International Journal of Contemporary Pediatrics
Eyong KI et al. Int J Contemp Pediatr. 2017 Jul;4(4):1128-1131
http://www.ijpediatrics.com
pISSN 2349-3283 | eISSN 2349-3291

DOI: http://dx.doi.org/10.18203/2349-3291.ijcp20172656

Original Research Article

Challenges of care givers of children with cerebral palsy in a developing country

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Received: 14 November 2016
Accepted: 07 December 2016

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ABSTRACT

Background: The role of caregiving takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. The main challenges for parents of children with disabilities are their ability to cope with their children's chronic health problems and effectively carry on with daily requirements of everyday living. The aim of this study is to evaluate the challenges parents encounter in caring for children with cerebral palsy in a developing country.

Methods: Consenting parents of children with cerebral palsy presenting in the neurology clinic of the University of Calabar Teaching Hospital, Calabar, south-south Nigeria were recruited for the study. The bio data of the parents were obtained. The challenges encountered by parents of children with cerebral palsy were determined using a semi structured questionnaire.

Results: Seventy parents of children with cerebral palsy were recruited into the study. Majority of the subjects (61.4%) are from the low socio economic while the least represented was the high socioeconomic class. Sixty-four (91.4%) of the parents worry about the handicap and comorbidities of cerebral palsy. Similarly, 91.4% of parents admitted that their social life has been adversely affected by caring for these children. Also, more than half of the parents find it difficult to cope with their jobs or businesses and have their resources depleted. Family disharmony was found in over 40% of the parents. The task of caring for children with cerebral palsy is a daunting one as its negative impact on family, social and family resources are enormous especially in resource poor countries with little or no social support system. Parents caring for children with disabilities therefore need assistance and respite care to alleviate these challenges, since rehabilitation services are limited in most African countries, it has been suggested that community-based and outreach services are provided in order to decrease the burden of care.

Conclusions: Effort should therefore be geared toward prevention. The provision of a social support system and rehabilitation centres at subsidized rates will significantly ease the burden encountered by these parents.

Keywords: Cerebral palsy, Children, Parents, Semi structured questionnaire

INTRODUCTION

Cerebral palsy (CP) is a group of permanent and non-progressive disorders of movement and posture caused by a central nervous system lesion, damage or dysfunction occurring early in life (period of brain development).[1] Studies have shown that the prevalence ranges between 1.5 and 3.0 per 1000 live births.[2-4] It is the leading cause of chronic disability in children, making them physically and mentally handicapped and socially aloof.[5]

Although impaired motor function is the hallmark of cerebral palsy (CP), many children with this developmental disorder also have other comorbidities ranging from epilepsy, blindness, hearing impairment and intellectual retardation which place complex limitations in self-care functions.[5]

Caregiving is a normal part of being the parent of young children. This role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence.[6] The main challenges for parents of children with chronic illness are their ability to cope with their children's chronic health problems and effectively carry on with daily requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers.[6] The provision of such care may prove detrimental to both the physical health and the psychological well-being of parents of children with chronic disabilities.[6,7] with limited social support, there are likely to be more severe in resource-poor environment.[8]

The aim of this study is to evaluate the challenges parents encounter in caring for children with cerebral palsy in a developing country.

METHODS

The study is a prospective study of all consenting parents of children with cerebral palsy presenting in the neurology clinic of the University of Calabar Teaching Hospital, Calabar, south-south Nigeria.

Ethical approval for the study was obtained from the ethics committee of the hospital. The bio data of the parents and that of the children were obtained. The number of siblings was documented. The social class of the parent was also determined using Olusanya et al social class classification method which has been demonstrated useful in this environment.[9]

The challenges of parents to children with cerebral palsy were determined by assessing the impact of the condition on their social life, job/ business, emotions, marriage, family resources in caring for these children, using a semi structured questionnaire. Simple proportions and Tables were used to analyse the data. Chi square was used to analyse the relationship between the challenges and social class of the parents.

RESULTS

Seventy parents of children with cerebral palsy were recruited into the study. 52 (74.3%) of the parents were females while 18 (25.7%) were male. The mean age of parents was 40 years ranging from 22 to 65 years. 45 (61.4%) of the children were males while 25 (35.7%) were females.

Table 1 shows the social class distribution of the parents. Majority of the subjects are from the low socio-economic class accounting for 61.4% while the least represented was the high socioeconomic class.

Tables 1: Social class distribution of the parents.

Social class	Frequency	%
High	4	5.7
Middle	23	32.9
Low	43	61.4
Total	70	100

64 (91.4%) of the parents worry about the handicap and comorbidities of cerebral palsy. The same number of parents admitted that their social life has been adversely affected by caring for these children.

38 (54.3%) of parents are unable to cope well with their jobs and or businesses and these ranges from loss of jobs by 3 (4.3%) respondents, inability to pick up a job in 2 (2.9%) to inability to attend to their businesses regularly in 33 (47.1%) of the respondents.

48 (68.6%) of parents admitted that caring for these children has depleted their family resources while 22(31.4%) said the care of these children has no negative impact on the family resources.

30 (42.9%) of parents have their marriages adversely affected, 2 (2.9%) parents were divorced while others are no longer having bliss full marriages' as a result of the CP children in the family.

There was a statistical significant relationship ($p<0.05$) between social class and impact of CP on family resources, with the lower social class adversely affected. However, no statistical significant relationship exists between social class and parents worrying about child's disability, ability to cope with their jobs, marital relationship and social life.

Similarly, there is a statistical significant relationship ($p<0.05$) between the number of siblings (three or more) and the impact of CP on family resources, social life, ability to cope with care of other children and ability to cope with their business or jobs.

DISCUSSION

Cerebral palsy involves mainly impairment of motor function. Children with this condition also experience sensory, communicative, and intellectual impairments. They may have complex limitations in self-care functions which may pose a major challenge to parent and caregivers of children with this condition.[6]

The study reveals that caring for children with cerebral palsy is a daunting task to parents and caregivers as it has negative impact on virtually every aspect of their daily life. Majority of the parents in this study worry about the handicap and comorbidities of the children with cerebral palsy. The major concern of most parent in this study is the developmental delay and the comorbidities associated with CP notably epilepsy, speech disorders and visual impairment. Parents often wish for a healthy baby irrespective of the gender. The discovery that the child has a disability can be seen as destroying the hopes and dreams held by the parents.[10] Parents caring for children with disabilities therefore need assistance and respite care to alleviate these challenges, since rehabilitation services are limited in most African countries, it has been suggested that community-based and outreach services are provided in order to decrease the burden of care.[11]

More than half of the respondents admitted that having a child or caring for a child with CP negatively impacted on their jobs and businesses. Some parents in this study have lost their jobs while others are unable to cope well due to the daunting task of caring for a CP child. These findings collaborated well with studies in Ohio which showed that caring for a child with disability has negative impact on employment and income status; mothers of children with disabilities are less likely to be employed outside the home.[12]

The study shows that more than a third of the families surveyed have marital conflict ranging from marital disharmony to divorce and separation. Studies have shown that living with a child with disabilities can have profound effects on the entire family, and can affect all aspects of family functioning.[12] A study in Canada that investigated marital relations amongst families of children with disabilities reported that relationships suffered unduly from the added stress of blame, guilt, and anxiety.[13]

The marital disharmony in Africa occurs as a result of a blame game over who is responsible for the child’s predicaments between partners. Cultural beliefs in Zambia, just as in many African countries, dictate that physical disabilities of a child are caused by women.[14] Others believe that having a handicap child is a punishment for women involvement in unacceptable activities. The family caring for any child with cerebral palsy is likely to incur significant expenses related to the ongoing need for medical care, special education services, developmental assistance, and assisted living. Other factors, such as the indirect costs of lost productivity and wages, as well as occupational limitations, also contribute to the depletion of family resources.[15] In this study, more than half of the parents caring for children with cerebral have their family resources depleted. Brehaut et al noted that Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability.[16]

CONCLUSION

In conclusion, caring for cerebral palsy is a difficult one as its negative impact on family, social and family resources are enormous, especially in resource poor countries with little or no social support system. Effort should therefore be geared toward prevention. We recommend the establishment of a social support system to alleviate the burden of care on the parent of these children and also provision of rehabilitation centres to offer services at subsidized rate.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Eyong KI, Ekanem EE, Asindi AA. Challenges of care givers of children with cerebral palsy in a developing country. Int J Contemp Pediatr 2017;4:1128-31.