

Psychological impact of cerebral palsy on families: The African perspective

Olajide A Olawale, Abraham N Deih¹, Raphael KK Yaadar²

Department of Physiotherapy, Faculty of Clinical Sciences, College of Medicine, University of Lagos, Lagos, Nigeria,

¹Department of Physiotherapy, School of Allied Health Sciences, College of Health Sciences, University of Ghana,

²Department of Physiotherapy, Korle Bu Teaching Hospital, Accra, Ghana

ABSTRACT

Background: Psychological stress associated with cerebral palsy (CP) is known to be one of the most depressing conditions of families. In the traditional African society, some peculiar factors may contribute to the stress. **Aims:** The aims of this study were to identify and describe, from the African perspective, the psychological impact of CP on families and determine the strategies adopted by families in coping with it. **Settings and Design:** The study was a cross-sectional descriptive survey conducted in the Physiotherapy Department of a tertiary hospital. **Materials and Methods:** Participants were 52 parents of children with CP. They completed a questionnaire designed to determine the degree of psychological stress on the families and strategies adopted to cope with the stress. **Statistical Analysis:** Descriptive statistics were used to show responses in graphical formats. **Results:** Respondents agreed that having adequate knowledge of CP would help them cope well with the demands of taking care of children with CP. 38.5% of respondents said that people in the society accused them of some wrongdoing that has made their children to have CP. Personal problems experienced include loss of job, lack of concentration at work, loss of family joy, and derangement of financial affairs of the family. 26 (50%) of them resort to religious/spiritual intervention as an alternative or complementary mode of treatment for their children while 28% resort to dependence on the extended family system for support. **Conclusion:** Families caring for children with CP generally have a positive attitude towards their children. However, there is need to educate the public on the causes of CP and treatment options available to families.

Key words: Cerebral palsy, coping strategy, family, psychological stress

Introduction

Impaired motor function is the hallmark of cerebral palsy (CP), although many children with the disorder also experience sensory, communicative, and intellectual impairments and may have complex limitations in self-care functions. Care-giving is a normal part of being the parent of a young child, but this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence.^[1,2] One of the main challenges for parents is to manage the child's chronic health problems effectively in addition to that of coping

with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. 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.^[1]

Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability.^[3] Children with cerebral palsy have also been reported to exhibit psychological problems and this adds to the burden of care.^[4] It has been shown that mothers' depression status was significantly affected by the presence of speech problems in children with CP.^[5] It is not fully understood why some caregivers cope well and others do not. However, there is a need periodically to assess the mental health of the caregiver, even as the rehabilitation of the child progresses.^[6]

Parents of children with cerebral palsy (CP) often experience higher levels of stress than other parents.^[7-9]

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Address for correspondence:

Dr. Olajide A. Olawale, Department of Physiotherapy, Faculty of Clinical Sciences, College of Medicine, University of Lagos, Lagos, Nigeria.

E-mail: jideolawale@yahoo.com

As stated in one study, the disabled child's dependence on others in daily activities had a significant effect on mother's psychological distress; and the more dependent the child, the greater the mother's distress.^[10] Coping with the psychological effects of cerebral palsy (CP) could be very difficult. This is because children with CP need long-term care. The impact of cerebral palsy on parenting stress is usually influenced by factors such as increased care-giving demands, low maternal education and ethnic background. Hence, coping strategies should be directed at easing the burden of daily care, minimizing hospital re-admissions and targeting appropriate psychosocial support at specific subgroups to change parental perception and expectations.

Attitudes of people towards children with CP and the family also add up to the psychological trauma. The attitudes and stigmatization could be very disturbing. The child can be deprived of educational opportunities, recreational facilities, and opportunities to develop friendships. A good sense of self-esteem is therefore required to cope effectively and promote good mental health for the parents and care-givers. Typically in the African society, conditions such as cerebral palsy are normally associated with witchcraft and sorcery. Most families perceive it as a punishment from "gods" for a wrong act committed by a family member, most especially the mother. Normally the blame is shifted to the vulnerable group i.e. the women, thereby initiating and causing family and marriage breakdown. This study attempted to identify and describe, from African perspective, the peculiarity of the psychological impact of CP on families and determine the strategies adopted by families in coping with it.

Materials and Methods

Participants in the study were 52 individuals who were parents of children with cerebral palsy (CP). The study was carried out at the Physiotherapy Department of Korle Bu Teaching Hospital, Accra, Ghana. The participants completed a structured questionnaire designed to explore the degree of psychological stress on the families/carers of children with CP. The questionnaire was initially administered on 60 individuals but full responses were obtained from 52 of them. The questionnaire contained different sections which collected information on the demographics of the respondents, knowledge about CP, personal and societal attitudes towards children with CP, benefits of physiotherapy management, personal problems associated with caring for children with CP and strategies employed in coping with the psychological stress arising from such problems. Content validity of the

questionnaire was determined by a group of academic and clinical physiotherapists drawn from the institution where the study was conducted.

Data analysis

Data was analyzed using the SPSS version 15.0 for Microsoft Windows. Response frequencies for the survey questions were collated and displayed in graphic formats.

Results

Demographic profile of the respondents

Sixty (60) individuals were contacted for participation in the study. Fifty-two (52) of them completed the study questionnaire. They comprised 35 women (67.31%) and 17 men (32.7%). All respondents were parents of children with cerebral palsy (CP). The ages of the parents ranged from 23 to 49 years while those of the children were from 2 to 13 years.

Knowledge about cerebral palsy

Generally, most of the respondents stated that they first learnt of cerebral palsy after they had a child with CP in their families. As many as 70% of them claimed to have adequate knowledge about CP while 30% agreed that they did not have adequate knowledge of it. When asked whether having adequate knowledge about cerebral palsy can help them cope better with the condition, 52 (100%) responded yes. Only 10 (20%) of the respondents said yes to the question on whether it was some other health professionals who enlightened them on CP apart from the physiotherapist.

Personal attitude towards the CP child

Generally, all respondents held positive attitudes toward the CP child. None of the respondents agreed with the question of being fed up with having a CP child in the family. Also, 52 (100%) of them disagreed with the question that asked whether they ever contemplated terminating the life of the CP child. Equal number of respondents {26 (50%) each} responded yes and no when they were asked whether they felt ashamed about having a child with CP. Responses were varied when respondents were asked whether they were optimistic about their child's condition; 32 (60%) agreed, 10 (20%) were neutral, 5 (10%) disagreed while the remaining 5 (10%) strongly disagreed. Fifty-one (98.1%) were of the opinion that physiotherapy was a beneficial intervention in the management of their children's condition.

Societal attitude towards the CP child

Twenty (38.5%) of the respondents claimed that other people in the society expressed opinion that having a CP child was as a result of some wrongdoing on the part of

the parents. Only 5 (9.6%) of the respondents stated that other people advise them to terminate the life of their children. When asked whether other people in the society advised them to consult a herbalist/spiritualist as an alternative or complementary mode of treatment for their children, 31 (59.6%) of the respondents answered in the affirmative [Figure 1].

Personal problems associated with having a CP child

Almost all respondents claimed to have experienced one problem or another as a result of having a child with CP [Figure 2]. Five (9.6%) of the respondents said they have lost their jobs as a result of having a CP in the family. 26 (50%) of the respondents no longer concentrate fully at work. When respondents were asked whether the CP child has caused the family to lose the family joy and happiness that existed before, 16 (30.8%) said yes while 36 (69.2%) said no. However, none of the respondents had marriage breakdown as a result of having a child

with CP. Forty-six (88.5%) of the respondents claimed that financial affairs of the family has been negatively affected because of caring for the CP child.

Coping strategies adopted by families

Respondents expressed themselves as to what strategies they adopt to cope with the problem of having a child with CP in their families. Twenty-six (50%) of them resort to religious/spiritual intervention as an alternative or complementary mode of treatment for their children, 15 (29%) resort to dependence on the extended family system for support, 6 (12%) to alcoholism and 5 (10%) to hopelessness. Respondents in the last 2 categories were males.

Discussion

In this study, we examined the psychological impact of cerebral palsy on families who have and care for children with CP. The family means parents and their children. In the context of this study, the impact of CP on parents was assumed to denote impact on the family because of the central role played by the parents in a traditional African family. The study participants were parents of children with CP who were the main care-givers of the children. They completed a structured questionnaire designed to obtain information on the degree of the psychological stress and coping strategies adopted by the families. Respondents agreed that there was a need for adequate knowledge of cerebral palsy by families. They generally had a positive personal attitude towards the children with CP. However, societal attitudes towards the children were not encouraging. The families experienced a number of problems as a result of caring for children with CP, and they adopted some strategies to cope with the stress associated with such problems. This study was a cross-sectional single-centre survey with a relatively small sample size. The influence of respondents' level of education and family income on the psychological impact was not examined. Also, CP severity was not independently assessed. These factors were notable limitations of the study.

The result showed that most of the respondents were in favour of getting knowledge about CP to help them cope better with the challenges of taking care of the children. Majority of the parents acquired knowledge about CP after having a child with the condition in their family. They consult other sources such as the internet, health professionals, or books written on the subject matter, thereby increasing their knowledge about CP. It is also not surprising that all respondents agreed that having adequate knowledge about CP will assist them

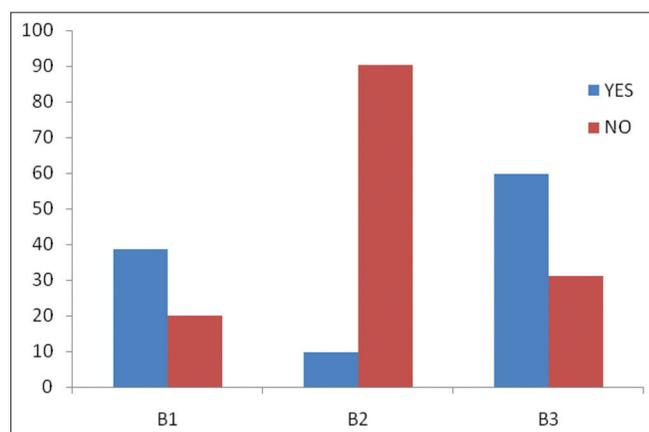


Figure 1: Societal attitude towards the CP child B1: People tell me that having a CP child was as a result of some wrongdoing on my part. B2: People advise me to terminate the life of the child. B3: People advise me to consult a herbalist/spiritualist

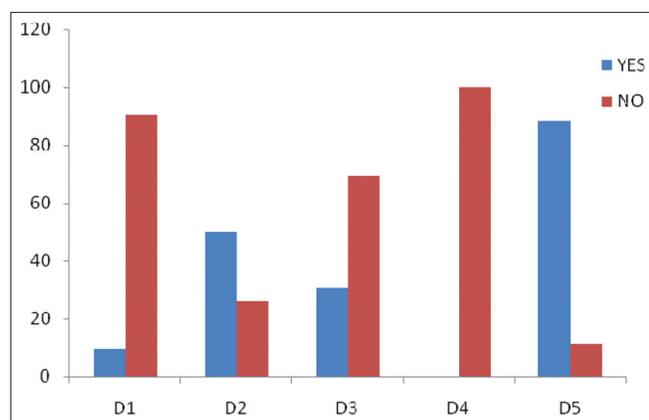


Figure 2: Problems associated with having a CP child in the family D1: Loss of job. D2: Lack of concentration at work. D3: Loss of family joy and happiness. D4: Marriage breakdown. D5: Negative effect on the financial affairs of the family

to cope adequately with all matters relating to the care of the children. Child-rearing education has even been suggested for caregivers.^[10] The results also showed that physiotherapists have been doing much to enlighten people about the causes, prevention and the meaning of CP. This could be attributed to the fact that they have adequate knowledge of the condition and are willing to assist parents by sharing such knowledge with them.

The present study showed that parents' personal attitude towards the CP child was positive. Most of the respondents proved their love towards their children by strongly disagreeing with being fed up with the CP child. They were optimistic about the condition of their children and also believed that physiotherapy was a beneficial intervention in the management of their children. This study revealed a negative societal attitude towards caring for children with CP. Some parents were advised to terminate the life of the children while some were blamed for some wrong-doing that resulted in having a child with CP. These views are highly disturbing. It is not only erroneous to attribute CP to some form of wrong-doing on the part of the parents but highly condemnable to think that a solution exists in terminating the life of the child.

Quality of life has been reported to be significantly lower in mothers of children with CP than in mothers of other children.^[10-12] In the present study, almost all respondents claimed to have experienced one problem or another as a result of having a child with CP. The problems include loss of job, lack of concentration at work, loss of family joy, and derangement of family income—all of which might have contributed to a lower quality of life of the parents. It is therefore not surprising that they adopted some strategies to cope with the condition of having a child with CP in their families. In a typical African society, life is highly valued, and parents enjoy some level of support from members of the extended family in caring for their children. This was demonstrated by the results of this study. Such social support has a slight to moderate role in mediating the impact of stress on mothers caring for children with cerebral palsy and it has been reported to bring about significant improvement of motor development of children with CP.^[13-16] It has also been shown that a family-centred approach to the care of children with cerebral palsy and their families is essential to ensure both receive adequate care and support.^[17]

With greater experience of illness or impairment and increasing exposure to information and social support, the family may successfully tackle the stressful nature to CP through a range of active strategies. Such strategies promote health and quality of life generally. It is not

surprising that a sizable number of respondents in this study resorted to religious/spiritual means in coping with the stress associated with caring for children with CP. Religion plays a significant role in the life of a typical traditional African man. Strong religious beliefs connote finding solutions to health problems through religious and spiritual means. Dependence on the extended family system for support as a coping strategy was also adopted by some respondents. This is not surprising as the traditional African setting promotes and encourages the sharing of other peoples' problem especially by close relatives. This enables affected families to cope better with the stress of caring for children with CP. However, it is difficult to understand why some respondents (all males) resorted to alcoholism and hopelessness in trying to cope with the stress of caring for children with CP.

Conclusion

In the African context, parents of children with CP demonstrated certain psychological problems associated with caring for their children. They adopt different strategies to cope with the problems and enjoy some level of support from members of the extended family in caring for the children.

References

1. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, *et al.* The health and well-being of caregivers of children with cerebral palsy. *Pediatrics* 2005;115:e626-36.
2. Huang YP, Kellett U, St John W. Being concerned: Caregiving for Taiwanese mothers of a child with cerebral palsy. *J Clin Nurs* 2012;21:189-97.
3. Brehaut JC, Kohen DE, Raina P, Walter SD, Russell DJ, Swinton M, *et al.* The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics* 2004;114:e182-91.
4. Parkes J, White-Koning M, Dickinson HO, Thyen U, Arnaud C, Beckung E, *et al.* Psychological problems in children with cerebral palsy: A cross-sectional European study. *J Child Psychol Psychiatry* 2008;49:405-13.
5. Unsal-Delialioglu S, Kaya K, Ozel S, Gorgulu G. Depression in mothers of children with cerebral palsy and related factors in Turkey: A controlled study. *Int J Rehabil Res* 2009;32:199-204.
6. Amosun SL, Ikuesan BA, Oloyede JJ. Rehabilitation of the handicapped child—what about the caregiver? *P N G Med J* 1995;38:208-14.
7. Ong LC, Afifah I, Lve MS. Parenting stress among mothers of Malaysian children with cerebral palsy: Predictors of child- and parent-related stress. *Ann Trop Paediatr* 1998;18:301-7.
8. Ketelaar M, Volman MJ, Gorter JW, Vermeer A. Stress in parents of children with cerebral palsy: What sources of stress are we talking about? *Child Care Health Dev* 2008;34:825-9.
9. Parkes J, Caravale B, Marcelli M, Franco F, Colver A. Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Dev Med Child Neurol* 2011;53:815-21.
10. Breslau N, Staruch KS, Mortimer EA Jr. Psychological distress in mothers of disabled children. *Am J Dis Child* 1982;136:682-6.
11. Ho SM, Fung BK, Fung AS, Chow SP, Ip WY, Lee SF, *et al.* Overprotection and the psychological states of cerebral palsy patients

- and their caretakers in Hong Kong: A preliminary report. Hong Kong Med J 2008;14:286-91.
12. Ones K, Yilmaz E, Cetinkaya B, Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). Neurorehabil Neural Repair 2005;19:232-7.
 13. Skok A, Harvey D, Reddihough D. Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. J Intellect Dev Disabil 2006;31:53-7.
 14. Aran A, Shalev RS, Biran G, Gross-Tsur V. Parenting style impacts on quality of life in children with cerebral palsy. J Pediatr 2007;151:56-60.
 15. Fung BK, Ho SM, Fung AS, Leung EY, Chow SP, Ip WY, *et al.* The development of a strength-focused mutual support group for caretakers of children with cerebral palsy. East Asian Arch Psychiatry 2011;21:64-72.
 16. Polovina-Prolosic T, Vidovic V, Polovina A. Family as a factor in cerebral palsy prevention. Coll Antropol 2008;32:137-42.
 17. Parkes J, McCullough N, Madden A, McCahey E. The health of children with cerebral palsy and stress in their parents. J Adv Nurs 2009;65:2311-23.

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