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ORIGINAL PAPER

The Applicability of the “Revised Burden Measure” in Pediatric Settings: Measuring Parents’ Caregiving Burdens and Uplifts

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Abstract
In pediatric settings, a valid and reliable assessment of negative and positive dimensions of caregiving can inform intervention processes and improve parent–child adaptation outcomes. While caregiving is a normative component of parenting, the experience can be quantitatively and/or qualitatively different for parents of children with a chronic health condition. The aim of this study was to systematically examine the psychometric properties of the “Revised Burden Measure” in a sample of parents of children with and without chronic health conditions. The “Revised Burden Measure” and self-reported measures of quality of life and mental health were administered to a sample of parents who had children with ($n = 277$) or without ($n = 117$) chronic health conditions. Classical test theory, item response theory, multi-group confirmatory factor analysis, and multivariate and univariate analyses of covariance were conducted to investigate the reliability and validity of the instrument. The “Revised Burden Measure” was shown to have good reliability, as well as criterion and known-groups validity. The data showed minor DIF by children’s health status. Confirmatory factor analyses revealed a second-order model of caregiving burden (with Relationship, Objective and Subjective burdens loading on Overall Burden) and the construct validity of the complementary Uplifts subscale. Additionally, multi-group analyses ascertained the measurement and structural invariance of the model by children’s health status. The results generally confirm the reliability and validity of the “Revised Burden Measure” and demonstrate its overall clinical and developmental applicability in pediatric settings.

Keywords Caregiving burden · Caregiving uplifts · Children and adolescents · Chronic health conditions · psychometrics

Highlights

- The “Revised Burden Measure” is a valid and reliable measure for use in pediatric settings.
- This clinically informative instrument is easy to administer, score and interpret.
- The “Revised Burden Measure” enables a comprehensive assessment of negative and positive dimensions of caregiving.
- This measure may be used to assess the caregiving experience of parents who have children with or without chronic conditions.
- The instrument is recommended for the assessment of caregiver’s burdens and uplifts across different life-span periods.

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Abbreviations

AVE	Average variance extracted
CFA	Confirmatory factor analysis
CFI	Comparative fit index
CR	Composite reliability
CRDIFF	Critical ratios of difference between parameters
df	Degrees of freedom
DIF	Differential item functioning
IRT	Item Response Theory
ISR	Item Separation Reliability
MH	Mantel-Haenszel
PSR	Person Separation Reliability
QoL	Quality of life
RMSEA	Root mean square error of approximation
SES	Socioeconomic status
SRMR	Standardized root mean squared residual

Caregiving is a universal component of human relations that involves the motives and behavior to care for, look after, and provide resources for others, especially kin (Gilbert 1998). While caring is the affective component of one's commitment to the well-being of another, caregiving may be regarded as the behavioral demonstration of that commitment, thus being present in all relationships where people intend to protect or improve each other's welfare, as in parent-child relationships (Pearlin et al. 1990). However, under challenging circumstances, such as caring for a child with a chronic health condition, the amount and quality of care provided often exceed the pattern of assistance that is typically required of parents. In such contexts, the expression "caregiving burden" has been coined to encompass the physical, psychological, social and financial strains experienced by individuals who care for family members with special healthcare needs (George and Gwyther 1986).

Over the past three decades, caregiving burden has emerged as a crucial focus of psychosocial and health economic research. This trend reflects an increase in the prevalence of caregivers due to extended life expectancy for the chronically ill and the prevalence of chronic health conditions across the life-span, including childhood-onset disabilities. Additionally, complex changes in health care, such as deinstitutionalization and technological advances have required families to engage in more complex and demanding care tasks (Pearlin et al. 1990; Raina et al. 2004; Sales 2003).

To date, the most extensive and comprehensive studies of caregiving burden have focused on family members caring for Alzheimer's patients and adults with severe mental illness (Sales 2003). The challenges of family caregiving, however, have gained more attention in pediatric settings as the number and prevalence of chronic health conditions among children have increased and as treatments have become available and extended the life expectancy for persons with these conditions (Bruil and Detmar 2005). For example, it has been estimated that nearly 10% of children have some developmental disorder that requires extensive caregiving that can often extend through childhood into adulthood (Raina et al. 2004). At the same time, recent reviews point to an overall prevalence of 15–20% of chronic conditions in childhood and adolescence (Jin et al. 2017). Consequently, theoretical frameworks from the distinct fields of pediatrics and geriatrics were integrated effectively into comprehensive conceptual models to broadly guide research and practice on caregiving burden assessment (Raina et al. 2004).

As traditional outcomes, such as symptom reduction, and improved life expectancy, became insufficient for assessing medical outcomes and the processes of care, the consideration of patient-oriented markers became warranted (Gerharz et al. 2003). Therefore, developmental contexts and multidimensional outcomes emerged as crucial targets for pediatric assessment and intervention routines (Christakis et al. 2001), specially within a parent-child perspective (Carona 2013). Given the fact that caregiving burden is a major determinant of parent-child adaptation outcomes (e.g., quality of life [QoL], psychological adjustment), both in pediatric and normative populations (e.g., Carona et al. 2013, 2014; Raina et al. 2005; Wallander et al. 1989), there is a need to supply pediatric healthcare providers with multidimensional instruments that can help assess complex areas of burden (Chou et al. 2003). Reliable and valid assessment tools will enable more accurate planning and implementation of interventions that can prevent or attenuate the deleterious effects of caregiving burden on parents and their children with chronic health conditions. Equally important, identification and measurement of commonly ignored positive dimensions of caregiving (e.g., gratifications associated with giving care) (Sales 2003), will enhance professionals' understanding of the family caregivers' experience and help them identify and promote the development of internal resources that are often overlooked in intervention processes.

In general, stressors in the context of family caregiving have been defined as "the problematic conditions and difficult circumstances experienced by caregivers (i.e., the demands and obstacles that exceed or push to the limit one's ca pa city to adapt)" (Aneshensel et al. 1995, p. 34). While the term "caregiver burden" is widely applied to the stressful experiences of caregiving, a variety of terms have been used to label and describe negative experiences linked with caregiving including: "strain of illness" (Townsend 1957), "chronic parenting stress" (Quittner et al. 1990), "role strain" (Quittner et al. 1992), "handicap-related problems" (Wallander and Marullo 1997), "family burden"

(Sales 2003), “caregiver strain/stress” (Raina et al. 2004), and “caregiving demands” (Klassen et al. 2010).

In recent years, as professionals have attempted to provide appropriate support to caregivers, the term “caregiver burden” has been used as an indicator of the caregiving experience despite vague and inconsistent definitions of the concept (Bastawrous 2013). For the most part, however, research has largely failed to provide robust empirical support for the link between caregiver support services and reduction of caregiver stress (Montgomery and Kosloski 2013). This lack of evidence highlights the need to improve the measurement of caregiver burden and articulate the implications of caregivers’ scores for clinical practice and relevance to policy making (cf. Bastawrous 2013).

In contrast to many measures of caregiver stress, caregiver burden as conceptualized and measured by the Revised Burden Measure is a multidimensional construct, encompassing tension and anxiety (subjective burden), changes in dyadic relationships (relationship burden), and time constraints (objective burden) resulting from caregiving (Savundranayagam et al. 2011). The Revised Burden Measure is an enhanced version of the Montgomery-Burden Scale originally used to examine caregiver burden among caregivers of older adult s (Montgomery et al. 1985). Findings from this study made a decisive contribution to the literatures as it rejected caregiver burden as a unidimensional concept by distinguishing two types of burden that could be predicted by different factors. Objective burden captures caregivers’ sense that performance of care tasks infringes on their time and ability to engage in other activities and responsibilities. Stress burden captures the emotional strains associated with caregiving. The instrument was later renamed as the “Montgomery-Borgatta Caregiver Burden Scale” and submitted to an exploratory factor analysis that revealed a new structure with three distinct subscales (Montgomery et al. 2000). The new subscale captured the extent to which the caregivers perceive a care recipient’s demands for care to be over and above to what the caregiver perceives to be warranted. Consequently, the Burden measure was enhanced to reliably measure all three dimensions of caregiver burden: Objective burden, Subjective Burden and Relationship Burden.

The current Revised Burden Measure (Montgomery and Kosloski 2006) also integrates items that capture the positive psychological states (e.g., direct enjoyment from tasks, improved relationship with the care receiver, general positive affect) derived from caregiving responsibilities. These items are included in a complementary Uplifts scale. The Uplifts scale is theoretically aligned with the acknowledgement of the adaptive role of co-occurring positive emotions in stress processes. The positive aspects not only sustain the coping efforts under stressful situations but also facilitate the development of personal meaning attributed to those efforts (Folkman 1997; Folkman and Moskowitz 2000). The subscale is scored independently from the three burden subscales and provides a more comprehensive view of the caregiving experience. The importance of this distinction is well acknowledged in three reviews of caregiving burden measures (Bastawrous 2013; Chou et al. 2003; Vitaliano et al. 1991), which also commented other major strengths of the scale, namely its contribution in extending the conceptualization and measurement of burden, by encouraging researchers to approach burden as a product of a dyadic interaction that is best understood over time. Limitations of the instrument, on the other hand, included the lack of examination of its criterion validity; the conduct of minimal research with an unpublished inventory that stood with no manual; low internal consistency values for the objective and subjective burden subscales; and the absence of research on the scales’ susceptibilities to deceptive response (Chou et al. 2003).

Over the last decade, valuable efforts have been made to lessen those limitations. First, criterion validity (and specifically, concurrent validity) has been explored, with subjective burden correlating moderately with caregivers’ self-rated health status (Savundranayagam et al. 2011). Second, a brief manual for a previous version of the instrument has been made easily accessible for the wider audience (Montgomery 2006; for additional information, upon request: Montgomery and Kosloski 2006), and a manual for the Portuguese version was published as a book chapter in an anthology of psychological assessment instruments for clinical and health psychology (Gonçalves et al. 2017). Third, the instrument has been used in a number of studies within psychosocial pediatrics research (family caregivers of youths with chronic health conditions), systematically revealing adequate to excellent internal consistency values (e.g., Carona et al. 2012, 2013, 2014; Silva et al. 2015a, b).

The aim of this study was to systematically examine the psychometric properties of the “Revised Burden Measure” in a sample of parents of children with and without chronic health conditions. Although the original version of the Revised Burden Measure was developed and tested in geriatric contexts, the authors acknowledged that children are the most prevalent group of dependents, with mothers usually being the main responsible for general nurturing and care, as well as for the special care required by children with chronic conditions or disabilities (Montgomery et al. 2000). Considering this, the main goal of this study was to demonstrate the applicability of the “Revised Burden Measure” in normative parenting and pediatric contexts by testing its psychometric properties in a Portuguese sample of parents of children with and without chronic medical conditions.

Specifically, this study aimed to examine: (1) the differential item functioning (DIF) by children's health status (i.e., parents of healthy children *vs*. parents of children with chronic medical conditions); (2) the reliability of the questionnaire; (3) the original correlated four-factor model of the Revised Burden Measure, as well as an alternative second-order model of caregiving burden, and its invariance by children's health status, through confirmatory factor analysis (CFA); (4) its concurrent validity with parents' QoL and psychological distress and well-being as indicators of their overall psychosocial adaptation; and (5) known-groups validity with regard to the care receiver's health status.

Method

Participants and Procedure

The participants were 394 parents of a child/adolescent between 8 and 18 years of age, with asthma ($n = 115$), cerebral palsy ($n = 95$), epilepsy ($n = 67$), or no medical conditions ($n = 117$). Parents of children with chronic health conditions were enrolled at the pediatric outpatient services of three Portuguese public hospitals and ten Portuguese Cerebral Palsy Associations, between March 2009 and July 2011, after the study has been approved by the respective Ethics Committees and/or Direction Boards. To be included in the clinical group, the parents had to meet the following criteria: (1) having a child aged between 8 and 18 years old, with a clinical diagnosis of asthma, cerebral palsy or epilepsy established by a physician according to the International Classification of Diseases system (ICD-10), and no comorbidities with other health conditions; and (2) being the parent self-identified as currently assuming the role of primary caregiver for the child's disease management. Cases that met the inclusion criteria were identified by health professionals, based on the children's clinical records. Adopting a non-probabilistic convenience sampling method, detailed information about the study's aims and procedures was provided to all eligible parents who visited the health institution during the period of data collection. After obtaining informed consent from those who agreed to participate in the study, the parents completed a set of self-report questionnaires in a room assigned for research purposes, with the assistance of a psychologist or social worker acquainted with the research project.

Parents of healthy children/adolescents were recruited by convenience in two public schools of the district of Coimbra, between January and June 2010, considering two inclusion criteria: (1) having a child aged between 8 and 18 years old with no chronic health condition or disability; and (2) being the parent who spent more daily time with the child/adolescent. After the Direction Boards of participating schools had authorized the study, selected classes were visited by a researcher, who delivered informed consent forms and assessment protocols to students, to be completed by their parents at home and returned to schools a week later.

The parents' and their children's sociodemographic and clinical characteristics are presented in Table 1.

No significant differences in socio-demographic characteristics were observed between parents of healthy children and parents of children with chronic health conditions, except for socioeconomic status (SES), with a higher percentage of parents with low SES in the clinical group. Children's age and sex were also homogeneously distributed across healthy and clinical samples.

Measures

Revised Burden Measure

The Revised Burden Measure (Montgomery and Kosloski 2006) is a self-report questionnaire that includes distinct but complementary Burden and Uplifts measures. For both measures, respondents were asked to indicate the extent to which various aspects of their lives have changed due to caregiving ("As a result of assisting the care receiver, have the following aspects of your life changed?"). The Burden measure comprises 16 items focused on changes in parent-child relationships (Relationship Burden; 5 items; e.g., "Have your caregiving responsibilities caused conflicts with your relative?"), time constraints resulting from instrumental caregiving activities (Objective Burden; 6 items; e.g., "Have your caregiving responsibilities left you with almost no time to relax?") and generalized negative affect (Subjective Burden; 5 items; e.g., "Have your caregiving responsibilities created a feeling of hopelessness?"). CFA attested this multi-dimensional structure of the caregiving burden construct, as well as its invariance across different groups of caregivers, namely spouses and adult children of patients with chronic illnesses (Savundranayagam et al. 2011). Complementarily, the Uplifts measure comprises six items assessing gratifications and positive psychological states arising from caregiving, namely the direct enjoyment from caregiving tasks, an improved relationship with the care receiver and generalized positive affect (e.g., "Have your caregiving responsibilities given your life more meaning?"). The 22 items were answered in a 5-point response scale ranging from 1 (*Not at all*) to 5 (*A great deal*). Mean scores were calculated for each burden dimension and for uplifts, with higher scores indicating a greater change in those negative or positive dimensions of caregiving.

Table 1 Socio-demographic and clinical characteristics of the sample ($N = 394$)

		Healthy group ($n = 117$)	Clinical group ($n = 277$)	Differences between groups
Parents' sociodemographic characteristics				
Age, *M* (*DP*)		42.78 (5.18)	41.76 (6.24)	$t_{(391)} = 1.55$
Sex, *n* (%)	Female	95 (81.2%)	243 (87.7%)	$\chi^2_{(1)} = 3.20$
	Male	22 (18.8%)	33 (11.9%)	
	Missing	0 (0%)	1 (0.4%)	
Marital status, *n* (%)	Married/living together	100 (85.5%)	225 (81.2%)	$\chi^2_{(1)} = 0.66$
	Single/divorced/widowed	17 (14.5%)	49 (17.7%)	
	Missing	0 (0%)	3 (1.1%)	
Socioeconomic status, *n* (%)	Low	31 (26.5%)	168 (60.6%)	$\chi^2_{(1)} = 41.22$**
	Medium/high	86 (73.5%)	103 (37.2%)	
	Missing	0 (0%)	6 (2.2%)	
Children/adolescents' sociodemographic and clinical characteristics				
Age, *M* (*DP*)		12.31 (2.97)	12.34 (2.79)	$t_{(391)} = -0.11$
Age-group, *n* (%)	Child 8–12 years	61 (52.1%)	141 (50.9%)	$\chi^2_{(1)} = 0.05$
	Adolescent 13–18 years	56 (47.9%)	136 (49.1%)	
Sex, *n* (%)	Female	58 (49.6%)	120 (43.3%)	$\chi^2_{(1)} = 1.30$
	Male	59 (50.4%)	157 (56.7%)	
Diagnosis, *n* (%)	Asthma	–	115 (41.5%)	–
	Epilepsy	–	67 (24.2%)	–
	Cerebral palsy	–	95 (34.3%)	–
Age at the time of diagnosis, *M* (*DP*)		–	5.77 (4.21)	–
Disease length, *M* (*DP*)		–	7.14 (4.35)	–
Medication intake, *n* (%)		–	195 (70.4%)	–
	Missing	–	6 (2.2%)	–
Hospital admissions in the last year, *n* (%)		–	30 (10.8%)	–
	Missing	–	10 (3.6%)	–

*$p < 0.05$; **$p < 0.01$, two-tailed

EUROHIS-QOL 8-item index

The EUROHIS-QOL 8-item index (Schmidt et al. 2006; Portuguese version: Pereira et al. 2011) was used to assess parents' QoL. This self-report questionnaire was derived from the World Health Organization Quality of Life Assessment (WHOQOL-100 and WHOQOL-Bref instruments) and includes eight items representing the physical (e.g., "Do you have enough energy for everyday life?"), psychological (e.g., "How satisfied are you with yourself?"), social (e.g., "How satisfied are you with your personal relationships?"), and environmental (e.g., "How satisfied are you with the conditions of your living place?") domains of QoL. The eight items were scored on a 5-point response scale ranging from 1 (*Not at all/Very dissatisfied*) to 5 (*Completely/Very satisfied*). A standardized overall QoL score ranging from 0 to 100 was computed from the sum of the eight items, with higher values indicating better QoL. In the current sample, the questionnaire presented good reliability, with a Cronbach's alpha coefficient of .82.

Five-item version of the Mental Health Inventory (MHI-5)

Parents' psychological distress and wellbeing were assessed with the Mental Health Inventory (MHI-5; Veit and Ware 1983; Portuguese version: Pais-Ribeiro 2001). The MHI-5 consisted of five items that focused on the psychological symptoms of depression, anxiety, loss of emotional and behavioral control, and positive affect. The five items were answered in a 6-point response scale ranging from 1 (*None of the time*) to 6 (*All of the time*), allowing the computation of mean scores for Psychological Distress (three items) and Psychological Well-being (two items). In the current sample, good reliability was observed for both Psychological Distress and Psychological Well-being dimensions, with Cronbach's alpha coefficients of 0.88 and 0.78, respectively.

Socio-demographic and clinical data

The parents also completed a socio-demographic datasheet, which collected information on their age, sex, marital status, educational level and occupational status, as well as their children's age and sex. Using a classification system specifically developed for the Portuguese context and based on the educational level and current job of the primary caregiver (Simões 1994), the family SES was classified into low (e.g., unqualified employees in construction or manufacturing without completing the 9th grade of school education) and medium/high (e.g., officials of government, army, commerce or industry, with intermediate or university courses). Parents of children with chronic health conditions also provided information on their child's diagnosis, age at the time of diagnosis, comorbidities with other health conditions, use of medication and hospital admissions during the last year.

Statistical Analyses

The statistical analyses were performed with the Statistical Package for the Social Sciences, v.20 (IBM Corp., Armonk, NY). Descriptive statistics were calculated for socio-demographic and clinical variables and the homogeneity of sample characteristics between healthy and clinical groups was examined by independent-samples *t*-tests or chi-square (χ^2) tests for continuous and categorical variables, respectively. The distributional characteristics of items and domains were examined by calculating mean values (*M*) and standard-deviations (*SD*), percentage of missing values, floor and ceiling effects and skewness and kurtosis in the distributions of scores. Missing data, which were random and lower than 5% of the values, were handled by replacement with the individual mean score for each scale.

The Winsteps software (version 3.69.1.6; Linacre 2011) was used to conduct the analyses regarding DIF, i.e., whether the items performed equally across parents of healthy children and parents of children with chronic health conditions. DIF was evaluated by applying the Mantel–Haenszel (MH) approach using the criteria derived of the Educational Testing Service (Padilla et al. 2012). First, the delta MH (Δ_{MH}) was computed by multiplying the difference in item location estimates between the groups by −2.35 (Holland and Thayer 1988). Based on the proposal of Zwick and Ercikan (1989), DIF was classified as follows: negligible (A) if $|\Delta_{MH}|$ was less than 1 and $p < 0.05$; moderate (B) if $|\Delta_{MH}|$ was between 1 and 1.5 and $p < 0.05$; and large (C) if $|\Delta_{MH}|$ was >1.5 and $p < 0.05$. DIF was also considered to be substantial if there was one absolute difference >0.5 logit and statistical significance between the difficulty parameters of the reference and focal groups (Prieto et al. 2010).

The reliability of the Revised Burden Measure was examined using classical test theory (i.e., Cronbach's α) and Item Response Theory (IRT: Person Separation Reliability [PSR], and Item Separation Reliability [ISR]). PSR and ISR statistics (range: 0–1) are similar to the classical reliability coefficient, and values above 0.70 are recommended (Tennant and Conaghan 2007).

The factor structure of the Revised Burden Measure was examined with CFA, using the Analysis of Moment Structures, v.20 (AMOS Development Corporation, Meadville, PA). The models' goodness-of-fit was assessed based on the maximum-likelihood χ^2 statistic, the comparative fit index (CFI), the root mean square error of approximation (RMSEA) and the standardized root mean squared residual (SRMR). A model was considered to have a good fit when CFI ≥ 0.95, RMSEA ≤ 0.06 ($p > 0.05$) and SRMR ≤ 0.08, and was considered to have an acceptable fit when CFI ≥ 0.90 and RMSEA ≤ 0.10 (Browne and Cudeck 1993; Hu and Bentler 1999). Complementarily, a χ^2/degrees of freedom (*df*) ratio of 5 or less was assumed as indicative of acceptable model fit (Ullman 1996). The factorial validity was evaluated based on the significance and strength of standardized factor loadings (λ), assuming that the factor had good factorial validity if λ ≥ 0.05 for all items. Convergent validity (i.e., the extent to which indicators of a specific latent construct share a high proportion of variance) was established when the average variance extracted (AVE) for the items loading on a latent construct, as calculated from the sum of λ^2 divided by the sum of λ^2 and error terms, was 0.50 or greater (Hair et al. 2010). Discriminant validity (i.e., the extent to which a latent construct is able to account for more variance in the observed variables associated with it than measurement error or other constructs within the model; Farrell and Rudd 2009) was supported when the AVE for each factor was greater than its shared variance with any other construct (Fornell and Larcker 1981). In addition, construct reliability was assessed using the composite reliability (CR) value calculated from the squared sum of λ divided by the squared sum of λ plus the sum of the error variance terms. Good construct reliability was established if CR was higher than 0.70 (Hair et al. 2010).

The factorial invariance of the models across children's health status was tested with multi-group analyses comparing the unconstrained model with a model in which factor loadings (measurement invariance) and structural weights (structural invariance) were constrained to be equal across groups (Byrne 2010). The model's invariance was established when the chi-square difference ($\Delta\chi^2$) was non-significant, and the difference in CFI values (ΔCFI) was lower than 0.01 (Cheung and Rensvold 2002). Critical ratios of differences (CRDIFF) between parameters were also examined, considering an absolute CRDIFF >1.96 ($p < 0.05$)

as indicative of significant differences in unstandardized factor loadings between the groups.

Concurrent validity was examined by calculating Pearson correlation coefficients between the Revised Burden Measure and previously validated measures of parents' overall psychosocial adaptation, namely the EUROHIS-QOL 8-item index and the MHI-5. Regarding known-groups validity, a multivariate analysis of covariance (MANCOVA) was performed to compare the scores in burden dimensions (i.e., Relationship Burden, Objective Burden, and Subjective Burden) and univariate analyses of covariance (ANCOVA) were conducted to compare the scores in the burden total score and Uplifts between parents of healthy children and parents of children with chronic medical conditions, while controlling for SES. When multivariate effects were significant, univariate analyses were performed to examine which dimensions of caregiving burden significantly differed between the groups.

Results

Descriptive Statistics

Table 2 presents an overview of distributional characteristics of items and domains for the Revised Burden Measure. The percentage of missing values per item ranged from 0.0 to 1.5%. Floor or ceiling effects were detected for the majority of items (i.e., more than 15% of respondents achieved the lowest or highest possible score, respectively; Terwee et al. 2007). However, no floor or ceiling effects were observed across dimensions or for the Burden total score, indicating good content validity, except for a floor effect in the Relationship Burden dimension. No substantial departures from normality were observed in the distribution of items and dimensions, considering an absolute skew coefficient > 2 and an absolute kurtosis coefficient > 7 as reference values for samples with more than 300 participants (West et al. 1995).

Differential Item Functioning

The results of DIF analyses, conducted to explore the likelihood that individual items of the Revised Burden Measure may work differently for parents of children with different health status (i.e., healthy children *vs*. children with chronic health conditions), are presented in Table 3. The data showed minor DIF by children's health status. Four out of 22 items (9.1%) showed significant DIF (i.e., contrast > 0.50 logits and probability $p < 0.05$). Three items (H, K, and T) were more difficult to answer by parents of healthy children, while one item (P) was more difficult for parents of children with chronic health conditions. Considering the value of Δ_{MH}, five items showed moderate DIF and two items showed large DIF. Both of the items showing large DIF (item D—"Have your caregiving responsibilities given your life more meaning?", and item P—"Have your caregiving responsibilities left you feeling good?") are part of the Uplifts measure and were more difficult to answer by parents of children with chronic health conditions.

Reliability

The internal consistency of the Revised Burden Measure was good whether using classical test theory (α = 0.83 for Relationship Burden; α = 0.87 for Objective Burden; α = 0.87 for Subjective Burden; and α = 0.81 for Uplifts) or separation reliability in IRT (PSR = 0.60 for Relationship Burden; PSR = 0.77 for Objective Burden; PSR = 0.79 for Subjective Burden; PSR = 0.78 for Uplifts; ISR = 0.91 for Relationship Burden; ISR = 0.98 for Objective Burden; ISR = 0.99 for Subjective Burden; ISR = 0.93 for Uplifts). Cronbach's α for the Burden total score was 0.92. The PSR and ISR coefficients were 0.83 and 0.98, respectively, for the Burden total score.

Confirmatory Factor Analysis (CFA)

The initial correlated four-factor model

The original correlated four-factor (Relationship Burden, Objective Burden, Subjective Burden, Uplifts) model of the Revised Burden Measure had a nearly acceptable fit to the parents' data, with $\chi^2_{(203)} = 679.98$, $p < 0.01$; $\chi^2/df = 3.35$; CFI = 0.89; RMSEA = 0.08 ($p < 0.01$; 90% CI = 0.07/0.08); and SRMR = 0.07. The inspection of modification indices suggested that items T and V might be correlated. Because these two items were hypothesized to load on the same latent factor (Uplifts) and they both refer to the caregiver's satisfaction of being with/ spending time with the care receiver, their measurement errors were allowed to covary. The modified model had an acceptable fit, with $\chi^2_{(202)} = 578.59$, $p < 0.01$; $\chi^2/df = 2.86$; CFI = 0.91; RMSEA = 0.07 ($p < 0.01$; 90% CI = 0.06/0.08); and SRMR = 0.06, which was significantly better than the original model, with $\Delta\chi^2_{(1)} = 101.39$, $p < 0.01$. All factor loadings were statistically significant and, except for item T, were above the threshold of 0.50 (λ ranging from 0.36 to 0.86).

The AVE for each burden factor was ≥0.50 (AVE = 0.50 for Relationship Burden; AVE = 0.54 for Objective Burden; AVE = 0.58 for Subjective Burden), suggesting adequate convergent validity, i.e., each burden latent construct is able to explain a significant amount of variance in their observed variables (items). In addition, the three burden

Table 2 Descriptive statistics for items and dimensions of the Revised Burden Measure

Items: *Have your caregiving responsibilities…*	Missing	*M*	*SD*	Floor	Ceiling	Skewness	Kurtosis
Relationship Burden	1.3%	1.73	0.76	27.7%	0.0%	1.07	0.36
(A) increased attempts by our relative to manipulate you?	0.3%	1.82	1.01	51.8%	0.8%	0.97	−0.10
(E) increased the number of unreasonable requests made by your relative?	0.3%	1.77	1.02	54.3%	1.5%	1.18	0.55
(I) caused you to feel that your relative makes demands over and above what he/she needs?	1.0%	1.89	1.08	51.0%	1.3%	0.91	−0.32
(M) made you feel you were being taken advantage of by your relative?	0.3%	1.49	0.89	71.3%	0.8%	1.81	2.49
(Q) caused conflicts with your relative?	0.8%	1.63	0.94	61.2%	0.8%	1.40	1.14
Objective Burden	2.3%	2.12	0.85	12.9%	0.0%	0.46	−0.74
(B) decreased time you have for yourself?	0.0%	2.52	1.17	24.9%	2.3%	0.15	−1.19
(F) kept you from recreational activities?	0.3%	1.97	1.05	42.9%	1.0%	0.80	−0.38
(J) caused your social life to suffer?	0.3%	1.70	0.97	57.9%	0.5%	1.21	0.44
(N) changed your routine?	1.3%	2.39	1.21	29.4%	3.6%	0.41	−1.04
(R) given you little time for friends and relatives?	0.0%	1.95	1.01	44.7%	0.5%	0.64	−0.70
(U) left you with almost no time to relax?	0.5%	2.16	1.12	38.8%	2.0%	0.50	−0.83
Subjective burden	0.8%	2.27	0.97	9.4%	0.5%	0.63	−0.41
(C) created a feeling of hopelessness?	0.0%	1.93	1.16	50.5%	2.8%	1.01	−0.15
(G) made you nervous?	0.0%	2.30	1.26	35.8%	4.8%	0.55	−0.95
(K) depressed you?	0.8%	1.87	1.10	52.3%	1.5%	1.03	−0.86
(O) made you anxious?	0.0%	2.34	1.23	33.2%	3.3%	0.43	−1.09
(S) caused you to worry?	0.0%	2.90	1.23	17.3%	6.3%	−0.17	−1.17
Burden Total Score	3.8%	2.04	0.74	3.8%	0.0%	0.59	−0.50
Uplifts	4.1%	3.42	0.85	1.3%	2.3%	−0.39	−0.06
(D) given your life more meaning?	0.5%	3.56	1.24	9.4%	23.9%	−0.69	−0.51
(H) made you more satisfied with your relationship?	0.5%	3.37	1.01	7.6%	8.6%	-0.73	0.25
(L) given you a sense of fulfillment?	1.3%	3.15	1.31	17.0%	16.0%	−0.31	−0.98
(P) left you feeling good?	1.0%	3.27	1.25	15.2%	14.7%	−0.54	−0.68
(T) made you enjoy being with your relative more?	1.5%	3.50	1.17	10.9%	16.5%	−0.84	−0.03
(V) made you cherish your time with your relative?	0.5%	3.66	1.08	7.1%	18.5%	−1.00	0.52

latent constructs were positively and strongly correlated (r ranging from 0.65 to 0.71, $p < 0.01$), indicating a significant amount of shared variance, but the squared correlations between factors (r^2 between Relationship and Objective Burden was 0.48; r^2 between Relationship and Subjective Burden was 0.42; and r^2 between Objective and Subjective Burden was 0.51) were lower than the AVE for each factor, providing evidence for discriminant validity between the burden constructs and suggesting the existence of a meaningful second-order factor. However, the Uplifts latent construct presented an AVE = 0.42 and was not significantly correlated with the Relationship and Objective Burden factors ($r = -0.01$, $p = 0.82$ and $r = 0.11$, $p = 0.06$, respectively) and was negatively and weakly correlated with the Subjective Burden factor ($r = -0.22$, $p < 0.01$), suggesting that the Uplifts measure should be considered independently of the caregiving burden scales.

The second-order model for the Burden Measure

The second-order model for the Burden Measure, in which the Relationship Burden, Objective Burden and Subjective Burden factors were proposed to load on a second-order factor of overall caregiving burden (Fig. 1) had an acceptable fit, with $\chi^2_{(101)} = 328.83$, $p < 0.01$; $\chi^2/df = 3.26$; CFI = 0.93; RMSEA = 0.08 ($p < 0.01$; 90% CI = 0.07/0.09); and

Table 3 Differential item functioning analyses by children's health status

Item	Factor	Contrast	Welch *t*	*p*	Δ_{MH}	*p*
A	Relationship Burden	−0.41	−2.30	0.023	−1.20	0.029
B	Objective Burden	−0.09	−0.55	0.582	0.05	0.798
C	Subjective Burden	−0.13	−0.74	0.459	0.96	0.537
D	Uplifts	0.36	2.36	0.019	−1.60	0.017
E	Relationship Burden	0.15	0.87	0.384	−0.19	0.261
F	Objective Burden	0.35	2.12	0.035	−0.52	0.131
G	Subjective Burden	0.00	0.00	1.000	−0.38	0.855
H	Uplifts	−0.70	−4.43	<0.001	0.21	<0.001
I	Relationship Burden	−0.04	−0.21	0.832	0.16	0.835
J	Objective Burden	−0.47	−2.65	0.009	0.28	0.014
K	Subjective Burden	−0.58	−2.94	0.004	1.06	0.001
L	Uplifts	0.34	2.36	0.019	−1.41	0.061
M	Relationship Burden	0.06	0.35	0.725	−0.45	0.721
N	Objective Burden	0.14	0.90	0.370	−0.80	0.344
O	Subjective Burden	0.13	0.83	0.410	−0.33	0.130
P	Uplifts	0.68	4.35	<0.001	−01.74	<0.001
Q	Relationship Burden	0.25	1.44	0.151	−01.27	0.313
R	Objective Burden	0.24	1.40	0.162	−0.47	0.154
S	Subjective Burden	0.40	2.46	0.015	0.28	0.110
T	Uplifts	−0.59	−4.13	<0.001	1.10	0.003
U	Objective Burden	−0.21	−1.30	0.194	−0.66	0.219
V	Uplifts	−0.26	−1.65	0.101	0.96	0.064

SRMR = 0.06. All items loaded significantly in their respective factors, with $\lambda \geq 0.05$ (ranging from 0.60 to 0.84). Similarly, all three first-order factors loaded significantly in the second-order factor, with λ ranging from 0.79 to 0.87 and AVE = 0.69, attesting the factorial and convergent validity of the overall burden factor. The examination of CR coefficients confirmed the construct reliability of the three burden dimensions (CR = 0.83 for Relationship Burden; CR = 0.88 for Objective Burden; and CR = 0.87 for Subjective Burden) and of the overall burden factor (CR = 0.87).

The multi-group analysis by children's health status (Table 4) confirmed that the second-order model was valid for both healthy and clinical groups, with $\Delta\chi^2_{(13)} = 14.51$, $p = 0.34$ (measurement invariance) and $\Delta\chi^2_{(3)} = 1.18$, $p = 0.76$ (structural invariance). In addition, the examination of differences in unstandardized regression weights of factor loadings between the data from parents of healthy children and from parents of children with chronic medical conditions indicated that only the factor loading for item Q was significantly stronger for the healthy group (regression weight = 1.09) than for the clinical group (regression weight = 0.68; CRDIFF = 2.15, $p = 0.03$), although both parameters were statistically significant. No significant differences in critical ratios were found for factor loadings of burden dimensions on the second-order factor.

The model for the Uplifts Measure

The independent model for the Uplifts Measure (Fig. 2) had an acceptable fit, with $\chi^2_{(8)} = 21.09$, $p = 0.01$; $\chi^2/df = 2.64$; CFI = 0.98; RMSEA = 0.07 ($p = 0.21$; 90% CI = 0.03/0.10); and SRMR = 0.04. Except for the item T ($\lambda = 0.37$), all of the items showed factorial validity, with $\lambda \geq 0.05$. The CR coefficient was 0.80, confirming the reliability of the Uplifts construct.

Table 5 presents the multi-group analyses comparing the unconstrained model with the nested model in which factor loadings were fixed to be equal across the healthy and clinical groups. The multi-group analyses attested the model's measurement invariance, with $\Delta\chi^2_{(6)} = 11.27$, $p = 0.08$; and the examination of CRDIFF showed only a significant difference between parameters for item D, with unstandardized regression weights of factor loadings of 0.62 for the healthy group and 0.87 for the clinical group (CRDIFF = 2.42, $p = 0.02$).

Concurrent Validity

As presented in Table 6, the caregiving burden dimensions and total score were moderately and negatively correlated with QoL and psychological well-being and positively correlated with psychological distress; conversely, the caregiving Uplifts were moderately and positively associated with QoL and psychological well-being and negatively associated with psychological distress, supporting the concurrent validity of both the Burden and Uplifts Measures with previously validated measures of parents' overall psychosocial adaptation.

Known-Groups Validity

A significant multivariate effect of children's health status was found on the caregiving burden dimensions, with Wilks' $\lambda = 0.90$, $F_{(3,\ 383)} = 13.79$, $p < 0.01$, and $\eta_p^2 = 10$. The univariate effects (Table 7) showed that parents of children with chronic health conditions reported more subjective burden than parents of healthy children. In addition, parents of healthy children reported more caregiving uplifts than parents of pediatric patients, attesting the known-groups validity of both the Burden and Uplifts Measures.

Discussion

This was the first study to systematically examine the psychometric properties of the "Revised Burden Measure" in pediatric contexts, thus extending the overall conceptualization and measurement of caregiving burden as well as the scope of applicability of a well-established instrument designed to assess negative and positive dimensions of family caregiving processes. The observed results attest to the reliability and validity of the measure, making it appropriate for the assessment of caregiving burden across different developmental stages and health contexts.

The comprehensive examination of the psychometric performance of the "Revised Burden Measure" in parents of school-aged children and adolescents documented the overall internal consistency of the burden and uplift subscales and their invariance across children's health status. Additionally, a second-order model of caregiving burden was confirmed for the factorial structure of the instrument and shown to be invariant across children's health status.

Of interest, however, the analyses, revealed significant difference in difficulty for three items. Although the magnitude of such differential functioning was small, three items that were found to be more difficult to answer by parents of healthy children either placed an emphasis on a relational, positive comparative appraisal (i.e., (H) *Have your caregiving responsibilities made you more satisfied with your relationship?*; (T) *Have your caregiving responsibilities made you enjoy being with your relative more?*), or were formulated in nearly clinical terms (i.e., (K) *Have your caregiving responsibilities depressed you?*). In the former cases, both items relate to some form of "benefit finding", which is defined as the identification of positive ways in which people's lives have changed a s a result of

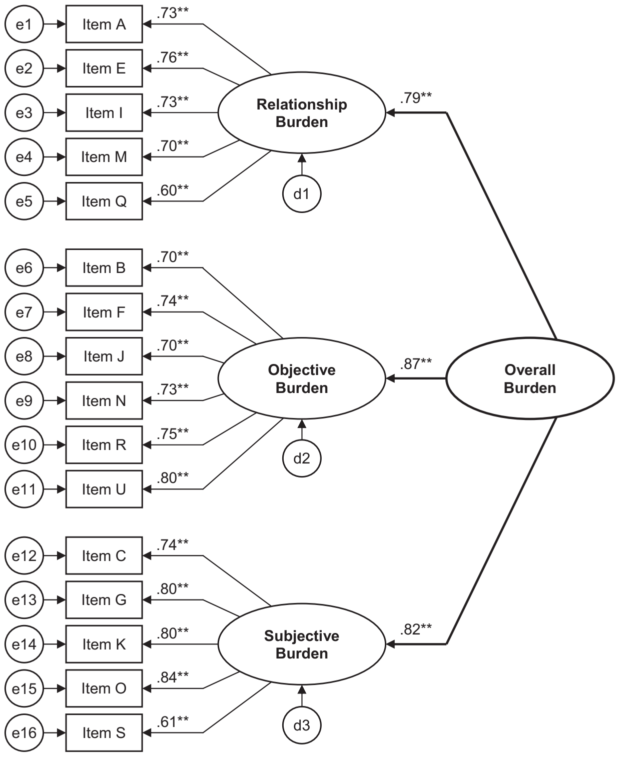

Fig. 1 Second-order model for the Burden Measure. Values shown in the figure represent standardized regression weights of factor loadings. e = measurement errors for observed indicators. d = disturbances for latent variables. $*p < 0.05$, $**p < 0.01$, two-tailed

Table 4 Comparison of the factorial model for the Burden Measure across children's health status

	χ^2	*df*	*p*	CFI	RMSEA [90% CI]	$\Delta\chi^2$	Δdf	*p*	ΔCFI
Summary of fit statistics									
Healthy group	235.34	101	<0.01	0.88	0.11 [0.09/0.13]				
Clinical group	255.09	101	<0.01	0.93	0.07 [0.06/0.09]				
Multi-group analyses									
Unconstrained model	490.88	202	<0.01	0.91	0.06 [0.05/0.07]	–	–	–	–
Measurement weights	505.39	215	<0.01	0.91	0.06 [0.05/0.07]	14.51	13	0.34	<0.01
Structural weights	506.57	218	<0.01	0.91	0.06 [0.05/0.07]	1.18	3	0.76	<0.01

some adversity, such as parenting children with severe health problems (Helgeson et al. 2006). It is likely then that those items may appear awkward to parents caring for typically developing children, who only occasionally go through little or normative infirmity, which is not expected to challenge earlier and stable meaning-making appraisals. In the latter case, the term "depressed" may seem disproportionate to describe the emotional experience of burden in normative parenting, where terms like "sad", "unhappy" or "disappointed" may be intuitively hypothesized to better describe that experience. Moreover, high levels of negative (distressed) affect tend to occur more frequently in parents of disabled children than in parents of nondisabled children (Margalit and Ankonina 1991), who may thus not readily recognize their parenting experience under more clinical terms. For parent of children with chronic conditions, it is noteworthy that the two items displaying greater DIF (i.e., (D) *Have your caregiving responsibilities given your life more meaning?*; (P) *Have your caregiving responsibilities left you feeling good?*) belong to the complementary Uplifts scale, suggesting its cautionary use in pediatric settings; in fact this is aligned with a similar admonition highlighted by some authors, who have argued for more convincing data to effectively support notions such as psychological growth (e.g., Wortman 2004).

Concurrent validity of the Burden and Uplifts subscales was supported by the moderate correlations of the scales with QoL, psychological distress and well-being. Bearing in mind the theoretical models that have proposed burden (and to a lesser extent, caregiving gratifications) as predictors or antecedents of caregivers' adaptation outcomes (Raina et al. 2004; Wallander et al. 1989), the correlations observed in the current study point to the modifiability of burden as a potential pathway to improve caregivers' adaptation outcomes (e.g., Carona et al. 2013; Raina et al. 2005; Silva et al. 2015a, 2015b).

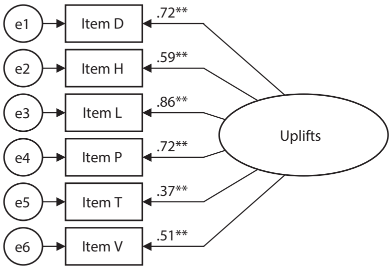

Fig. 2 Model for the Uplifts Measure. Values shown in the figure represent standardized regression weights of factor loadings. e = measurement errors for observed indicators. *$p < 0.05$, **$p < 0.01$, two-tailed

Finally, the analysis demonstrated the accuracy of the Revised Burden Measure in discriminating the clinical and healthy samples: parents of children with chronic conditions reported more Subjective burden (small to medium effect size) and less Uplifts (medium to large effect size) than parents of healthy children. This specific result highlights the psychological dimension of the caregiving experience, and depicts an increased vulnerability of parents who have children with chronic conditions to experience distinctive deleterious effects of their caregiving routines in terms of increased psychological burden paired with decreased gratifications. Similar findings have been previously reported for the parenting context of pediatric cerebral palsy (Carona et al. 2012), where satisfaction with social support was found to mediate the links between parental burdens and psychological distress (Carona et al. 2013). A possible explanation to this may be found in the social support deterioration model, which posits that chronic and/or stigmatizing stressful events deteriorate the perceived availability or effectiveness of support (Barrera 1986; Lin and Ensel 1984). While objective and relationship burdens are respectively related to instrumental demands and parent-child co-regulation, subjective burden describes the emotional turmoil that parents of disabled and chronically-ill children may go

Table 6 Correlations between the Revised Burden Measure, the EUROHIS-QOL 8-item index and the MHI-5

	Quality of life	Psychological distress	Psychological well-being
Relationship Burden	−0.24**	0.31**	−0.20**
Objective Burden	−0.23**	0.29**	−0.28**
Subjective Burden	−0.39**	0.52**	−0.44**
Burden total score	−0.34**	0.44**	−0.37**
Uplifts	0.22**	−0.22**	0.30**

*$p < 0.05$; **$p < 0.01$, two-tailed

Table 5 Comparison of the factorial model for the Uplifts Measure across children's health status

	χ^2	*df*	*p*	CFI	RMSEA [90% CI]	$\Delta\chi^2$	Δdf	*p*	ΔCFI
Summary of fit statistics									
Healthy group	29.30	8	<0.01	0.93	0.15 [0.10/0.21]				
Clinical group	16.11	8	0.04	0.98	0.06 [0.01/0.10]				
Multi-group analyses									
Unconstrained model	45.49	16	<0.01	0.96	0.07 [0.05/0.09]	–	–	–	–
Measurement weights	56.76	22	<0.01	0.95	0.16 [0.04/0.08]	11.27	6	0.08	0.01

Table 7 Univariate analyses of covariance of burden and uplifts by children's health status

	Healthy group ($n = 117$) *M* (*SD*)	Clinical group ($n = 271$) *M* (*SD*)	$F_{(1, 385)}$	*p*	η_p^2
Relationship Burden	1.73 (0.72)	1.72 (0.78)	0.11	0.74	0.00
Objective Burden	2.20 (0.85)	2.07 (0.85)	0.94	0.33	0.00
Subjective Burden	1.93 (0.81)	2.40 (0.99)	15.82	<0.01	0.04
Burden total score	1.97 (0.72)	2.07 (0.74)	1.11	0.29	0.00
Uplifts	3.89 (0.75)	3.23 (0.81)	57.77	<0.01	0.13

through. In those circumstances, where issues such as negative social comparisons (e.g. social put-down), self-blame and self-criticism tend to be salient, eliciting social support may often result in avoidant, disparate or invalidating responses from others (Carona 2013). In the meantime, this pattern of discrepancy between felt needs and perceived unsupportive responses from others is expected to heighten parents' emotional distress and hamper the related capacity of benefit finding.

Clinical implications

Altogether, these findings have important clinical implications. First, the "Revised Burden Measure" is easy to administer, score and interpret, making it a first-line choice for clinical routine assessments. In fact, the questionnaire's brevity also makes it a suitable choice for clinical epidemiological studies, when time is of essence in achieving large sample sizes.

Second, the instrument correlates well with psychological distress and QoL measures and discriminates parents facing different developmental challenges, thus enabling its use as a screening tool for identifying high-risk parents in pediatric settings and evaluating parenting-related interventions. This may ultimately increase the effectiveness and efficiency of procedures for referral. In any case, clinicians and researchers may find it useful to consider (whenever appropriate) the cut-off points that have been previously determined for the burden and uplifts scales from a large-scale North American study sample (cf. Montgomery and Kosloski 2006), in order to straightforwardly interpret or explore their findings.

Third, given its multidimensionality in caregiving burden assessment, the "Revised Burden Measure" facilitates targeted interventions, by linking the detection of specific needs to the corresponding allocation of therapeutic resources. When planning clinical interventions, for instance, increased objective burden may call for time management or task sharing arrangements; elevated subjective burden may be lessened in psychotherapeutic processes; and high relationship burden may be monitored in parenting programs targeting the modification of parent-child behavioral dynamics.

Finally, the instrument captures the positive dimensions of caregiving that can be fostered as a means to prevent or reduce the deleterious effects of burden (Carona et al. 2012). Interestingly, it has been suggested that meaning-making reappraisals may be developed through intentional mindfulness (Larson 2010) or mindfulness-based cognitive therapy (Carona 2013), although such claims need further empirical examination.

Limitations & Need for Future Research

Despite the aforementioned utility and applications of the "Revised Burden Measure", the instrument has some limitations including the inherent to self-reported questionnaires (cf. Cummings et al. 2000), such as the potential risks for memory or response bias (e.g., social desirability while reporting positive qualities in coping with adversity); the fixed specificity of the dimensions under assessment (e.g., financial burden is not assessed with the "Revised Burden Mea sure"); and the limited ability of a quantitative measure to capture contextual features that may be relevant to caregiving outcomes (Bastawrous 2013). Nevertheless, these limitations are likely to be mitigated when the assessment of caregiving burden conjunctively comprises behavioral observations and clinical interviews.

This study had the merits of performing a systematic in-depth psychometric analysis of the "Revised Burden Measure", which had been argued for some time (Chou et al. 2003), while demonstrating the clinical and developmental applicability of the instrument in pediatric contexts, where the existing measures are often rather specific (e.g., Parham et al. 2014) and/or targeting distinct concepts, such a s caregivers' self-efficacy or QoL (cf. Ekim and Ocakci 2016). Nevertheless, the current study has a number of methodological limitations that should be noted. First, it is based on a convenience sample, which prevents the straightforward generalization of results. Second, it encompasses more than 80% of mothers under the overall designation of "parents", thus calling for greater caution in interpreting its results and applying the corresponding inferences to fathers. Third its cross-sectional design impeded the examination of more robust hypotheses, such as the predictive value of burden in relation to a number of adaptation outcomes. Fourth, the use of data collected between 2009 and 2011, as time boundaries may affect the external validity of results (Bickman and Rog 2009).

Finally, but crucially, it bears noting that our study was conducted using a sample of Western European parents. The available cross-cultural research supports a common core model that is invariant across ethnicity and that links care recipient's behavioral and functional characteristics to caregivers' burden and adaptation outcomes. However, the effects of cultural values (e.g., individualistic versus collectivistic societies) in stress and coping processes seem to influence social support and coping styles rather than burden perceptions (Knight and Sayegh 2010). The psychosocial correlates of caregiving burden appraisals appear to vary considerably across cultures. For instance, low burden of Korean caregivers has been related with increased family support and filial responsibility, while the burden of American caregivers was associated with the use of formal support and higher gratifications from caregiving. Conversely, the high burden of Koreans was associated with limited access to formal services and low caregiving gratifications, while that of the Americans was related to low family support and filial responsibility (Lee and Sung 1998). Clearly, future examination of this cross-cultural variability in the developmental pathways leading to burden appraisals is needed in order to expand the scope of generalizability of findings that have been reported to date.

Additionally, future research using the "Revised Burden Measure" in longitudinal, mixed methods designs would be desirable to ascertain the instrument's test-retest reliability, its usefulness in predicting parent-child global health outcomes, as well as its sensitivity to detect changes throughout intervention processes. Moreover, the examination of the instrument's psychometric properties, namely its items performance, should proceed with other clinical and normative samples in order to gradually and reliably ensure its intended cross-contextual applicability.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval This study was approved by the appropriate institutional and/or national research ethics committees (cf. "Participants and procedure" section) and has been performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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