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The affective disorder-related burden imposed on the family environment: an overview

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Summary

The family burden (FB) has been defined as a multidimensional impact imposed by an illness on caregivers. FB can be divided into objective (i.e. related to measurable problems) and subjective one (i.e. related to caregivers' emotions arising in response to objective difficulties). FB is known to be related to disturbances in the functioning of the family system, higher level of stress, and the presence of financial problems. Some gender-dependent differences in the characteristics of FB have been found. As since a family member's illness can be not only a ballast, but also a potential source of satisfaction, it has been found that the level of caregiving-related satisfaction is a significant predictor of FB severity. FB dynamics does not seem to be parallel to the course of illness. Problem-focused and task-focused coping strategies are known to be related to lower values of FB.

There is evidence suggesting that in families of patients with BD depressive episodes trigger substantially higher severity of FB, as compared to manic episodes. Data on FB related to major depressive disorder (MDD) are scarce.

Assertive community treatment strategies are the main option of reducing FB in the context of affective disorders, yet data on their effectiveness are inconclusive.

Key words: bipolar disorder, major depressive disorder, family burden

Introduction

The landmark changes in psychiatric practice that have been taking place since 1960s (i.e. deinstitutionalization, dehospitalization, progress in assertive community treatment, and advances in psychopharmacotherapy) have led to some unobvious consequences. While patients had had better prospects of living more active and independent lives, some specific problems within their familial relationships have begun to emerge [1, 2]. The impact of an individual's mental disorder exerted on other members of his or her familial system is known as family burden (FB) [3].

In an attempt to define FB, Awad and Voruganti [4] have emphasized that: “ ‘Burden of care’ is a complex construct that challenges simple definition, and is frequently criticized for being broad and generally negative. Frequently, burden of care is more defined by its impacts and consequences on caregivers. In addition to the emotional, psychological, physical and economic impact, the concept of ‘burden of care’ involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame.”

The aim of this paper is to discuss both theoretical and therapeutic aspects of burden of bipolar disorder (BD) or major depressive disorder (MDD) on patients’ caregivers.

The development of the notion of family burden

While the term of FB had initially been used in a research paper by Yarrow et al. [5], the first attempt to grasp the nature of the impact exerted by patients’ mental disorders on their families was made nearly a decade later by Grad and Sainsbury [3]. The latter authors observed that members of patients’ families had experienced heavy sense of responsibility for their relatives, as well as higher levels of emotional and economic load. They also found that the two kinds of events: re-hospitalizations and physicians’ home visits had negatively correlated with the burden perceived by caregivers.

According to Hoenig and Hamilton [6] FB can be divided into objective and subjective one. While the notion of the objective FB relates to measurable problems (e.g. patients’ troublesome behaviours), the idea of subjective FB is bound to caregivers’ emotions arising in response to the objective difficulties.

In subsequent years more attention had been paid to emotions experienced by patients’ caregivers [7], the problem of burden was also analysed in the context of stress-coping strategies [8]. In 1980s some researchers pointed out at the need of supporting and educating members of patients’ families. Accordingly, Pai and Kapur [9] found that FB is related to disturbances in the functioning of the family system, higher level of stress, and the presence of financial problems. Thompson and Doll [10] noticed that FB implies such negative reactions on the caregivers’ side as emotional overload, embarrassment, and resentment. Potasznik and Nelson [11] observed that a vast majority of caregivers had expressed concerns over patients’ future, as well as sense of help- and hopelessness. Other authors [12-14] were examining the impact of psychoeducation and family care on the level of anxiety, severity of intra-familial conflicts, and level of FB.

The relationship between caregivers’ gender and severity of FB has also been analysed. In course of a trial on this field, Noh and Avinson [15] found some gender-dependent differences in the characteristics of caregivers’ burden. While they did not confirm any significant inter-gender disparities in terms of the overall burden severity, the level of burden among male caregivers was positively correlated both with severity of symptoms exhibited by their partners, as well as stressful events. On the other hand, the burden severity among females was positively correlated with their age, subjective coping abilities, and a feature of living together with children.

The prominent themes of the studies performed in 1990s were both the issue of burden-related coping strategies, and the importance of social support and education of members of patients' families.

Thus, Kane et al. [16] observed that subjects receiving psychoeducation (as compared to participation in self-help meetings) had been more satisfied with this form of management, as well as with the knowledge gained. They had also been less depressed. In another study psychoeducation had seemed to strengthen caregivers' trust in their abilities to influence the course of their families members' illnesses, ultimately alleviating the burden [17]. Halford and Hayes [18] demonstrated that providing patients with social skills training and delivering psychoeducation to members of their families improve the quality of relationships between them, decreasing the burden severity and diminishing the risk of relapse. However, Orhagen and D'Elia [19] did not find any dependency between positive outcomes of caregivers' psychoeducation (e.g. enrichment of knowledge about the illness, increase in criticism, and decrease in emotional overinvolvement) and reduction of FB.

Notably, some researchers considered a family member's illness not only as ballast, but also a potential source of satisfaction. Accordingly, Lawton et al. [20] demonstrated that the level of caregiving-related satisfaction is a significant predictor of FB severity. Farran et al. [21] noticed that subjects who had been more capable of making sense of their role as caregivers were less prone to developing depressive symptoms.

In the 21st century, the main research areas on the field of mental disorder-related FB involve the general quality of family functioning, support strategies both for the affected individuals and their families, as well as ways and resources of coping with the burden [22].

The relationship between coping with a relative's illness and the burden

Family member's illness is a source of significant stress for his or her close relatives. Both objective and subjective troubles (on one hand: an illness' impact towards other family members' health, potential of fulfilling their needs, and family's economic outcomes; on the other: a sense of anxiety or burn-out due to over-involvement in caregiving) contribute to mental disorder-related stress and FB [23].

Minuchin [24, 25] has claimed that a family's capability of adapting to a difficult situation of the presence of its member's psychiatric disorder depends both on particular individuals' resources, as well as the pace of the development of psychopathological symptoms'. Accordingly, a mild and slowly developing disorder would offer more space for family's adaptation, while rapid progress or sudden relapses of an illness may trigger destabilization or even break-up of a family. Recently, however, this idea has been challenged, as research suggests that illness dynamics is not the main determinant of FB. Chadda et al. [26] have found that burden experienced by caregivers of patients with BD does not decrease significantly over time, even though the severity of the illness wanes.

Contemporarily, less research attention is paid to the stressful situation itself, while the issue of coping with stressors goes to the forefront [22].

The phenomenon of coping is seen in the perspective of the following three complementary dimensions: process, strategy, and style [27]. It seems that a preferred copying strategy exerts a major impact on the magnitude of mental disorder-related FB. Available evidence suggest that problem-focused coping strategies and low level of criticism (implying low level of expressed emotions) are related to lower values of FB [28, 29]. Östman and Hansson [30] observed that the preference for task-focused coping strategies in families of patients with BD was related to lower levels of FB and lower rates of chronicity, while emotion-focused coping strategies are bound to persistence of symptoms or lack of changes in patients' behaviors. In a study regarding families of subjects with MDD or schizophrenia Möller-Leimkühler [29] found that avoidance coping strategy is strongly correlated with both high level of EE and FB. In an earlier study Wendel et al. [31] had also noticed a positive correlation between the values of EE and FB.

By applying Hoening and Hamilton's [6] classification of burden into objective and subjective subtypes, Thompson and Doll [10] came to conclusion that while in about 50% of psychiatric patients' caregivers heavy subjective burden had been accompanied by corresponding scale of objective burden, 70% of families members who had been denying objective burden had been experiencing severe subjective burden. Although 2/3 of the patients participating in the study enjoyed stable clinical status, their caregivers suffered from emotional overload.

Burden of spouses of patients with bipolar disorder or major depressive disorder

While discussing the issue of affective disorders on the basis of systemic paradigm, it is vital to analyse phenomena occurring in the spousal subsystem. As spouses are the primary caregivers of patients with affective disorders, they seem to be the ones who suffer from FB of particular severity. With regard to this population, Perlick et al. [32] observed that the level of burden experienced by members of procreative families is significantly higher compared to subjects from generative families.

Of note, while Cuijpers [33] had found that FB in the families of patients with affective disorders is lower as compared to familial systems of subjects with other psychiatric disorders, Hadryś et al. [34] argued that the level of FB is unspecific towards diagnostic categories. According to the latter authors the FB severity in cases of affective disorders is comparable to the values observed in families of patients with schizophrenia or severe medical illnesses. Similarly, both the prospective study by Chadda et al. [26] and the research performed by Nehra et al. [35] have found that the FB severity observed in families of patients with schizophrenia is no different from the one seen among relatives of BD sufferers. However, Grover et al. [36] have noticed that while both caregivers of patients with schizophrenia or BD had been aware of simultaneously negative and positive aspects of taking care of their loved ones, the FB level had been higher among the relatives of subjects with schizophrenia. It seems that the severity of burden in families of subjects with psychiatric disorders depends rather on the existence of difficulties in the relationships with patients and lack of support

[37], overall level of patients' functioning [38], and the higher frequency of relapses [39], than on the specific diagnosis.

There are data suggesting that worse psychosocial functioning of patients with BD implies higher degree of FB [40]. In this clinical population depressive episodes trigger substantially higher severity of FB, as compared to manic episodes [40, 41]. Reinares et al. [42] found that the main determinants of significant level of FB in cases of BD were: an occurrence of depression during the previous two years, and a diagnosis of rapid cycling. Notably, none of the following: duration of illness, total number of mood disorder episodes (including episodes with psychotic features), and history of suicidal attempts were significantly related to the severity of FB. According to the authors cited, high level of FB are sustained also during remission, as this form of burden seems to be driven by fear of illness recurrences, social withdrawal, and patients' social impairment. Nevertheless, it is hard to formulate any firm conclusions on the differences in FB severity between periods of remissions and relapses, as most of the researchers on this issue have focused on the acute mood episodes.

In course of a study regarding caregivers of BD patients, Bauer et al. [43] demonstrated that the main source of burden experienced by women was deterioration of the quality of relationships with their partners. By comparison, men suffered mainly because of lack of autonomy, **uncertainty concerning their judgment of patients' capacity**, and uncertainty because of the changing symptoms of illness.

Van der Voort et al. [44] analyzed the problem of 'being alone together' – an important source of distress among partners of patients with BD. The main origin of FB in this context was the experience of loneliness in everyday activities, with further consequences of the sense of 'abandonment' for caregivers' lives. The researchers found that the characteristic outcome of caregivers' coping strategies had been the tendency to consider the patients' needs to be of major importance, while not fully abandoning the goal of fulfilling their own requirements. Some of the spouses had kept on searching for a balance between self-fulfillment and the requirements of providing care to their partners, and the others had given those attempts up. In the latter cases, either the caregivers submitted their lives to the partners' illness or they decided to break the relationships up. The authors cited also emphasized the role of external support, e.g. the access to somebody who would be keen on hearing about caregiver's problems and on providing help in assessing current situation of a family. Of note, the intensity of the acts of support seems to be more important than their length.

Assessing burden's presence and severity

Several diagnostic tools have been used in assessment of presence and severity of burden related to providing care for a challenged family member. Ciałkowska-Kuźmińska and Kiejna [45] described the following five questionnaires that can be utilized in assessing both subjective and objective burden.

1. Perceived Family Burden Scale (PFBS) [46] was developed and validated for measuring FB related to abnormal behaviors of patients with schizophrenia. It has been found to be characterized by greater predicting power for early symptomatic

- relapse in the illness, as compared to the tools designed to measure the level of expressed emotions.
2. Zarit Caregiver Burden Scale (ZCBS) [47] is an 22-item tool, encompassing questions related to caregiver's health condition, psychological well-being, finances, and social life. It is characterized by excellent psychometric properties (interclass correlation coefficient = 0.71; alpha = 0.91) [48]. In both PFBS and ZCBS consecutive items are rated on a scale 0–4, proportionally to the severity of the given problem.
 3. Experience of Caregiving Inventory (ECI) [49] is a vast, 66-item tool covering both negative and positive aspects of providing care.
 4. Family Problems Questionnaire (FPQ) [50] is an inventory enabling assessment of both perceived severity of burden, and level of support received from other family members, healthcare, and social services.
 5. Involvement Evaluation Questionnaire (IEQ) [51, 52] consists of 31 items regarding various aspects of caregiver's involvement. 27 out of those items have been classified into four subscales: interpersonal tension (9 items), supervision (6 items), worrying (6 items), and urging for activity (8 items). The overall result is computed on the basis of partial scores (as derived from consecutive subscales) and the sum of points gained in each of the 27 items. Partial scores are interpreted in dichotomous manner: the score of 0 or 1 pts. are treated as 'no consequences', while the score of ≥ 2 pts. are considered to be indicative for 'substantial consequences'.

The problem of family burden in the context of assertive community treatment

Assertive community treatment (ACT) strategies have become the mainstay of psychiatric healthcare [53]. One of the key presumptions of ACT is providing support and education to patients' relatives, with consideration of their needs (as indicated by van der Voort et al. [37]). ACT has been shown to improve functioning and independence of subjects with chronic psychiatric disorders [54], thus substantially decreasing the level of FB.

Psychoeducation is one of the ACT interventions that can be provided to members of psychiatric patients' families. Results of the pilot study performed by Chow et al. [55] (encompassing participants of Chinese and Tamil descent) suggest that multi-family psychoeducation effectively reduces level of FB perceived by relatives of subjects with severe mental disorders. However, the effectiveness of psychoeducation in diminishing MDD-related FB is not clear. Although a randomized controlled trial (RCT) by Shimazu et al. [56] indicate that providing psychoeducation to relatives of patients with MDD (in the absence of patients themselves) over the period of nine weeks did reduce FB severity, a review by Luciano et al. [57] does not bring that optimistic result. The latter team of researchers found that insufficient amount of data precludes drawing any firm conclusions on the effectiveness of psychoeducation in this population. Nevertheless, preliminary reports are quite encouraging.

As far as BD is concerned, an RCT by Madigan et al. [58] suggest that caregivers who had joined group psychoeducation or group problem-solving therapy enjoyed

greater reduction in FB, as compared to patients' relatives who had been receiving treatment as usual. Reinares et al. [42, 59] have also noted that psychoeducation effectively decreases severity of FB in relatives of BD patients during remission. Psychosocial and family interventions seem to be the key elements of BD treatment, especially in view of progressive, debilitating nature of the disorder [60].

Discussion

Over the past decades an increasing attention has been paid to the issue of mental disorder-related FB, and the research field has been gradually broadening from the impact of patient's symptoms on the functioning of his or her family, to the issue of emotions, needs and difficulties encountered by caregivers. Contemporarily, patients' relatives are increasingly seen as active participants of the process of treatment rather than passive witnesses. This has been a 'positive side effect' of the trend towards shifting the psychiatric and psychotherapeutic care from institutions to patients' communities.

Spouses of patients with affective disorders are the ones who are the most strongly engaged in solving their partners' problems. Thus, they seem to be carrying the heaviest burden. It has been shown that implementing a proper model of care over patient and his or her family (including family psychoeducation, group therapy, and other available forms of support) can substantially reduce the level of FB.

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