

Review Article

The burden on informal caregivers of people with bipolar disorder

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Abstract: Caregivers of people with bipolar disorder may experience a different quality of burden than is seen with other illnesses. A better understanding of their concerns is necessary to improve the training of professionals working with this population. Conceptualizing caregiver burden in a conventional medical framework may not focus enough on issues important to caregivers, or on cultural and social issues.

Perceptions of caregivers about bipolar disorder have important effects on levels of burden experienced. It is important to distinguish between caregivers' experience of this subjective burden and objective burden as externally appraised. Caregivers' previous experiences of health services may influence their beliefs about the illness. Caregiver burden is associated with depression, which affects patient recovery by adding stress to the living environment. The objective burden on caregivers of patients with bipolar disorder is significantly higher than for those with unipolar depression. Caregivers of bipolar patients have high levels of expressed emotion, including critical, hostile, or over-involved attitudes. Several measures have been developed to assess the care burden of patients with depressive disorders, but may be inappropriate for patients with bipolar disorder because of its cyclical nature and the stresses arising from manic and hypomanic episodes. Inter-episode symptoms pose another potential of burden in patients with bipolar disorder. Subsyndromal depressive symptoms are common in this phase of the illness, resulting in severe and widespread impairment of function. Despite the importance of assessing caregiver burden in bipolar disorder, relevant literature is scarce. The specific effects of mania and inter-episode symptoms have not been adequately addressed, and there is a lack of existing measures to assess burden adequately, causing uncertainty regarding how best to structure family interventions to optimally alleviate burden. The relatively few studies into caregiver burden in bipolar disorder may largely reflect experiences in the US Veterans Affairs health service, but the findings may be limited in their generalizability. Nevertheless, available data suggest that caregiver burden is high and largely neglected in bipolar disorder. Clinically effective, well-targeted and practically viable interventions are needed. However, services cannot be enhanced on a rational basis without an improved understanding and capacity to measure and target caregiver burden the impact of any change in services be evaluated.

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Bipolar disorder is a major cause of suffering for patients, but the burden it indirectly imposes upon families and caregivers is a matter of increasing clinical concern. Caregiver burden has been described as 'the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant other(s), e.g. members of the household and/or the family' (1),

although significant others can be considered to extend to include close and supportive friends. It is known that people who care informally for those with long-term illnesses suffer from increased levels of stress, depression and ill-health (2–5). Despite the extent of the impact of bipolar disorder, very little work has been done to define more precisely the caregiver burden associated with the illness

compared with the relatively extensive literature on schizophrenia, dementia and unipolar depressive disorder.

What do we mean by 'burden' and 'informal caregivers/carers'? What is the size of the problem arising from bipolar disorder? What do we currently know about the nature of this burden? Why is it important? Where should we go from here? These are all questions that warrant further consideration.

Informal caregivers are the usually unpaid non-professionals, such as family and friends, who have a significant input to the care and support of those affected by severe psychiatric illnesses. In the UK, the National Service Framework for Mental Health (6) recognized the vital role of informal caregivers in the delivery of health care. However, this document treats the needs of adults of working age as generic, and is heavily influenced by evidence from research in schizophrenia (7) and the dementias (8), where the needs and particular stresses upon caregivers have been relatively well identified. In contrast, the literature concerning bipolar disorder is sparse. This sits uncomfortably beside the fact that bipolar disorder is a cause of equivalent disability to schizophrenia in younger people (9).

It could be argued that differences in disease characteristics make it difficult to extrapolate caregiver burden in patients with schizophrenia or dementia to bipolar disorder based on the available literature. Bipolar disorder is episodic and cyclic in nature, hence the caregiver burden over time may vary more than that seen in either schizophrenia or dementia (10). Moreover, the average age of onset of bipolar disorder is lower than that of schizophrenia or dementia and likely affects the extent and degree of caregiver burden. A particular uncertainty, neglected hitherto, is the impact of manic states upon caregivers.

How big a problem is bipolar disorder?

Mood disorders were identified by the World Health Organization (WHO) in its 1999 annual report as among the most common causes of morbidity and mortality in developed countries (9). Unipolar depressive disorder and bipolar disorder together caused more lost quality of life, lost productivity, and chronic impairment than ischaemic heart disease and cerebrovascular disease. In high-income countries, mood disorders were considered to be among the most burdensome diseases when measured by productive years of life lost because of a disability. In the Americas they were ranked as the most burdensome disorder, and in

Europe as the third most burdensome. Epidemiologic estimates (11) suggest that up to 1 million individuals with bipolar disorder live in the UK alone, most of whom will spend many years of their lives dealing with the symptoms and consequences of mania, hypomania and depression (12).

A recent US survey using the Mood Disorders Questionnaire suggests that the prevalence of bipolar disorder may be higher than previously estimated. The results of the community-based survey found that 3.7% of 125 000 adults screened probably had bipolar I or II disorder (13). In the United States alone, bipolar illness accounts for more than 16 million outpatient physician visits each year (14).

Bipolar disorder imposes a significant burden on a personal, medical and socioeconomic level (15). Conventionally, the difficulties associated with bipolar disorder on the personal level are highlighted for patients themselves. However for their families, who often end up supporting and caring for them, the consequences of the illness may also be far-reaching and the rate of marital and long-term partnership breakdown is very high (16).

In a 20-year prospective follow-up study in the US, Judd et al. (17) found that patients with either bipolar I or II disorder experience depressive symptoms for longer periods than manic/hypomanic symptoms (3:1 for patients with bipolar I disorder and 37:1 for patients with bipolar II disorder). However, although probably shorter in cumulative duration, manic episodes usually require a period of hospitalization; can be devastating to personal relationships, career prospects, and financial independence; and carry an increased risk of aggression towards caregivers and self. Even if bipolar symptoms spontaneously subside, such as during untreated inter-episode periods, impaired functioning persists for many patients (18). This loss of social functioning exacts a considerable toll on caregivers and families that, in turn, can adversely affect the clinical outcome for the patient (10, 19–21).

Why is informal caregiver burden an important issue?

We need to better understand caregivers' views and personal perceptions of the stresses and demands arising from caring for someone with bipolar disorder. This will be necessary in order to develop practical, appropriate, and acceptable interventions, and to improve the training of professionals working with caregivers. It is likely that there are complex inter-relationships between the breakdown of informal caring relationships, increasing social instability, the need for input from formal/professional caregivers (including psychoeducation), and health and economic outcomes of care.

If caregivers' beliefs about bipolar disorder are primarily based on cultural as opposed to medical models of illness, we need to make professionals aware of this when offering psychoeducation and support to individuals and groups of informal caregivers.

There is a paucity of existing work on caregivers' own views or experiences. Despite a general recognition of the toll of caring for a relative or friend with long-term health problems, relatively little research has been carried out on how informal caregivers themselves experience the care process. While there is some published work on informal caregivers' experiences in relation to illnesses such as schizophrenia and depression (22) and Alzheimer's disease (8, 23), the work on informal caregivers' experiences of caring for someone with bipolar disorder is minimal and largely confined to US healthcare settings.

If we are to introduce suitable psychosocial interventions for caregivers then we need to know more about their experiences. In the area of Alzheimer's disease and dementia, interventions with informal caregivers have been evaluated (24). In order to understand how and why these work, we need to be aware of their different approaches.

Charlesworth (25) usefully differentiates between interventions that aim to have an impact directly on caregivers from those that use the caregiver as an 'agent of change' for the person with dementia and those that combine these approaches. For example, interventions may target caregiver self-care (e.g. social support, stress management), caregiver appraisal of the person they care for (e.g. providing information about the illness, or modifying attributions and beliefs about the illness and locus of control, etc.), or promote caregiver skills (e.g. cognitive stimulation, pleasurable activities, behaviour modification).

This conceptualization could be usefully transferred to the field of bipolar disorders, allowing us to develop psychosocial interventions with informal caregivers. However, before this is possible, it would be helpful to develop a thorough and in-depth understanding of the nature of caregiver burden in relation to bipolar disorders. In what ways is it similar and different to the burden experienced by those who care for people with other chronic illnesses?

Conceptualizing caregiver burden

What do we mean by caregiver burden? When conceptualizing caregiver burden we need to recognize that caring roles are usually an integral part of family life. Parents generally expect to have to care

for their children, children are dependent upon their parents or guardians, and many spouses care for their partners. Thus, a level of caregiver burden usually exists within family roles and relationships, and the implicit or explicit obligations these carry with them. These are, in turn, shaped by cultural and social class expectations. For example, in a relationship characterized by traditional gender roles, the care burden experienced is likely to differ substantially depending on whether the husband or the wife is the patient.

Burden is also related to the development and nature of a person's self-identity in their role as caregiver. Most people who view themselves as informal caregivers have experienced an important transition in which the relationship of 'carer-cared for' has become superimposed onto existing spousal, family, or friendship relationships. These qualitative changes in the relationship between informal caregiver and patient are likely to be associated with specific symptoms, key illness-related events, and the stage of the disorder, yet very little is known about the factors mediating these changes with respect to bipolar disorder. Opie (26) identifies three ways in which people take on the identity of informal caregivers: (i) in the context of positive long-term relationships, (ii) as a result of feelings of duty and obligation, and (iii) in relation to strong feelings of anger and resentment. Each of these situations probably needs to be approached in a different way rather than via a generic approach, but can only be done if the patterns and their various combinations are recognized.

When attempting to understand the informal caregiver burden of bipolar disorder, there may be hazards associated with viewing the issues solely within a conventional medical framework. Health professionals may fail to focus on issues regarded by caregivers as important, paying more attention to ones they perceive as key. There is also a risk of paying insufficient attention to the views of caregivers, the nature of the relationship between caregiver and patient, social circumstances, and culturally situated health beliefs, all of which may have an impact upon both treatment interventions and the burden of care experienced by informal caregivers.

Policy issues and economic impact of bipolar disorder

The economic impact of bipolar disorder can be considered at a societal and personal level. Although our main emphasis here is at the interpersonal level, the economic impact of bipolar disorder is considerable, although precise estimates

vary in cost-of-illness studies because of the guesswork involved in estimating indirect costs. In a study undertaken under the auspices of the US National Institute of Mental Health, the total annual costs to US society of bipolar disorder in 1991 alone were estimated to be US\$45 billion (about 70% of the costs estimated for schizophrenia over the same period) (27). Of this, \$38 billion was associated with indirect costs, including lost productivity of patients and caregivers. However not many studies have reported on costs specifically associated with caregiver burden. Clark (28) documented that family members of individuals with severe mental illness, especially those with a dual diagnosis, spend considerably more money and time on the individual than those who do not have relatives with chronic illnesses (28).

Care giving may have an economic impact in various ways. Informal caregivers may take time off from paid work to fulfil caring obligations, choosing not to work full-time, being unable to offer the flexibility that employers might normally require and thus not fulfilling their potential in economic/career terms, etc. There are also direct economic consequences and there is evidence that family members, especially parents and siblings, often make significant financial contribution to the support of their bipolar relatives (29).

The UK government has recently recognized that the large number of informal caregivers have needs in their own right. *Caring about Carers: a National Strategy for Carers* attempts to address three issues: information, support and care for caregivers (30). There is recognition of a relative paucity of reliable information about caring activities, and promotion of a two-way information exchange between caregiver and service providers to redress this. The need to support both informal caregivers' care activities and their psychological needs is acknowledged through, for example, regular breaks from caregiving activities. If such well-meaning government interest is to be successfully translated into effective action, more research will be needed to reliably chart the nature of informal caregiving experiences. It should be recognized that these caring experiences are likely to vary depending not only on the disorder of the person being cared for, but also on caregivers' and patients' relationships and social circumstances.

Burden of care in schizophrenia, dementia and unipolar depression

The scope of the literature on caregiver burden in affective disorders, including unipolar depression and bipolar disorders, has been neglected thus far.

Furthermore, the literature from unipolar depression is unlikely to accurately capture the specific caregiver impact associated with bipolar disorder. In particular, manic episodes and the loss of patient insight into their illness often casts the informal caregiver in an oppositional role.

A more extensive body of work on the burden of caregiving in schizophrenia and the dementias has shaped our approach to the neglected problem of bipolar disorder. It is useful therefore to briefly summarize the conclusions from these related areas of literature (22):

- In the literature on schizophrenia, dementia, and unipolar depression, the burden upon informal caregivers is common, if not universal, and has significant impact on multiple domains of life (7, 8, 22).
- The perceptions and beliefs of caregivers about the specific disease have important effects on levels of burden experienced (21). It is important to distinguish between caregivers' experience of this subjective burden and objective burden as externally appraised, as the two may be surprisingly discrepant.
- Caregivers' previous experiences (negative or positive) of mental health services may strongly influence the beliefs and expectations they have about the illness (30, 31).
- Caregiver burden is strongly associated with caregiver depression, which affects patient recovery by adding stress to the living environment and the caregiver not being able to provide enough support for the patient. In schizophrenia, informed interventions on the part of the family can reduce the burden of disease (32).
- Fadden et al. (22) examined the effects of 'persistent depression' in 24 spouse caregivers in the UK using the Social Behaviour Assessment Schedule (SBAS) (33) and the shortened version of the Camberwell Family Interview (34). Burden arose from practical issues (e.g. giving up work, loss of income and less social activity), coping with 'problem behaviours' (e.g. social withdrawal and complaints), and psychological adjustments (e.g. a sense of loss and change in the relationship balance).

Literature on caregiver burden in bipolar disorder

At the time of writing, we know of no comprehensive studies of family burden specifically for bipolar affective disorder in a representative community sample. The only relevant study of a significant size (21) was based in a US Veterans Affairs centre,

which assessed the primary caregiver to 266 bipolar patients on illness appraisal (awareness of mental illness, and the volitional nature or otherwise of symptoms or behaviour), social adjustment, and burden (objectively, subjectively and globally rated), again using the SBAS. Only spouse/equivalent caregivers were included; sibling and non-spouse caregivers were excluded. Severe levels of burden were reported by over 50%, and moderate or severe levels were reported by over 90% of the caregivers interviewed. This study has limitations, including 10% of patients having bipolar II in the sample and a large proportion of patients with schizoaffective disorder (35%). Further limitations may arise from the possible lack of sensitivity or selectivity of the rating instrument used to detect the unique features of bipolar caregiver burden, the rationale for the assessment period (within 2 weeks of discharge), and the fact that no data were presented in the initial study about the polarity or duration of the index mood episode.

These factors may account for findings that we find puzzling on the basis of clinical experience: the highest burden was related particularly to misery, irritability and withdrawal, i.e. depressive episodes were rated as significantly more burdensome than manic/hypomanic episodes. Although we accept that the duration of depression is long in bipolar disorder we cannot believe severe manias have no significant impact on care burden and patient-caregiver relationships.

Nevertheless, at follow up (10) high caregiver burden at the index rating predicted ongoing affective episodes at 7 and 15 months. One interpretation of this finding is that patients living with an 'over-burdened' caregiver may have an increased risk of relapse.

Chakrabarti et al. (19) found that the objective burden on caregivers of hospitalized patients and outpatients with bipolar disorder was significantly higher than for those with unipolar depression. They looked at burden of care in 90 patients and caregivers recruited in India. The sample included 17 unipolar patients, the remaining 73 having bipolar disorder. This study has problems with limited generalizability as it used locally developed instruments and there are considerable socio-cultural differences in family structure and cultural norms compared with a Western context. Nevertheless they found that the objective burden on caregivers of bipolar patients was significantly higher than for those caring for major depressive disorder patients, although the statistical presentation of the data is unclear. They suggest that this finding may have been caused by the social disruption of the manic phase in bipolar patients,

although this inference is not directly supported by data. A number of smaller studies appear to support this finding in other settings, examining burden of care in siblings of individuals with severe mental illness, the perceptions of relatives and professionals of family burden in schizophrenia, and a comparison of caregiver burden in Black, Hispanic and White families (35, 36). All of these studies suggest that the order of caregiver burden experienced is considerable (7, 34–36). Finally, two small qualitative studies have explored the perceptions of family members on professional interventions for relatives with bipolar disorder or schizophrenia (37) and coping patterns among caregivers of patients with bipolar disorder (37).

We are also aware of one study that has attempted to explore the perceptions of family members of bipolar individuals using qualitative methods (36). However, this study is limited by a small sample size, a mixture of bipolar disorder and schizophrenia, and its specific focus on families' evaluations of professional interventions and support. None of these studies were carried out in the UK.

Fadden et al. (22) went on to research the effects of affective disorder on a small number of spouse caregivers. They recruited 24 patients who suffered from 'persistent depression,' including eight bipolars, eight unipolars, and eight 'neurotic' depressed patients from the London area in the UK. They used their own interview schedule (based on the SBAS and the Camberwell Family Interview), developed because they found no measures available to meet their specific aims. It was found that spouses raised issues of a practical nature (e.g. giving up work, loss of income and less social activity), difficulties coping with 'problem behaviour' (e.g. certain symptoms, such as social withdrawal and complaints), and psychological strains and adjustments they had to make (e.g. a sense of loss or grief and a change in the relationship balance). Spouses were also asked about the nature and cause of the patient's condition and how satisfied they felt about their contact with mental health services. They did not feel that they had been adequately provided with information and support by the services that were offered to the patient. The focus by Fadden et al. (22) on the depressive symptoms of the subjects does not take into account the manic symptoms of bipolar patients and the impact that these may have on the patient and their spouse. They also appear to view bipolar patients as consistently episodic in nature, with patients being well between episodes. However, the reality is that bipolar patients are frequently affected by inter-episode incomplete recovery and the persistence of chronic subsyndro-

mal symptoms, which may have a major impact on quality of life and relationships.

Expressed emotion and family interventions in bipolar disorder

Caregiver burden and expressed emotion (EE) are two different constructs that may be related. Four independent studies from three countries describe high levels of critical, hostile, or emotionally overinvolved attitudes (high EE) in parents or partners of bipolar patients (38–41). Subsequently, six large controlled studies of family-based psychoeducation or interpersonal therapy (42) that entered 395 experimental and 135 control patients suggest that family-orientated interventions are likely to be an effective approach in bipolar disorder. While agreeing with Miklowitz (43) that target areas for intervention such as EE should be a priority for psychosocial research, caregiver burden is probably a better and more inclusive starting point and may be easier to measure and a better outcome variable than EE itself.

Assessment instruments for family or caregiver burden

Several standardized measures exist to assess the care burden of patients with depressive disorders [Family Burden Questionnaire (22), Family Distress Scale for Depression (44)] and schizophrenia [Family Distress Scale (45), Significant Other Scale (46)]. In our opinion these instruments do not capture the specific difficulties associated with the cyclical nature of bipolar disorders and, in particular, the stresses arising from manic and hypomanic episodes.

In reviewing the 21 available instruments, Schene et al. (47) highlighted the common absence of a detailed analysis of their psychometric properties. Furthermore, only two instruments were developed in consultation with caregivers and/or patients, an issue we would consider to be absolutely vital (see Lewis, pp. 33–37, this issue). Most instruments for assessing the burden of bipolar disorder sample over relatively short time frames (e.g. the last 4 weeks prior to assessment), may not reflect the long-term aspects of caregiving.

The importance of inter-episode symptoms

Two studies have shown the importance of inter-episode symptoms on psychosocial functioning and their potential as a source of burden in bipolar disorder (48, 49). Patients who had no relapses in 2 years had severe and widespread impairment in

function, largely attributed to inter-episode subsyndromal depressive symptoms (48), which predominate during the course of illness (50, 51).

Even when relapse occurred, cumulative affective morbidity (inter-episode symptoms and relapse) predicted psychosocial function over 4 years better than the number of relapses in bipolar patients receiving aggressive maintenance medication (49).

Conclusions

Despite the importance of assessing caregiver burden in bipolar disorder, there is a dearth of relevant literature, a failure to explore the specific effects of mania and inter-episode symptoms, and a lack of existing measures designed to assess burden adequately. A result of this situation is uncertainty regarding how best to structure family interventions in order to optimally alleviate burden. The relatively few studies into caregiver burden in bipolar disorder reflect experiences in a very specific healthcare system: the US Veterans Affairs health service. Findings from studies such as these may be limited in their generalizability. Nevertheless, available data suggest that caregiver burden is high and largely neglected in bipolar disorder.

In common with many other estimates of psychiatric morbidity, the caregiver-burden assessment scales that exist do not appear to pay enough attention to the views of caregivers themselves. Informal caregivers are central to the well-being of patients, yet researchers, policy makers, and formal service providers often take for granted their co-operation and welfare. Given this view, we consider it important that a quantitative instrument for the assessment of caregiver burden obtains information on issues that caregivers themselves consider important.

Although we cannot speak from personal experience on the situation in countries other than the UK, we are convinced that current services for patients with bipolar disorder are generally inadequate (52). In practice, it seems that attention is focused very much upon acute treatment of the affected individual, with remarkably few resources directed towards caregivers despite the conventional recommendations to do so. However, services cannot be enhanced on a rational basis without an improved understanding and capacity to measure and target caregiver burden, nor can the impact of any change in services be evaluated. There is a need for a formal instrument with practical utility, informed by the experiences of existing caregivers and with defined psychometric properties, specifically designed to capture the nature and extent of burden in caregivers of bipolar patients. We must

not continue to merely pay lip service to the sometimes extreme stresses imposed by caring for a person with bipolar disorder, be they a family member or close friend. We wish to stem the breakdown of close, caring relationships, along with all the interpersonal and social destruction that arises from the ravages of bipolar disorder. To be able to focus our psychosocial efforts to this end, we need to develop clinically effective, well-targeted and practically viable interventions.

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