Mental Health and Quality of Life of Caregivers of Individuals with Cerebral Palsy in a Community Based Rehabilitation Programme in Rural Karnataka

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ABSTRACT

Background: *Cerebral palsy is a type of non-progressive central nervous system disorder with multiple impairments. As there are sensory, communicatory and intellectual impairments, providing care at home may be stressful and affect to the physical and mental health of the caregivers. This in turn could interfere with rehabilitation of persons with cerebral palsy.*

Purpose: *This study assesses the mental health status and quality of life of caregivers of persons with disabilities. The study group consisted of caregivers of 23 children with cerebral palsy and intellectual disability.*

Method: *The needs of the children with disabilities were assessed using a pre-tested interview schedule, while caregivers were administered GHQ-28 and WHO-QOL.*

Results: *Thirteen (56.52%) of the primary caregivers tested positive for GHQ. The psychological and environmental domains of QOL were found to be most affected, while the physical and social domains were relatively better.*

Conclusion: *There was a significant ($p<0.05$) correlation between the GHQ scores and quality of life.*

INTRODUCTION

Community Based Rehabilitation (CBR) is a strategy for equalising opportunities, poverty reduction and social inclusion of persons with disabilities (ILO, WHO, UNESCO, CBR, 2004). This rehabilitation takes place within the community and is part of community development, as opposed to the earlier concept of institutional rehabilitation. The focus of a CBR programme therefore is not only

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the strengthening of persons with disabilities, but also the caregivers and the community, so as to enable them to take care of such persons (Thomas & Thomas, 2002). The physical and psychological well-being of a caregiver is important for the well-being of the person receiving care. Chronic illness and disability are highly demanding conditions, requiring consistent care (Kersten et al, 2001), as is the case with cerebral palsy and more severe degrees of intellectual disabilities. Though cerebral palsy is a type of non-progressive central nervous system disorder with predominantly impaired motor function, it may also be associated with sensory, communicatory, and intellectual impairments. Children with cerebral palsy have constant health needs for very long periods in their life. They may have limitations in activities of daily living and communication abilities. Apart from the area of health, they have social, educational, empowerment and livelihood needs. Thus the primary caregivers, usually the parents, are under constant stress to maintain their child's health and well-being. Parents of children with chronic health conditions run the risk of emotional distress and poor adjustment to the demands of caring for a child with special needs (Kersten et al, 2001). Multiple stressors may contribute to this increased risk, including feelings of uncertainty over child health outcomes, daily difficulties associated with medical regimens, social isolation, role restrictions, and financial strains. In addition, parents often report significant difficulty in navigating the complex system of rehabilitation care to obtain needed medical, mental health, educational, and social services (Kersten et al, 2001; Brehaut et al, 2004). Adverse health status of the primary caregiver could interfere with the ability to meet the needs of the child, and might thereby affect the child's rehabilitation. A CBR programme would take into consideration all these needs, to rehabilitate the person in all aspects (WHO, 2005).

An assessment of the health status of the primary caregivers and their quality of life is therefore important, for interventions targeted at rehabilitation of children with disabilities. This assumes further importance in rural areas where there is poverty and limited access to rehabilitation services.

OBJECTIVES

1. To assess the mental health status and quality of life of caregivers of children with cerebral palsy and intellectual disability.
2. To assess the association between the mental health status and quality of life of the care- giver and the needs of the child with disability.

METHODS

This was a cross-sectional descriptive study conducted in ten villages of the rural field practice area of the Department of Community Health, St John's Medical College, Bangalore, India. The study group consisted of children with cerebral palsy and intellectual disability, and their caregivers, in these ten villages. The children with cerebral palsy and intellectual disability were identified as part of a disability survey. The needs of persons with disabilities were assessed using a pre-tested interview schedule based on the five components of Community Based Rehabilitation (Health, Education, Livelihood, Empowerment and Social needs) detailed by WHO. The assessment of persons with disabilities was quantified, and scores were given to each component of the CBR strategy.

The caregivers of the persons with disabilities were administered GHQ-28 and WHO-QOL BREF. Mental health status was assessed using the GHQ-28. This is a self-administered screening instrument for adult populations, to detect psychiatric disorders in community settings and non-psychiatric clinical settings, such as primary care or general practice. A score of 5 was used as the cut-off for positive GHQ (Goldberg & Hillier, 1979).

Quality of Life was assessed using the WHO-QOL BREF. The WHO-QOL scale consists of 26 items. Items 3, 4, 10, 15, 16, 17, and 25 represent satisfaction with physical functioning; items 5, 6, 7, 11, 18 and 26 represent psychological dimensions; items 19, 20, and 21 represent social dimensions; whereas items 8, 9, 12, 13, 14, 22, 23 and 24 reflect satisfaction with one's environment (WHO, 1998). The GHQ-28 data were entered on an Excel spreadsheet and analysed with descriptive statistics using SPSS version 10 and Epi 6. The WHO-QOL data were analysed separately using an SPSS syntax file that automatically checks, re-codes data and computes the domain scores. Chi-square and Spearman's correlation were used as the statistical tests, to find the association between the needs assessment of the child with disability and the mental health and quality of life of the caregivers.

RESULTS

Demography

Twenty three persons with developmental delay, from nine villages, were included in the study. The mean age was 12.9 years (SD= 8.25) with a range from 3 to 30 years. 69.6% of the study population was comprised of boys (Table 1).

Table 1: Age and gender distribution of persons with disabilities

Group	Gender Distribution		Age Distribution
	Male	Female	
<=5yrs	3	1	4 (17.4%)
6-15 yrs	9	3	12 (52.2%)
16-30yrs	4	3	7 (30.4%)
Total	16 (69.6%)	7 (30.4%)	23 (100.0%)

The severity of disability was assessed based on independence in activities of daily living such as bathing, sitting, standing, and walking. Most of those included (20 or 87%) had moderate to severe disability, while 3 had mild disability.

22 of the twenty three caregivers were females. 20 (87%) caregivers were the mothers of the individuals. The other caregivers were the father, the grandmother and in one case the sister-in- law. The mean age of the caregivers was 37.8yrs (SD = 9.9).

Mental Health Status

The mean GHQ score was 5.3 (SD 4.95) (Table 2).

Table 2: Mean scores of caregiver GHQ with individual subscales

	Somatic illness	Anxiety	Social Dysfunction	Depression	GHQ total
Mean	1.65	2.09	.70	.87	5.30
Std. Deviation	1.90	2.11	.97	1.63	4.95

Quality of Life

Quality of Life of the caregivers of persons with disability was assessed using the WHO–QOL BREF scale. The scores for the various domains are shown in Table 3.

Table 3: Mean Scores of Quality of Life scale in various domains

	Physical	Psychological	Social	Environmental
Mean	13.71	12.64	14.43	12.78
Std deviation	3.35	3.58	3.43	2.97

Associations Between Disability and Caregiver Assessments

GHQ score of the caregivers of persons with moderate to severe disabilities was higher than for those with mild disability (Table 4). However this was not statistically significant.

Table 4: Severity of disability and GHQ score

Severity	GHQ total Score		Total
	<5 (negative)	>=5(positive)	
Mild	2	1	3(13.0%)
Moderate to severe	8	12	20(87.0%)
Total	10(43.5%)	13(56.5)%	23(100.0%)

Fischer exact p value= 0.55 –Not significant

The needs of the persons with disabilities were assessed based on their level of independence in carrying out their activities of daily living. There was a negative correlation between the mental health and ADL needs, health, educational, livelihood and the total needs, but it was not significant (Table 5).

Table 5: Association between Needs and the GHQ scoring

Sl No	Assessment	Scores	GHQ		Mean Scores	SD	Spearman's Correlation Coefficient	Significance*
			-Ve	+Ve				
1	Activities of Daily Living	< 13	6	11	8.13	5.88	-.163	.457
		13-16	4	2				
2	Communication Ability	<8	5	5	6.09	3.9	.217	.320
		8-10	5	8				
3	Health needs	<8	9	13	4.35	2.87	-.067	.762
		8-10	1	0				
4	Educational needs	<9	7	13	3.65	4.04	-.081	.715
		9-12	3	0				
5	Livelihood needs	<8	3	6	6.13	4.77	-.226	.301
		8-10	7	7				
6	Empowerment needs	<14	6	8	8.22	7.35	.064	.773
		14-18	4	5				
7	Social-legal needs	<3	3	3	3.26	1.66	.149	.497
		3-4	7	10				
8	Social-other needs	<9	4	9	7.96	3.54	.113	.607
		9-12	6	4				
9	Grand Total	<74	7	11	50	19.6	-.063	.775
		74-92	3	2				

* Significant if value <0.05

There was a negative correlation between the disability needs and the social Quality of Life of the primary caregivers, though it was not significant (Table 6). There was no significant correlation between the needs and the various other domains of Quality of Life.

Table 6: Association between the needs and the domains of the Quality of Life

Domain of QOL	Pearson's Correlation Coefficient	Significance value
Physical	0.145	0.509 (not significant)
Psychological	0.102	0.643 (not significant)
Social	-0.049	0.824 (not significant)
Environmental	0.283	0.191 (not significant)

There was a significant association between the GHQ scores and the Quality of Life. All the domains were negatively correlated with GHQ and the values were found to be statistically significant (Table 7).

Table 7: Correlation between GHQ and Quality Of Life

Domain	Pearson's Correlation Coefficient	Significance
Physical	-.581	.004**
Psychological	-.503	.014*
Social	-.642	.001**
Environmental	-.460	.027*

** Correlation is significant at the .01 level (2-tailed).
* Correlation is significant at the .05 level (2-tailed).

Correlation between Quality of Life and socio-economic status was found to be significant in the social, environmental and psychological domains, as seen in Table 8.

Table 8: Correlation between standard of living and the Quality of Life

Domain	Pearson's Correlation Coefficient	Significance
Environmental	.715	.000**
Social	.632	.002**
Physical	.431	.051
Psychological	.458	.037*

** Correlation is significant at the .01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

DISCUSSION

The study showed that care-giving, especially towards a person with a disability like cerebral palsy, can be stressful, as demonstrated by the high mean GHQ scores. Adverse mental health status corresponded to the severity of the disability. A similar finding in a study done in Virginia, noted that the higher the severity of disability, the greater was the risk of mental illness (Houlihan et al, 2004). When children with disability complained of pain, it affected the parents' emotional status. This US-based study observed that these impairments also had social and educational consequences.

In the present study, the needs of people with disability were assessed in the areas of health, education, social, livelihood and empowerment. Where the needs were more, the adverse mental health status of the caregiver was seen to be higher. Where the individual was better able to cope with the ADL, the lower were the GHQ scores of the primary caregivers. Mothers of children with cerebral palsy also reported that independence in activities of daily living was an immediate need, calling attention to the importance of ADL training for people with moderate to severe categories of impairment and disabilities.

In a study to determine the Quality of Life of parents whose children have pervasive developmental disorder (PDD), as compared to the QOL of parents of healthy children, parents in the PDD group reported impairment in physical activity and social relationships ($p < 0.01$), and worse overall perception of their QOL and health ($p < 0.01$) (Mugno et al, 2007).

It is common knowledge that people caring for loved ones with cancer and other chronic illnesses, will often neglect their own physical well-being, such as forgetting to eat, losing sleep, and skipping exercise. New evidence shows that they may also neglect their mental health, which may have a bearing on the intervention for the person with disability as well as the caregiver. Caregivers of cancer patients are reported to experience a clinically significant level of distress (Vanderwerker, 2005).

Parenting style is a significant factor for children with cerebral palsy. It is the only known factor to impact on the psychosocial domains and even exceeds the effect of disease severity (Brehaut et al, 2004). Early family interventions, particularly those focusing on parenting style, should be considered. Parenting style is also a significant factor in Quality of Life in cerebral palsy, and the QOL is an important treatment goal in children with cerebral palsy (Aran et al,2007). It is not fully understood why some caregivers cope well and others do not. The approach of estimating the "independent" or "direct" effects of the care recipient's disability on the caregiver's health is of limited value because single-factor changes are rare outside the context of constrained experimental situations. Assumptions of additive relationships and perfect measurements rarely hold, and such approaches do not provide a complete perspective because they fail to examine indirect pathways that occur between predictor variables and health outcomes. A more detailed analytical approach is needed to understand both direct and indirect effects simultaneously (Raina et al, 2005). In a study done on the caregivers of children with cerebral palsy in Ontario, Canada, measures of caregiver psychological health showed greater reported distress, chronicity of distress, emotional problems, and cognitive problems (Brehaut et al, 2004). A higher level of behaviour problems was associated with lower levels of both psychological and physical health of the caregivers, whereas fewer child behaviour problems were associated with higher self-perception and a greater ability to manage stress. Lower care-giving demands were associated with better physical and psychological well-being of caregivers (Raina et al, 2005).

CONCLUSIONS

The mental health status of the primary caregivers, based on the GHQ-28, was found to be positive for more than half of the caregivers. There is a negative correlation between the needs of the people with disabilities and the mental health of the primary caregivers, though it was not significant. There is a significant negative correlation between the Quality of Life and the mental health of the primary caregivers.

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