Archives of Psychiatric Nursing, November 2019

DOI: 10.1016/j.apnu.2019.11.001

Resilience as a moderator between objective and subjective burden among parents of children with ADHD

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Abstract

The caring related challenges reported by parents of children with Attention Deficit and Hyperactivity Disorder (ADHD) were widely investigated. Little information is instead available on the resources mobilized by these parents in facing caring burden. In the attempt to fill this gap, the present study aimed at exploring the moderating role of resilience in the relationship between the amount of time parents of children with ADHD devote to caring tasks (objective burden) and their emotional and social burden (subjective burden). A multidimensional model of resilience was adopted, comprising six components: Self-Perception, Planned Future, Structured Style, Social Competence, Family Cohesion, and Social Resources. Participants were 44 parents (81.8% females, aged 31-53) of children with ADHD (86.4% males, aged 6-14). They completed the Caregiver Burden Inventory, the Resilience Scale for Adults, and the 36-Item Short Form Health Survey. Hierarchical regressions were performed to test the moderating role of resilience as a global construct, and of each resilience dimension separately, on the relation between objective and subjective burden; participants' gender and mental health scores were employed as control variables. Total resilience, Family Cohesion and Self-Perception emerged as protective factors, weakening the relationship between subjective and objective burden. Findings suggest that the potential of individual and family resources in promoting parents' adjustment to caring burden could be more effectively exploited in clinical interventions addressed to parents of children with ADHD. Overall, the identification of caregivers' strengths and resources could help practitioners to better support children with ADHD and their families.

Keywords Attention Deficit and Hyperactivity Disorder; Caregiving burden; Resilience

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Introduction

Attention-Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, hyperactivity and impulsivity. In childhood ADHD has an estimated prevalence rate of 5-7% (American Psychiatric Association, 2013; Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007; Willcutt, 2012; Thomas, Sanders, Doust, Beller, & Glasziou, 2015); during the transition to adolescence a significant reduction of clinical manifestations is usually observed. Males are more often involved, with a gender ratio of 2:1 in clinical samples and 4:1 in population samples (American Psychiatric Association, 2013; Faraone et. al, 2015)

The consequences of ADHD manifestations on the daily lives of children and their families have been extensively described (Harpin, 2005; Wehmeier, Schacht, & Barkley, 2010; Weiss, 2015; Faraone et. al, 2015). Impulsivity and inattention to social cues can lead children to experience rejection by peers, whereas difficulties in tasks requiring sustained attention often undermine their academic performance (Arnold, Hodgkins, Kahle, Madhoo, & Kewley, 2015; Daley & Birchwood, 2010; Faraone et al., 1993; Pastura, Mattos, & Araújo, 2009) and negatively affect their self-esteem (Edbom, Granlund, Lichtenstein, & Larsson, 2008; Mazzone et al., 2013). As concerns daily interactions, children with ADHD tend to disregard parents' ordinary requests and advice, fight with siblings and peers, disturb people in public spaces, and have difficulties in the relationship with teachers. In order to adequately manage all these daily problems, they require more attention and assistance from parents than their typically-developing peers. As a consequence, parents of children with ADHD have to invest a remarkable amount of resources in supporting their children's performance of daily tasks and pursuit of developmental goals.

ADHD: a challenge for parents

The relevant amount of time and energies that parents must invest in caring practices, in order to deal with the behavioral complexity and emotional lability of their children with ADHD, has negative implications for both their daily planning and mental health. Parents face difficulties in combining family and work responsibilities (Sellmaier, Leo, Brennan, Kendall, & Houck, 2016), they have little time to devote to leisure and personal interests (Harpin, 2005; Neff, 2010) and their attempts to promote children's socialization often fail, resulting in withdrawal from social and public activities (Walerius, Fogleman & Rosen, 2016). Compared to parents of typically developing children, parents of children with ADHD report worse marital relationships (Befera & Barkley, 1985; Murphy & Barkley, 1996; Shelton et al., 1998), lower levels of perceived family support (Shur-Fen Gau, 2007), lower parenting self-esteem (Mash & Johnston, 1983), lower expectancies for success in managing their children's behavior (Sobol, Ashbourne, Earn, & Cunningham, 1989) and lower parental self-efficacy (Primack et al. 2012; Rogers, Wiener, Marton, & Tannock, 2009).

As concerns mental health, parents of children with ADHD report more psychological disorders then parents of children without ADHD, in particular depression, anxiety and alcohol abuse (Cheung & Theule, 2016; Durukan, Kara, Almbaideen, Karaman, & Gül, 2018; Faraone & Biederman, 1997; Margari, et al., 2013) and higher levels of stress than parents of children with learning disabilities or with typical development (Baker & McCal, 1995; Fisher, 1990). Prominent stress related factors include child symptoms' severity and behavioral disturbance, major and minor life events, as well as parents' psychological characteristics (such as perceived parental control over child behaviors and self-esteem), and parental psychological disorders (Fischer, 1990; Harrison & Sofronoff, 2002; Mash & Johnston, 1983; Theule, Wiener, Tannock, Jenkins, 2013; Vitanza & Guarnaccia, 1999). ADHD itself may co-occur in both parents and children (Biederman, et al. 1995; Faraone, Biederman, & Milberger, 1994), leading to further impairments in parental functioning and higher parenting stress (Johnston & Mash, 2001; Theule, Wiener, Rogers & Marton, 2011). Overall, these findings suggest that the high demands involved in caring for children with ADHD, as well as personal strains contribute to undermine the positive adjustment of parents.

The problematic aspects associated with raising a child with ADHD were globally investigated in terms of caregiving burden, a multidimensional construct including objective components (e.g. daily time investment in parenting) and subjective ones (e.g. fatigue, negative emotions and perceived lack of socialization opportunities) (Caserta, Lund, & Scott, 1996). Among the measures available to assess burden globally and in the major life domains, the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980) is widely used in ADHD research.

A large study conducted in ten European countries among caregivers of children and adolescents diagnosed with ADHD showed the negative implications of burden in a variety of daily domains; more specifically caring burden, measured through a survey developed by the authors using concept elicitation methods, was related to missed/altered work opportunities, avoidance of social activities, increased parental worry/stress, and family life strain in spite of children's pharmacological treatment (Fridman et al., 2017). Another study conducted in Oman through the Arabic version of ZBI highlighted that parents' gender, family

income, number of siblings, and severity/subtypes of ADHD were significantly related to burden levels (Al Balushi, Al Shukaili, & Al Adawi, 2017). High levels of burden, assessed through the ZBI, were also detected among caregivers of children and adolescents with ADHD living in Nigeria (Adeosun, Ogun, Adegbohun, Ijarogbe & Fatiregun, 2017). Data collected in the UK among parents of adolescents and young adults, using a brief version of ZBI (Cadman et al., 2012), highlighted that burden was specifically associated with the perception of children's unmet needs at the emotional and relational levels.

Overall, the relevant role of caring burden identified across studies calls for a deeper investigation of this phenomenon, in order to clarify the unique contribution of both the objective and subjective components of burden, their mutual relationship, and the role of other sociodemographic variables in the experience of parents raising children with ADHD.

Parents' well-being and resilience: recent topics in disability research

During the last two decades, researchers' focus on the strain and stress associated with the caring role was progressively expanded towards including caregivers' well-being, personal resources and social support. This broadening in focus characterized research on ADHD as well.

Across disease conditions, at the individual level successful adjustment to the caregiving role was associated with high positive and low negative affect (Robertson, Zarit, Duncan, Rovine, & Femia, 2007; Song, et al., 2014), adaptive coping strategies (Bauer, Koepke, Sterzinger, & Spiessl, 2012), internal locus of control (Lloyd & Hastings, 2009), and high sense of coherence (Oelofsen & Richardson, 2006). At the relational level, adaptive management of care-recipient needs was associated with perceived support and cohesion within the family and in the social context (Delle Fave, Fianco, & Sartori, 2015; Motl, McAuley, Snook, & Gliottoni, 2009; Rolland & Walsh, 2006).

As specifically concerns ADHD research, the traditional assessment of parental well-being as absence of psychological distress and negative emotions was integrated by the investigation of positive indicators of mental health (Neff, 2008; 2010). Studies were conducted to assess stress-related personal growth (Modesto-Lowe, Chaplin, Godsay, & Soovajian, 2014; Finzi-Dottan, Triwitz & Golubchik, 2011) and positive parenting (Ellingsen, Baker, Blacher, & Crnic, 2014), as well as their predictors. Parents' adoption of adaptive coping strategies, such as problem appraisal and problem management, was associated with better quality of life, greater sense of control and higher personal fulfillment, while perceiving the child's condition as a threat or a loss and adopting emotion-focused coping strategies predicted poorer quality of life (Cappe, Bolduc, Rouge, Saiag, & Delorme, 2017).

Adaptive responses and positive adjustment to adversarial life conditions are often investigated within the framework of resilience (Luthar, Chicchetti, & Becker, 2000; Masten & Wright, 2009), defined as a global regulatory capacity to effectively manage stressful situations (Masten & Obradovic, 2007) through the mobilization of personal and social resources, that include psychological assets and potentials, family cohesion and value sharing, and social support (Di Corcia & Tronick, 2011). Resilience was operationalized through different empirical models (Zautra et al., 2012) in studies involving parents of children with physical and mental disabilities. Resilience facets were identified among primary caregivers of children and adolescents with autism (Bayat, 2007), among mothers of children and adults with disabilities (Lee, Park, & Recchia, 2015), and in couples of parents of young children with severe disability (Graungaard, Andersen, & Skov, 2011). Resilience processes and trajectories were detected and analyzed among families of 3-year-old children with intellectual disabilities (Gerstein, Crnic, Blacher, & Baker, 2009); results highlighted the relevance of individual parent characteristics, quality of dyadic relationships and inter-parental influences in the adjustment to child disability. A systematic review of studies conducted among parents of children with intellectual and/or developmental disabilities (Peer & Hillman, 2014) identified coping style, optimism, and social support as main resilience factors. Parental resilience was positively associated with well-being indicators such as self-reported health (Ruiz-Robledillo, De Andres-Garcia, Perez-Blasco, Gonzalez-Bono, & Moya-Albiol, 2014), and quality of life (Migerode, Maes, Buysse, & Brondeel, 2012).

The relationship between resilience and caregiving burden was predominantly investigated among caregivers of adults. Significantly negative correlations between burden and resilience were detected among caregivers of older persons with dementia (Gönen Şentürk, Akyol, & Küçükgüçlü, 2018) and of adults with spinal cord injury (Vagharseyyedin & Molazem, 2013). In a study conducted among parents of persons with autism spectrum disorders (Bekhet, Johnson, & Zauszniewski, 2012), positive cognitions were identified as mediators between caregiving burden and resourcefulness (considered as an indicator of resilience). In a group of caregivers of older adults, the relationship between burden and resilience was mediated by perceived social support (Ong et al., 2018). Finally, a study involving parents of persons (aged 5–53), diagnosed with cognitive and neuromotor disorders, investigated resilience and life satisfaction (well-being indicators) and depression related emotions (an ill-being indicator) as predictors of caregivers' subjective burden (Fianco et al., 2015); life

satisfaction and resilience emerged as significant predictors of burden; after accounting for their contributions, depression related emotions did not show any significant association with caregivers' subjective burden levels.

Overall, these findings suggest that psychological resources and positive mental health indicators, such as resilience, could be usefully included in intervention programs, by virtue of their role as protective factors against burden perception. This research avenue seems to be promising for applications in the context of childhood disabilities (and particularly ADHD); a thorough literature search, however, did not yield any results.

Study aims

Despite the growing body of research addressing stress, burden and well-being indicators among parents of children with ADHD, to the best of our knowledge no studies have been conducted yet to investigate parental resilience and its role in buffering caregiving burden and stress. The present study was therefore aimed at investigating the role played by resilience in the relationship between objective burden (the amount of time devoted to care activities) and subjective burden (perceived social, emotional and psychophysical burden) among parents of children with ADHD. To the purpose of this study, resilience was conceptualized and operationalized following Friborg and colleagues (Friborg, Hjemdal, Rosenvinge & Martinussen, 2003; Werner, 2000), who developed a comprehensive model comprising six dimensions: four of them refer to individual positive characteristics, one to family support and cohesion, and one to social supportive networks (Hjemdal, 2007). Individual characteristics include self-perception (confidence in one's own abilities, self-efficacy, positive outlook toward oneself), planned future (positive outlook toward one's own future, ability to formulate and pursue clear goals), social competence (flexibility in social interactions, ability to build new relations), and structured style (being able to organize daily time and activities). The dimension family cohesion refers to shared values, amount of family conflict, cooperation, support, loyalty and stability within the family. Social resources include quality of support perceived from social networks and significant others outside the family, as well as appreciation from others.

In statistical terms, resilience was analyzed as a moderator of the relationship between the two components of burden. On this basis, a general hypothesis was formulated:

 H_1 : Resilience would moderate the relationship between objective and subjective burden, so that high levels of resilience have a significant effect on burden perception compared to low levels of resilience. More specifically, higher resilience levels are expected to reduce the magnitude of the bivariate relation between the two dimensions (buffering effect).

In the case of H_1 confirmation, the following additional hypotheses were formulated, in order to more specifically verify the moderating role of each of the six dimensions of resilience in the relationship between objective and subjective components of burden:

H₂: Family Cohesion;

H₃: Social Resources;

H₄: Self Perception;

H₅: Social Competence;

H₆: Planned Future;

H₇: Structured Style.

Method

Procedure and participants

A cross-sectional design was adopted for this study, conducted in collaboration with two child neuropsychiatric units in Northern Italy: IRCCS E. Medea – La Nostra Famiglia in Bosisio Parini and Manzoni Hospital in Lecco. After approval by the Ethics Committees of the two institutions, clinicians identified families matching the research inclusion criteria: eligible participants were parents of children with ADHD (either Hyperactive-Impulsive, Inattentive, or Combined subtype), never enrolled in Parent Training programs. A researcher contacted eligible participants either by phone or in person, informing them about the main project aims. A total of 45 parents agreed to take part in the study. They were invited to a meeting at the unit, in which they filled out an informed consent form and were provided with a set of questionnaires. In each family, the parent most involved in child daily care was selected for participation in the study.

Participants could complete the questionnaires immediately or at home, returning them to the researcher within two weeks. In both cases, they were offered a debriefing session in which they could express personal comments and doubts, and receive further information on the study aims. Anonymity was guaranteed in all research phases.

Research instruments

Participants filled out the following scales:

Caregiver Burden Inventory (CBI, Novak & Guest, 1989; Italian version Marvardi et al., 2005). It comprises 24 items on 0–4 Likert-type scales, grouped into five dimensions: Objective Burden (OB; time devoted to the care activities, 5 items), developmental burden (5 items), physical burden (4 items), social burden (5 items) and emotional burden (5 items). Scores for each dimension are obtained by summing up the respective item values; the sum of developmental, physical, social and emotional burden scores is globally interpreted as Subjective Burden (SB); a total burden score can also be calculated as the sum of OB and SB (values range 0-96). The CBI validity, well documented in caregivers of adults, has been recently supported in caregivers of children with Pediatric Acute-onset Neuropsychiatric Syndrome (Farmer et al. 2018); the CBI was employed with parents of children with Autism Spectrum Disorders (Ji, Sun, Yi, & Tang, 2014) and adapted for use with parents of children with Rett Syndrome (Lane et al., 2017).

Resilience Scale for Adults (RSA; Friborg et al., 2003, Italian version: Peveri, 2010). RSA investigates positive adaptation to aversive conditions through 33 items based on 1–5 semantic differential-type response format. The instrument is consistent with the six factor model of resilience proposed by Friborg et al. (2003) and Hjemdal (2007); items are thus grouped in the following dimensions: Family Cohesion (FC), Social Resources (SR), Self Perception (SP), Planned Future (PF), Social Competence (SC), and Structured Style (SS). The total resilience score is obtained by summing the item values of each dimension (range 33-165). Higher scores indicate higher levels of resilience. More specifically, low resilience levels correspond to values below 77, moderate levels to values in the 78-121 range, and high levels to values above 122.

36-Item Short Form Health Survey (SF-36; Ware & Sherbourne, 1992; Italian version: Apolone, Cifani, Liberati, & Mosconi, 1997). The instrument assesses perceived health and well-being in eight different areas: Vitality, Physical Functioning, Bodily Pain, General Health, Role Limitations due to Physical Health Problems, Role Limitations due to Emotional Problems, Social Functioning and Mental Health. Items' weighted sums are calculated for each area, and transformed into 0-100 scales. Higher scores correspond to higher levels of perceived health in that area. For the purposes of this study only the Mental Health (MH) subscale was included in the analyses; MH is assessed trough 5 items on a 1-6 Likert-type format.

Data analysis

As a first step, data were inspected to detect missing values in scaled answers. Cronbach's alpha reliability indices were calculated for each instrument; only dimensions with α values >.69 were retained for further analyses.

Descriptive statistics and correlation coefficients were calculated for demographic features and study measures. In line with the literature, associations were interpreted as meaningful with coefficient values >.30. Above this threshold, values lower than .50 were interpreted as indices of low correlation, between .50 and .70 as indices of moderate correlation, and above .70 as indices of high correlation between variables (Hinkle, Wiersma & Jurs, 2003).

In order to test H_1 , a hierarchical regression analysis using Ordinary Least Square (OLS) estimation technique was employed. Subjective Burden was considered as a criterion variable, while Objective Burden and Total Resilience (TR) were treated as predictor and moderator respectively. All measures showing a correlation value > |.30| with SB (criterion variable) were inserted as control variables in Step 1. In order to reduce multicollinearity (Aiken & West, 1991), OB (the predictor) and TR (the moderator) were centered at their mean values and inserted in Step 1 as well. The interaction term (centered OB X centered TR) followed in Step 2. All variables in the model were inspected for assumption of OLS multivariate regression to be met. In presence of a significant interaction, a post-hoc simple slope analysis was employed to clarify the role of Total Resilience (the moderator) in the relationship between Objective Burden (the predictor) and Subjective Burden (the criterion variable).

Results

Preliminary analyses

Participants

One participant was excluded from analyses due to a percentage of missing answers in the RSA scale (15%) beyond acceptability threshold. No missing values were found in the other participants' questionnaires. The analyses were thus conducted on 44 participants, 81.8% mothers, aged 31-53 (M=41.05; SD=5.38). Most caregivers (75%) had a paid job; as regards education, 56.8% had a high school diploma, 27.3% a middle school one, and 15.9% a college degree. The majority (63.6%) had two children, 13.6% had one child, 15.9% three children, 2.3% four children and 4.5% five children. Children with ADHD were predominantly males (86.4%), aged 6-14 (M=9.86; SD=2.29).

Descriptive statistics

Instruments' reliability values are reported in Table 1, along with descriptive statistics of all study measures and correlation indices. Two resilience subscales (Planned Future and Structured Style) did not meet the α requirement for acceptability and were thus excluded from subsequent analyses.

TABLE 1 about here

Participants' Mental Health scores did not significantly differ from the Italian normative data¹ at a *t*-test comparison. The Total Resilience mean score was comprised in the high resilience range; in addition, no participant reported values in the low resilience range. In order to detect the prominence of Objective vs. Subjective Burden, total OB and SB scores were first divided by the number of related items, and a *t*-test for dependent samples was then performed. Subjective Burden showed significant lower values than Objective Burden (M_{OB} =1.16, SD_{OB} =0.67; M_{SB} =0.54, SD_{SB} =0.47; t(43)=7.80; p<.001).

As concerns associations among the variables, Subjective Burden showed: a moderate positive correlation with Objective Burden, a low positive correlation with participants' gender, low negative correlations with Family Cohesion, Social Resources and Self Perception, moderate negative correlations with Mental Health and Total Resilience, and no significant correlation with Social Competence. The correlations between Objective Burden and the potential moderators (Total Resilience and the four resilience subscales selected for analysis) did not hit significant values.

Participants' gender and Mental Health emerged as the sole measures showing a correlation value > |.30| with Subjective Burden, They were included as control variables in the subsequent hierarchical regression analysis.

The moderating role of Total Resilience between objective and subjective burden

In order to test H_1 , a hierarchical regression with Subjective Burden as criterion was employed. Mean centered Objective Burden (predictor) and Total Resilience (moderator) were inserted in Step 1, together with control variables (participants' gender and Mental Health). The interaction term (Objective Burden x Total Resilience) was inserted in Step 2. As a preliminary step, data were inspected for violations of multivariate regression assumption. Comparison of Mahalanobis Distance values with χ^2 probability distribution did not led to detection of multivariate outliers. Normal distribution of the error terms was checked trough the probability plot of standardized residuals and Shapiro-Wilk (W) test; both procedures excluded significant deviations from normality (W(44)=.96, p=.11). Homoskedasticity was confirmed by a non-significant result of Koenker alternative to the Breusch-Pagan test: $B^{Koenker}$ =5.12; p=.40 (Koenker, 1981). All Variance Inflation Factor values (VIF) ranged from 1 to 1.25, indicating a very low, and thus acceptable, level of multicollinearity. Durbin-Watson test value (DW=2.2) suggested absence of relevant autocorrelation in residuals. Results of the hierarchical regression analysis are reported in Table 2.

TABLE 2 ABOUT HERE

The first step of the regression model was significant (F(4,39)=29.5, p<.001); as expected, Objective Burden was positively related to Subjective Burden, while Total Resilience was negatively related to it. The interaction term accounted for an additional 3% of the model variance (F(1,38)=5, p=.03), supporting the moderation hypothesis. The moderating effect of Total Resilience was inspected through a post-hoc simple slope analysis, illustrated in Figure 1. The interaction was probed by testing the conditional effects of Objective Burden at three levels of resilience: one standard deviation below the mean; at the mean, and one standard deviation above the mean. Objective Burden was significantly related to Subjective Burden when resilience was both below the mean (B=1.7, t=6.84, p<.001) and at the mean (B=1.21, t=5.36, p<.001), but not when it was above the mean (B=0.71, t=1.90, t=1.90, t=1.90). These results supported H1, as a buffering effect of resilience on the bivariate relationship between objective and subjective components of burden was identified.

FIGURE 1 ABOUT HERE

The Johnson-Neyman technique (Bauer & Curran, 2005) showed that the relationship between Objective and Subjective Burden was significant when resilience was lower than .94 standard deviations above the mean score. For higher resilience values, reported by 22.7% of the participants, this relationship was not significant. No gender differences emerged among participants reporting values higher or lower than this threshold (p=.35, Fisher's exact test).

¹ Detailed results are available from the corresponding author upon request

Resilience dimensions as moderators between objective and subjective burden

Since H_1 was confirmed, the same procedure was adopted in order to identify the specific role played by each resilience dimension in moderating the relationship between objective and subjective components of burden. Based on the reliability values reported in Table 1, only hypotheses referring to Family Cohesion (H_2) ; Social Resources (H_3) ; Self Perception (H_4) and Social Competence (H_5) were tested.

Therefore, four separate hierarchical regressions were performed, with Subjective Burden as criterion. Participants' gender and Mental Health were retained as control variables and inserted in Step 1 of each regression, together with Objective Burden (predictor) and, separately, the moderators. The associated interaction term followed in Step 2 of each regression. Violations of OLS requirements² were detected for the models including Family Cohesion and Social Competence. In both cases, one participant was identified as a multivariate outlier and thus excluded from the subsequent analysis. As a result, the regression models with these two dimensions as predictors included 43 participants.

Table 3 and 4 show the results of the regression analyses performed with Family Cohesion and Self Perception as predictors (H_2 and H_4 respectively).

[TABLE 3 ABOUT THERE]

[TABLE 4 ABOUT THERE]

In both models, moderators were not found to be significantly related to Subjective Burden. However, a significant R^2 change associated to Step 2, containing the interaction term derived from Family Cohesion (F(1,37)=6.55, p=.01), and Self Perception (F(1,38)=4.21, p=.047) respectively, supported the moderation hypothesis.

Post-hoc simple slope analyses were further employed to separately inspect the moderating effect of Family Cohesion (Figure 2) and Self Perception (Figure 3) on the relationship between Objective and Subjective Burden.

Objective Burden was significantly related to Subjective Burden when Family Cohesion was both one standard deviation below the mean (B=1.96, t=5.76, p<.001) and at the mean (B=1.21, t=4.91, p<.001), but not when it was one standard deviation above the mean (B=0.46, t=1.1, p=.28), in line with the hypothesized buffering effect (H_2).

[INSERT FIGURE 2 ABOUT HERE]

More specifically, the relationship between Objective and Subjective Burden was significant for values of Family Cohesion lower than .68 standard deviations above the mean. Out of 43 participants, 34.9% reported values higher than this threshold; no gender difference was detected with participants reporting lower values (p=1, Fisher)'s exact test).

As shown in Figure 3, Objective Burden was significantly related to Subjective Burden when Self Perception was both one standard deviation below the mean (B=1.74, t=6.22, p<.001) and at the mean (B=1.21, t=5.04, p<.001), but not one standard deviation above the mean (B=0.69, t=1.68, p=10.), supporting the buffering effect (H_4).

[INSERT FIGURE 3 ABOUT HERE]

More specifically, the relationship between Objective and Subjective Burden was significant for values of Self Perception lower than .85 standard deviations above the mean. Out of 44 participants, 20.5% showed values higher than this threshold; no gender difference emerged between them and participants reporting lower values (p=.33, Fisher's exact test).

In the models using Social Resources and Social Support as predictors, the contribution of the interaction term to the explained variance change was not significant (ΔR^2 =.011, F(1,38)=1.58, p=.25; and ΔR^2 =.006, F(1,37)=0.96, p=.33 respectively). Therefore, H_3 and H_5 were not confirmed.

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² Detailed results are available from the corresponding author upon request

Discussion

The purpose of this study was to investigate the relationship between resilience and caring burden in a group of Italian parents of children with ADHD. More specifically, resilience was expected to play a moderating role in the relationship between the objective component of burden (time devoted to care activities) and the subjective one (perceived developmental, physical, social and emotional strain and limitations).

The relation between subjective and objective burden was often investigated among family caregivers; results were however contradictory and sometimes difficult to compare, as burden measures differed across studies. A negligible association between subjective and objective burden was detected in family members of persons with psychiatric disorders (Potasznik & Nelson, 1984); a high correlation instead emerged in adult caregivers of persons with depression (Coyne et al., 1987); a moderate correlation was detected in family members of adults with Multiple Sclerosis (Bayen, Papeix, Pradat-Diehl, Lubetzki, & Joël, 2015), and a low correlation in partners of persons with spinal cord injury (Fekete, Tough, Siegrist, & Brinkhof, 2017).

In the present study, the first one exploring this issue among parents of children with ADHD, subjective and objective burden showed a moderately positive correlation; participants' subjective burden levels were however comparatively lower than objective burden ones. The degree of correlation between the two burden components, as well as their average values, can be interpreted taking into account the parents' double responsibility for both performing routine childrearing tasks, and dealing with the social and emotional challenges connected with the peculiar behavioral characteristics of children with ADHD. Although parenting by definition includes supporting children in daily living activities, during the performance of these tasks children with ADHD require higher attention as well as emotional and relational effort from parents, compared with their typically developing peers; across daily circumstances, parents strive to adequately manage their children's behaviors, the relationship with them and their interactions with the society. Nevertheless, the relatively low levels of the subjective component of burden compared to the objective one suggest that these participants do not experience caregiving as a substantial obstacle to their global adjustment. Demographic features that can further clarify this result comprise participants' relatively young age and related amount of psychophysical resources; the status of workers characterizing the majority of these parents, allowing them to experience a different and less emotionally demanding context during daily life; their parenting role towards other children, whose developmental progresses may represent a source of gratification and a support of their self-esteem and parental self-efficacy, counterbalancing their difficulties with the child with ADHD.

In order to better understand the relationship between the two components of burden, we investigated the role of resilience, identified as an important resource in the process of adaptation to stressful and challenging life conditions (Masten, Cutuli, Herbers & Reed, 2009; Rutter, 1987). We primarily hypothesized that resilience could represent a moderator between objective and subjective burden in parents of children with ADHD. In addition, the multidimensional model of resilience adopted in the present study (Friborg et al., 2003) allowed us to explore the contribution of different resilience dimensions to this moderating role. Results confirmed the primary hypothesis, showing that burden perception was related to participants' levels of Total Resilience. In particular, parents with resilience scores higher than .94 standard deviations above the mean were less likely to experience high subjective burden than parents with total scores below this threshold. For these participants resilience acted as a protective factor for subjective burden, weakening its relationship with objective burden. These results are consistent with the positive relationship between resilience and adaptability to stressors detected among adults (Friborg et al., 2006), older adults (Ong, Begerman, Bisconti & Wallace, 2006) and caregivers of adults with dementia (Gaugler, Kane & Newcomer, 2007) or schizophrenia (Chen, et al., 2016). In addition, they contribute with novel evidence to the scanty literature addressing these topics among caregivers of children with developmental disabilities, predominantly focused on autism (Lindsey & Barry, 2018; Weiss et al., 2013).

The relationship of resilience with burden was further explored by testing the moderating role of each of its dimensions. Planned Future and Structured Style were discarded from analysis due to unacceptable α values, also detected in other studies using the same resilience assessment scale (Friborg, Barlaug, Martinussen, Rosenvinge, & Hjemdal, 2005). A moderating role was instead detected for the dimensions of Family Cohesion and Self Perception (H_2 and H_4), that emerged as protective factors buffering parents' subjective burden in the face of objective burden. These dimensions refer to two different domains of resilience development, the family and the individual domain respectively.

Family Cohesion is a broad dimension, encompassing the components of perceived support, shared values, absence of conflict, cooperation, and relational stability in the family. Its relevance has been highlighted in ADHD research, especially for the component of family support, analyzed as a mediator between family hardiness and global family functioning (Chen, Clark, Chang, Liu, & Chang, 2014), or as an insufficient resource requiring implementation (Lange et al., 2005). Other components of family cohesion indirectly explored in parents of children with ADHD were marital problems (family conflict), significantly higher than in

parents of children without ADHD (Murphy & Barkley, 1996), and parental agreement on child rearing (referable to shared values and cooperation), showing a positive association with better marital adjustment and lower conflict levels (Harvey, 2000).

Findings from the present study contribute to the current literature by suggesting that a stable and coherent family environment, where both parents agree upon clear rules, apply them consistently over time, and provide consistent feedback (both positive and negative) to the child's behavior may represent a useful resource to effectively manage the behavioral and emotional difficulties of children with ADHD. In particular, family cohesion could be fruitfully addressed in clinical intervention programs such as Behavioral Parent Training (BPT), a treatment of choice for families of children with ADHD (Pelham, Wheeler & Chronis, 1998; Pelham & Fabiano, 2008; Zwi, Jones, Thorgaard, York, & Dennis, 2009), that provides parents with behavior modification techniques aimed at increasing positive outcomes with their children (Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004; Pelham, Wheeler, & Chronis, 1998). Although marital dissatisfaction and interparental discord were highlighted as factors potentially interfering with the long term outcomes of BPT among parents of children with ADHD (Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004), no explicit evidence is reported about the potential usefulness of reinforcing parental agreement and cooperation (Harvey, 2000).

Our findings finally suggest that specifically targeting family cohesion in BPT programs could also contribute to the promotion of parents' wellbeing, by virtue of its buffering role in the relationship between objective and subjective burden. Further research is however needed to better disentangle the role of family cohesion, as its relational nature calls for studies involving both parents or all the family members, whereas data referring to parental practices or parent-child relationships are primarily derived from only one parent, or from each parent separately (Johnston & Mash, 2001; Deault, 2010). A laudable exception is represented by a study (Harvey, 2000) evaluating mother's and father's similarities in parenting values, beliefs, and practices, and showing their positive relation with better marital adjustment, lower marital conflict and fewer comorbid disruptive behaviors in children.

Caution is instead needed in interpreting the study results concerning the resilience dimension of Self Perception, whose moderating role between subjective and objective burden was only marginally significant. A vast literature is available on the association between parents' positive self-evaluation (assessed in terms of perceived abilities and competences, in general or in relation to parenting) and their successful management of parenting tasks and difficulties. Several studies explored the positive role of parental self-efficacy in promoting parent and child adjustment was detected in both clinical and non-clinical populations (see Jones & Prinz, 2005, for a review). In the context of ADHD research, perceived self-efficacy in parenting practices (Ardelt & Eccles, 2001; Bandura, 1997) was associated with higher expectations about the effectiveness of behavioral strategies suggested by clinicians to manage child conducts (Johnston, Mah, & Regambal, 2010; Jiang, Gurm, & Johnston, 2014). In the same vein, low parenting efficacy in fathers and low self-esteem in mothers were associated with worse child treatment outcome (Hoza et al., 2000). Overall, these findings suggest the usefulness of promoting parents' self-efficacy through a careful evaluation of the congruence between objective abilities and perception of possessing them (Bandura, 1997). In the context of this literature, the only marginal buffering role played by Self-Perception against burden in our study could be related to the still limited knowledge and awareness of the participants - not yet enrolled in Parent Training programs - about the resources they could mobilize to more effectively manage their child's problems. Longitudinal studies could better elucidate this aspect, by exploring variations in the moderating role of Self Perception between objective and subjective burden over time, taking into account child treatment evolution and parents' exposure to training programs.

Differently from our expectations, the two resilience dimensions of Social Competence and Social Resources did not moderate the relationship between objective and subjective burden. These dimensions reflect different aspects of the person's interaction with the social context. Social Competence refers to the individual's flexibility in social interactions and disposition toward social relations; Social Resources instead refers to the perception of support from other persons or social networks outside the family. Previous studies with caregivers (including parents of children with ADHD) highlighted a significantly negative association between social support and distress (Lindsey & Barry, 2018; Theule et al., 2011); the specific role of social support as a moderator between objective and subjective burden was however not investigated yet. Nevertheless, research evidence attests to the difficulties faced by families of children with ADHD in the interaction with their social environment, including stigma and discredit of their parental competences due to their children's inability to fit into social norms (Mueller, Fuermaier, Koerts, & Tucha, 2012), leading to a relative isolation of these families within the social context. These findings contribute to explain the irrelevance of the social dimensions of resilience in moderating the relationship between burden components, detected in our study. Due to the remarkable consequences of this situation for families' well-being and social integration, additional research efforts are required to better understand the relationship between perceived social resources, social competence and self-perception among families of children with ADHD. Related findings could also help verify the

moderating role of self-perception in the relationship between objective and subjective burden, vis-à-vis the absence of such role for social support, and clarify the underlying mechanisms.

In the present study, parents' gender and mental health level were taken into account as control variables, based on their significant correlations with subjective burden. Gender showed a low association with Subjective Burden, with mothers reporting higher values than fathers. This result is consistent with other studies involving parents of children with autism spectrum disorders (Picardi et al., 2018), even though it should be interpreted with caution, due to the low percentage of fathers included in our sample (18.2%). It is however worth noting that worldwide women represent the vast majority of caregiving parents, for children with ADHD (e.g. Theule et al., 2011) and other disabilities (Negri, Piazza, Sartori, Cocchi, & Delle Fave, 2018). With regard to Mental Health, in line with other studies (Bayen, et al., 2015; Fekete, et al., 2017), it was negatively correlated with Subjective Burden, and not significantly associated with Objective Burden. Participants did not differ from the Italian normative sample in mental health levels, in line with studies suggesting that, in spite of increased stress levels, the risk of developing poor mental health in families of children with disabilities may not be as high as expected (Emerson, et al., 2010; Montes & Halterman, 2007).

Strengths, limitations, and future directions

Taken together, findings from the present study underscore the role of both individual and family resources in parents' adjustment to the burden of caring for a child with ADHD. To the best of our knowledge, no study had previously investigated subjective and objective burden separately, as well as in conjunction with resilience, in this specific population. Although the lack of previous evidence prevents from drawing comparisons, these results can pave the way to future research on this specific topic. Overall, the findings suggest the usefulness of complementing research on parental stress and difficulties with the investigation of individual and family resources and protective factors, that can promote caregivers' wellbeing and family adjustment. At the clinical level, these dimensions can be implemented both as protective factors in prevention programs, and as resources contributing to the effectiveness of parent training protocols, beyond child symptom control (Heath, Curtis, Fan & McPherson, 2015; Tarver, Daley, & Sayal, 2015).

Despite its innovative aspects, this study has several limitations. The sample size was small and imbalanced as concerns gender. Participants and their children attended two Italian rehabilitation institutions representing positive models of integrated care. Therefore, results cannot be generalized and further investigation is required, involving users of different typologies of healthcare services. Another study limitation concerns the age of participants' children, all attending primary or secondary school. As age related changes in ADHD clinical manifestations pose specific challenges to caregivers (Cadman et al. 2012; DuPaul, McGoey, Eckert, & VanBrakle, 2001; Harpin, 2005), it would be important to investigate caregiving burden and its relation with resilience in parents of younger and older children. Finally, the cross-sectional study design does not provide evidence of directionality and causality between the examined variables. Longitudinal studies with larger samples are needed to this purpose.

As concerns future research directions, the investigation of the relationship between child and family features, dimensions of caregiver burden, and dimensions of resilience could provide useful suggestions to practitioners, helping them broaden and strengthen the support offered to children with ADHD and their families. The promotion of caregivers' awareness and mobilization of individual and family resources could represent a useful implementation of parent training programs, allowing families to more effectively manage ADHD related challenges.

Funding: This work was financially supported by Italian Ministry of Health (Ricerca Corrente 017/14).

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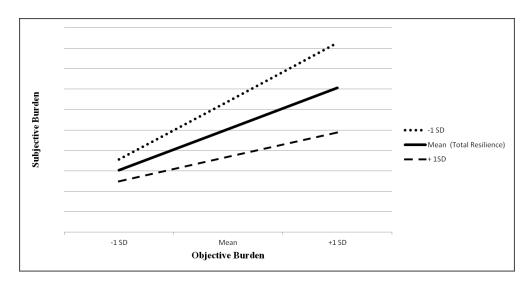


Figure 1. Simple slopes predicting Subjective Burden from Objective Burden at three levels of Total Resilience

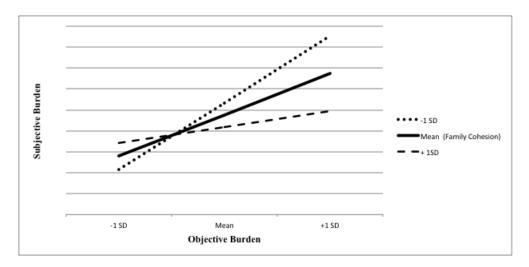


Figure 2. Simple slopes predicting Subjective Burden from Objective Burden at three levels of Family Cohesion.

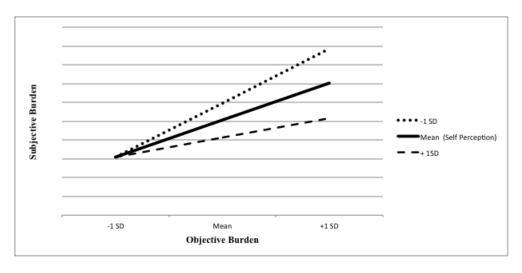


Figure 3. Simple slopes predicting Subjective Burden from Objective Burden at three levels of Self Perception.

Table 1. Descriptive statistics and correlation indices among study measures.

(N=44)	α	M	SD	Range	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.
Participant gender	-	-	-	0-1	-														
2. Participant age	-	41.05	5.38	31-53	19ª	-													
3. Employment	-	-	-	0-1	26 ^b	02ª	-												
4. Level of education	-	-	-	0-2	.01°	14 ^d	15¢	-											
5. Number of children	-	2.2	0.88	1-5	09ª	.03	18ª	.14 ^d	-										
6. Child age	-	9.86	2.29	6-14	24ª	.38*	.18ª	15 ^d	.23	-									
7. Child gender	-	-	-	0-1	31*b	00ª	02 ^b	.07c	02ª	$.02^{a}$	-								
8. Mental Health	.81	70.27	15.03	36–96	36*	.08	.18a	.14 ^d	.01	.35*	.08	-							
9. Objective Burden	.72	5.82	3.35	0-17	.01ª	.14	25a	03d	.04	06	18	19	-						
10. Subjective Burden	.88	10.25	8.99	0-40	.34**	13	15ª	06d	00	29	20	64**	.62**	-					
11. Total Resilience	.90	128.98	15.78	94–154	13ª	.08	.01ª	00 ^d	.07	.02	03	.45**	10	51**	-				
12. Family Cohesion	.83	24.59	4.17	15-30	07ª	.02	03ª	.13 ^d	02	09	.07	.42**	23	48**	.74**	-			
13. Social Resources	.85	30.31	4.33	18-35	09ª	00	.04ª	.16 ^d	.06	08	01	.38*	16	48**	.87**	.75**	-		
14. Self Perception	.75	21.77	4.44	9–28	32*	02	.11ª	02 ^d	.18	.16	.10	.42**	08	45**	.72**	.33*	.47**	-	
15. Social Competence	.85	24.25	4.33	12-30	.03ª	.18	02ª	12 ^d	01	04	25	.11	.23	15	.71**	.37*	.55**	.32*	-
16. Planned Future	.63	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
17. Structured Style	.30	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Note. Participant gender: 0=male, 1=female; Employment: 0=not employed, 1=employed; Level of education: 0=middle school diploma, 1=high school diploma, 2=college degree; Child gender: 0=male, 1=female; α= Cronbach alpha reliability index; M=mean; SD=standard deviation; ²=point biserial correlation; ^b=tetrachoric correlation; ^c=rank biserial correlation; ^d=Spearman rank correlation; Where not otherwise indicated, Pearson correlation indices are reported; *p<05; **p<01;

Table 2. Moderation analysis (Total Resilience)

N=44				Subjective Burden (SB)				
Variable	В	SE B	β	t	ΔR^2	p		
Step 1					.33	<.001		
Gender	4.12	1.98	.18	2.09		.04		
Mental Health	-0.21	0.06	35	-3.64		.001		
Objective Burden (OB)	1.40	0.22	.52	6.40		<.001		
Total Resilience	-0.160	0.05	28	-3.15		.003		
Step 2					.03	.03		
Gender	3.90	1.88	.17	2.08		.04		
Mental Health	-0.21	0.05	36	-3.88		<.001		
Objective Burden (OB)	1.21	0.22	.45	5.36		<.001		
Total Resilience	-0.17	0.05	30	-3.54		.001		
OB x Total Resilience	-0.03	0.01	-0.18	-2.23		.03		

Table 3. Moderation analysis (Family Cohesion)

N=43				Subjective Burden (SB)			
Variable	В	SE B	β	t	ΔR^2	p	
Step 1					.29	<.001	
Gender	4.17	2.16	.18	1.93		.06	
Mental Health	-0.24	0.06	41	-3.85		<.001	
Objective Burden	1.34	0.26	.48	5.22		<.001	
Family Cohesion	38	.24	17	-1.62		.12	
Step 2					.04	.01	
Gender	3.38	2.04	15	1.65		.11	
Mental Health	-0.25	0.06	42	-4.28		<.001	
Objective Burden (OB)	1.21	0.25	.43	4.91		<.001	
Family Cohesion (FC)	-0.29	0.22	13	-1.32		.20	
OB x FC	-0.19	0.07	22	-2.56		.01	

Table 4. Moderation analysis (Self Perception)

N=44	Subjective Burden (SB)					
Variable	В	SE B	β	t	ΔR^2	p
Step 1					.29	<.001
Gender	3.05	2.15	.132	1.42		.16
Mental Health	25	0.06	41	-4.17		<.001
Objective Burden (OB)	1.40	0.23	.52	5.99		<.001
Self Perception (SP)	-0.38	0.19	19	-1.97		.06
Step 2					.03	.047
Gender	2.58	2.08	.11	1.24		.22
Mental Health	-0.26	0.06	44	-4.57		<.001
Objective Burden (OB)	1.22	0.24	.45	5.04		<.001
Self Perception (SP)	-0.38	0.19	19	-2.02		.05
OB x SP	-0.12	0.06	18	-2.05		.047