

Depression and quality of life among caregivers of children with psychiatric disorders

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Abstract

Background

Providing care for children with mental health issues creates a huge burden on their primary caregivers and depression is recognized as one of the commonest mental health problems among caregivers of children who are unwell with psychiatric disorders. In addition, these caregivers have also been found to have a poor quality of life.

Aims

To compare the level of depression and quality of life among caregivers of children with mental and behavioural disorders with age and sex-matched controls and to describe the psychiatric disorders in children which are associated with depression and reduced quality of life in their caregivers.

Methods

A cross-sectional descriptive study was carried out at the child psychiatry clinic of the Teaching Hospital Peradeniya. The study population included primary caregivers of children aged less than 18 years with mental and behavioural disorders who attended the above clinic. The control group was obtained from age and sex-matched primary caregivers of school children without any psychiatric diagnosis in the same area. The Patient Health Questionnaire-9 (PHQ-9) score

and the WHOQOL-BREF quality of life assessment scores were used to determine the level of depression and quality of life, respectively.

Results

We recruited 54 cases and 53 controls. The prevalence of depression was significantly higher in the cases when compared with the controls ($P < 0.001$). The caregivers of children with mental and behavioural disorders had a significantly lower quality of life in the psychological ($P = 0.028$) and social ($P = 0.025$) subdomains when compared with the cases. The proportion who had depression was higher in the caregivers of children with autism, attention deficit hyperactivity disorder, conduct disorder and depression than in the caregivers of children with other psychiatric disorders even though this difference was not statistically significant.

Conclusions

Caregivers of children with mental and behavioural disorders had a higher prevalence of depression and lower quality of life when compared with controls. These findings highlight the need to strengthen social support networks to improve the lives of caregivers of children with mental and behavioural disorders.

Key words: caregivers, children with psychiatric disorders, depression, quality of life

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Introduction

Caring for children with long-standing medical conditions, whether physical or mental, poses significant challenges to their caregivers (1). Caregivers of children with psychiatric disorders have the added burden of dealing with stigma and having to manage challenging behaviours such as temper outbursts, verbal and physical aggression and suicidal behaviour of the unwell child (2). This is in addition to their concerns about what the future holds

for their child, missing work, and the costs of treatment and these in turn may predispose them to develop carer burden as well as to develop various psychiatric conditions (2,3).

Globally, one in seven, 10- to 19-year-old children has been reported to experience a mental disorder, accounting for 13% of the global burden of disease in this age group (4). A Sri Lankan study reports that the

prevalence of emotional and behavioural problems among children is 13.8% and that 8.8% of the children had internalizing problems and an equal percentage had externalizing problems (5).

Psychiatric disorders place a huge demand on the caregiver due to the nature of the illness and conditions such as attention deficit hyperactivity disorder (ADHD), anxiety disorders and depression are found to cause a higher burden on the primary caregivers (6).

Depression is one of commonest mental health problems in adults, with a prevalence of approximately 5% and this accounts for 4.3% of the global burden of disease (7). It is among the largest single cause of disability worldwide, particularly for women and is recognized as one of the leading healthcare issues that affect the quality of life of caregivers of children with behavioural and psychological disturbances (8). The rates of depression in caregivers of children with mental disorders are estimated to vary from 19-79% depending on the psychological condition of the child (9).

Providing care for people with psychiatric disorders is reported to have an impact on the socioeconomic aspects of life, including the burden of stigma and the quality of life of the carer (10,11). This may in turn affect the management of the child with the mental and behavioural disorder which increases the burden further.

The objectives of this study were to compare the level of depression and the quality of life among caregivers of children with mental and behavioural disorders with age and sex-matched controls and to describe the psychiatric disorders in children which are associated with depression and lower quality of life in the caregivers.

Methodology

A cross-sectional descriptive study was conducted among the primary caregivers of children with psychiatric disorders attending the Child and Adolescent Clinic of Teaching Hospital, Peradeniya. All consenting adult caregivers were included in the study which was conducted from January to June 2021. The demographic information was collected using a semistructured questionnaire prepared for this study.

The Patient Health Questionnaire-9 (PHQ-9) and the World Health Organization Quality of Life Scale (WHOQOL-BREF) are two of the best-known instruments that have been developed for making criteria-based diagnoses of depressive disorders commonly encountered in primary care and the quality of life respectively (12, 13). The validated Sinhala translations of the above two scales were used to detect depression and the quality of life among the study population (14,15). A score of 1-4 on the PHQ-9 was taken to indicate none or minimal symptoms of depression, 5-9 mild depression,

10-14 moderate depression and 15-27 severe depression. A score ≥ 5 was taken to indicate depression. The required information was gathered from the caregivers while they were waiting for their child to be reviewed at the clinic.

The controls consisted of age and sex-matched adult caregivers of children from a school close to the Peradeniya Teaching Hospital who did not have a previously diagnosed psychiatric disorder.

Ethical clearance was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Peradeniya. Permission was obtained from the Director of the Teaching Hospital, Peradeniya and the educational authorities to meet the parents. Written informed consent was obtained from all the participants.

Results

Among the 54 cases, 90.7% (n=49) were mothers of the child while the rest were either fathers or grandparents. The ages of the caregivers ranged from 24 to 68 years and 22% of them (n=12) were employed. Among the controls, 26.4% (n=14) were employed.

More than half of both the cases and the controls had an educational level up to grade 10 (Table 1). The two groups did not significantly differ when the levels of education were compared. A higher proportion of depression was seen among the cases compared to the controls ($X^2=34.62$, $P<0.001$) (Table 2). Although there was no significant difference in depression in caregivers of children with different disorders ($X^2= 34.453$, $P=0.398$), caregivers of children diagnosed with autism, ADHD, depression and conduct disorder showed a higher percentage of depression than those with children with other disorders (Table 3).

The overall quality of life was significantly lower among the cases when compared with the control group. Further, the quality of life was significantly lower in the psychological ($P=0.028$) and social ($P=0.025$) subdomains on the WHOQOL-BREF among the cases when compared with the control group. However, there was no significant

Table 1. Level of education among the cases and controls

Level of education	Cases (n=54)	Controls (n=53)
Up to grade 5	23 (43%)	26 (49%)
Up to ordinary level	21 (39%)	21 (39%)
Up to advanced level	8 (15%)	3 (5.6%)
Graduate	2 (3%)	3 (5.6%)

Table 2. Comparison of rates of depression among caregivers of children with mental and behavioural disorders and controls

Severity of Depression (PHQ-9 cut-offs)	Cases	Controls
No depression (1-4)	21 (38.9%)	44 (83.0%)
Mild (5-9)	3 (5.6%)	7 (13.2%)
Moderate (10-14)	16 (29.6%)	2 (3.8%)
Severe (15-27)	13 (25.9%)	0
Total	54	53

Table 3. Percentage of depression among caregivers according to the psychiatric diagnosis of the child

Diagnosis of the child	Percentage of depression among caregivers
Autism	16.6% (9/54)
ADHD	12.9% (7/54)
Depression	9.2% (5/54)
Conduct disorder	11.1% (6/54)
Tourette syndrome	3.7% (2/54)
Obsessive compulsive disorder	1.8% (1/54)
Oppositional defiant disorder	1.8% (1/54)
Schizophrenia	1.8% (1/54)
Panic disorder	0 (0/54)
Specific phobia	0 (0/54)

statistical difference in the environmental and physical subdomains between the two groups.

Discussion

To the best of our knowledge, this is the first study conducted in Sri Lanka which highlights the psychological morbidity of carers of children with mental disorders. The proportion of caregivers with depression was significantly higher among the cases compared with the controls and these results are similar to a study done in the USA (16). The rates we found are higher than the prevalence rates of depression among the general

population of Sri Lanka, which is estimated to be approximately 5% (7).

Caregivers of children with autism, ADHD, conduct disorders and depression had higher rates of depression than the caregivers of children with other psychiatric illnesses. However, this difference was not statistically significant.

Caregivers of children with psychiatric disorders experience several challenges in parenting/caregiving, which may have a negative impact on their well-being and quality of life. Therefore, it is to be expected that

support from one's spouse, the wider family, and the community would be important coping resources for caregivers. In the present study, most parents/caregivers reported that their quality of life was strongly affected by the need to care for their child. Many of these caregivers did not have any additional source of self-identity and self-esteem other than being the caregiver of the child attending the psychiatry clinic. All the caregivers of children with psychological morbidity had low scores in their quality of life. Previous research has established that caregivers of children with autism and ADHD show higher levels of burden and lower levels of quality of life (6,9).

Conclusion

Caregivers of children with psychiatric disorders had increased rates of depression and lower quality of life overall and in several of the subdomains when compared with the age and sex-matched controls. Therefore, it is pertinent that clinicians inquire about the mental well-being and quality of life of all caregivers of children with psychiatric disorders and offer relevant psychosocial support and treatment when and where needed.

Statement of contribution

SRP did the proposal and the literature survey. TDN and RMNCS collected the data. ST did the data analysis. TDN, PG and SRP wrote the manuscript. All authors approved the final manuscript.


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