Burden and Treatment Satisfaction among Caregivers of Adolescents with Borderline Personality Disorder

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Abstract
Despite the fact that family involvement is encouraged in early interventions for Borderline Personality Disorder (BPD), there is a limited knowledge on the experience of caring for adolescents with BPD. This study is an exploratory retrospective study nested within a randomized controlled trial that compared Mentalization-based treatment (MBT) in groups to treatment as usual for adolescents with BPD. Caregivers received six MBT-Parents sessions or standard care over one year. Three months after end-of-treatment (EOT), 75 caregivers (35 in MBT, 40 in TAU) filled out the Burden Assessment Scale, and 71 (34 in MBT, 37 in TAU) the Family Satisfaction Survey. The adolescents filled out the Borderline Personality Features Scale for Children at baseline and after twelve months at EOT. We tested whether caregiver demographics, adolescents’ severity of BPD, treatment and adolescents’ drop-out from treatment predicted levels of caregiver burden and satisfaction with treatment. The caregivers reported high levels of burden on the BAS (M = 40.3, SD = 12.2). Our study suggests that higher BPD severity at EOT among the adolescents predicted caregiver burden (p = .03), whereas higher baseline BPD severity predicted satisfaction with treatment (p = .04), and that biological mothers could be more burdened than other types of caregivers but also might be more satisfied with treatment. Treatment and adolescents’ drop-out from treatment were not related to caregiver burden or satisfaction with treatment. To help inform future research and to devise appropriate interventions for caregivers and adolescents with BPD, it is important to identify possible predictors of caregiver burden. The results of this initial exploratory study indicate that caregivers (and particularly biological mothers) of adolescents with more severe levels of BPD could be particularly vulnerable towards feelings of burden and therefore are in need of support.
Introduction

Borderline Personality Disorder (BPD) usually manifests itself during childhood or adolescence when the young person most often resides with his or her caregivers. However, little is known about the experiences of caring for an adolescent with BPD. This raises concern, since studies show that caregivers of adolescents with BPD are important for the adolescents’ outcome of treatment (Whalen et al., 2014; Infurna et al., 2016), and because caring for an individual with BPD can be challenging. BPD is highly interpersonal in nature, and many BPD features have a direct impact on relationships, e.g., self-harm and suicidal behaviors, impulsivity, anger, and fear of abandonment. These features influence the way others relate to people with BPD. An emotionally and behaviorally dysregulated child might challenge caregivers and evoke dysfunctional responses that in a reciprocal manner promote further dysregulation and maladaptive behaviors in the child (Stepp et al., 2014).

Caregivers of people with BPD report significant feelings of burden (i.e., grief, impaired caregiver well-being and interpersonal strain) related to their caregiving role. Bailey and Grenyer’s (2013) review found that caregivers of adults with BPD scored approximately half a standard deviation above the mean on the Burden Assessment Scale (BAS), i.e., significantly higher than caregivers of psychiatric inpatients with mood, substance, neurotic and psychotic disorders.

Despite the abovementioned findings, we have little knowledge on which aspects contribute to these feelings of burden among caregivers of people with BPD, and to our knowledge, no studies have investigated this in samples that solely consisted of caregivers of adolescents with BPD. Specifically, it is not clear whether caregiver burden is related to caregiver characteristics, severity of BPD pathology, or dissatisfaction with treatment.

Regarding caregiver characteristics, aspects such as the relationship to the adolescent and socio-economic background could be important contributors to feelings of burden. Biological mothers are generally more involved in parental rearing and could therefore be prone to feeling particularly burdened by their caregiving role (Dotti Sani & Treas, 2016). Additionally, BPD runs in families and studies indicate that genetic effects explain 35 to 45% of the variance in BPD and BPD features (Distel et al., 2009; White et al., 2003). Biological parents may therefore experience BPD features themselves and thus be more vulnerable towards caregiver burden.

BPD is, furthermore, related to low socio-economic background (Cohen et al., 2008). This is a cause for concern since BPD also is very costly to treat. In a sample of caregivers that included adolescents and young adults (median age 22, range 12 to 55 years) with BPD in the United States,
Goodman et al. (2011) found that their mean out-of-pocket expenses per year related to the
treatment of BPD were $56,604, in addition to a mean of $108,251 in insurance costs. Not
surprisingly, they found that these financial costs were highly related to burden severity among the
caregivers (Goodman et al., 2011). In Denmark, health care is free, but a recent register-based study
found that the annual costs of adult patients with BPD in terms of direct healthcare costs and lost
productivity costs amounted to €40,441, which is sixteen times higher than matched controls
without BPD (Hastrup et al., 2019). The same study also identified that BPD is associated with
financial burden on relatives. For instance, after diagnosis of BPD, spouses of patients with BPD
have up to four times higher direct health care costs and productivity loss compared to matched
controls (Hastrup et al., 2019). Therefore, educational background and employment status are
important facets to consider, since these could relate to caregiver burden in families generally
characterized by limited resources.

The severity of BPD pathology could likewise influence caregiver burden. This is particularly
relevant to consider for caregivers of adolescents since they most often still reside with their child
and thus are directly exposed to BPD features on a daily basis. Goodman et al. (2011) found that
burden among caregivers of people with BPD was related to specific acting out behaviors in
adolescence such as property destruction. This finding is in line with previous research that shows
that disruptive behaviors strongly correlate with caregiver burden (Harvey et al., 2001).

Family treatment is encouraged in BPD treatments. Good Psychiatric Management for BPD
specifically mentions family involvement such as family psychoeducation group, “Family
Connections” multifamily group or conjoint sessions with family (Price, 2019). Likewise, family
psychoeducation and support as well as parenting skills training are mentioned as potential early
interventions for people with subthreshold features of BPD (stage 1b) or first episode of threshold
BPD (stage 2) in the Clinical Staging Model for BPD proposed by Chanen, Bourke and Thompson
(2016). A recent systematic review identified eleven intervention studies for caregivers of people
with BPD, and concluded that significant improvements were obtained on most of the outcome
measures (i.e., emotional burnout, pain, guilt, depressive-anxious symptoms and improvement of
relationship skills and the family climate) (Guillén et al., 2020). However, only two of these studies
were randomized controlled trials (RCTs) (Bateman & Fonagy, 2018; Grenyer et al., 2018), and
only one non-randomized study was specifically designed for caregivers of adolescents with BPD
pathology (Pearce et al., 2017).
Early intervention programs for BPD aim to target BPD in its early stages where BPD features still are flexible and malleable (Chanen & McCutcheon, 2013). Adolescents have significant involvement with their families. Therefore, caregivers of adolescents are prime candidates for family interventions (Gunderson, 2001). Family treatment is included in early intervention treatments such as Dialectical Behavior Therapy for Adolescents (e.g., Mehlum et al., 2014; McCauley et al., 2018) as well as Mentalization Based Therapy for Adolescents (Rossouw & Fonagy, 2012). To our knowledge, however, no RCT on early intervention for adolescents with BPD or BPD features included analyses of caregivers’ experience of burden or satisfaction with their child’s treatment or the family treatment, and therefore we do not know whether the family treatment contributed incrementally to the adolescents’ outcome of treatment nor to reductions of caregiver burden.

To summarize, caregivers of adults with BPD report significant findings of burden, but there is a paucity of research on caregivers of adolescents with BPD, who could be particularly vulnerable towards feelings of burden due to the significant involvement with the adolescent with BPD. There are so far no RCTs on family treatments for caregivers of adolescents with BPD. To devise interventions that target caregiver burden, it is important to conduct studies that help elucidate possible prognostic variables that could be associated with caregiver burden and satisfaction with treatment.

**Aims and hypotheses**

In the present study, we wanted to investigate levels of caregiver burden and satisfaction with treatment among caregivers of adolescents with BPD or BPD features who participated in an RCT that compared Mentalization-based Group Therapy (MBT-G) with treatment as usual (TAU) for Adolescents with BPD or BPD features (i.e., the M-GAB trial) (Beck et al., 2016; 2020). In the original RCT, no statistically significant differences between the two treatment arms were detected on any adolescent outcome (primary and secondary outcomes) at end of treatment (EOT) and in the follow-up period (Beck et al., 2020; Jørgensen et al., 2020). Despite the fact that caregiver treatment was included in the MBT-G arm, the RCT did not include any investigation into the effectiveness of this treatment program on caregiver outcomes. In the current exploratory study, we wanted to investigate whether caregivers of adolescents with BPD would report levels of burden comparable to previous findings on burden among caregivers of adults with BPD, and we hypothesized that the following aspects would predict burden as well as satisfaction with treatment:
1) Caregiver demographics, where we hypothesized that: a) biological parents (and especially biological mothers) would feel more caregiver burden than paid caregivers, i.e., foster parents and contact persons, and b) that low SES (i.e., lower educational background and unemployment) would be associated with more caregiver burden.

2) The adolescents’ severity of BPD pathology, where we hypothesized that: a) more severe BPD pathology at baseline and EOT would be associated with more caregiver burden, b) lower levels of change in BPD severity from baseline to EOT would be associated with more caregiver burden and less satisfaction with treatment, and c) lower levels of BPD severity at EOT would be associated with more satisfaction with treatment

3) Treatment and adolescent drop-out from treatment, where we hypothesized that: a) caregivers in the MBT arm would feel less caregiver burden and more satisfaction with treatment, and b) that adolescent drop-out from treatment would be associated with more caregiver burden and less satisfaction with treatment.

Methods

Sample and procedures

We contacted caregivers of the 111 adolescents (110 females and one male) who participated in the M-GAB trial that compared MBT-G to TAU in four child and adolescent psychiatric outpatient clinics in Region Zealand, Denmark (Beck et al., 2016; 2020). The adolescents were included in the trial if they scored above cut-off (67) on the Borderline Features Scale for Children, were aged 14-17 at the time of inclusion, and met a minimum of four DSM-5 criteria as measured by the Childhood Interview for DSM-IV Borderline Personality Disorder (Zanarini, 2003). Furthermore, caregivers of the adolescents had to give consent on behalf of their child, agree to participate in the MBT-Parents program (if randomized to the MBT-G arm), and fill out questionnaires.

In the present study, caregivers were contacted three months after EOT and asked if they would participate in this supplementary study. Seventy-five caregivers of seventy-five female adolescents agreed to participate. Seventy-five caregivers filled out a measure of caregiver burden (35 in MBT-G and 40 in TAU), and seventy-one filled out a measure on satisfaction with treatment (34 in MBT-G and 37 in TAU). Caregivers of thirty-seven participants refused to participate for
varying reasons, including lack of motivation, and disappointment with the treatment offer in the trial. These two measures of caregiver burden and satisfaction with treatment were thus not collected at baseline but only administered three months post-treatment (i.e., fifteen months after baseline) as an initial exploratory and retrospective study, whereas the participating adolescents filled out questionnaires at baseline and at EOT (a flow diagram is presented in Figure 1).

Insert Figure 1 around here

Treatment

The adolescents were randomized to either one year of MBT-G or TAU in four child and adolescent psychiatric outpatient clinics. The MBT-G program consisted of three MBT-Introduction sessions, thirty-seven MBT-group sessions, five individual case formulation sessions, and six MBT-Parent sessions. MBT-G was delivered by trained and supervised clinical psychologists and psychiatrists. TAU consisted of at least twelve non-manualized individual supportive sessions (with at least one monthly session). TAU was delivered by psychologists, psychiatrists, nurses or social workers who were not trained in nor practiced MBT. For a more thorough description of the treatments, please see Beck et al. (2016). Caregivers in MBT-G were offered six 1.5 hour manualized MBT-Parents sessions (one every second month) adapted from Karterud and Bateman’s manual (2011). MBT-Parents sessions were delivered in groups and covered core concepts within a mentalization-based framework such as attachment theory, emotion regulation and mentalization. The MBT-Parents groups were slow-open and included psychoeducation on BPD, roleplays, and plenary analyses of difficult interpersonal events between the caregiver and their child (Beck et al., 2016). Caregivers in TAU received non-manualized standard care, where caregiver treatment was delivered as a part of the clinics’ regular work when this was considered relevant and resources were available. Since TAU was non-manualized, the content and length of caregiver treatment are unknown.

Assessment

Caregiver burden was measured with the Burden Assessment Scale (BAS) (Reinhard et al., 1994). BAS consists of 19 items that measure objective and subjective burden in relation to caring for the seriously mentally ill. Objective burden (10 items) refers to areas such as financial distress, limitations on personal activity, household disruption, and potential negative effects on social interactions. Subjective burden (9 items) covers areas such as shame, stigma, guilt, resentment, grief

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and worry. The means of the two subscales were calculated to give indications to the distribution of scores, but the aggregated total score was used in the analyses. The questionnaire is rated on a 4-point Likert scale ranging from 1 (not at all) to 4 (a lot) (range 19-76) and higher scores represent greater levels of objective and subjective caregiver burden. The questionnaire was translated into Danish by the first author and back-translated by a Danish speaking British psychologist. Internal consistency on the BAS in this sample was excellent with a Cronbach’s alpha of .92.

*Satisfaction with treatment* was measured with the Family Satisfaction Survey (FSS). FSS is a 12-item questionnaire developed by Lubrecht (1992). It measures caregivers’ satisfaction with the treatment their child has received, the quality of the interaction between therapists and the family, and whether they would recommend the treatment to others. Items are rated on a 4-point Likert Scale, and the satisfaction score is calculated by dividing the summed total score by the amount of items (12) (range 1-4) (Ogden & Hagen, 2008). Higher scores represent greater treatment satisfaction. The Norwegian version of the questionnaire was translated into Danish and back-translated by a Danish speaking Norwegian psychologist (OJS) and the first author. Internal consistency on the FSS in this sample was good to excellent with a Cronbach’s alpha of .88.

*Caregiver demographics* were based on caregiver reports on 1) their relationship to the adolescent (biological mother, biological father, foster parent or contact person), 2) level of education (municipal primary and lower secondary school, vocational education, high school, bachelor of science, or master of science), and 3) employment status (employed versus unemployed).

*The adolescents’ severity of BPD pathology* was measured using the Borderline Personality Features Scale for Children (BPFS-C). BPFS-C was developed by Crick, Murray-Close and Woods (2005) for use with children from 9 years of age. The measure consists of 24 items rated on a 5-point Likert Scale ranging from 1 (not at all true) to 5 (always true) with higher scores representing more severe levels of borderline personality pathology (range 24-120). A score above 66 on the BPFS-C is considered to be within the clinical range. It includes four domains: Affective instability, identity problems, negative relationships and self-harm. Two psychologists translated this measure into Danish as a part of the M-GAB trial (Beck et al., 2016). Internal consistency was found to be good to excellent in the M-GAB trial (Cronbach’s alpha: .85) (Beck et al., 2020).

*Treatment and adolescents’ drop-out from treatment* was known to the authors due to the adolescents’ involvement in the M-GAB trial. Treatment was defined as MBT-G or TAU, and participants were considered to have dropped out of treatment if they terminated treatment.
prematurely, were taken out of treatment for clinical or extra-therapeutical reasons or if they were not offered the promised amount of treatment in the M-GAB protocol (Beck et al., 2016; 2020).

Statistical analyses

For the statistical analyses, we employed data from three questionnaires (BAS, FSS and BPFS-C) and sociodemographic information on the caregivers, treatment and information about the number of participants who dropped out of treatment. All hypotheses were tested using two-tailed tests.

To test our first hypothesis on caregiver demographics, we used One-way ANOVAs to test for differences in means between unrelated groups (relationships to the adolescent and levels of education). In cases of statistical significant results, a Tukey test was used in conjunction to the ANOVA to find means that were significantly different from each other to make pairwise comparisons. To compare the means of BAS and FSS on employment status, we used an independent samples t-test.

To test our second hypothesis on severity of BPD pathology, we used a simple linear regression to investigate the relationship between a continuous dependent variable (BAS, FSS) and a continuous independent covariate (BPD severity at baseline and at EOT, and change in BPD severity from baseline to EOT). Change in BPD severity was measured by calculating a difference score on the basis of mean scores at baseline and at EOT and controlling for baseline BPD severity in the statistical analysis. Likewise, since low SES (measured here as educational background and/or unemployment) could be a confounder between BPD severity and caregiver burden, we also controlled for these variables in the statistical analyses.

To test our third hypothesis on treatment and drop-out from treatment, we used an independent samples t-test to compare the means of two unrelated groups (MBT-G versus TAU) on the same continuous, dependent variables (FSS and BAS), and an independent samples t-test to compare the means of two unrelated groups (dropouts versus completers) on the same continuous, dependent variables (FSS and BAS).

Results

Description of sample

Caregivers: The seventy-five caregivers mainly consisted of biological mothers (n = 51, M_age 45.9, SD = 6.31) and biological fathers (n = 14, M_age 48.4, SD = 11.1), but also paid caregivers, i.e., foster parents (n = 6, M_age 57.3, SD = 11.5) and “contact persons” (municipal workers that coordinates
activities around the patient and who stood in as parent substitutes in the study, n = 4, M\text{age} = 36.3, SD = 2.8). For additional sociodemographic information on the caregivers, please see table 1. The aggregated mean score on BAS for the total sample of caregivers was 40.3 (SD = 12.2, n = 75) with evenly distributed scores on objective burden (M = 20.3, SD = 6.8) and subjective burden (M = 19.9, SD = 6.4). The level of satisfaction with treatment was midrange (i.e., “somewhat satisfied”) with a mean score on FSS of 2.47 (SD = .27). Satisfaction with treatment did not significantly predict caregiver burden (R$^2$ = .04, F(1, 70) = 3.2, p = .08).

**Adolescents:** The seventy-five adolescents were all female and had a mean baseline age of 15.7 (SD = 1.04, range 14 to 17). The mean BPFS-C score at baseline was 82 (SD = 8.99), and 71.2 (SD = 15.5) at EOT, i.e., above clinical cut-off (67) at both time points. Thirty-five adolescents received MBT-G treatment and forty received TAU. Mean number of therapy sessions for the entire sample was 17.4 (SD = 11.3, range 0 to 40). Participants in MBT-G received statistically more therapy sessions (group sessions and case management) (M = 26, SD = 11.3, range 0 to 40) compared to the participants in TAU (M = 10, SD = 4.9, range 2 to 24), t(73) = 8.1, p = .000. We did not find any significant differences on the BPFS-C between participants in MBT-G compared to TAU at baseline (p = .49) or at EOT among participants in MBT-G (M = 71.2, SD = 15.7) and TAU (M = 71.2, SD = 15.5), t(61) = .01, p = .99). Twenty-seven (36%) of the adolescents dropped out of treatment. At EOT, there were missing outcomes on twelve adolescents (six in MBT-G and six in TAU). There were no statistically significant differences in baseline BPFS-C scores between those who were missing at EOT (M = 82.1, SD = 8.38) and those who were not missing (M = 81.9, SD = 9.17), t(73) = .997, p = .36.

To test whether the adolescent participants whose caregivers chose to participate in the current study were representative of the original sample in the M-GAB trial, we compared non-participating and participating adolescents’ age, baseline BPFS-C score and frequency of drop-out from treatment. There was no significant difference in baseline age between the participants (M\text{age} = 15.7, SD = 1.04, n = 75) and non-participants (M\text{age} = 16.0, SD = 1.07, n = 36; t(109) = 1.38, p = .17). Likewise, there were no significant differences in baseline BPFS-C scores between participants (M = 82, SD = 8.99, n = 75) and non-participants (M = 83.2, SD = 10.3, n = 36); t(109) = 0.66, p = .51. However, significantly more participants had completed treatment (n = 48 out of 75, 64%) compared to the non-participating adolescents (n = 14 out of 36, 39%), p = .02. To summarize, the participants in the current study are assumingly representative of the entire sample of adolescents in the M-GAB trial in terms of age and BPD severity, but not in terms of drop-out status.
Caregiver demographics

Results of the analyses on caregiver burden and satisfaction with treatment are reported in Table 2 and 3.

Relationship to the adolescent significantly predicted caregiver burden in the total sample of caregivers ($R^2 = .21$, $F(3, 74) = 6.1, p = .001$). A Tukey test showed that biological mothers felt significantly more caregiver burden than foster parents ($p = .04$) and contact persons ($p = .006$). Level of education did not significantly predict caregiver burden ($R^2 = .02$, $F(4, 74) = .43, p = .79$), and we found no significant difference in caregiver burden between caregivers who were employed ($M = 40.1, SD = 12.2$) compared to those who were unemployed ($M = 40.6, SD = 12.6$), $t(73) = -.14, p = .89$).

Relationship to the adolescent also significantly predicted satisfaction with treatment ($R^2 = .14$, $F(3, 70) = 3.5, p = .02$). A Tukey test showed a significant difference between biological mothers and contact persons with biological mothers feeling more satisfaction with treatment ($p = .03$). Level of education did not significantly predict satisfaction with treatment ($R^2 = .07$, $F(4, 70) = 1.2, p = .31$), and we did not find a significant difference in satisfaction with treatment among those who were employed ($M = 2.47, SD = 0.25$) compared to those who were unemployed ($M = 2.48, SD = 0.35$), $t(69) = -.25, p = .81$).

Severi ty of BPD pathology

A linear regression confirmed our hypothesis that BPD severity at EOT significantly predicted caregiver burden ($R^2 = .08$, $F(1, 62) = 5.02, p = .03$). This finding remained statistically significant when controlling for caregivers’ level of education and employment status ($p = .04$). Caregiver burden was, however, not predicted by baseline BPD severity ($R^2 = .01$, $F(1, 74) = .71, p = .40$), neither when controlled for caregivers’ level of education and employment status ($p = .53$).
Caregiver burden was also not predicted by change in BPD severity ($R^2 = .03$, $F(1, 62) = 2.12, p = .15$), neither when controlled for baseline BPD severity ($p = .13$).

Higher baseline BPD severity significantly predicted caregivers’ satisfaction with treatment ($R^2 = .06$, $F(1, 70) = 4.5, p = .04$). This finding remained statistically significant when controlling for caregivers’ level of education and employment status ($p = .02$). Contrary to our hypotheses, satisfaction with treatment was neither predicted by BPD severity at EOT ($R^2 = .00$, $F(1, 58) = .00, p = .97$) nor by the level of difference in BPD severity from baseline to EOT ($R^2 = .02$, $F(1, 58) = 1.1, p = .30$), neither when controlled for baseline severity ($p = .37$).

**Treatment and drop-out**

As expected, caregivers in the MBT-G arm received statistically significantly more sessions ($M = 3.09, SD = 2.7$) than caregivers in the TAU group ($M = 0.95, SD = 1.7$), $t(73) = 4.2, p = .00$. Contrary to our hypotheses, no significant differences in caregiver burden were found between caregivers in the MBT-G arm ($M = 40.8, SD = 12.4$) and TAU ($M = 39.8, SD = 12.2$), $t(73) = .34, p = .73$. Likewise, no significant difference in satisfaction with treatment were found among caregivers in the MBT-G arm ($M = 2.48, SD = .25$) and TAU ($M = 2.46, SD = .29$), $t(69) = .40, p = .69$.

A total of 27 participants (36%) dropped out of treatment. We found no significant difference in caregiver burden between caregivers whose child dropped out of treatment ($M = 43.9, SD = 10.2, n = 27$) and caregivers whose child stayed in treatment ($M = 38.2, SD = 12.9, n = 48$), $t(73) = 1.96, p = .06$. Similarly, there was no significant difference in caregiver satisfaction with treatment for caregivers whose child dropped out of treatment ($M = 2.47, SD = .33, n = 27$), compared to caregivers whose child stayed in treatment ($M = 2.47, SD = .23, n = 44$), $t(69) = -.08, p = .93$.

**Discussion**

Given that BPD is a disorder that is highly interpersonal in nature and that an accumulating amount of studies shows that caregivers of adults with BPD are burdened by their caregiving role, there is a noticeable lack of research on caregivers of adolescents with BPD. Parenting adolescents is viewed as the most difficult parenting stage by the majority of parents (> 60 %) (Deković, 1999), and caring for an adolescent with a psychiatric disorder is particularly demanding because the caregiver is exposed to symptoms of the disorder on a daily basis, and also has to attend meetings and perhaps assist their adolescent in attending treatment usually during the work day.

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Our novel and exploratory investigation found a mean score of 40.3 ($SD = 12.2$) on the BAS among caregivers of adolescents with BPD. This level of burden is equivalent to somewhere between that found in caregivers of adults with BPD ($M = 43.91$, $SD = 11.62$, $n = 131$) and caregivers of psychiatric inpatients with mood, substance, neurotic and psychotic disorders ($M = 38.54$, $SD = 13.27$, $n = 135$) in a systematic review (Bailey & Grenyer, 2013). It is worth noticing that the high level of caregiver burden found in our study was reported after the adolescents and caregivers received one year of treatment since baseline levels of burden were not investigated. To compare with an RCT of another MBT family intervention, MBT-Family and Carers Training and Support (MBT-FACTS), the level of burden in the control group that did not receive any intervention decreased from a BAS score of 58.3 ($SD = 2.48$) at baseline to 38.1 ($SD = 3.32$) after twelve weeks (Bateman & Fonagy, 2018). Given this twelve-week reduction in feelings of burden without any intervention, we can only speculate about the more than one-year development of burden in our sample of caregivers.

**Caregiver demographics**

Our sample mainly consisted of unpaid caregivers (biological mothers and fathers) but also paid caregivers (foster parents and contact persons). The finding that biological parents had higher mean scores of burden is perhaps not surprising given that they share a genetic link with the adolescent, and because they could be more personally invested as biological parents. Biological mothers had the highest mean score on the BAS, which was significantly higher than foster parents and contact persons (albeit underpowered). There are no indications that this finding is BPD-specific; most likely it is a reflection of a general phenomenon, namely that mothers are more involved in child rearing (Dotti Sani & Treas, 2016). Therefore, mothers could be obliged, for example, to take more time off work to take care of the needs of their child. Several studies have found that mothers experience more parenting stress and burden than other caregivers (including biological fathers), and that parental involvement may partially or fully mediate the relationship between type of caregiver and parenting stress (Karst & Vaughan Van Hecke, 2012; Martin et al., 2013; Johansson et al., 2015). This is perhaps best reflected in the skewed distribution of different types of caregivers in the current study where biological mothers constituted 68% of the total sample. Interestingly, we found that even though biological mothers experienced the highest level of caregiver burden they also had the highest mean level of satisfaction with treatment (albeit only significantly different from contact persons). This runs counter to findings from a previous study where dissatisfaction...
with treatment correlated with greater caregiver burden among caregivers of people with BPD (Goodman et al., 2011). A possible explanation to our finding may be that those with the highest burden also are the ones most grateful for receiving help, but this finding needs replication.

We did not find significant correlations between caregivers’ level of education or employment status and burden or satisfaction with treatment. This finding was surprising and perhaps counterintuitive given that studies such as Goodman et al. (2011) found that financial costs related to the treatment of BPD were highly correlated with severity of caregiver burden, and that BPD at the same time often is related to low socio-economic background (Cohen et al., 2008). Given the strong association between financial costs and caregiver burden in previous studies, it was unclear whether burden was a reflection of limited financial resources rather than the caregiving role in itself. A tentative interpretation of our finding could be that caregiver burden in our sample reflects the intrapersonal and interpersonal impact of caring for an adolescent with BPD, and not aspects related to low socio-economic background. Whether the publicly financed health care in Denmark and thereby free access to mental health care contributed to this lack of association ought to be corroborated in future studies.

Adolescents’ BPD severity

Among our sample of caregivers, burden was unrelated to baseline BPD severity, but correlated with BPD severity at EOT. Given that BPD in adolescence still is in its early stages, and that the caregiver burden in our sample seems comparable to that found among caregivers of adults with BPD, this could mean that burden is unrelated to the duration of exposure to BPD symptoms, and that it is more a reflection of the current impact of the disorder. Unfortunately, we did not collect data on burden at baseline, and therefore we do not know whether baseline burden and baseline BPD severity likewise would have shown a significant association. Therefore, this finding needs to be replicated in future studies. Satisfaction with treatment was, conversely, only related to baseline BPD severity. We believe that this could be a reflection of finally getting help, but this finding clearly also needs replication. Surprisingly, neither caregiver burden nor satisfaction with treatment were related to change in BPD severity.

Treatment and adolescents’ drop-out from treatment

The caregivers felt “somewhat satisfied” with treatment. Contrary to our hypothesis, we found no differences in caregiver burden and satisfaction with treatment among caregivers in MBT-G and
TAU. This finding should, however, be interpreted with caution since baseline levels of burden among our sample of caregivers is unknown and, therefore, could have been skewed initially. This finding was surprising, because we assumed that a manualized treatment for caregivers (MBT-Parents) would be associated with significantly lower caregiver burden and more satisfaction with treatment compared to TAU where caregiver treatment was non-manualized and of a significantly lower dosage. However, both interventions were short and probably not extensive enough to cover the needs of caregivers that deal with a severe mental disorder like BPD. If we compare the treatment dosage to that seen within early intervention studies of first-episode psychosis, like the Scandinavian TIPS study, those caregivers received up to two years of family intervention, including multifamily groups (Lyse et al., 2007; Fjell et al., 2007). Interestingly, treatments of a severe and highly interpersonal disorder like BPD seem to entail less family treatment. For instance, MBT-FACTS consists of five 1.5 hour sessions and thus of an even smaller dosage than the MBT-Parents program in M-GAB (Bateman & Fonagy, 2018), Dialectical behavior therapy-oriented Family Connections consists of 12 two hour sessions (Hoffman, Fruzzetti & Buteau, 2007), and psychoeducational programs such as Making Sense of BPD specifically designed for relatives of adolescents with BPD consists of three two-hour sessions (Pearce et al., 2017).

Caregiver burden was reduced in studies of Family Connections and Making Sense of BPD but in both of these studies, there were no control groups (Hoffman, Fruzzetti & Buteau, 2007; Pearce et al., 2017). MBT-FACTS also led to reductions in caregiver burden, but at no time point did burden significantly differ between MBT-FACTS and delayed intervention (i.e., no intervention) (Bateman & Fonagy, 2018). This failure to find superior outcomes on caregiver burden within an MBT treatment setting could either mean that the content (i.e., MBT) is not acceptable or useful for the caregivers or the format of the intervention is not sufficient in providing the caregivers with the necessary skills to deal with BPD. According to Gunderson (2001), more sustained family interventions for BPD are usually needed to change a family’s way of communicating or relating. Gunderson developed psychoeducational multifamily groups influenced by McFarlane’s work with families with a member who has schizophrenia, and this program consists of 1.5 hour meetings every two weeks for one year up to 18 months. Gunderson (2001) notes that changes usually begin to manifest themselves after three months, i.e., after significantly more treatment exposure than in the previously mentioned MBT interventions for caregivers of people with BPD.
Another possible explanation for the lack of difference in caregiver burden and satisfaction with treatment could be that these are associated with adolescents’ outcome of treatment. Since there was no difference in BPD severity between participants in MBT-G and TAU in this study as well as the original RCT (Beck et al., 2020; Jørgensen et al., 2020), this may be reflected in caregivers’ experiences of burden and satisfaction with treatment. This could possibly also explain why drop-out did not significantly impact caregivers’ experience of burden and satisfaction with treatment. This hypothesis should be tested in future trials of treatments for BPD-affected adolescents and their caregivers.

Limitations

There are significant limitations to this initial exploratory study. First, a major limitation to our retrospective study is the fact that caregiver burden was not assessed at baseline, and we therefore do not know whether burden was unevenly distributed in the two treatment arms at the time of inclusion into the study or whether burden increased or decreased throughout the duration of the trial. Secondly, our sample consisted of a reduced sample of caregivers (seventy five out of one hundred eleven) who participated in an RCT, and a sample in which significantly more adolescents completed treatment. Therefore, the experience of the participating caregivers could vary from the non-participating caregivers. Furthermore, the sample was highly skewed towards biological mothers, and accordingly the results should only be generalized to other caregivers with caution. It is, likewise, a limitation that the adolescent sample exclusively consisted of females and, therefore, we do not know whether caring for male adolescents could be different. Furthermore, we chose not to control for treatment type, because for one, the original RCT found no significant differences between the groups on any outcomes (Beck et al., 2020; Jørgensen et al., 2020), and secondly, because we replicated this finding in the current study, where the mean score on the BPFS-C in both groups was 71.2 at EOT ($p = .99$, 95% Confidence Interval: -7.8 to 7.9). For MBT, the range in BPFS-C scores was between 43 and 103 and the SD was 15.7 compared to a range of 40 to 101 and an SD of 15.5 in TAU. Based on the identical mean scores, SDs and the confidence interval, we do not believe that treatment contributed to significant or insignificant findings in the current study, although it is possible that some of the variance could be explained by treatment type. Lastly, the instruments used to assess the participants (BPFS-C, BAS, and FSS) were translated as a part of this study and thus not piloted in a Danish sample before use. This could have affected the reliability of the instruments.
Caring for adolescents can be challenging even among well-adjusted adolescents. Therefore, it is a limitation that this study did not include a non-clinical control group that would allow for a disentanglement of BPD-related caregiver burden and normal parenting stress. It is, however, specified in the BAS that feelings of burden must be caused by “(name’s) illness”, which should disentangle normal parenting stress from BPD-related feelings of caregiver burden (Reinhard et al., 1994). Future studies should include larger samples to clarify whether the findings and tendencies we found among our sample of caregivers will persist.

**Conclusions**

The current study explored correlations between caregiver demographics, adolescents’ clinical outcomes and treatment among a clinical sample of caregivers and adolescents impacted by BPD in adolescence. Despite the abovementioned limitations, this initial exploratory study identified characteristics that could be associated with caregiver burden and satisfaction with treatment, namely that biological mothers could be specifically vulnerable towards feeling burden, and that caregivers’ experience of burden and satisfaction with treatment could be predicted by more severe BPD pathology.

To our knowledge, this is the first larger-scale study that assesses caregiver burden among caregivers of adolescents with BPD, and the first one that is nested within an RCT. This allowed us to relate the caregivers’ reports at three months post treatment to the adolescents’ severity of BPD pathology pre and post-treatment. Retrospective studies like these are important to elucidate possible prognostic variables associated with caregiver burden that can help guide future research and planning of treatment strategies for a group of caregivers who constitute an understudied group in high demand of support.

Our sample of caregivers in MBT did not feel less caregiver burden than caregivers in TAU despite the fact the caregivers and the adolescents both received manualized treatments with significantly more treatment exposure compared to standard care. Our study indicates that there might be a relation between adolescent BPD severity and caregiver burden. It is possible that the lack of difference on the adolescents’ clinical outcomes (Beck et al., 2020) explains the lack of difference between the two groups of caregivers. Future trials on treatments for BPD in adolescence should include caregiver outcomes to investigate this hypothesis. Our study also highlights the need for future research into the content and format of family work to help reduce burden, rather than
adding pressure on caregivers that might have limited resources with treatments that do not work adequately.

References


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Reciprocal-effects of parenting and borderline personality disorder symptoms in adolescent girls With suicide rates almost 50 times higher in those with BPD than in the, 26(2), 361–378.


### TABLE 1. Caregiver characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total</th>
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<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
<td>77.3</td>
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<tr>
<td>Age (M, SD)</td>
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Marital status

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<td>Single</td>
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<td>Cohabiting</td>
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<td>14.7</td>
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<td>Divorced</td>
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Highest level of education

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<td>Vocational</td>
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<tr>
<td>High school</td>
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<td>10.7</td>
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<td>Bachelor of science</td>
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<td>Master of science</td>
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<td>7.6</td>
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Currently employed

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<td></td>
<td>57</td>
<td>76</td>
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TABLE 2. Summary of statistical analyses predicting caregiver burden

<table>
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<td><strong>Caregiver demographics</strong></td>
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<td>Relationship to the adolescent</td>
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<td>43.5</td>
<td>11.6</td>
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<td>37.3</td>
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<td>30.7</td>
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<td>Contact person</td>
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<td>12.3</td>
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<tr>
<td>Master of science</td>
<td>43.0</td>
<td>12.9</td>
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</table>
Employment status (employed versus unemployed)  
- .47  
-7.1 to 6.2  
.89

**Adolescents’ severity of BPD pathology**

Adolescents’ baseline BPD severity  
.13  
-.18 to .45  
.40

Adolescents’ end of treatment BPD severity  
.22  
.02 to .42  
.03*

Difference in BPD severity from baseline to end of  
treatment  
-.15  
-.36 to .06  
.15

**Treatment and drop-out**

MBT-G versus TAU  
.97  
-4.69 to 6.64  
.73

Drop-outs versus completers  
5.62  
-.12 to 11.37  
.06

TABLE 3. Summary of statistical analyses predicting satisfaction with treatment

<table>
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<td><strong>Caregiver demographics</strong></td>
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<td>2.49</td>
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<tr>
<td>Contact person</td>
<td>2.15</td>
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<td>Educational level</td>
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<td>Municipal primary and lower secondary school</td>
<td>2.49</td>
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<td>Mean difference/B</td>
<td>CI</td>
<td>p</td>
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<tr>
<td><strong>High school</strong></td>
<td>2.55</td>
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<td>-.17 to .14</td>
<td>.81</td>
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<td>.04*</td>
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<td>Adolescents' baseline</td>
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<td>-.00 to .00</td>
<td>.97</td>
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<td>Adolescents' end of</td>
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<td>-.00 to .00</td>
<td>.97</td>
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<tr>
<td>Treatment and drop-out</td>
<td>.03</td>
<td>-.10 to .16</td>
<td>.69</td>
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<td>MBT-G versus TAU</td>
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<td>-.14 to .13</td>
<td>.93</td>
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**Adolescents’ severity of BPD pathology**

**Treatment and drop-out**

Figure 1 Flow diagram
Randomized (n = 111)

Allocated to MBT Group: n = 55
Adolescents fill out baseline reports
Part of the caregiver study: n = 35

End of treatment (12 months)
Adolescents self-reported outcome in caregiver study: n = 29
Missing: n = 6

Caregiver study (15 months)
Caregivers: n = 35
Caregivers' self-reported burden (n = 35)
Caregivers' self-reported satisfaction with treatment (n = 34)

Allocated to TAU intervention: n = 55
Adolescents fill out baseline reports
Part of the caregiver study: n = 40

End of treatment (12 months)
Adolescents self-reported outcome in caregiver study: n = 34
Missing: n = 6

Caregiver study (15 months)
Caregivers: n = 40
Caregivers' self-reported burden (n = 40)
Caregivers' self-reported satisfaction with treatment (n = 37)