

REVIEW ARTICLE

Quality of life, Perceived Stress, Coping and Burden among caregivers of Behavioral Disorder Children: A Narrative Review

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ABSTRACT

Childhood mental health problems demanded a holistic care approach from the health professional and family caregivers. Children under 15 years of age consist of roughly 33% of the total populace and around 5 to 15% of them are disabled with behavioural problems and their caregiver's mental health is under great threat. Family caregivers play a crucial role in managing and caring for these patients. So, the researchers conducted a narrative review regarding caregiver's stress, quality of life, burden and coping mechanism of children with behavioural disorder. The original research papers from different countries were searched through the electronic databases, Pro-Quest, Embase, Pub Med, Psyche ARTICLES, EBSCO, Research Gate, EORTC, Scopus etc. A total of 464 articles were retrieved from search engines. Finally, 15 articles were included in the review. Evidence of research work on attention deficit hyperactive disorder (ADHD) were plenty. The dearth of literature in Eastern India concerning caregiver's psychological health was surveyed. Mothers experienced high stress than the stress level in fathers. Family caregivers had poor quality of life, higher financial burden and find it hard to cope with the adverse situation. Interventional study results revealed that stress, depression and burden were significantly diminished after need-based education programs, coping skill training etc. Family care approach and need for interventional studies were recommended. The outcome of the review can be incorporated into nursing research to empower the family caregivers.

Keywords: Quality of Life, Stress, Coping, Burden, Caregiver, Behavioural Disorders

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INTRODUCTION

Children are considered as the future of the nation and their strong nurturing is not only essential for their upbringing in the family itself but also equally important for the nation's development. Keeping them physically and psychologically fit is a great challenge for every parent. Mental health-related issues like behavioural disorders in children aggravate the situation. Parents and family caregivers are in a dilemma regarding the management of the children and handling their psychological wellbeing. Children under 15 years of age consist of roughly 33% of the total populace and around 5 to 15% of them are disabled with socially incapacitating behavioral conduct. The emotional and behavioural issues range from 6.33% to 43.1% in the Indian setting (1).

Behavioural Disorder and its seriousness include

fits of rage, lying, cheating, resistance, burglary and attack. The individual may be diagnosed with Conduct disorder (CD) sometimes seen with Attention Deficit Hyperactivity Disorder (ADHD), oppositional defiant disorder (ODD) in combination or alone (2).

Children reared in the nuclear family in urban areas with poor socioeconomic status showed a higher prevalence of behavioural and emotional problems. Family history of mental illness and parenting by alcoholic father had a significant association with the disease (3)

Increased ADHD symptoms are associated with increased parental mental health problems, family environment, aggressive behaviour and poor social support. The prevalence of ADHD among children ranges from 1.30% to 28.9%. Therefore, it was evident from this, that ADHD influences enormous number of children in India (4,5).

Studies reveal that the predominance of CD was more among younger students. The males (66.67%) have higher pervasiveness in contrast to females (33.33%) (6). Parents of children with medical-surgical illness

experienced reduced quality of life in which case prayer and social support played as crucial factors of adaptation (7,8).

Guardian's/ parental/ caregiver's/ care giver of children with disorders frequently experience huge stress related to caring and managing. These include monetary pressure, clashes between relatives, highly sensitive and overprotection in families, stress and impact on family public activity, interference at work, helplessness, exhaustion, pity and constraints on schedule, individual flexibility, and privacy (9).

While being attached to these affected children the caregivers are sometime burdened and are prone to develop stress-related issues and also forced to live a compromised life which ultimately may harm their quality of life (10). Special attention is needed for children with neurodevelopmental disorder which can create a high level of distress, burden, anxiety and poor quality of life among caregivers (11). Over time, caregivers also develop their coping strategies to deal with this changed situation.

In this study, researchers attempted study the effect on caregiver having children with behavioural disorders, and the amount of stress, compromised quality of life of these caregivers associated in these cases. The study also deals with the coping strategies that they develop. The study involves an in-depth narrative literature review.

MATERIALS AND METHODS

The literature review was designed as a narrative study. The original research papers were searched and included from various countries to identify the number of studies carried regarding the understanding of the caregiver's stress, caregiver's quality of life, burden and coping strategies. The following electronic databases were searched: Pro Quest, Embase, Pub Med, Psyche ARTICLES, EBSCO, Research Gate, EORTC, Scopus, Educational Resources Information Centre (ERIC), and Allied Health Literature (CINHAL). The existing literature was very systematically searched to recruit into this narrative review.

Inclusion Criteria

1. The research papers were directly related to caregiver's stress or their quality of life or coping strategies in dealing with behavioural disorder children.
2. Only three kinds of behavioural disorders were included namely ADHD, CD and ODD.
3. The paper should be freely accessible online/offline and full text available.
4. The studies must be in the English language.
5. Articles were included from the year 2010 to 2021.

Exclusion Criteria

1. Poor quality journal publications.
2. The research study is published without ISSN number journals.
3. The research studies are not available in the journal database.
4. The research studies in which only abstract is available.
5. The studies were published in the local language.

RESULTS

A total of 464 articles were found from search engines. Considering the exclusion criteria 332 articles were rejected. Among remaining 132 in numbers, out of the 36 were published behind the review limit, 1 was not in the English language, 44 articles were not relevant well as 15 abstracts did not consider. The final retrieved articles were 36; Twenty-one full articles were excluded depending on inclusion criteria. Finally, 15 articles were included in this narrative review. The flow of the selected article is presented in Figure 1.

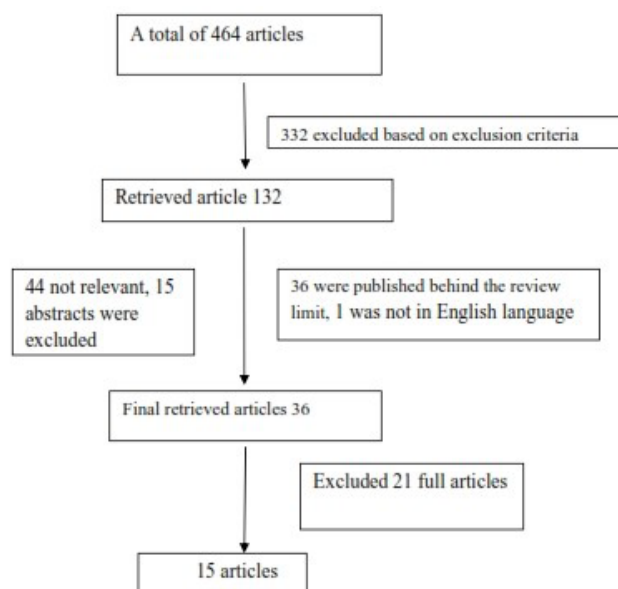


Figure 1: Flowchart of the selecting articles for narrative review of literature

Summary of the study characteristics organized in tabular form and narrated sequentially. Table I shows the summary of study characteristics and care-givers' quality of life. Table II summary of study characteristics and perceived stress of caregivers. COping mechanism of caregivers and burden of caregivers is shown in Table III and Table IV.

DISCUSSION

Caregiver's Quality of Life

A study at Rutgers New Jersey revealed that caregiver's of ADHD, ASD and neurotypical children faced the threat of the Covid -19 pandemic. Significantly there is

Table I: Summary of study characteristics; Care-givers' Quality of life

SL/no. Authors and year And reference	Title of article	Sample	Methods
1. Keith W. Pecor et al (2021) (12)	Quality of Life Changes during the COVID-19 Pandemic for Caregivers of Children with ADHD and/or ASD	n=575 caregivers of children with NT, diagnosed with ADHD, diagnosed with ASD, or diagnosed with co-morbid ADHD and ASD attending Rutgers New Jersey Medical School or University Hospital.	Convenience sampling Recruitment from medical records; email, text message, and telephone invitations. Cleared from institutional review board. Family Impact Module (FIM) & Pediatric Quality of Life Inventory
2. Karuna Sandra Thomas et al (2020) (13)	Quality of life, perceived stress and caregiver burden in mothers of children with childhood psychiatric disorders in Kerala, India.	n=336 Mothers of children with ADHD, PDD and LD attending Outpatient department of psychiatry, Kerala	Cross-sectional study. In depth interview. September 2012 to August 2014. Burden of Care Scale, Perceived Stress Scale, Quality of Life Scale, Depression and Anxiety Scale.
3. Ho-Chang Kuo et al (2020) (14)	Allergic diseases do not impair the cognitive development of children but do damage the mental health of their caregivers.	Parent of 109 patients with atopic sensitivities and 82 children with advancement delay and ADHD	Clinical partner study. The Chinese Form of the Swanson, Nolan, and Pelham IV Scale (SNAP-IV) and Modified Chinese Wellbeing Poll (CHQ-12). Cleared from Institutional Review Board.
4. Pawan Sharma et al (2020) (15)	Prevalence and correlates of Attention Deficit Hyperactive Disorder (ADHD) risk factors among school children in a rural area of North India	All kids in aged 6 to 12 in the Govt. Grade Schools of Miran Sahib Wellbeing zone in R.S Pura square of Jammu region of J&K state.	A cross sectional study. Vanderbilt ADHD indicative educator rating Scale for teacher. Personal information questionnaire (PIQ) – parent.
5. Android Elisa Meirelles et al (2016) (16)	Quality of life in care givers of ADHD children and Diabetic patients.	n=63 caregivers of ADHD children. n=52 adult with type 1, type 2 diabetic patient	Cross sectional assessment of two samples. WHO Quality of life –BREF, Beck and Hamilton Depression Scale.

Table II: Summary of study characteristics; Perceived Stress of Care-givers

SL/no. Authors and year And reference	Title of article	Sample	Methods
6. Chih-Cheng Chang et al (2020) (17)	Affiliate Stigma and Related Factors in Family Caregivers of Children with Attention-Deficit/Hyperactivity Disorder.	n=400 Guardians of children with ADHD attending juvenile mental outpatient facilities of two clinical focuses in Kaohsiung, Taiwan.	A cross-sectional survey study. June 2018 to April 2019 The Subsidiary Shame Scale (ASS), a self-appraised 22-item survey estimating parental figures' disguise of disgrace toward relatives' psychological maladjustment applied. Relationship of associate disgrace with guardians' troublesome mentalities toward kids' judgments, pharmacotherapy, conduct treatment etc. were inspected.
7. Sharifeh Mousavi et al. (2019) (18)	Evaluating the Effect of a Need-based Program for Caregivers on the Stress, Anxiety, Depression, and the Burden of Care in Families of Children with Attention Deficit-hyperactive Disorder	n=70 parents of children with ADHD aged 7-12 years. Attending the psychiatric center in Noor and Al-Zahra Hospital. (35 in experimental group and 35 in control group).	Two-group three-stage randomized clinical trial. June and September 2016. Zarit Burden Interview scale (22) and Brown et al (DASS)-42 scale. 8 session, 90 minutes duration. Ethical clearance from Isfahan University of Medical Sciences. Randomized clinical trial no. IRCT201611232200N4.
8. Linda M. Kronenberg et al (2016) (19)	Burden and Expressed Emotion of Caregivers in Cases of Adult Substance Use Disorder with and Without Attention Deficit/Hyperactivity Disorder or Autism Spectrum Disorder	122 patients with ADHD and their parent	A cross-sectional study. The examination was affirmed by institutional audit board. The Involvement Evaluation Questionnaire (IEQ) and Level of Expressed Emotion (LEE) scale.
9. Emuella Flood et al (2016) ²⁰	The Caregiver Perspective on Paediatric ADHD (CAPP) survey in Europe.	Parent of Children aged six to seventeen with ADHD and had of having pharmacotherapy in last six months.	A cross-sectional bench mark exploration. Subjective information obtained from 38 guardians and 28 youths on spaces of neglected need.

Table III: summary of study characteristics; Coping mechanism of Care-givers

SL/no. Authors and year And reference	Title of article	Sample	Methods
10. Agnieszka Pisula et al. (2019) (21)	General health, sense of coherence and coping styles in parents participating in Workshops for Parents of Hyperactive Children	n=Guardians of 199 children (186 mothers and 139 fathers) were included. Participant of the experiment were 23 mothers and 19 fathers (guardians of 24 kids)	An experimental examination. Guardians from the two gatherings were surveyed twice utilizing (1) the Overall Wellbeing Poll (GHQ), (2) the Existence Direction Survey (SOC-29), and (3) the Adapting Stock for Upsetting Circumstances (CISS). The study was cleared from ethical point of view and obtained formal ethical permission.
11. H V Suresh et al (2019) (22)	Burden and coping among caregivers of children with psychological disorders	n=70 caregivers of children with ADHD, ADHD with MR and oppositional behaviour Disorder at out patient department of Govt. Hospital, Andhra Pradesh .	A cross sectional study. Randomly selected caregivers. October- December 2017 Burden assessment schedule and Brief Cope Scale Cleared from IEB.
12. H Tamsyn., T Julie and Marnet Juhis (2018) (23)	Coping and adjustment in care givers	n=27 papers. Total participants 2084.	Systematic review of literature (1996-2015). Thematic analysis. Dementia, ADHD, Autism spectrum disorder, intellectual disabilities, Mental illness, etc.

Table IV: Summary of study characteristics; Burden of Care-givers

SL/no. Authors and year And reference	Title of article	Sample	Methods
13. Moshe Fridman et al (2017) (24)	Factors associated with caregiver burden among pharmacotherapy-treated children/adolescents with ADHD in the Caregiver Perspective on Pediatric ADHD survey in Europe	A parent or legal guardian of a child/adolescent aged 6–17 years diagnosed with ADHD at least 6 months before study enrolment and with no severe intellectual disability.	The CAPPA online overview. Middle of November 2012 to April 2013. Trouble meant their work, public activity, day to day life and stress. Total 2326 caregivers from ten European countries.
14. Floyd R. Sallee (2015) (25)	Early Morning Functioning in Stimulant-Treated Children and Adolescents with Attention-Deficit/Hyperactivity Disorder, and its Impact on Caregivers	n= 201 primary caregivers of children and adolescents with ADHD.	An online quantitative study. December 31, 2012 and January 24, 2013.
15. Alana D. Koehler et al (2014) (26)	Elevated Burden for Caregivers of Children with Persistent Asthma and a Developmental Disability	Care givers of Children aged three to ten and suffering with asthma /ADHD, CD. n= 530	A cross-sectional study endorsed by IRB (Institutional Review Board).

a reduction in the quality of life for all caregivers. But the family function of the care providers in case of neurotypical (NT) children remain unaffected. ADHD, ASD and comorbid ADHD and ASD caregivers experienced lower quality of life than that of NT children with pre-Covid 19 to Covid -19 situation (12).

An Indian study reported that 35% of the mother had anxiety, 37% had depression, higher mean perceived stress score in case of pervasive developmental disorder, the burden of care score was the same in ADHD and PDD, lowest in LD groups. There is a statistically significant difference in mean QOL of ADHD, PDD and LD (75.489, 77.520 and 86.394) (13). Another study stated that guardians of children with ADHD faced more trouble and their quality of life score was more terrible. Investigators express that guardian of a patient diagnosed with asthma or numerous infections with ADHD endure more noteworthy psychological disturbances and therefore needs support (14).

Another study stated that 69.3% ADHD positive children were living in a joint family and had a place with the lower working group. Creators reasoned that dependent on the present commonness of ADHD; the parent needs to be prepared to manage the changed conduct of their children (15). A Brazilian study reported that 84.1% were female ADHD caregivers. The physical domain of quality of life of the caregivers had a higher score than social and environmental domain score in ADHD cases compared to the general population of Brazil. It was evident that ADHD impacts the whole family. Awareness of health care professionals will help in the early detection of high-risk caregivers and the need for referral services were emphasized (16).

Perceived Stress of Caregivers

In China it was reported that Mothers had more raised degrees of disgrace than did male parents. Highly educated parents with recklessness signs in youths are related to more raised degrees of parental distress. A

feeling of critical shame was associated with distress in the course of their pharmacotherapy, direct treatment, and etiology for ADHD (17). An Iranian study reported that a need-based education programme for ADHD caregivers is effective to diminish the symptoms and problems of stress, anxiety, depression and burden of care. This indicates the necessity of predicting and providing need-based mental health care services and education programmes for caregivers. Further study on larger sample size and longer follow up was the recommendation of the researchers (18).

In addition, the parent of the patients with substance abuse disorder along with ADHD or autism spectrum disorder both showed moderately high frequencies of distress contrasted with the parent of patients with just substance abuse disorder (45% and 55% versus 25%). The stress is fundamentally associated with parental feelings of distress (19). A study in Europe uncovered that a greater part of guardians (68–88%) declared issues with schoolwork, social associations or activities and family associations, regardless of ADHD medications adherence. Researchers inferred that parents of children with ADHD without or even with medicines were feeling depleted and their social or family life was affected (20).

Coping mechanism of Caregivers

Mothers in the experimental group showed a critical improvement in their physical wellbeing and stress/sleeping disorder were improving and overall development among the mothers and fathers. The practice of emotion-focused adaptation among mothers decreased (21). A study uncovered that caregivers of children with ADHD, ADHD with MR and oppositional behaviour show mean maladaptive BCS scores of 24.50, 26.1 and 24.3 respectively. Female caregivers had higher mean maladaptive BCS scores than males (22). Findings of a systematic review explored that most of the methodologies used were qualitative and quantitative type only one was longitudinal. Caregivers practiced problem-focused coping as a positive adjustment than an emotion-focused coping mechanism. Cognitive strategies were positively related to adjustments and availability of social support in regard to physiological outcomes. The investigators recommended that practicing a combination of problem focus, was on emotional and cognitive strategies which is the most effective way to cope with situations among caregivers (23).

The burden of caregivers

A European study showed that guardians experienced a missed/adjusted work, staying away from social gathering, expanded parental concern/stress, and strain in everyday life, despite utilizing ADHD pharmacotherapy. Most grounded co-morbidity was arranging the day around the child/juvenile and adjust compromised work. Expanded medicine adherence were associated with diminished trouble for modified

work. It was inferred that the burden was identified with accustomed work, social action, change in everyday life, and parental concern/stress and need for emotional help (24). Inappropriately controlled ADHD problems were evaluated as generally extreme during the evening schoolwork time and early morning school schedule. Most of the guardians perceived early morning ADHD problems and impedance of early daytime working (EMF) as moderate to serious (25). Guardians were having a most noticeably terrible score in misery ($p=0.003$), nurturing certainty ($p<0.001$) and contending request ($p=0.013$) and personal satisfaction ($p=0.035$) in contrast with youngsters with ADHD or with asthma (26).

Previous studies also show that ongoing education is an effective way to improve knowledge and skills of caregivers and will make the parents more knowledgeable and confident in early identification of birth defects, developmental delays and mental disabilities (27).

CONCLUSION

Studies published within the time frame of this review have been limited in scope and dimensions. ADHD, CD and ODD prevalence is increasing gradually across the globe where India is also not an exception. Through this scientific investigation, it was seen that caregivers of behavioural disorders children are facing very stressful situations with diminished Quality of life, affected interpersonal relationships, family functions and family supports are the dimensions mostly jeopardized. Mothers play the role of main caregivers in most of the studies and practice emotional focus coping. ADHD caregivers' related research from UK, Europe, Iran and India dominated the literature. There is a dearth of literature related to information on caregivers' mental health. Family care approach and empowering the caregivers through appropriate interventions are the concept that are needed to implement in mental health services for both the children and caregivers.

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