Stress and Support for Parents of Youth with Bipolar Disorder

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ABSTRACT

Background: This article reviews stress related to parenting a youth with bipolar disorder (BD), maladaptive coping, immunologic and physical functioning related to chronic stress; presents preliminary findings about the association between immune parameters and health conditions, mental health indices and interpersonal functioning in parents of children with mood disorders; and provides recommendations for stress management based on clinical trials of family-based psychoeducational psychotherapy (PEP).

Data: Interleukin-6 (IL-6), tumor necrosis factor-alpha (TNF-α), C-reactive protein (CRP), Epstein Barr Virus (EBV), nutritional markers and measures of physical health, mental health and interpersonal functioning were collected from 26 parents of mood disordered children. Higher CRP was associated with more perceived stress, more depression, increased incidence of illness/physical conditions, and lower albumin levels. Elevated IL-6 was associated with higher nicotine use.

Limitations: Sample size and demographics were restricted, limiting generalizability.

Conclusion: Pilot data are consistent with literature from adult caregivers, and suggest caregivers who are more stressed also evidence some signs of immune abnormality. Evidence-based strategies to support parents are discussed.

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INTRODUCTION

Raising a child with bipolar disorder (BD) is a daunting task. In addition to the struggles one can experience simply obtaining an appropriate diagnosis, developing a functional treatment plan, and dealing with the myriad of difficult symptoms at home and at school, stigma and blame can further challenge parents, who often battle mood disorders themselves, or in their immediate family members (1).

In this article, we review the literature on parenting stress related to raising a child with BD. Next, we focus on stress associated with parental BD, as children with BD often have parents with a mood disorder, adding to the parenting challenge. Then, we discuss maladaptive coping related to chronic stress. Subsequently, we provide findings from a pilot study that assessed immunologic functioning in caregivers of children with mood disorder. Finally, we suggest strategies to support parents in managing the stress associated with parenting a child with BD based on clinical trials of family-based psychoeducational psychotherapy (PEP).

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tion levels, may not be sufficient to relieve the parental burden associated with caring for a child with BD. Hellander and colleagues (5) surveyed 732 caregivers of children with BD via the Child and Adolescent Bipolar Foundation (CABF) website. Most respondents were female (97%), White (97%), married (75%), and financially middle-class or above (two-thirds of respondents reported income over $50,000). Many were professionals including doctors, teachers and social workers. Presumably, this sample had greater access to adequate professional care for their children with BD than the overall population of parents raising children with BD. Despite this, significant levels of stress were reported. The three most stressful aspects of caregiving were: “walking on the eggshells around child to avoid rages”; “trying to get child to do chores or self-care”; and “having less time to take care of self.” The authors speculated that caregivers from non-affluent and less educated families would likely experience even more stress. This stress can be caused by many aspects of raising a child with BD, one common and particularly difficult phenomenon being blame for the child’s symptoms.

Historically parents of children with mood disorders have been blamed rather than supported in their parenting (4). Caregivers report condemnation and social isolation from family gatherings, church and community events, and extended social networks due to their child’s difficult behavior and stigma associated with mental disorder (3, 5). Blame often includes the presumed etiology for their child’s mental illness and associated behavioral problems (6). Caregivers focus attention and devote time to caregiving, leading to neglect of self and others in the family (5). Often parents develop anxiety and depressive symptomatology associated with chronic stressors comparable to those described for caregivers of dementia (6).

Attempting to obtain appropriate services or accommodations can also be a challenging experience. Barriers to receiving adequate care include: professionals not believing parental report of behavior; professionals insinuating that poor parenting strategies have caused the child’s symptoms; and professionals who lack training and knowledge that results in inappropriate questioning, erroneous diagnosis, and unsuitable treatment (1). In addition to not being helpful in the moment, encounters such as this can prevent families from seeking professional assistance later in the course of the child’s development if they have learned through experience that interventions cost them time, money and hope without the benefit of symptomatic relief.

Bidirectional causes of stress are common in families of children with BD. In addition to the stress of raising a child with BD, parents often have a mood disorder themselves, further complicating family life.

PARENTS WITH A MOOD DISORDER

Genetic risk. Mood disorders are highly heritable. Having a first degree relative with BD increases the risk of this illness 10-fold (7). Individuals with BD have an increased likelihood of marrying a person with a mood disorder, a phenomenon referred to as “assortative mating” (7), which places the children of such couplings at an even higher risk for developing a mood disorder. A child who has one parent with a mood disorder has a 27% lifetime risk of a mood disorder whereas a child who has two parents with a mood disorder carries a 74% lifetime risk (7). Thus, children with BD not infrequently have parents with a mood disorder.

Psychosocial risk. In addition to the genetic risk, parental mood disorders may expose children to mal-adaptive child rearing practices, which can contribute to an earlier onset of disorder for the child and/or make recovery from an episode more prolonged (7-9). Even if parents of children with BD do not have a mood disorder themselves, they often have experienced the effects of BD within their family of origin. Having grown up with a parent or sibling who has BD colors what adults bring to their parenting.

Several predictors of poorer outcome for adults with BD are also factors that increase familial stress. These include less social support and lower social adjustment (10), familial negative expressed emotion and negative interaction (11), impaired social and leisure activities, poor quality of relationship with extended family (12), more stressful life events (13), and poorer marital adjustment (14). Targum and colleagues (15) found that the social problems that resulted from BD included marital problems, unemployment, financial difficulties, social withdrawal due to depression, and relapse leading to re-hospitalization.

Impact on parenting. Children benefit by consistency in parenting behavior. When parents have BD, consistency in parenting practices may be challenging. Parenting behavior may be influenced by the parent’s depression, mania/hypomania, or mixed state, chronicity of episodes, suicidality/suicide attempts, risky behavior associated with mania, difficulty with treatment adherence, withdrawn/irritable behavior during
depressed mood, relapse in spite of treatment adherence, and recovery time between episodes. In sum, parents with a mood disorder experience life stressors due to their own diagnosis. Raising a child with BD amidst these stressors can be challenging.

PSYCHOLOGICAL AND PHYSICAL CONSEQUENCES OF CAREGIVING

Clearly, parents of children with BD experience ongoing stress. Prior research indicates that caregiving has long-term impact on psychological well-being even after caregiving ceases. For example, in a study conducted by Robinson-Whelen and colleagues (16), even though perceived stress and negative affect decreased in former caregivers of a relative with a progressive dementing illness, scores on measures of psychological well-being (depression, positive affect and loneliness) did not return to non-caregiver levels within three years after caregiving demands ceased. The stress of caregiving for children with mental health problems, due to the physical and emotional challenges involved in early years of caregiving, lack of service coordination among service providers, and inadequate time and energy for self care, might similarly negatively influence caregivers’ psychological well being and physical health in later years (17, 18).

Numerous studies have linked chronic psychological stress and adverse health outcomes (19-22). For example, chronic psychological stress has been associated with increased risk for developing mild hypertension (19), hastening the progression of coronary artery disease (20), aggravating the course of rheumatoid arthritis (21), and increasing susceptibility to colds (22). Research further indicates that individuals with chronic stress are more likely to abuse substances, including alcohol, nicotine and caffeine, as a method of coping (23, 24). They are also likely to eat “comfort foods” instead of nutritionally healthy foods (25) and may have sleep-related problems such as difficulty falling asleep, awakening in the middle of the night or waking in the early morning (26). Moreover, individuals with chronic stress may lack the time to devote to physical exercise and other healthy habits due to caregiving demands (27). This combination of stress and maladaptive coping can also negatively influence physical health in later years (16).

Chronic stress and poor health behaviors have also been linked to adverse immune and neuroendocrine consequences. Studies have shown that chronic stress and depression can provoke immune dysregulation, including elevations in inflammatory markers (interleukin-6 [IL-6], tumor necrosis factor - alpha [TNF-α], C-reactive protein [CRP] and Epstein Barr Virus [EBV]) (26-30). Elevations of proinflammatory cytokines (IL-6 and TNF -α), CRP and EBV have serious health consequences, including increased morbidity and mortality (28-30). Studies of the effects of poor health behaviors have found that alcohol abuse is associated with decreased natural killer cell activity and/or daytime increase of IL-6 (31); cigarette smoking is associated with elevated levels of cortisol (32); caffeine is associated with increase in plasma ephinephrine and cortisol (24); and depressive mood in individuals with obesity is associated with elevated levels of CRP (33). Individuals who experience partial night sleep deprivation are prone to over-secrete IL-6 during the daytime and under-secrete IL-6 during nighttime (34). This is a problem, as good quality night sleep is associated with decreased secretion of daytime IL-6 levels (35). Sleep deprivation elevates daytime IL-6 levels, resulting in drowsiness and fatigue during the next day (35). Not surprisingly, physical activity and exercise are associated with improved immune functioning, with regular exercise producing anti-inflammatory effects (36).

IMMUNE FUNCTIONING IN PARENTS OF CHILDREN WITH MOOD DISORDER

Immune dysregulation associated with caregiving stress has been studied in older adults (37, 38), but no studies have assessed IL-6, TNF-α, CRP and EBV in parents of children with mood disorders. To document the relationship between stress and immune functioning in caregivers of children with mood disorder, IL-6, TNF-α, CRP, EBV and health conditions, mental health indices and interpersonal functioning were measured in 26 caregivers of children participating in a family-based psychosocial intervention for children with mood disorders.

PILOT STUDY

Participants. Twenty-six caregivers (M = 41.0 years, SD = 6.2) from the Multi-Family Psychoeducational Psychotherapy (MF-PEP) treatment study participated in this study after providing informed consent. Both this research study and the MF-PEP parent study, results of which have been published elsewhere (39, 40), were approved by the university medical center Institutional Review Board. Participants were primarily female
who used nicotine had higher levels of IL-6 than those perceived stress and depression (38, 49, 50). Parents of youth with mood disorders who are more stressed are also showing some signs of immune inflammation (51). In short, preliminary results suggest an effect in older individuals without cytokine-mediated inflammation (51). In short, preliminary results suggest that parents of children with mood disorders who are more stressed are also showing some signs of immune abnormality.

### Measures

Levels of IL-6, TNF-α, CRP, EBV, and nutritional markers (total iron binding protein, plasma transferrin and albumin) were assessed. Information regarding physical health (health-related behavior questions [26], physical activity (frequency of exercise [41]; general health (questions from the Older Adults Resources Survey [42]); sleep (Pittsburgh Sleep Quality Index [43], parenting stress (Parent Stress Survey Sisson [44])); depression (Center for Epidemiological Studies Depression Scale [45], anxiety (Beck Anxiety Inventory [46]), stress (Perceived Stress Scale [47]); interpersonal functioning (social functioning subscale, Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire [42]); and parent-child relations (Expressed Emotion Adjective Checklist [48]) were also collected.

### Data Analysis

Q-Q Plots were used to verify normality of the distribution for IL-6, TNF-α, and CRP. Distributions for IL-6 and CRP were normal; however, the distribution for TNF-α was not. TNF-α values were transformed by taking the reciprocal of the data, Q-Q plots were used to verify normality of the distribution of transformed data. To explore the relationship between immune parameters, nutritional markers, physical health conditions, health-related behaviors, mental health indices, and interpersonal functioning, Pearson Product Moment correlations were calculated. As this was an exploratory study, analyses were not corrected for the 68 multiple comparisons made; therefore, some significant findings could be expected by chance.

### Results and Discussion

Higher CRP levels were associated with lower levels of albumin, more illnesses/physical conditions, higher perceived stress and higher reported depression levels (Table 1). Higher usage of nicotine was associated with higher levels of IL-6. No significant relationships between TNF-α, EBV and other variables were detected.

Findings indicated that parents with higher CRP levels had increased illnesses/physical conditions, consistent with past research indicating that elevations of proinflammatory cytokines have significant health consequences (29, 30). Also consistent with past research, higher CRP levels were associated with higher perceived stress and depression (38, 49, 50). Parents who used nicotine had higher levels of IL-6 than those who did not. Parents with higher CRP levels had lower albumin levels. Higher serum albumin has a protective effect in older individuals without cytokine-mediated inflammation (51). In short, preliminary results suggest that parents of children with mood disorders who are more stressed are also showing some signs of immune abnormality. As these parents continue to age while caring for their children, it will be important to provide psychological interventions that target caregiving stress.

### Limitations

This pilot study was limited by the small and homogenous sample, thereby limiting the generalizability of results to other groups.

### Conclusions

Parents of youth with BP may experience chronic stress due to the demands of caregiving and stigma associated with the disorder (52). Due to the genetic aspect of BD, parents themselves may have

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**Table 1. Pearson Product Moment Correlations between IL-6, TNF-α, CRP, EBV and Physical Health Behaviors and Indices, Mental Health Indices, and Measures of Interpersonal Functioning**

<table>
<thead>
<tr>
<th>Variables</th>
<th>IL-6</th>
<th>TNF-α</th>
<th>CRP</th>
<th>EBV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Health Behaviors and Indices</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td>-0.14</td>
<td>0.33</td>
<td>-0.1</td>
<td>-0.17</td>
</tr>
<tr>
<td>Caffeine</td>
<td>0.34*</td>
<td>-0.32</td>
<td>0.16</td>
<td>0.28</td>
</tr>
<tr>
<td>Nicotine</td>
<td>0.67**</td>
<td>-0.11</td>
<td>-0.06</td>
<td>-0.12</td>
</tr>
<tr>
<td>Physical activity</td>
<td>0.03</td>
<td>0.18</td>
<td>-0.15</td>
<td>-0.06</td>
</tr>
<tr>
<td>Weight changes</td>
<td>-0.14</td>
<td>0.28</td>
<td>-0.03</td>
<td>-0.01</td>
</tr>
<tr>
<td>Medications</td>
<td>-0.18</td>
<td>0.22</td>
<td>-0.11</td>
<td>-0.12</td>
</tr>
<tr>
<td>Illnesses</td>
<td>0.21</td>
<td>-0.27</td>
<td>0.58***</td>
<td>0.004</td>
</tr>
<tr>
<td>PSQI</td>
<td>0.13</td>
<td>0.16</td>
<td>0.1</td>
<td>-0.15</td>
</tr>
</tbody>
</table>

| **Nutritional Measures** | | | | |
| Albumin   | 0.21 | -0.27 | -0.54*** | -0.23 |
| Transferrin | 0.02 | 0.25 | 0.14 | 0.16 |
| TIB       | 0.01 | 0.25 | 0.14 | 0.16 |

| **Mental Health Indices** | | | | |
| BAI       | -0.09 | -0.24 | -0.10 | -0.70 |
| CES-D     | -0.21 | 0.23 | 0.50***| 0.05 |
| PrSS      | -0.24 | -0.009 | 0.37 | 0.08 |
| PSS       | -0.21 | 0.17 | 0.58***| 0.22 |

| **Interpersonal Functioning** | | | | |
| EEAC      | 0.05 | -0.09 | -0.19 | -0.02 |
| OARS      | -0.22 | 0.27 | -0.24 | -0.07 |

Note: IL-6 = Interleukin-6; TNF-α = tumor necrosis-alpha; CRP = C-reactive protein; EBV = Epstein Barr Virus; PSQI = Pittsburgh Sleep Quality Index; TIB = Total Iron Binding; BAI = Beck Anxiety Inventory; CES-D = Center for Epidemiological Studies Depression Scale; PrSS = Parent Stress Survey; PSS = Perceived Stress Scale; EEAC =Expressed Emotion Adjective Checklist; OARS = Social support functioning from the Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire.

*i* = 19 and for all remaining variables N = 26; *p = 0.09; **p = 0.000; ***p < 0.009
a mood disorder, which can further exacerbate the situation. Instead of receiving support and understanding from friends and/or family, community, social network, and church groups, parents may experience isolation, guilt and blame due to child’s difficult behavior. Chronic stress has been associated with decreased utilization of healthy habits, immune dysregulation and poor physical health outcomes. Long-term caregiving has clearly documented consequences on emotional and physical health, including immunologic functioning. Our pilot data suggest that parents of children with mood disorders who are more stressed also show some signs of immune abnormality. Thus, interventions supportive of parents may be particularly important, both for parents’ mental and physical well-being. Psychoeducational interventions are designed to provide social support, enhance coping, encourage healthy behaviors (e.g., regarding sleep hygiene, less nicotine/smoking usage, diet and exercise) and improve family climate; they may positively impact these immune parameters in caregivers of children with mood disorders. Below we discuss components of family-based psychoeducational psychotherapy, which can support parents as they care for children with BD.

CLINICAL IMPLICATIONS

UTILIZING PSYCHOEDUCATIONAL PSYCHOTHERAPY (PEP)
Parents are ultimately responsible for the care of their child with BD; thus, it is imperative that mental health providers make available interventions that provide the information, support and skill building so that parents can dismiss guilt and move forward productively with their child to more effectively manage symptoms. This includes learning about various mood diagnoses, monitoring mood states, recognizing prodromal symptoms and patterns, developing strategies to enhance treatment adherence, understanding medication — how to monitor its effectiveness and manage side effects, safety planning for risky behaviors, building school and mental health treatment teams, and learning to differentiate the child from the disorder (2). This psychoeducational approach has been demonstrated in three randomized controlled trials to improve outcomes for children and families (39, 53, 54), in part by helping parents become better consumers of care (40).

PRE-PLANNING FOR CRISSES
Crisis pre-planning can decrease the emotional intensity that surrounds crisis points. In many families, simply having a crisis plan defined and in place can avert the frequency with which it actually needs to be implemented. Pre-planning strategies might include: 1) preemptive visits to the local police precinct to determine the most appropriate steps for calling the police, if needed to deescalate a violent situation; 2) preparing and maintaining a binder that includes: the child’s list of medications and side effects, treatment providers’ names and emergency contact information; insurance information; 3) determining the route to the most appropriate emergency department if hospitalization is being considered; 4) developing “safe places” for siblings to go to during periods of escalation at home.

IMPROVING FAMILY CLIMATE
Learning to manage symptoms of BD in a matter of fact, problem solving manner using clear, direct communication is highly beneficial in improving the emotional climate in the home. Reducing critical, hostile, and over-involved family interactions, a trio of family interaction behaviors referred to as “expressed emotion, or EE,” provides a more stable environment in which the child can recover. Asarnow and colleagues (55) have demonstrated that depressed children who return post-hospitalization to a low EE environment are less likely to relapse over the course of a year than those who return to a high EE home. High EE is associated with increased relapse rates in children and adults with BD (56, 57). Moreover, higher maternal warmth is associated with lower relapse rates post-recovery in youth with BD (58, 59). This highlights the importance of treatments that focus on family adaptability, cohesion and conflict (60). Mediators of effective family interventions may include enhancing medication adherence, family communication, problem solving and ability to recognize prodromal symptoms (61). In addition to improved symptom management, overt attention to all relationships within the family can improve family climate. This includes making time for and valuing the marital/couple relationship and addressing sibling needs.

MAINTAINING PHYSICAL HEALTH
As evidenced by the immunologic data previously presented, the importance of maintaining physical health is important. This includes engaging in health behaviors such as regular check-ups, regular exercise, healthy eating habits and sufficient sleep. In addition to promoting “healthy habits” in children, parents can, and
should, role model reliance on these SEE (Sleep, Eating, Exercise) behaviors themselves.

Improving quality of sleep can make a critical difference for family functioning. Insufficient sleep can trigger a manic episode or intensify depressive symptoms. Thus, sleep hygiene is important for all family members. When a parent’s lack of sleep is secondary to worrying about a child’s risky behavior at night while manic, use of a motion detector on the door can provide some assurance of the child’s whereabouts.

Eating habits are largely set by parents within a family. Thus, if children are to engage in eating nutritious food that does not lead to excessive weight gain (a problem for many children on weight-gaining medications), parents typically need to be involved to plan, purchase and prepare the food. Including children in this process is desirable, whenever possible.

Parents may choose to interact with their child around exercise, such as going to the park together or playing together on a video/TV interactive game console, for example, or they may use exercise as their chance either for solitude or adult interactions, perhaps going for a long run, or attending an exercise class or game of basketball with friends. Regardless, engaging in exercise both helps to promote health in the parent as well as to model healthy behavior for the child.

MAINTAINING MENTAL HEALTH

In addition to pursuing the previously described strategies, attention to parental mental health is of obvious critical importance. This can include seeking professional assistance, be it psychotherapy and/or medication management, as well as utilization of relaxation techniques such as mindfulness meditation. A growing scientific literature supports the use of stress reduction via mindfulness practice. Studies have demonstrated that regular practice of various relaxation techniques can lower blood pressure, slow breathing rate, increase blood flow to major muscles, reduce muscle tension, reduce chronic pain, improve concentration, and reduce anger and frustration (62-64). No-cost relaxation techniques such as self massage, guided imagery, yoga, progressive muscle relaxation, Tai Chi and deep breathing can be useful for stress reduction. Again, utilization of these techniques can not only be beneficial to the parent, but also provide good role modeling for the child, as some therapy manuals (e.g., MF-PEP) incorporate breathing exercises for children and their parents as part of the overall intervention.

REDUCING CAREGIVING BURDEN

Accessing formal or informal respite care can allow for parents to take a break as well as to meet other family obligations. While some formal respite is available in many communities, most families do not have as much access to this formalized assistance as would be desired. Thus, helping parents to problem-solve how to arrange for additional informal respite can be a useful step in therapy. Informal respite might be available via extended family, supportive friends, church youth groups, through a bartering arrangement (e.g., the parent might exchange gardening for a friend for that friend taking the child with BD on a weekly outing), or a paid provider such as a baby sitter. There are various ways of using respite time. Caregivers might use this time to spend quality time with their significant other, with the child’s siblings, to run errands alone, or to simply do something relaxing alone or with friends. It is vital that parents not feel guilty about this “me” time.

INCREASING SOCIAL SUPPORT

Maintaining social networks via family, friends, neighbors, religious communities and social networking all are options for parents. One specialized form of social support comes from internationally accessible Internet support networks such as The Balanced Mind Foundation (formerly known as Child and Adolescent Bipolar Foundation, CABF). The Balanced Mind Foundation has been found beneficial to parents for support and guidance as the website offers informative resources, chat rooms, message boards and email support group (5). Other advocacy and support organizations include in the United States, Depression and Bipolar Support Alliance (DBSA) and the National Alliance on Mental Illness (NAMI) and in Israel, the Israel Mental Health Association (ENOSH). These organizations work with patients and their families by offering educational programs, self-help support groups, telephone hotlines for emergencies, referrals to mental health professionals and newsletters. Moreover, through advocacy parents may feel empowered as they may be able to influence services and supports, and fight stigma associated with the disorder, in turn giving them a sense of strength and control. Finally, face-to-face and Internet support groups provide a means to make new friends while learning tips from others with similar concerns. Information on these resources may be made available to parents at their first appointment through offices of mental health professionals.
SUMMARY

Raising a youth with BD can be stressful. Our pilot data suggest that parents of children with mood disorders who are more stressed are also showing some signs of immune abnormality. Interventions may help caregivers avoid premature aging of the immune system due to chronic stress, which makes caregivers vulnerable to a range of diseases (37, 38, 50). Our previous RCTs of family-based psychoeducational psychotherapy indicate that children and parents benefit from psychoeducational interventions designed to provide information, support and stress management skill building. Reducing caregiving stress may positively impact immune parameters in caregivers of children with mood disorder. Additional study of family-based psychosocial interventions to aid the child and family in recovery from BD is recommended.

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References


