4(138)	1.1(3)	.0(0)
Chi-Square P-value*		.002			.018	

* Fisher's Exact

Financial challenges associated with care of children with CP: Majority of the respondents, 93.3%(266), experienced financial problems in the day to day life in the upbringing of the CP children. Out of these, a majority of 81.7% (233) reported that the main challenge involved the cost of meeting healthcare expenses of the child. Further, nearly half of the respondents 49.1% (140) cited needing some support in order for them to meet the regular medical expenses of the children (Table 9).

These findings were in agreement with sentiments by FGD respondents. They reported that: *"Cost of getting health care like physiotherapy which may take very long for child to improve and obtaining assistive equipment /aids is high and some people like me cannot afford. Maybe if I was able to get the equipment, my child would have improved more than she has this far. Drugs and foods are also expensive."(FGD1, 2015)* *"… I cannot go to work as I have to be the one caring for my child. My husband is the only one working and most of the money he gets goes towards treatment of the child that is buying medication and bringing him for physiotherapy."(FGD7, 2015) and "… if someone is a working mother like me; you have to take frequent offs from work."(FGD5, 2015)*

Table 9

Financial challenge and Support need areas of respondents

	Count	Column N %
Areas of high financial challenge (N = 285)		
Meeting child healthcare expenses	233	81.7
Obtaining assistive devices required	16	5.6
Cost of employing someone to help the child	11	3.9
Child schooling expenses	5	1.8
Meeting basic needs	1	0.3
No financial challenge experienced	19	6.7
Total	285	100
Felt need support areas (N = 285)		
Medical expenses	140	49.1
Obtaining appropriate school	48	16.8
Obtaining assistive devices	43	15.1
Support in day to day care	39	13.7
Information on the condition	11	3.9
Meeting of basic needs	4	1.4
Total	285	100

Association between Socio-demographic characteristics of respondents and functionality of CP Children: None of the socio-demographic characteristics of the guardians including age, level of education, marital status, and monthly income was significantly associated with functionality of cerebral palsied children, therefore, the null hypothesis was accepted (Table 4.10).

Table 10

Socio-Demographic Characteristics of respondents and Functionality of CP Children

	Functional mobility			ADL performance			Functional mobility p-value*	ADL p-value*
	Mild	Moderate	Severe	Severe	Moderate	Fully		
Age							.087	.086
18-24	10.0%	24.1%	35.6%	33.8%	0.0%	50.0%		
25-30	70.0%	69.0%	57.6%	59.2%	81.8%	0.0%		
31-36	20.0%	6.9%	4.7%	5.1%	18.2%	50.0%		
37-42	0.0%	0.0%	1.3%	1.1%	0.0%	0.0%		
≥43	0.0%	0.0%	0.8%	0.7%	0.0%	0.0%		
Education level							.256	.644
Primary	5.0%	3.4%	10.2%	9.2%	9.1%	0.0%		
Secondary	55.0%	31.0%	44.9%	44.1%	54.5%	0.0%		
College	40.0%	65.5%	44.9%	46.7%	36.4%	100.0%		
Marital status							.112	.306
Married	100.0%	79.3%	78.4%	79.4%	90.9%	100.0%		
Single parent	0.0%	13.8%	18.2%	17.3%	0.0%	0.0%		
Separated	0.0%	6.9%	3.4%	3.3%	9.1%	0.0%		
Employment status							.086	.058
Yes	60.0%	72.4%	51.3%	52.6%	81.8%	100.0%		
No	40.0%	27.6%	48.7%	47.4%	18.2%	0.0%		
Average monthly income							.272	.328
Ksh 0-9,999	30.0%	34.5%	32.2%	32.0%	45.5%	0.0%		
Ksh 10,000-19,999	50.0%	31.0%	37.3%	38.2%	27.3%	0.0%		
Ksh 20,000-29,999	5.0%	20.7%	22.9%	21.3%	18.2%	50.0%		
Ksh 30,000-39,999	15.0%	13.8%	5.5%	6.6%	9.1%	50.0%		
≥Ksh 40,000	0.0%	0.0%	2.1%	1.8%	0.0%	0.0%		

** Fisher's Exact*

DISCUSION

The study found out that all the guardians of children with cerebral palsy who participated in this study were women. A majority of participants in this study were married; aged between 25 and 30 years, had attained college education or above, were currently engaged in one form of employment and were mostly earning average monthly income of between Kshs 10,000 and 19,999(USD 98.81-197.62).This indicates that women, mostly mothers, of children with cerebral palsy are the ones involved with the caring role of affected children in the family set up. These results also concur with those of the FGD carried out by the researcher in which all the participants were the mothers of CP affected children.

These finding were consistent with those reported by other studies which indicated that a majority of caregivers of children with CP; 85% and 67.3% respectively were women and more so the mothers of children (6,10).

The caregiver's education and the family income are basic elements that determine the child's health, because they are indicators of available resources, and knowledge or behavior in relation to health and well-being of children (11). In this study there was no evidence associating functional mobility of a CP child with age, education level, marital status, employment status, and income level of the guardian. Also age, education level, marital status, employment status and income level of the guardian were not significantly associated with ability of CP child to perform ADLs. These results concur with those of a study carried out in Brazil that indicated absence of a significant association between socioeconomic status of parents of children with cerebral palsy and functional performance of children with cerebral palsy. However, findings indicated that children with mild cerebral palsy and low socioeconomic status presented with low social function scores as compared to those of high socioeconomic status, therefore, suggesting that socioeconomic status may influence development process of children with cerebral palsy therefore must be considered a risk factor in educational and health practices directed this group (11).

Most of the cerebral palsied children whose guardians were interviewed were aged between 2 to 4 years having mostly started attending physiotherapy sessions before the age of 2 years. Similarly, findings of another hospital based study in Bangladesh indicated that majority of the CP children attending physiotherapy sessions were aged between 1-4 years (12).Another institution based study among guardians of children with cerebral palsy attending three early intervention centers in south-east Spain also revealed that most of the children attending these sessions were over two years (13). The GMFCS-Expanded and Revised scale was used to assess the level of functional mobility of the children with CP. Results indicated that majority of the children with CP whose guardians were seeking services had severe limitation in functional mobility while very few had mild limitation in functional mobility.This finding of the study implies that a majority of guardians seeking occupational and physiotherapy interventions of their children with CP are those with children with GMFCS rating of III and above. These results are consistent with those of another study which indicated that physical health in addition to motor problems of children in levels IV/V is more compromised thus requiring more healthcare intervention leading to more hospitalizations (3). The findings are also consistent with those of Lillo-Navarro in which a majority of guardians of children with cerebral palsy seeking early intervention were those with children with GMFCS above III(13).Similarly, a study among CP children attending psychotherapy sessions in a teaching hospital in Turkey indicated that a majority of 66.4% were found to have GMFCS scale III and above (14).

Contrary to these findings, another study showed that a half of the pre-school children aged 2-7 years receiving services from two rehabilitation centers and one hospital in Latvia were found to mostly have GFMS scale of II or less. This was attributed to the fact that parents of children with minor gross motor and communication limitations seemed to have fewer unmet family and high expectation on achievements by the children. Therefore the degree of child impairment needs to be taken into account while planning rehabilitation, social and educational services of CP children especially in cases of limited financial resources (15).

This study found out that regarding ability to perform ADLs, a majority of the children had severe impairment while only 0.7% of children were classified as fully functional with ability to clothe, to go to toilet and clean genital area without help and complete self-control over urination and defecation being the most uphill tasks among the sampled guardians' children. These findings suggest that functional mobility CP children may be associated with ability of affected children to perform ADLs. This is in agreement with the fact that most of the children in level GMFCS IV and V are known to have behavioral, psychological and emotional disturbances apart from motor function limitations, thus, need for continual and specialized care(3).

Results of this study showed presence of association between fatigue level of guardian and functional mobility of CP child. This concurs with findings of another study that found out that limited mobility promoted dependence on a caregiver to perform daily routine tasks (16).

Two thirds of the guardians of CP children who participated in the study were classified as having high knowledge about cerebral palsy condition. The study also revealed that knowledge level was significantly high among guardians of CP children with low functionality. However, the association between the knowledge level of guardians and functionality of cerebral palsied children was not significant. These findings are consistent with those of a qualitative study conducted in West Africa in which most parents of children with cerebral palsy first learned about CP after having an affected child and admitted seeking for more information in relation to the condition of their children (10).

Majority of the guardians were experiencing self-stigmatization as they had not felt self-acceptance as a result of having a child with CP while others had experienced stigma from family and friends. While a majority of the study participants reported having support from their relatives and neighbours, only a third reported to have experienced acceptance from other people as a result of having a child with CP. Only a minority of 15.8% of respondents had not experienced any form of stigmatization. This implies that there is need for public health education on the topic of cerebral palsy in order to overcome the problem of stigma both at individual and community level.

The findings of this study are in agreement with those of a study that indicated that parents often struggle with guilt; they feel as though they somehow caused the child to have a disability (17) In support of these findings, another study also reported that parents experience isolation from community members as a result of having a child with a form of disability (18). Similar results were also noted in a study conducted in Tanzania where it was reported that most mothers of disabled children were rejected by their spouses and/or relatives with very few of them reporting having received any form of support. In addition, the members of the families who accepted the disabled children were also isolated (19).

A majority of the guardians of cerebral palsied children reported having felt between moderately stressed and very stressed fourteen days preceding the data collection exercise. Study results further showed that guardians of children with low functional mobility were more stressed. This could be attributed to the fact that low functional mobility associated with poor performance of ADLs in CP children thus high dependence on the guardians. In concurrence with this study, another reported that pessimism expressed regarding the child's ability towards achieving self-sufficiency was found to be most stress producing factor among parents of cerebral palsied children (20). Another study with similar results found out that a majority of guardians undergo pain and devastation when they realize that their future dreams and expectations would not be met as a result of having a child with a disability (18).

A study conducted on parenting stress in children with CP showed that parents of children with cerebral palsy presented high levels of parental stress as compared with the general population (21). Another study also reported that mothers of CP children presented high levels of stress especially those whose children had severe motor impairment (3). This may be explained by the fact that Physical functioning is positively related with cognitive functioning in children with CP. Children who moved more actively showed higher scores in terms of physical and cognitive functioning than the children who showed fewer active movements and as such most guardians were stressed by the cognitive functioning of the child in addition to the physical functioning (22).

In this study, nearly half of guardians reported to have less time to commit and concentrate on work activities as a result of having a child with CP child since they spent considerate amount of time taking care of the CP children. In addition, almost half of them did not have someone who helped them to take care of their children on day to day basis. According to findings of the FGD, one participant stated that it was difficult to find someone to take care of such a child as well as the mother does. A minority of guardians reported not feeling tired. This study finding concur with those of a study carried out in India in which results showed that a considerable number of parents of children with cerebral palsy experienced fatigue and frustration due to the high care requirements which were time consuming and clashed with other household chores(6). Guardians of children with special health care needs in home care reported to be too tired to do the things they liked to do (23). Other related studies reported that caring for children with disabilities is demanding and as such guardians are left with little opportunity for household chores, social activities, income-generating schemes, and caring for other children leading to more stress on the parent (18,24).

Results further indicated that guardians of children with low functional mobility were more fatigued. This implies that low functionality in CP children translates to high dependence on guardians in terms of requirements of care which in turn leads to fatigue. This concurs with findings of another study that found out that limited mobility promoted dependence on a caregiver to perform daily routine tasks (16). Another study also on care of disabled children indicated that the task of caring according to caregivers varied based on the type and severity of disability. Physically carrying the child in the case of children who are unable to walk was difficult for caregivers especially for more grown up children (19). This indicates that, in addition psychological support, guardians of children with CP also require physical support especially in regard to the care giving role. Majority of the guardians reported experiencing financial problems in their care of the CP children in regard to several areas in day to day life and needs of the children. These areas included; meeting basic needs, employing someone to care for the child, healthcare needs of child, acquisition of appropriate assistive devices and, expenses related to schooling of CP child. A majority of guardians experienced financial constraint in meeting healthcare related expenses of affected children while a minority experienced constraint in meeting basic needs. Another study reported that care required by children with CP was a hindrance to mothers of such children looking for jobs and as such, financial difficulties were experienced in meeting the needs of such children (3). These study findings concur with those reported in India whereby a majority of parents of children with CP admitted that the major financial challenge they faced involved meeting medical expenses and related expenses such as transport of children to medical facilities and paying doctor consultation fees (6). Further, a large proportion of the respondents cited needing support in order for them to meet the regular medical expenses of the child. CP children continuously require special care, frequent medical checkups, and continuous occupational and physiotherapy treatment modalities which may be costly (14). According to the study, other areas in which some respondents noted to require help included finding appropriate schools and education for their children, assistance with obtaining assistive devices for the children, and help with day to day caring of their children. Only a small percentage of them cited needing help on information about the condition and meeting basic needs. These results are in agreement with those of a different study whose results showed that most guardians reported needing financial support to aid them acquire specialized equipment for their children (25). Similarly, another study reported that financial help and the need for supplies is a major need area among guardians of children with disabilities (19).

CONCLUSION

The knowledge level about cerebral palsy among guardians of children with cerebral palsy was relatively satisfactory due to a majority of respondents being classified as either having moderate or high level

of knowledge about CP. Knowledge level was also noted to be high among guardians with children with low functional mobility and poor ability to perform ADLs as compared to those guardians whose children had mild limitation in functional mobility.
Guardians of children with cerebral palsy faced negative Psycho-social experiences within the society including stigma and stress.

The study established that guardians of children with cerebral palsy experienced fatigue and financial challenges in the course of caring for their children. According to the results, there were several areas in which financial constraints were expressed including meeting basic needs, employing care givers of affected child, meeting healthcare expenses, acquiring assistive devices as well as meeting schooling expenses. Among these, a majority of guardians reported that financial constraint related to meeting healthcare expenses of their CP children was the major issue of concern. Fatigue was a challenge due to the many hours that guardians used in the caring process. A majority used more than 6 hours per day in the caregiving functions.

RECOMMENDATIONS

According to the study, a majority of guardians had moderate to high knowledge on CP, therefore, measures need to be taken to ensure the sources of information about cerebral palsy available to or utilised by guardians of affected children are increased for availability. This will help sustain and/or improve the knowledge level on the condition which may promote better care giving to the children by their guardians.

The stakeholders in healthcare should take proactive efforts to sensitize the public through public health education programmemes on cerebral palsy as a chronic condition in an effort to eliminate negative social challenges such as stigma and stress among those with affected children. Also, social support services such as counselling and formation of social support groups for guardians of CP children should be provided to help with stress alleviation.

Healthcare services and assistive equipment required by CP children need to be subsidised to ensure they are affordable to a majority of guardians so that they are accessible to the children as required for their health and well being as well as maximum function.

Relatively affordable respite care services need to be made available to guardians of CP children to relieve them of the burden of care, for example, specialised care centres as well as support from within the family unit.

ACKNOWLEDGEMENTS

To my supervisors Dr. Gilbert Munyoki and Dr. Priscillah Kabue, both of Kenyatta University who devoted their time to advice and work hand in hand with me to completion of this work. I also thank the management of the Cerebral Palsy Society of Kenya and Kenyatta National Hospital for allowing the use of their institutions for this study along with all participants who took their precious time to participate in this exercise.

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