

Prevalence and predictors of psychological problems among principal caregivers of children with cerebral palsy in Galle, Sri Lanka

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Abstract

Background

Caregivers of children with disabilities are easy victims of psychological ill-health. Assessment of psychological problems and identification of factors predicting such outcomes are vital in identifying high-risk caregivers, to prevent them from becoming second order patients.

Aim

To describe the prevalence and predictors of psychological problems among principal caregivers of children with Cerebral Palsy (CP) in the Galle district.

Methods

The study included 375 caregivers of children with CP, attending Teaching Hospital, Karapitiya, Galle. Prevalence of psychological problems of caregivers was assessed using the General Health Questionnaire (GHQ). Level of caregiver burden was assessed using Caregiver Difficulties Scale, developed and validated by the authors. An interviewer administered questionnaire was used to collect data on other study variables. Predictors of psychological problems in caregivers were determined using logistic regression analysis.

Results

Fifty six percent (95% Confidence Interval = 51.0% 61.0%) of caregivers had GHQ scores above the cut off threshold for psychological disorders. The strongest predictor for presence of psychological problems was high level of caregiver burden {Odds Ratio (OR)=19.99(5.54-72.13), $p<0.001$ }. Lower educational level of the caregiver {OR=3.65(1.78-7.48), $p<0.001$ } and younger age of the child {OR=3.97(1.88-8.37), $p<0.001$ } were also predictive of psychological problems. Other predictors included the use of more treatment types {OR=2.04(1.13-3.67), $p<0.05$ } and not seeking support for care giving {OR=1.82(1.00-3.31), $p<0.05$ }.

Conclusions

Caregivers of children with CP show a high prevalence of psychological problems. There are a number of factors predictive of caregiver psychological problems, particularly the level of caregiver burden, which need to be considered when developing long term care plans for children with CP.

Key words: caregiver burden, psychological problems, cerebral palsy

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Introduction

Although care giving is a normal and routine part of a parent's life, this assumes a different perspective in parenting a child with a chronic disabling condition. The majority of children with disabilities lives within their family environment and require the help of their family members to fulfill their basic care and treatment needs¹. Apart from challenges of the dual role of day-to-day living and providing special care for the child, the parents may need to adjust emotionally to accept the child's difference from their expectations, which can be a significant source of stress for them². Thus, care giving has its effects not only on caregiver's resources such as time, finances and relationships, but also on their very health. The strain or load born by the caregivers as a result of care giving is conceptualized as caregiver burden³.

Caregiver burden in childhood disabilities and its impact of on caregiver health and well-being have been extensively studied throughout the world^{4,6}. Among the health consequences of care giving, psychological problems of caregivers are considered as the most frequent and serious⁷⁻¹⁰. Psychological problems refer to a multitude of conditions relating to or arising from the mind or emotions that can interfere with a person's emotional and physical health. Common psychological problems encountered among caregivers of children with disabilities include stress, depression and anxiety^{4,7,11-13}. These effects could be even more pronounced among caregivers in developing countries, due to difficult living conditions, limited resources and little access to appropriate services⁴.

The health and well-being of caregivers is viewed as an essential pre-requisite for provision of quality care to the care recipients^{3,14}. Regular assessment of caregivers, particularly in terms of the level of burden experienced by them and the impact of care giving on their health, is a vital step in preventing them from becoming second order patients.

Cerebral palsy (CP) is a life-long, developmental disorder that can cause a considerable degree of burden on the caregivers. It is the most common form of childhood physical disability among children in many countries, including Sri Lanka¹⁵⁻¹⁷. The global incidence of CP has remained constant over the years, around 2.5 per 1000 live births^{18,19}. This study is

an attempt to assess the prevalence and the predictors of psychological problems among caregivers of children with CP, attending a tertiary care setting in Southern Sri Lanka, with a special emphasis on the perceived burden of care giving.

Materials and Methods

The study was a descriptive, cross sectional study which included a sample of principal caregivers of children under 12 years with CP, receiving services from the paediatric clinics, wards, Rheumatology and Rehabilitation Unit and Speech and Language Therapy Unit of the Teaching Hospital, Karapitiya, Galle. Principal caregiver was defined as 'the person who is most responsible for the day-to-day responsibilities of providing care to the child with CP', based on their self-identification. The sample size for the study was calculated using the formula given by Lwanga and Lemeshow²⁰, to estimate the population proportion of psychological problems, which was considered to be 42% based on available evidence (4). Considering a confidence level of 95% and an absolute precision of 5%, the computed sample size for the study was 374 caregivers. Principal caregivers with a diagnosis of a psychological or psychiatric disorder prior to the diagnosis of CP in the child, those who have other care giving responsibilities such as caring for a disabled adult or an elderly person and those who live outside the district of Galle were excluded from the sample. Ethical clearance for the study was obtained from the Ethical Review Committee of the Faculty of Medicine, University of Ruhuna.

Prevalence of psychological problems of the caregivers was determined using a Sinhala version of the 30-item General Health Questionnaire (GHQ), which was translated and validated for Sri Lankan population and which has been successfully used for research purposes in Sri Lanka^{21,22}. A GHQ score of 6 or above was considered as evidence for presence of psychological problems in the caregivers.

The level of caregiver burden was assessed using Caregiver Difficulties Scale (CDS), a self administered questionnaire developed and validated by the authors using a combined qualitative-quantitative approach²³. CDS includes appropriate items selected from existing caregiver assessment instruments, identified through consensus of a panel

of experts who were involved in provision of health and social care for children with CP. It also includes new items reflecting experiences of caregivers in the local socio-cultural context, which were developed through key informant interviews with caregivers and service providers of children with CP. This 25-item instrument is a multidimensional scale with four subscales measuring (i) caregivers' concerns for the child, (ii) impact on self, (iii) support for care giving, and (iv) social and financial concerns. Each item is followed by a Likert scale with five response alternatives, indicating the extent or frequency of occurrence of the care giving experience described by that particular item. The score assigned for each response varies from 0-4, leading to a maximum possible score of 100.

The face validity, content validity and consensual validity of CDS was established through the process of item generation. The construct validity of CDS was confirmed using a sample of 90 caregivers, by demonstrating anticipated correlations ($r = \pm 0.3$) of CDS score with two hypothesized constructs: caregiver quality of life and severity of disease in the care recipient²³. All dimensions of caregiver quality of life demonstrated significant moderate negative correlations ($r > -0.5$, $p < 0.01$) with CDS score, where as the severity of disease demonstrated a significant moderate positive correlation ($r = 0.479$, $p < 0.01$) in the validation study. Both the internal consistency of CDS (Cronbach's $\alpha = 0.9$) and test-retest reliability over a 2 weeks interval ($t = 0.66$, $p > 0.05$) were found to be satisfactory.

Data on socio-demographic characteristics of caregivers and children and other variables related to caregiver psychological health were collected using a pre-tested, interviewer administered questionnaire. Association of caregiver psychological problems with level of caregiver burden, selected caregiver/child characteristics, disease related and treatment related variables were tested using chi-square test. Logistic regression analysis was carried out to identify the predictors of psychological problems among caregivers. The factors that demonstrated significant associations ($p < 0.05$) with the presence of psychological problems in the bivariate analysis were included as independent variables in the logistic regression analysis. All the analyses were done using SPSS (15.0) statistical

software package.

Results

A total of 375 principal caregivers of children with CP participated in the study and 11 (2.9%) caregivers declined participation due to lack of time. The comparison of basic demographic characteristics of respondents and non-respondents confirmed that there was no difference between the two groups.

The characteristics of the sample revealed that 364 (97%) of the principal caregivers of the children with CP were their mothers. Of the remaining, 1.9% were grandmothers and fathers contributed as principal caregivers in 1.1% of the children. The majority of the sample were Sinhalese ($n=347$, 92.6%), aged between 30-39 years ($n=161$, 42.9%), living in rural areas ($n=269$, 71.8%) and had low socio-economic backgrounds ($n=275$, 73.3%). Approximately 60% of the caregivers ($n=224$) had completed post-primary education, although only 6.7% ($n=25$) of them were employed at the time of study (Table 1).

Table 1: The distribution of basic socio-demographic characteristics of the principal caregivers

Basic characteristics	No. (n=375)	%
Age (in completed years)		
<20	3	0.8
20-39	305	81.3
40-59	63	16.8
≥60	4	1.1
Sector		
Urban	104	27.7
Rural & Estate	271	72.3
Ethnicity		
Sinhalese	347	92.6
Muslim	24	6.4
Other	4	1.0
Average monthly income		
= Rs.10,000.00	263	70.1
>Rs.10,000.00	112	29.9
Level of education		
Primary education and below	62	16.5
Post primary education	224	59.7
Secondary education and above	89	22.8
Current employment status		
Employed	25	6.7
Not employed	350	93.3

Table 2. List of variables included in logistic regression analysis

Variable	Categories	Coding
Level of caregiver burden	High	1
	Low and Moderate	0
Educational level of the caregiver	Primary education or below	1
	Above primary education	0
Type of family	Extended + Nuclear family	1
	Three generation family	0
Age of the child	<5 yrs	1
	5 yrs	0
Schooling status of the child	Not schooling	1
	Schooling	0
Co-morbidities	Present	1
	Absent	0
Number of associated problems	>6	1
	6	0
Number of treatment types	3 types	1
	1-2 types	0
Type of main alternative caregiver	Other caregivers	1
	Spouse	0
Care giving support as a coping method	No	1
	Yes	0

Table 3: Summary table of logistic regression analysis

Dependent variable	Independent variables	Adjusted Odd Ratio	P value	95% CI for Odd ratio	
				Lower	Upper
Psychological problems	Level of caregiver burden	19.99	< 0.001	5.54	72.13
	Educational level of the caregiver	3.65	< 0.001	1.78	7.48
	Type of family	1.60	0.07	0.96	2.67
	Age of the child	3.97	< 0.001	1.88	8.37
	Schooling status of child	1.04	0.94	0.37	2.88
	Co-morbidities	1.09	0.77	0.16	1.93
	No. of associated problems	1.62	0.32	0.62	4.24
	No. of treatment types	2.04	0.02	1.13	3.67
	Type of main alternative caregiver	0.41	0.28	0.08	2.08
Care giving support	1.82	0.04	1.00	3.31	

The caregiver burden experienced by the principal caregivers of children with CP was classified in to 3 levels: low, moderate and high burden. The cut off thresholds for the different levels were determined based on the mean and the standard deviation of the total CDS score: Low burden (below mean-1SD) = 30, Moderate burden (mean±1SD) = 31-65, High burden (above mean+1SD) = 66. According to this categorization, 253 (67.5%) of the caregivers experienced a moderate level of burden, where as the proportion of caregivers who experienced low and high levels of burden were 17.1% and 15.4% respectively.

Fifty six percent (n=210) of caregivers had higher total scores for GHQ, above the cut off threshold for psychological disorders (95% confidence interval = 51.0%-61.0%). According to bivariate analysis, a high level of caregiver burden was strongly associated with presence of psychological problems among the principal caregivers (p<0.001). The presence of psychological problems was also significantly associated with low educational level of the caregiver (p<0.01), being in an extended family (p<0.05), younger age of the child (p<0.05), non-

schooling states of the child (p<0.05), presence of co-morbidities (p<0.001), having a higher number of associated problems (p<0.001) and more treatment types such as drug therapy, physiotherapy, speech therapy or occupational therapy (p<0.01), lack of spousal support (p<0.05) and not seeking support from a trusted person to cope with the care giving responsibilities (p<0.001). The other variables included in bivariate analysis, i.e. the age, urban/rural residence, employment status, income and social class of the caregiver, the sex of the child, number of siblings and birth order, the type of cerebral palsy, duration of illness and average monthly expenditure for the treatments did not show a significant association with caregiver psychological problems (p>0.05).

The variables which demonstrated a significant association with presence of psychological problems in the bivariate analysis were then included in a logistic regression analysis in order to identify the variables which can be used to predict psychological problems in the caregivers (Tables 2 & 3). The strongest predictor for presence of psychological problems was the level of caregiver burden {Odd

ratio (OR) = 19.99, $p < 0.001$ }, indicating that the caregivers with high levels of caregiver burden had approximately 20 times higher risk of having psychological problems. The low educational level of the caregiver (OR=3.65, $p < 0.001$) and the younger age of the child (OR=3.97, $p < 0.001$) were also predictive of caregiver psychological problems. The other predictors included use of more treatment types (OR=2.04, $p < 0.05$) and not seeking caregiving support from a trusted person (OR=1.82, $p < 0.05$).

Discussion

This study revealed that a considerable proportion (56%) of the principal caregivers of children with CP experience psychological problems. The caregivers who are more likely to suffer from psychological problems were those having a high level of caregiver burden, low educational status or a younger child with CP. Using more treatment types and not seeking care giving support were also predictive of the presence of psychological problems in these caregivers.

In this study, the presence of psychological problems among caregivers was assessed using the 30-item General Health Questionnaire (GHQ-30). It is the most widely used screening tool for assessing psychiatric disorders worldwide and several studies on caregiver psychological health have been conducted using the GHQ to assess the presence of psychological problems^{12,24}. Most of the psychological problems detected by this instrument are anxiety status and depressive illnesses²⁵. One disadvantage of GHQ highlighted in the literature is the ambiguity of response category 'no more than usual', which makes it difficult to distinguish between good health and chronic illness²⁶. Some believe that the GHQ may underestimate chronic illness as it is only sensitive to changing symptoms of psychiatric disorders²⁷. According to Goldberg, there is more likelihood for false positives with the GHQ than a clinical diagnosis; however, most of these false positives are those experiencing transient mood disorders that will benefit from an opportunity to speak to a doctor²⁸.

The results of the present study demonstrated that 56% of caregivers of children with CP had higher total scores for GHQ, which are above the cut off threshold for psychological disorders. Previous

studies conducted in Sri Lanka revealed varying prevalence rates for psychological problems in the general population, ranging from 15%-23% among individuals attending general practice²¹. This clearly shows that, compared to general Sri Lankan population, caregivers of children with cerebral palsy appear to be at a higher risk of having psychological problems.

In a review of literature, Wilkinson and Barczak found that the prevalence of psychiatric disorders in general population generally vary between 10-20% and may be even higher as 34% in certain instances²⁷. However, literature on caregiver outcomes show that, the proportion of caregivers having mental health problems is greater in comparison. According to Oyebo²⁹, the research on impact of care giving suggests that about 1/3 to 1/2 caregivers suffer significant psychological distress and although derived from caregivers of elderly, it could be true for a wider range of individuals who provide care for the disabled.

A study on Bangladeshi mothers of children with CP using a modification of GHQ demonstrated 41.8% mothers with potential psychiatric morbidity⁴. In two studies conducted in Canada, it was found that 25 – 29 % of the caregivers of children with CP had reported emotional problems^{6,30}, although it was believed that, the greater reporting of psychological problems among caregivers could be partially explained by their relatively frequent contacts with the health systems⁶. Even higher rates of parenting stress were observed by others, where 84% of the mothers of children with developmental disabilities in UK had high levels of stress in the clinical range, where as fathers scored substantially lower¹². These findings are consistent with the results of the present study and it confirms that, irrespective of cultural and environmental differences, the negative impact of care giving on psychological health of caregivers is a universal phenomenon.

The distinct relationship between level of caregiver burden and caregiver psychological problems in this study provides useful hints on caregivers at risk of psychiatric morbidity. The strong association between CDS score and GHQ score implies that CDS can be used as a predictor of subjects who will emerge positive in a screening for psychological

disorders. CDS, at the same time, will quantify the degree of caregiver burden and provide insight into major areas of caregiver concerns, allowing the service providers to assess two aspects of care giving using one instrument; i.e. 'mediators of caregiver burden' and 'potential for negative outcomes'. Depending on the major area of concern contributing to burden, measures can be developed to minimize the degree of burden, which in turn will be helpful in improving psychological health of the caregivers.

There are a number of similarities and differences in the findings of this study, in comparison to those of other studies conducted worldwide. Although in this study caregiver's educational status emerged as a predictor of their psychological health, other studies provide inconclusive evidence on this association^{4,31}. The type of family did not show any association with caregiver psychological problems in the multivariate analysis, in concurrence with other studies⁴. Although one would assume that the contact with a wider family circle can decrease stress experienced by caregivers, the ultimate outcome is dependant on the state of affairs within the family²⁹. If this wider family is experiencing other stressful events, then the likelihood of psychological effects is more among the caregivers.

Similar to our study, the age of the child was found to be a predictor of stress in mothers of children with CP in Bangladesh⁴. However, the highest predictor of stress according to this study was child behavioural problems. Although we did not evaluate this aspect in our study, the findings of others have supported this conclusion^{32,33}. The association of severity of disability with caregiver psychological problems had been assessed in other studies with contrasting findings^{4,9,32}. However, such evidence should be interpreted with caution as the methods used to ascertain severity of disability is not uniform in the different studies.

Seeking help of a trusted person to look after the child in caregiver's absence was identified as one of the predictors of caregiver psychological problems. This finding is in accordance with the results of other studies^{32,34,35}. Although, a lower income level and rural residence were found to be predictive of caregiver stress in other settings⁴, both these variables failed to show any association with caregiver psychological

problems in our study. The availability of free health services, wider accessibility of facilities such as health care and transport even in rural areas and availability of financial support schemes (through Department of Social Services) may partially explain the above differences.

While contributing to the knowledge base on caregiver health, this study however is not without limitations. The study sample had been selected from the caregivers of children with CP attending a tertiary care setting. It is likely to result in an over-representation of children with more severe forms of disease and the levels of caregiver burden and prevalence rate of psychological problems found in this sample may not be representative of the population of caregivers in general. Secondly, the cut off thresholds for low, moderate and high levels of caregiver burden were determined on the basis of the standard deviations from the mean burden score of the sample. Lack of a control group and inability to identify a definite cut off level for caregiver burden are the other limitations in this study. Thirdly, the design of the study is limited by its cross sectional approach, because of which, the temporal relationship between caregiver burden and psychological problems could not be ascertained. Finally, the wider confidence interval observed in relation to the odds of having high caregiver burden as a predictor of caregiver psychological problems indicates the need to replicate this study in a larger sample, in order to obtain a more precise risk estimate.

Conclusions: This study concludes that, a considerable proportion of caregivers of children with cerebral palsy experience psychological problems, especially in association with high levels of caregiver burden. Assessment of caregiver burden is useful in predicting psychological problems among these caregivers. A number of factors are associated caregiver psychological problems, which needs to be considered when developing long term care plans for children with cerebral palsy.

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Disclosure of interest

The authors declare no potential competing interests to the research, authorship and / or publication of this article.

Contribution to authorship

All authors contributed in conceptualizing and designing the study. CJW planned and implemented the data collection, data entering and analysis. All authors were involved in interpretation of data and preparation/review of the manuscript of this article.

Details of ethical approval

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