BJMP 2010;3(3):a327

Review Article

Psychological Distress in Carers of People with Mental Disorders

Aadil Jan Shah, Ovais Wadoo and Javed Latoo

Abstract
The recent literature on carers' burden in mental disorders is reviewed. Families bear the major responsibility for such care. Carers face mental ill health as a direct consequence of their caring role and experience higher rates of mental ill health than the general population. The production of burden in carers is a complex process and is related to gender, age, health status, ethnic and cultural affiliation, lack of social support, coping style, in addition to the stressors of the disorder itself. Carers appear to suffer from at least moderate levels of psychological symptomatology. The behavioural problems associated with mental disorders further increase the stress levels of carers. The findings from the review afford a comprehensive understanding of the care-giving situation with its outcomes, and its practical application in devising effective support strategies for family carers.

Keywords: Carers, caregivers, care recipients, psychological distress, burden, stress, mental disorders.

Introduction

Carers play a vital role in supporting family members who are sick, infirm or disabled.[1] There is no doubt that the families of those with mental disorders are affected by the condition of their near ones. Families not only provide practical help and personal care but also give emotional support to their relative with a mental disorder. Therefore the affected person is dependent on the carer, and their well-being is directly related to the nature and quality of the care provided by the carer. These demands can bring significant levels of stress for the carer and can affect their overall quality of life including work, socializing and relationships. Research into the impact of care-giving shows that one-third to one-half of carers suffer significant psychological distress and experience higher rates of mental ill health than the general population. Being a carer can raise difficult personal issues about duty, responsibility, adequacy and guilt.[2] Caring for a relative with a mental health problem is not a static process since the needs of the care recipient alter as their condition changes. The role of the carer can be more demanding and difficult if the care recipient's mental disorder is associated with behavioural problems or physical disability. Over the past few decades, research into the impact of care-giving has led to an improved understanding of this subject including the interventions that help. It has now been realized that developing constructive working relationships with carers, and considering their needs, is an essential part of service provision for people with mental disorders who require and receive care from their relatives.

The aim of this review was to examine the relationship between caring, psychological distress, and the factors that help caregivers successfully manage their role.

'Family burden' - The role of families as carers

Caring for someone with a mental disorder can affect the dynamics of a family. It takes up most of the carers' time and energy. The family's responsibility in providing care for people with mental disorders has increased in the past three decades. This has been mainly due to a trend towards community care and the de-institutionalization of psychiatric patients.[3] This shift has resulted in the transferral of the day-to-day care of people with mental disorders to family members. Up to 90% of people with mental disorders live with relatives who provide them with long-term practical and emotional support.[4, 5] Carer burden increases with more patient contact and when patients live with their families.[6] Strong associations have been noted between burden (especially isolation, disappointment and emotional involvement), caregivers' perceived health and sense of coherence, adjusted for age and relationship.[7]

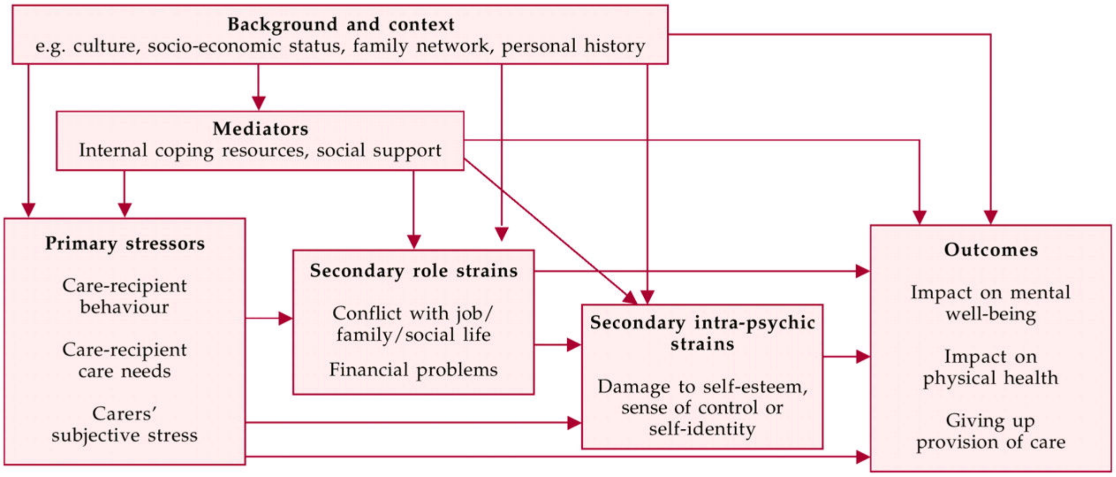
'Family burden' has been adopted to identify the objective and subjective difficulties experienced by relatives of people with long-term mental disorders.[8] Objective burden relates to the practical problems experienced by relatives such as the disruption of family relationships, constraints in social, leisure and work activities, financial difficulties, and negative impact on their own physical health. Subjective burden describes the psychological reactions which relatives experience, e.g. a feeling of loss, sadness, anxiety and embarrassment in social situations, the stress of coping with disturbing behaviours, and the frustration caused by changing relationships.[9] Grief may also be involved. This may be grief for the loss of the person's former personality, achievements and contributions, as well as the loss of family lifestyle.[10] This grief can lead to unconscious hostility and anger.[9,10]

The impact of caring on carers' mental health

The vehicles of psychological stress have been conceptualized as adjustment to change,[11] daily hassles,[12] and role strains.[13] Lazarus and Folkman (1984)[14] define stress as 'a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being.' The association between feelings of burden and the overall caregiver role is well documented.[15] Caregivers provide assistance with activities of daily living, emotional support to the patient, and dealing with incontinence, feeding, and mobility. Due to high burden and responsibilities, caregivers experience poorer self-reported health, engage in fewer health promotion actions than non-caregivers, and report lower life satisfaction.[16, 17]

The overarching theme from the findings is that carers and care recipients do not believe that care recipients' basic needs are being met, which causes them a great deal of distress and anger towards services and increases carer burden. Carers assert that the needs of care recipients and carers are interconnected and should not be seen as separate.[18] The stress in carers is best understood by Pearlin`s stress-process model as shown in Figure 1.

Figure 1: Pearlin's stress–process model of stress in carers (adapted from Pearlin et al, 1990)



The burden and depressive symptoms sustained by carers have been the two most widely studied care-giving outcomes. Reports indicate that depressive symptoms are twice as common among caregivers than non-caregivers.[19] Family caregivers who have significantly depressed mood may be adversely affected in their ability to perform desirable health-maintenance or self-care behaviours in response to symptoms.[20] Family caregivers experience more physical and mental distress than non-caregivers in the same age group.[16] Several studies suggest that many caregivers are at risk of experiencing clinical depression.[21] Nearly half of the caregivers in some studies were reported to meet the diagnostic criteria for depression when structured clinical interviews were used.[22] There is also some evidence to suggest that a diagnosis of depression can be causally related to the care-giving situation. Dura et al (1991) [23] found that nearly one quarter of caregivers met the criteria for depression whilst in the care-giving role, although they had never been diagnosed with depression prior to their assumption of this role. It has been proven that if the problem behaviours and the functional impairment in the care recipients is worse, the strain score is higher and the carer is more likely to be depressed.[24] The societal implications of this are underscored by reports indicating that the stressed caregiver is more likely to institutionalize the care recipient.[25, 26]

The impact of caring for different mental disorders

The impact of caring for different mental disorders, and associated risk factors, is shown in table 1. Although only limited data is available on the psychological distress experienced by the carers of people with other mental disorders, it seems that these disorders have a significant impact on families. Obsessive-compulsive disorder has a considerable impact on families and can lead to a reduction in social activities, causing isolation over time.[38] People with obsessive-compulsive symptoms frequently involve their relatives in rituals.[38] This can lead to an increase in anger and criticism towards them which has a negative impact on treatment outcomes.[38] Caring for patients with eating disorders can be overwhelming for the carer. Available data suggest that the impact on carers of persons with anorexia nervosa may be even higher than for psychoses.[39] Studies on bulimia nervosa indicate that carers have significant emotional and practical needs.[40]

Table 1: The impact of caring for different mental disorders and associated risk factors

Mental Disorder	Risk factors	Impact on the carer
Schizophrenia[28]	High disability, very severe symptoms, poor support from professionals, poor support from social networks, less practical social support, violence.	Guilt, loss, helplessness, fear, vulnerability, cumulative feelings of defeat, anxiety, resentment, and anger are commonly reported by caregivers.
Dementia [29,30]	Decline in cognitive and functional status, behavioural disturbances, dependency on assistance.[31]	Anger, grief, loneliness and resentment.
Mood disorders	Symptoms, changes in family roles, cyclic nature of bipolar disorder, moderate or severe distress.[32]	Significant distress,[33] marked difficulties in maintaining social and leisure activities, decrease in total family income, considerable strains in marital relationships.[34, 35] Psychological consequences during critical periods also persisting in the intervals between episodes in bipolar disorder,[36] poorer physical health, limited activity, and greater health service utilization than non-caregivers.[37]

Table 2: Risk factors for carer psychological distress

Caregiver factors	*Research findings*
Gender	• Women have higher rates of depression than men in the care-giving role.[42] • 39% of female caregivers, compared to 16% of male caregivers, qualified as being at-risk for clinical depression on The Center for Epidemiologic Studies-Depression Scale (CES-D).[43] • A randomized controlled trial[44] found that women were more likely than men to comply with a home environmental modification intervention, implement recommended strategies, and derive greater benefits. • Male carers tend to have more of a 'managerial' style that allows them to distance themselves from the stressful situation to some degree by delegating tasks.[45]
Age	• Age-associated impairments in physical competence make the provision of care more difficult for older caregivers. • There is a positive association of age and caregiver burden in Whites, but a negative association for African-Americans suggesting that older African-Americans are less likely to experience care-giving as physically burdensome.[46]
Caregiver health	• Caregiver health has also been identified as a significant predictor of caregiver depression.[46] • Poorer physical health among caregivers than age-matched peers. Such health problems are linked to an increased risk of depression.[47] • Longitudinal studies demonstrated that caregivers are at a greater risk, than non-care-giving age-matched controls, for developing mild hypertension and have an increased tendency to develop a serious illness[48] as well as increased risk for all-cause mortality.[49]
Ethnicity	• Ethnicity has substantial impact on the care-giving experience.[41] • Comprehensive reviews of the literature have identified differences in the stress process, psychological outcomes, and service utilization among caregivers of different racial and ethnic backgrounds.[50] • Studies consistently show important differences in perceived burden and depression among African-American, White, and Hispanic family caregivers.[51] • Caucasian caregivers tend to report greater depression and appraise care-giving as more stressful than African-American caregivers.[52] • Hispanic caregivers report greater depression and behavioural burden than Caucasians and African-Americans.[53]
Social support	• Social support has profound effects on caregiver outcomes. • More social support corresponds to less depressive symptomatology[47] and lower perceived burden.[54] • Care-giving is associated with a decline in social support, and increased isolation and withdrawal. [55] • Social support and caregiver burden have been found to mediate depression in caregivers.[55] • Social support has other important functions in that carers may find out about services from people who have used them before and form a network with others in similar situations.[41]

Factors associated with psychological distress of the carer

Risks for carer psychological distress or depression are related to gender, age, health status, ethnic and cultural affiliation, lack of social support, as well as certain other characteristics related to the caregiver (table 2).[41]

Some of the patient factors related to psychological distress in carers are: behavioural disturbances, functional impairments, physical impairments, cognitive impairments, and fear that their relative may attempt suicide.

The frequency with which behavioural disturbances are manifested by the patient has been identified as the strongest predictor of caregiver distress and plays a significant role in the caregivers decision to institutionalize the patient.[25] The literature consistently demonstrates that the frequency of behavioural problems is a more reliable predictor of caregiver burden and depression than are the functional and cognitive impairments of the individual.[56] Carers face unfamiliar and unpredictable situations which increases stress and anxiety. Anxiety may be increased by behavioural problems of patients who cannot be successfully managed on a consistent basis.[56] Anxiety is associated with depression, stress, and physical ill health.[56]

Findings regarding the relationship of functional impairment and negative caregiver outcomes have been inconclusive. Some studies document a weak association of objective measures of patient functional status and caregiver burden/depression,[57] whereas others report a stronger relationship.[54] Carers have reported great anxiety due to fear that their relative may attempt suicide.[58] Carers of people with both physical and cognitive impairments have higher scores for objective burden of caring than those caring for people with either type of impairment alone. [58] In contrast, scores for limitations on their own lives were higher among women caring for people with cognitive impairments (with or without physical impairments).[59]

Coping styles and interventions to reduce psychological distress in carers

There is increasing interest in examining the factors that help caregivers successfully manage their role, while minimizing the effect on their mood and general well-being.[60] Much of this research has been done within the general framework of stress and coping theory,[61] examining coping styles of caregivers and the relationship between types of coping styles and reported symptoms of depression.[62] A variety of interventions have been developed which support caregivers (table 3). Interventions include: training and education programs, information-technology based support, and formal approaches to planning care which take into account the specific needs of carers, sometimes using specially designated nurses or other members of the health care team.[63] Ballard et al (1995)[64] demonstrates that a higher level of carer education regarding dementia increases carers' feelings of competency. This is more likely to reduce their expectations of their dependents' abilities. Previous studies which have looked at these coping strategies and feelings of competence have shown that unrealistic expectations of a dependant increases carers' risk of depression,[65] and conversely a reduction of carers' expectations is associated with lower rates of depression.[66] Caregivers who maintain positive feelings towards their relative have a greater level of commitment to caring and a lower level of perceived strain.[67] Furthermore, carers who experience feelings of powerlessness, lack of control, and unpreparedness have higher levels of depression.[65] The most effective treatments in depression of carers appear to be a combination of education and emotional support.[68]

Spiritual support can also be considered a coping resource and has been studied in older African-Americans and older Mexican-Americans.[69] Previous work examining the role of spiritual support observed that African-American caregivers report higher spiritual rewards for caregiving,[70] and reliance on prayer and church support.[71]

Religious coping plays a paramount role, and it is often present at higher levels for African-Americans and Hispanics. For REACH caregivers, Coon et al (2004)[72] found that religious coping is greater for Hispanic and African-American than for White caregivers. Religious involvement is frequently associated with more access to social support as well.[73]

Anecdotal literature[74] suggests that caregivers who use more active coping strategies, such as problem solving, experience fewer symptoms of depression than do those who rely on more passive methods. Significant associations have been reported between positive strategies for managing disturbed behaviour, active strategies for managing the meaning of the illness, and reduced levels of caregiver depression. An important role for health-care professionals is in helping caregivers enhance their coping skills, supporting existing skills, and facilitating the development of new ones.[66]

Table 3: Coping styles and interventions to reduce psychological distress in carers

An important role for health-care professionals is in helping caregivers enhance their coping skills, supporting existing skills and facilitating the development of new ones.

- Training and education programs
- Information-technology based support
- Formal approaches to planning care
- Combination of education and emotional support
- Spiritual support
- Religious coping
- Positive strategies for managing disturbed behaviour
- High quality of informal relationships and presence of informal support
- Psychotherapy
- Cognitive-behavioural family intervention

Care-giving has some positive associations for caregivers, including pride in fulfilling spousal responsibilities, enhanced closeness with a care receiver, and satisfaction with one's competence.[75] These perceived uplifts of care-giving are associated with lower levels of caregiver burden and depression.[76] However perceived uplifts are more common among caregivers of colour than among Whites.[77]

High quality of informal relationships, and the presence of informal support, is related to lower caregiver depression[78] and less deterioration in the emotional health for African-American caregivers, but not for Whites.[79] Support of caregivers by others help to alleviate stress if the supporter is understanding and empathic.[74] In one study, caring for a family member was not perceived to be a burden, and caregivers reported notable limitations on their social networks and social activities. They reported higher levels of unemployment than would be expected for the general population and were over-represented in lower income groups. Family carers are at high risk of social and economic disadvantage and at high risk of mental health challenges.[80] Highly stressed persons may not be able to benefit from attempted social support of others as much as moderately stressed persons.[81]

Caregivers need to have the opportunity to learn more effective ways of coping with stress. If they can learn new ways to cope, they can reduce their anxiety and reliance on treatments.[41] Bourgeois et al (1997)[82] report that caregiver’s behavioural skills and effective self-management training programmes result in a lower frequency of patient behavioural problems and helps to improve the caregiver’s mood. Stevens and Burgio (2000)[83] designed a caregiver intervention that teaches caregivers behavioural management skills to address problem behaviours exhibited by individuals with dementia, as well as problem-solving strategies to increase pleasant activities for the caregiver. Passive coping styles have been associated with greater burden. Persons who use an escape-avoidance type of coping are known to have more depression and interpersonal conflicts.[41]

Psychotherapy may be of some benefit in patients with early dementia but, due to cognitive loss, some adaptation of the technique is required and the involvement of carers is often necessary.[84] Cognitive-behavioural family intervention can have significant benefits in carers of patients with dementia and has a positive impact on patient behaviour.[85] From a cognitive perspective, care-giving plays an important invisible part, which consists of interpreting the care receiver's behaviour, reflecting on the best way to adjust to it, and defining care objectives.[86] The interventions requiring active participation by the caregivers and those based on cognitive behavioural therapy can produce significant reductions in burden, anxiety and depression than those focused on knowledge acquisition.[87]

Among caregivers with depressive symptoms, 19% used antidepressants, 23% antianxiety drugs, and 2% sedative hypnotics. African-American caregivers were less likely than Whites to be taking antidepressants.[88] In their study, Kales et al (2004)[89] reported use of herbal products in 18% of elderly subjects with depression and/or dementia and in 16% of their caregivers.

In the Burdz et al (1988)[90] study, respite care proved to have a positive effect on the burden experienced by the caregivers, and it also had a positive effect, against all expectations, on the cognitive and physical functioning of the persons with dementia.

There are more than twenty instruments that could be used as outcome measures with mental health carers and have good psychometric properties. They can measure (i) carers' well-being, (ii) the experience of care-giving and (iii) carers' needs for professional support.[91] The caregiver burden scale and the sense of coherence scale seem to be highly useful for identifying carers at risk of stress, the pattern of burden, and coping strategies. Nurses can help family caregivers to identify their negative experiences about care-giving and can help them reflect upon their coping strategies to find balance in their situation. Risk groups of caregivers may be identified, especially those with a low perceived health and sense of coherence, for early interventions to reduce burden.[7]

Conclusion

The impact of caring for someone with mental illness brings the risks of mental ill health to the carer in the form of emotional stress, depressive symptoms, or clinical depression. Most individuals with mental disorders live in their own homes and are cared for by a family member. The caring process can be very taxing and exhausting, especially if the care recipient has a severe mental disorder. Providing such long-term care can be a source of significant stress. The behavioural problems associated with mental disorders further increase the stress levels of the carer and therefore impacts significantly on their mental health.

Carers face mental ill health as a direct consequence of their caring role and experience higher rates of mental ill health than the general population. This leads to negative effects on the quality of life of the carer and the standard of care delivered. Efforts to identify and treat caregiver psychological distress will need to be multidisciplinary, require consideration of the cultural context of the patient and caregiver, and focus on multiple risk factors simultaneously. The findings of the review underline the importance for early identification of carers, effective carer support, health promotion, monitoring high-risk groups, and timing appropriate interventions.

Competing Interests
None Declared

Author Details
AADIL JAN SHAH, MBBS, MRCPsych, Cheshire and Wirral Partnership NHS Foundation Trust, UK
OVAIS WADOO, MBBS, MRCPsych, Mersey Care NHS Trust, UK
JAVED LATOO, MBBS, DPM, MRCPsych, North East London NHS Foundation Trust, UK

CORRESSPONDENCE: Dr. Aadil Jan Shah, MBBS, MRCPsych, Speciality Registrar, General Adult Psychiatry, Cheshire and Wirral Partnership NHS Foundation Trust, Address: Early Intervention Team, Cherry Bank Resource Centre, 85 Wellington Road, Ellesmere Port, Chester CH65 0BY
Email: aadilshah@nhs.net

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