

Alma Mater Studiorum Università di Bologna
Archivio istituzionale della ricerca

Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R)

This is the final peer-reviewed author's accepted manuscript (postprint) of the following publication:

Published Version:

Landi G., Boccolini G., Giovagnoli S., Pakenham K.I., Grandi S., Tossani E. (2022). Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R). *DISABILITY AND REHABILITATION*, 44(5), 795-806 [10.1080/09638288.2020.1780478].

Availability:

This version is available at: <https://hdl.handle.net/11585/773003> since: 2024-01-31

Published:

DOI: <http://doi.org/10.1080/09638288.2020.1780478>

Terms of use:

Some rights reserved. The terms and conditions for the reuse of this version of the manuscript are specified in the publishing policy. For all terms of use and more information see the publisher's website.

This item was downloaded from IRIS Università di Bologna (<https://cris.unibo.it/>).
When citing, please refer to the published version.

(Article begins on next page)

This is the final peer-reviewed accepted manuscript of:

Landi, G., Boccolini, G., Giovagnoli, S., Pakenham, K. I., Grandi, S., & Tossani, E. (2020). Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R). *Disability and Rehabilitation*. <https://doi.org/10.1080/09638288.2020.1780478>

The final published version is available online at:
<https://doi.org/10.1080/09638288.2020.1780478>

Rights / License:

The terms and conditions for the reuse of this version of the manuscript are specified in the publishing policy. For all terms of use and more information see the publisher's website.

Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R)

Giulia Landi^{1,2}, Giada Boccolini^{1,2}, Sara Giovagnoli², Kenneth I. Pakenham³, Silvana Grandi^{1,2}, and Eliana Tossani^{1,2}

¹ *Laboratory of Psychosomatics and Clinimetrics, Department of Psychology, University of Bologna, Bologna, Italy*

² *Department of Psychology, University of Bologna, Bologna, Italy*

³ *School of Psychology, The University of Queensland, Brisbane, Australia*

Giulia Landi^{1,2}, <https://orcid.org/0000-0002-2576-3528>

Giada Boccolini^{1,2}, <https://orcid.org/0000-0003-4148-7014>

Sara Giovagnoli², <https://orcid.org/0000-0002-3252-8083>

Kenneth I. Pakenham³, <https://orcid.org/0000-0002-8653-4593>

Silvana Grandi^{1,2}, <https://orcid.org/0000-0003-3401-2301>

Eliana Tossani^{1,2}, <https://orcid.org/0000-0002-6197-4496>

Corresponding Author: Giulia Landi, Department of Psychology, University of Bologna, viale Berti Pichat 5, 40127 Bologna, Italy. E-mail: giulia.landi7@unibo.it

Abstract word count: 200 words. Manuscript main text word count: 6.068.

Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R)

Purpose: Parental illness or disability has wide ranging impacts on offspring. Due to the lack of an Italian contextually sensitive measure of youth caregiving, this study explored the factor structure, reliability and validity of the Italian version of the Young Carer of Parents Inventory-Revised (YCOPI-R). **Materials and methods:** 774 youth aged 11 to 24 (386 young carers and 388 young non-carers) completed a questionnaire regarding youth caregiving, parental illness, caregiving context variables, and youth adjustment. **Results:** The Italian YCOPI-R demonstrated good psychometric properties. Part A factor structure was replicated while two new factors emerged for Part B: Caregiving Stigma and Caregiving Resentment. Discriminant and convergent validity were evinced by differentiation between young carers and non-carers and associations between YCOPI-R factors and measures of caregiving activities and caregiving context. Predictive validity was supported as most Italian YCOPI-R factors were related to poorer youth adjustment, while Caregiving Confidence and Worry about Parents predicted higher levels of health-related quality of life. **Conclusions:** The Italian YCOPI-R is a psychometrically sound measure of caregiving experiences in Italian youth. Findings confirm the multidimensional nature of youth caregiving, the mix of costs and rewards associated with it, and the link between youth caregiving and diverse adjustment outcomes.

Keywords: young carers; Young Carer of Parents Inventory; parental illness or disability; psychometric properties; scale validation; psychosocial impact

Introduction

Children and adolescents who assume responsibilities associated with caring for a parent with an illness or disability are referred to as young carers [1,2]. Estimates in the literature suggest that approximately 5% to 15% of children and adolescents (aged 4-18) grow up with a parent who is affected by a chronic illness [3–5]. In Italy 6.6% of youth aged 15-24 help an ill family member at least once a week [6]. However, these numbers are likely to be an underestimation because of the hidden nature of youth caregiving and the tendency for young people not to self-identify as carers [7]. Furthermore, given the improvement in medical technologies, the increases in parental age at conception, and the global rise in chronic illnesses, more young people are living with a parent with serious chronic health problems [8,9].

Intensive youth caregiving increases the risk of negative psychosocial outcomes, including poorer health-related quality of life (HRQoL) [10–12], worse mental and physical health and restricted school and leisure activities [13–20]. On the other hand, youth caregiving is also associated with positive psychosocial outcomes such as benefit finding related to the caregiving role, increased perceived maturity and greater willingness to seek social support [17,21–24].

Despite the potential positive aspects of youth caregiving, the association between youth caregiving and greater risk of mental and physical health problems is a public health concern – many young carers report disadvantage through childhood, adolescence and young adulthood [10,16,19,20]. Therefore, the plight of young carers is recognized as a growing social crisis that has forced their inclusion on national and international political agendas. Hence, it is imperative that research targets the welfare of young carers.

The most widely used instrument assessing young caregiving responsibilities and experiences related to living with an ill parent is the Young Carer of Parents Inventory-Revised (YCOPI-R) [1,25]. The measure was first developed in English in Australia in a two-phase study in which youth caregiving themes were identified from qualitative research, and then an inventory assessing those themes was created, and its psychometrics were examined [1]. Its psychometric

properties were further analysed across three independent samples of youth (i.e., youth without a family member with a serious health condition, youth of a parent with a significant medical condition, and youth of a parent with multiple sclerosis). In this research new items were added to the YCOPI that reflected young carers' needs for information and support, a theme that emerged from initial qualitative phase. Confirmatory factor analyses showed that these new items formed an additional YCOPI factor that was called Caregiving Information/Support. From these investigations, the final revised version of the instrument was obtained. Validity has been supported through evidence of associations between YCOPI-R subscales and measures of caregiving activities and context variables [1,18,19,26,27], and youth adjustment outcomes [1,25].

The YCOPI-R is a psychometrically sound and contextually sensitive measure of the nature and breadth of youth caregiving experiences across a range of caregiving contexts [1,25]. In addition, the YCOPI-R can be used to compare youth with chronically ill parents and youth with 'healthy' parents and to distinguish among different types of parental chronic illnesses (i.e., physical illness, mental illness or substance use) [19,26–29]. The YCOPI-R has also been shown to be sensitive to the effects of young carer interventions [19,28,30] and it has also been validated in in a sample of Japanese young adult carers [31].

The YCOPI-R is composed of two sections: Part A investigates generic caregiving experiences and responsibilities of youth irrespective of levels of family caregiving demands and the presence or absence of an ill family member, while Part B specifically examines caregiving experiences in the context of living with an ill parent. Part A includes six domains: Caregiving Responsibilities, Perceived Maturity, Worry about Parents, Activity Restriction Global, Activity Restriction Study/Work and Isolation). Part B is composed of five domains specific to caring for an ill parent or other family member: Caregiving Guilt, Isolation, Confidence, Discomfort and Information/Support needs. The YCOPI-R dimensions include both the costs (i.e., Caregiving Responsibilities, Guilt and Discomfort) and rewards (i.e., Perceived Maturity and Caregiving Confidence) of caregiving and highlight the complex nature of youth caregiving [1,25]. The

dimensions of the YCOPI-R map and delineate the prominent themes associated with youth caregiving. They are summarised in table 1.

The YCOPI-R has been utilized in studies with self-identified young carer samples [27] and in research on children and adolescents who have an ill parent with no requirement for self-identification as a young carer [1,32]. Given evidence that children do not always identify themselves as carers, the lack of a widely agreed upon definition of young carer, and the large number of children exposed to family health situations who report involvement in caregiving and corresponding adverse psychosocial impacts, a restrictive definition of young carers was not used in the present study. Instead, consistent with prior research in this field, youth were deemed ‘young carers’ if they reported having a parent with a serious medical condition and or disability [1,33,34].

The only validated instruments that assess carers’ experiences [1,25,26,35,36] in the Italian context have been validated for adult carers [37,38]. There are no published instruments for assessing youth caregiving in the Italian context. Hence, the purpose of this study was to validate the Italian version of the YCOPI-R by examining the factor structure, reliability, and validity of the instrument in two different child and adolescent groups: youth of chronically ill parents and youth of ‘healthy’ parents.

Materials and methods

Scale translation

A multistep approach was selected [39]. The original version of the YCOPI-R was first independently translated by two authors and a bilingual translator. Ambiguities in these versions were identified, and a reconciled forward version was created. This preliminary version was back translated by one bilingual translator whose native language was English. This back-translated version was submitted to the original author for approval. After applying a few suggested changes, the Italian version of the YCOPI-R was administered to a pilot group of 30 youth to evaluate the extent to which the instrument was clear and understandable. Final modifications were carried out according to this pilot study.

Participants and recruitment procedure

Consistent with guidelines for conducting factor analyses in validation studies, we used a ratio of 10 participants per item for ensuring an adequate sample size [40]. The original YCOPI-R is composed of 44 items, therefore a minimum sample size of 440 participants was required in this study. The inclusion criterion was 11 and 24 years of age. This age range has been used to define adolescents and young people [41]. Exclusion criteria were insufficient command of Italian, severe somatic diseases, and cognitive disabilities that were evaluated by researchers through an interview before study enrolment. Participants were recruited through information brochures and posters displayed in primary and secondary schools, universities, libraries, youth groups (e.g., music and sporting groups), illness-related local community organizations (e.g., cancer, epilepsy, diabetes, cardiovascular disease and multiple sclerosis self-help and family support groups), and waiting rooms of health facilities (i.e., general practitioner, hospital and specialist clinics). Participation was also advertised through social media and through a snowballing procedure whereby participants were asked if they had any friends in similar circumstances who might like to participate. Potential participants who showed interest in taking part in the study contacted the researchers by telephone or email. Subsequently, a researcher administered the hard copy questionnaires face-to face after the required informed written consents were obtained by both parents if youth were underage or by youth themselves if they were 18 years old or above. The variation in recruitment methods precluded calculation of an overall response rate. For the purposes of this study, we report on data from only two sections of the questionnaire: section I was completed by all participants and included demographics, YCOPI-R Part A and youth adjustment outcomes; section II was completed by only young carers and included YCOPI-R Part B and other items examining aspects of living with a chronically ill parent. The study was approved by the University of Bologna ethics committee.

Measures***Demographics and family structure variables***

Youth indicated their age (date of birth), gender, education, employment (“Do you have a paid part-time job”) and ethnicity, and provided information on dual or single-parent family, number of family members, and number, gender and age of siblings.

Caregiving experiences

Validated in a sample of youth aged 9–20, the YCOPI-R [1,25] is a self-report instrument that assesses caregiving experiences and is divided in two parts. Part A is composed of 26 items measuring generic youth caregiving responsibilities and experiences and can be completed by all youth irrespective of family caregiving demands. It contains 6 factors: Caregiving Responsibilities, Perceived Maturity, Worry about Parents, Activity restriction Global, Activity Restrictions Study/Work and Isolation. Part B includes 18 items assessing family caregiving experiences more specific to youth who care for a parent with a significant medical condition and is therefore only completed by children who have a parent with such a condition. It is composed of five factors: Caregiving Guilt, Caregiving Isolation, Caregiving Confidence, Caregiving Discomfort, and Caregiving Information/Support. The YCOPI-R can be used to assess youth caregiving in relation to an ill family member other than a parent. The term “parent” can be changed to designate another family member (e.g., sibling) or any family member (e.g., ill family member) and has been used with these adjustments [e.g., 26]. All items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). Scores were averaged and higher scores on each subscales indicate greater caregiving experiences and responsibilities. The Italian version of the YCOPI-R will from here-on be referred to as the Italian YCOPI-R.

Parental illness variables

Information on parental illness was obtained by questions used in similar research [1]. Young carers indicated which parent had a health condition (mother, father, both). If “both” was selected, participants were requested to complete all questions with respect to the parent with the most severe health condition. Seriousness of illness: youth rated the seriousness of their parent’s health condition on a 5-point scale (1 *not at all serious* to 5 *very serious*). Illness duration: participants

indicated the duration of their parent's illness in years. Parental functional difficulty: participants rated the extent to which their parent had difficulty performing daily activities (e.g., eating and dressing) as a result of their illness on a 5-point scale (1 *no difficulty*, 3 *some difficulty*, 5 *extreme difficulty*) [1]. Illness unpredictability: youth indicated the extent to which they agreed with 5 items examining parental illness unpredictability (e.g., "My parent's condition could change at any time with little warning"). Items were rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*) [1].

Caregiving context variables

The following caregiving context variables were measured and have been used in prior young carer research [1]. Amount of caregiving: youth reported how much help they gave their parent on a 5-point scale (1 *no help at all* to 5 *lots of help*). Choice in helping the ill parent: participants rated the extent to which they perceived they had a choice in helping their parent on a 5-point scale (1 *no choice* to 5 *free to make any choice*). Daily contact: participants indicated whether or not they had daily contact with their ill parent.

Caregiving tasks

The Youth Activities of Caregiving Scale (YACS) [26] is a self-report measure that consists of 28 items assessing specific caregiving tasks. All items are rated on a 5-point scale, ranging from 0 for *No help at all*, to 4 for *Lots of help*. It consists of four subscales: Instrumental Care (e.g., paying bills and managing money, shopping, remembering things), Social/Emotional Care (e.g., helping them when they feel bad, keeping them company, helping them when they are tired), Personal/Intimate Care (e.g., dressing, going to the toilet, getting in and out of bed) and Domestic/Household Care (e.g., preparing meals, chores outside the house, looking after other children or family). The YACS has demonstrated good internal reliability (.74 to .92) and convergent and criterion validity. It was validated with Australian young carers aged 10 to 25 who had a parent or another family member with a chronic physical or mental illness [26].

Youth adjustment outcomes

The following positive and negative youth adjustment outcomes were assessed: health related quality of life and internalizing and externalizing problems.

Health-related quality of life (HRQoL). The Kidscreen-27 is a shorter version of the Kidscreen-52 [42,43] and consists of 27 items measuring child and adolescent HRQoL across five domains: Physical Well-being (5 items; e.g., “Have you felt fit and well?”), Psychological Well-being (7 items; e.g., “Have you been happy with the way you are?”), Autonomy and Parent Relations (7 items; e.g., “Have your parent(s) treated you fairly?”), Peers and Social Support (4 items; e.g., “Have you been able to rely on your friends?”), and School Environment (4 items; e.g., “Have you been happy at school?”). Items are rated on a 5-point Likert scale (0 *not at all* to 4 *extremely* or 0 *never* to 4 *always*). Raw scores were used in the analysis to allow for maximum variance [42]. Higher scores indicate greater HRQoL. The Kidscreen-27 was validated in a large population-based sample of children and adolescents from several European countries, including Italy, and it demonstrated adequate internal consistency, test-retest reliability and convergent and divergent validity [43]. Its construct validity was recently replicated in a sample of children and adolescents whose parents had a physical, mental, or substance abuse illness [11].

Internalizing and externalizing problems. The Internalizing and Externalizing Problem scales of the Youth Self-Report (YSR) were used to assess emotional and behavioural functioning of children and adolescents [44,45]. The YSR Internalizing scale reflects three dimensions: Anxious/Depressed (i.e., fears, nervousness and feeling of being worthless), Withdrawn/Depressed (i.e., loneliness, shyness and sadness) and Somatic Complaints (i.e., dizziness, vomiting and headaches). The YSR Externalizing scale is composed of two factors: Rule-breaking Behaviours (i.e., antisocial behaviours, substance use and lying), and Aggressive Behaviours (i.e., destructive behaviours, disobedience and acting out). Items are rated on a 3-point scale (0 *not true*, 1 *somewhat or sometimes true* and 2 *very true or often true*) and are summed to obtain a total score for internalizing and externalizing symptoms, with higher scores indicating more problems. The Italian version of the YSR has been validated [46]. The original YSR has demonstrated sound

psychometric proprieties including test-retest reliability (.79 to .88), internal consistency (.67 to .83) and good content, criterion-related and construct validity [45]. Raw scores were used in the analysis as recommended by Achenbach and Rescorla [45].

Data analysis

Confirmatory factor analyses (CFAs) and exploratory structural equation modelling (ESEMs) were performed with Mplus 8.3. All other analyses were conducted with the IBM SPSS version 24.

Factor analysis

As recommended by Marsh and colleagues [47], the first step was to verify the appropriateness of the a priori factor structure of the YCOPI-R. Therefore, two confirmatory factor analyses (CFAs) were carried out: one aimed to confirm the factor structure of the YCOPI-R Part A and was conducted on the total youth sample (i.e., young carers and non-carers), while the other aimed to confirm the factor structure of YCOPI-R Part B and was carried out on the young carer subgroup. Analyses that yielded inadequate fit indices, were followed up with exploratory structural equation modeling (ESEMs) [48]. ESEM has been developed in order to overcome CFA and exploratory factor analysis (EFA) limitations by integrating benefits of both. Like EFA, ESEM allows items with cross-loadings to load on other factors and, as with CFA, ESEM examines goodness-of-fit statistics, offering a more realistic representation of the data [47,48]. All factor analyses were estimated with the robust maximum likelihood estimator (MLR), while an oblique Geomin rotation was used in ESEM analyses [47]. Model fit was assessed by inspecting goodness-of-fit indices and the significance and magnitude of factor loadings. Loadings on the main factor had to be $\geq .32$ with a p value $\leq .05$, and cross-loadings were considered meaningful at or above .10 with a p value $\leq .05$ [49]. We used the following goodness-of-fit indices: chi-square, the comparative fit index (CFI), the Tucker-Lewis Index (TLI), the root mean square error of approximation (RMSEA), root mean square error of approximation confidence interval at 90% (RMSEA CI), and the standardized root mean square residual (SRMR). CFI and TLI values $> .90$, RMSEA values $\leq .08$, and SRMR values $\leq .09$ are representative of a good model fit [50].

Psychometric properties

Cronbach's alpha was used to estimate the internal reliability of all measures, with values greater than .60 considered acceptable, greater than .70 satisfactory and above .80 high [51]. Intercorrelations among the YCOPI-R factors were also carried out. In addition, correlations were used to investigate the relationship between Italian YCOPI-R factors and demographic, family structure and parental illness variables. In order to examine the *convergent validity* of the Italian YCOPI-R, correlations were conducted between the YCOPI-R Part A and Part B factors, caregiving tasks and caregiving context variables. *Discriminant validity* was investigated by comparing carers and non-carers on YCOPI-R Part A factors. Linear regressions were carried out on both the young carer and non-carer subgroups in order to test the *predictive validity* of the Italian YCOPI-R. Part A subscales (for both subgroups) and Part B subscales (for the young carer subgroup only) were examined as predictors of youth adjustment (i.e., HRQoL, Internalizing and Externalizing Problems).

Results

Sample characteristics

The sample consisted of 774 youth with a mean age of 17.86 years (range = 11 – 24). Just under half (41.7%) were male. Almost all youth (98.7 %) were native Italian. Six participants were of Ukrainian, Lithuanian, Brazilian, Polish, Albanese or Moldavian nationality. Of the total sample, 386 participants indicated they had a parent with an illness or disability, and they constituted the young carer subgroup and 388 reported they had 'healthy' parents and they formed the non-carer subgroup. Parental chronic illnesses or disabilities were classified according to the International Classification of Diseases 11th Revision (ICD-11) [52] into: cancer (32.6%), type 1 and 2 diabetes (15.5%), neurological diseases (11.8%), substance use (9.4%), rheumatic diseases (7.0%), mental illnesses (5.6%), autoimmune diseases (4.0%), cardiovascular diseases (3.2%), gastrointestinal diseases (2.9%), respiratory diseases (2.1%), physical disabilities and musculoskeletal diseases (2.1%), infectious diseases (1.6%), diseases of liver, kidney and genitourinary system (1.6%), and

others (0.6%). Descriptive data on young carers' and non-carers' demographics, family structure, parental illness and caregiving context variables are represented in table 2.

Factor analyses

Factor analysis of the Italian YCOPI-R Part A

Fit indices of the CFA of the Italian YCOPI-R Part A were inadequate for the original six-factor model: $\chi^2 (284) = 1122.515, p < .001$; CFI = .874; TLI = .856; RMSEA = .062; RMSEA CI = [.058, .066]; SRMR = .067. Therefore, we moved to ESEM analyses. To be consistent with the original YCOPI-R Part A, we explored a six-factor solution. However, three items did not comply with the criteria set for allocating an item to a specific factor and were eliminated – items 4, 11 and 19 belonging to the Perceived Maturity, Activity Restriction Global and Caregiving Responsibilities subscales, respectively. A second ESEM was conducted on the remaining 23 items leading to a six-factor solution with satisfactory fit: $\chi^2 (130) = 354.405, p < .001$; CFI = .961; TLI = .924; RMSEA = .047; RMSEA CI = [.041, .053]; SRMR = .025. The original six dimensions, with the exception of the discarded items were confirmed (see table 3).

Factor Analysis of the Italian YCOPI-R Part B

Fit indices of the CFA for the Italian YCOPI-R Part B were inadequate for the original five-factor model: $\chi^2 (126) = 582.829, p < .001$; CFI = .687; TLI = .620; RMSEA = .097; RMSEA CI = [.089, .105]; SRMR = .096. Therefore, we moved to ESEM analyses. To be consistent with the original YCOPI-R Part B, we explored a five factor solution. However, two items did not comply with the item loading criteria and were eliminated – items 4 and 12 belonging to Caregiving Discomfort and Caregiving Information/Support subscales, respectively. A second ESEM was conducted on the remaining 16 items leading to a five-factor solution with satisfactory fit: $\chi^2 (50) = 93.935, p < .001$; CFI = .966; TLI = .919; RMSEA = .048; RMSEA CI = [.033, .062]; SRMR = .024. However, two of the original dimensions (Caregiving Discomfort and Caregiving Isolation) were not maintained, while two new factors emerged (see table 4). Two items from the original Caregiving Discomfort factor (items 5 and 6) loaded together with the original Caregiving Isolation factor creating a new

factor reflecting stigma, and was therefore labelled Caregiving Stigma (Items 5, 6, 10, 11). Two other items from the original Caregiving Discomfort factor loaded together with item 16 creating a new factor depicting a theme of resentment associated with caregiving and it was labelled Caregiving Resentment (Items 1, 2, 16). Only two items from the original Caregiving Information/Support subscale loaded on this factor reflecting needs for more information about the ill parent's condition and it was therefore re-labeled Caregiving Information (Items 13, 18). Finally, the factors Caregiving Guilt and Caregiving Confidence were replicated in the Italian YCOPI-R Part B. All aforementioned changes are summarised in figure 1.

Italian YCOPI-R descriptive data

Descriptive data for the Italian YCOPI-R factors for the total sample and two subgroups are presented in table 5. Regarding Part A factors, the most strongly endorsed (i.e. the factor with the highest mean) was Worry about Parents, as in the original version [1]. This was followed by Perceived Maturity, Isolation and Caregiving Responsibilities. The two least strongly endorsed factors were Activity Restrictions Global and Activity Restrictions Study/Work. This pattern was consistent for both the young carer and the non-carer subgroups, however, young carers had higher mean scores on all Part A factors.

As for Part B factors, Caregiving Information was the most strongly endorsed factor, followed by Caregiving Confidence, Caregiving Guilt and Caregiving Stigma. Caregiving Resentment was the least endorsed factor.

Internal reliabilities

The internal reliability data for the Italian YCOPI-R factors are presented in table 5. Four Part A factors displayed high internal reliabilities ($\alpha \geq .80$), while two had satisfactory values (.70 to .79). All but two Part B factors exhibited good to high internal reliability: Caregiving Stigma ($\alpha = .66$) and Caregiving Resentment ($\alpha = .64$) had acceptable Cronbach's alpha values.

Correlations among Italian YCOPI-R factors

All but three of the correlations among the Italian YCOPI-R Part A factors were positive, significant and of a small to moderate magnitude (range = .14 to .56). The exception was Worry about Parents which was not significantly correlated with three Part A factors. The mean intercorrelation among all Part A factors was .25. A measure of the average shared variance was obtained by calculating the mean of the squared root of correlations, which indicated that the shared variance was 5%. Most of the correlations among Part B factors were also positive, significant and of a small to moderate magnitude (range = .18 to .40). The only negative correlation was between Caregiving Confidence and Caregiving Resentment. The mean intercorrelation among all Part B factors was .19 (shared variance = 4%). As for the correlations among Part A and Part B factors, most were also positive, significant and of a small to moderate magnitude (range = .10 to .33). The only negative correlation was between Caregiving Confidence and Isolation. Mean intercorrelation among Part A and Part B factors was .16 (shared variance = 4%). The mean intercorrelation data suggest the YCOPI-R factors are empirically distinct but related.

Relationships between Italian YCOPI-R factors and demographic, family structure, and parental illness variables

Weak but significant correlations emerged between one or more demographic variables and four of the six Part A factors (see table 6). In particular, older age and female gender were significantly related to higher Perceived Maturity and Isolation. Female gender was also associated with higher Worry about Parents. Being a student was related to lower Caregiving Responsibilities and higher Perceived Maturity. Regarding Part B, the only significant associations with demographics were between female gender and higher Caregiving Stigma and Caregiving Guilt.

Four of the Part A factors were significantly and weakly correlated with one or more family structure variables. Notably, single parent family was related to higher Caregiving Responsibilities, Activity Restriction Study/Work and Isolation. None of Part B factors were related to family structure variables.

All of the Part A and Part B factors were significantly correlated with one or more parental illness variables. Higher scores on most of the factors were significantly correlated with more serious parental illness and functional difficulties, and higher illness unpredictability.

Validity analyses

Convergent validity

All Part A factors were positively and significantly correlated with the total YACS score which assesses youth caregiving tasks (see table 6). These results were corroborated by significant associations between all Part A factors and one or more caregiving context variables with one exception, Activity Restrictions Study/Work. Three of the Part B factors were positively and significantly correlated with the total YACS score and all of the Part B factors were related to one or more of the YACS subscales. In general, regarding the significant correlations, caregiving context variables reflecting higher demands were associated with higher scores on the Italian YCOPI-R factors which is expected and is consistent with a similar pattern of correlations for the original YCOPI-R. The one exception was the significant, albeit weak, inverse association between Caregiving Resentment and Social/Emotional Care, indicating more engagement in this type of care is associated with lower resentment about the caregiving role.

Discriminant validity

There were no significant differences between young carers and non-carers on demographics and family structure variables. A multivariate analysis of variance (MANOVA) was conducted to determine whether young carers differed from non-carers on the Italian YCOPI-R Part A factors. The two groups were found to significantly differ, Wilks' $\lambda = .95$, $F(6,767) = 6.69$, $p < .001$, $\eta^2 = .05$. Univariate analyses revealed that compared to non-carers, young carers had higher scores on Caregiving Responsibilities, $F(1,773) = 11.85$, $p < .001$, Perceived Maturity, $F(1,773) = 27.54$, $p < .001$, Activity Restrictions Global, $F(1,773) = 16.67$, $p < .001$, Activity Restriction Study/Work, $F(1,773) = 13.51$, $p < .001$, and Isolation, $F(1,773) = 7.10$, $p < .01$. However, the two groups did not significantly differ on Worry About Parents $F(1,773) = .56$, $p = .45$.

Predictive validity

Linear regressions were conducted separately on the young carer and the non-carer subgroups to examine whether the Italian YCOPI-R factors predicted the youth adjustment outcomes (total HRQoL, Internalizing and Externalizing Problems). Results are summarised in table 7. Because YCOPI-R Part B was only completed by young carers, regressions for the non-carer subgroup were conducted only with Part A factors. These analyses indicated that in the young carer subgroup, the Italian YCOPI-R Parts A and B predicted 40%, 38% and 12% of the variance in total HRQoL, Internalizing Problems and Externalizing Problems, respectively. In the non-carer subgroup, the Italian YCOPI-R Part A predicted 19%, 29% and 12% of the variance in total HRQoL, Internalizing Problems and Externalizing Problems, respectively.

Three of the Part A factors emerged as significant predictors of one or more adjustment outcomes. Isolation was the strongest predictor of poorer youth adjustment across all three outcomes for both young carers and non-carers. Interestingly, for both subgroups Worry about Parents significantly predicted higher HRQoL and lower Externalizing Problems. In addition, Activity Restriction Global was significantly associated to lower HRQoL but only in the young carer subgroup. On the other hand, Caregiving Responsibilities, Perceived Maturity and Activity Restriction Study/Work were unrelated to all youth adjustment variables.

Regarding Part B, three factors predicted one or more adjustment outcomes in the young carer subgroup. Specifically, higher Caregiving Guilt predicted an increase in Internalizing Problems, and higher Caregiving Stigma predicted lower HRQoL. In contrast, higher Caregiving Confidence was associated with higher HRQoL, while Caregiving Resentment and Caregiving Information were not related to any of the youth adjustment variables. None of the Part B factors predicted Externalizing Problems.

Discussion

This study was designed to validate the Italian version of the YCOPI-R. We examined the factor structure, reliability, and validity of the instrument in two different child and adolescent samples:

youth of a chronically ill parent and youth of ‘healthy’ parents. Results from factorial analyses indicated that the Italian YCOPI-R Part A has the same factor structure as the original instrument [24], while two new factors emerged in Part B: Caregiving Stigma and Caregiving Resentment.

The new Caregiving Stigma factor reflects the frequently documented youth reported stigma difficulties associated with parental illness [13,17,53–55]. The emergence of this new factor might also be indicative of cultural differences between the Australian context in which the original YCOPI-R was developed and the Italian context. Young carers in Italy compared to those in Australia may perceive more stigma associated with their caregiving role and their parent’s illness. There is some evidence suggesting caregiving-related stigma may be more prominent in Italy than in other cultures. For example, a European cross-sectional study based on a sample of 22,000 adults indicated that self-reported perceived stigma in people with common mental disorders and disabilities was highest in Italy compared to the other European countries involved (i.e., Belgium, France, Germany, the Netherlands and Spain) [56]. A similar study showed that stigma associated with depression was more intense in Italy than in Canada [57]. Finally, a study rating the level of awareness around youth caregiving on a 7-point scale (7 being the lowest, 1 being the highest), classified Italy as level 5 (i.e., Emerging awareness), while Australia and other Anglo-Saxon countries had a much higher rating [58].

Emergence of the Caregiving Resentment factor reflects young carers’ feelings of anger and resentment towards their caregiving role and related obligations, which is a theme that has been neglected in the broader caregiving literature [59–61]. It may also reflect the resentment Italian youth experience in caring for their parents which stands in contrast to the culturally embedded delay in the transition of Italian adolescents towards adulthood [62]. Recent data shows that 84% of Italian offspring (aged 16-29) are still living with their parents [63]. Moreover, evidence indicates that Italian youth seem to “prolong their adolescence without taking on any responsibilities and in this respect they have the support of their parents who do not ask for their active participation in the daily running of the home” [64,p.12]. Hence, given the cultural context of offspring living at home

longer and the expectation that they will be cared for by their parents, it is understandable that Italian young carers may be vulnerable to feelings of resentment about their caregiving role. However, it should be noted that Caregiving Resentment was the least strongly endorsed Part B factor and evidenced a relatively low internal reliability coefficient.

Overall, the Italian YCOPI-R demonstrated adequate psychometric properties. All subscales exhibited good internal reliability, with Cronbach's alpha values decreasing only slightly for some factors from the original version (Italian YCOPI-R, $\alpha = .64$ to $.84$, vs original YCOPI-R $\alpha = .71$ to $.91$). The only values below $.70$ were displayed by the two newly emerged subscales in Part B: Caregiving Stigma and Caregiving Resentment. Furthermore, the mean intercorrelation data provided support for the validity of Italian YCOPI-R as its factors appeared to be empirically distinct but related.

Convergent validity was supported by associations between the Italian YCOPI-R subscales and a validated multi-item measure of caregiving tasks and a wide range of caregiving context variables. These associations demonstrated that the YCOPI-R was sensitive to variations in the youth caregiving context. In addition, the Italian YCOPI-R demonstrated good discriminant validity, whereby young carers scored significantly higher than non-carers on all YCOPI-R Part A factors (except Worry about Parents). These results are in line with the derivation study by Pakenham et al. [1].

The majority of YCOPI-R factors predicted youth adjustment outcomes in both young carers and non-carers, providing evidence for the instrument's predictive validity. Most factors predicted poorer adjustment. In contrast, Caregiving Confidence and Worry about Parents were related to higher levels of HRQoL, corroborating the costs and benefits of youth caregiving. Overall, the pattern of associations between the Italian YCOPI-R factors and adjustment outcomes was similar to that evidenced by the original YCOPI-R [1].

Consistent with prior research [1,25], higher Caregiving Confidence was associated with higher levels of HRQoL. This finding reflects the potential benefits of youth caregiving found in

similar research [24]. Interestingly, the Worry about Parents factor was positively related to HRQoL. One possible explanation for this finding is that worrying about the ill parent might reflect greater engagement in the family and lead to adaptive coping processes which, in turn, increase HRQoL. In support of this proposal, Pakenham et al. [1] found that Worry about Parents was associated with greater reliance on the acceptance coping strategy. Moreover, a recent Italian study demonstrated that when adult carers are engaged in the healthcare for the ill family member, they are better able to reframe their role and, thereby, achieve balance between their caregiving role and their broader life goals [65].

In view of the fact that only two of the eleven YCOPI-R factors changed in the Italian context, the instrument appears to be robust with respect to cross-cultural application. Part A of the measure seems to be particularly consistent across the Australian and Italian cultural contexts given that the factor structure was maintained with minimal changes in item-factor loadings. Furthermore, Part A demonstrated some stability in the Japanese context as well with half of its factors replicated, except for the creation of an overarching factor including, Activity Restriction Global, Activity Restriction Study/Work and some items from the Caregiving Responsibilities subscale relating to caregiving practical tasks [31]. Even if further research on Part B is required, Caregiving Confidence appeared cross-culturally as a consistent factor while the negative emotions around young caregiving (i.e., guilt, discomfort, stigma and resentment) and the seek for information/support related to it require additional studies to establish a stable structure. However, it should be noted that the original and Italian validations, are based on samples of youth caring for their ill parents while the Japanese sample is composed of young adults predominantly caring for their grandparents and other family members.

This study has several limitations. First, the use of non-random sampling limits the generalizability of findings. Second, given that the original YCOPI-R Part B required further work, its Italian structure is tentative as well. In fact, even though Caregiving Information was the most

endorsed Part B factor, it consisted of only two items. The recommended minimum number of items for a factor is three [66].

Despite these limitations, this study has several strengths including the sample size, which was higher than that recommended for validation studies [40]. In addition, the sample of youth utilized in this study consisted of young carers of parents with mixed diagnoses, providing further support for the generalizability of the Italian YCOPI-R. Future research should refine the factor structure of the YCOPI-R Part B in order to strengthen its factors. Additional studies based on random sampling are needed in order to further establish the generalizability of the instrument.

In conclusion, the Italian YCOPI-R is a psychometrically sound measure of caregiving experiences in Italian youth. Findings confirm the multidimensional nature of youth caregiving for carers and non-carers, the mix of costs and rewards associated with the caregiving role, and the link between youth caregiving and diverse adjustment outcomes. The Italian YCOPI-R shows potential utility in research designed to advance theoretical and empirical understanding of caregiving in young carers and non-carers. The instrument may also assist in identifying young carers who are at risk for mental health problems. The Italian YCOPI-R may also be used to evaluate young carer support services and preventive interventions in the Italian context. However, although the original YCOPI has been shown to be sensitive to intervention effects, longitudinal research is required to establish the utility of the Italian YCOPI-R in evaluating support services for young carers. Given the global rise in the number of youth caring for an ill or disabled family member, the hidden nature of youth caregiving, the vulnerability of children and adolescents taking on adult caregiving roles and the association between youth caregiving and greater risks for mental and physical health problems, elevated youth caregiving is a significant public health issue. The YCOPI-R is a psychometrically sound and contextually sensitive measure of youth caregiving that can be used to inform theory, clinical practice, and service and public policy developments in this field.

Declaration of interest

The authors report no declarations of interest.

References

1. Pakenham KI, Bursnall S, Chiu J, et al. The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabil Psychol*. 2006;51(2):113–126.
2. Pakenham KI, Cox S. The effects of parental illness and other ill family members on the adjustment of children. *Ann Behav Med*. 2014; 48(3):424–437.
3. Barkmann C, Romer G, Watson M, et al. Parental physical illness as a risk for psychosocial maladjustment in children and adolescents: epidemiological findings from a national survey in Germany. *Psychosomatics*. 2007;48(6):476–481.
4. Landi G, Andreozzi MS, Pakenham KI, et al. Psychosocial adjustment of young offspring in the context of parental type 1 and type 2 diabetes: a systematic review. *Diabet Med*. 2020; 10.1111/dme.14271.
5. Worsham NL, Compas BE, Sydney EY. Children's coping with parental illness. In *Handbook of Children's Coping*. Boston, MA: Springer; 1997. p. 195–213.
6. ISTAT. Condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea - Indagine EHIS 2015. 2017 [cited 2019 July 29]. Available from: <https://www.istat.it/it/archivio/204655>.
7. Aldridge J, Becker S. Children who care: Inside the world of young carers. Loughborough University, Loughborough, England: Young Carers Research Group; 1993.
8. World Health Organization. Noncommunicable diseases. Progress monitor 2020 [cited 2020 May 29]. Available from <https://www.who.int/publications-detail/ncd-progress-monitor-2020>.
9. Shifren K, Kachorek LV. Does early caregiving matter? The effects on young caregivers' adult mental health. *Int J Behav Dev*. 2003;27:338–346.
10. Chikhradze N, Knecht C, Metzger S. Young carers: growing up with chronic illness in the family-a systematic review 2007-2017. *J Compassionate Health Care*. 2017;4(1):1–12.
11. Hagen KA, Hilsen M, Kallander EK, et al. Health-related quality of life (HRQoL) in children of

- ill or substance abusing parents: examining factor structure and sub-group differences. *Qual Life Res.* 2019;28(4):1063–1073.
12. Lloyd K. Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children. *J Happiness Stud.* 2013;14(1):67–80.
 13. Bolas H, Wersch AV, Flynn D. The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychol Health.* 2007;22(7):829–850.
 14. Chen CYC. Educational functioning of children of parents with chronic physical illness: A systematic review. *Sch Psychol Int.* 2016;37(6):606–626.
 15. De Roos SA, De Boer AH, Bot SM. Well-being and need for support of adolescents with a chronically ill family member. *J Child Fam Stud.* 2017;26(2):405–415.
 16. Nagl-Cupal M, Daniel M, Koller MM, et al. Prevalence and effects of caregiving on children. *J Adv Nurs.* 2014;70(10):2314–2325.
 17. Pakenham KI, Cox S. Test of a model of the effects of parental illness on youth and family functioning. *Health Psychol.* 2012a;31:580–590.
 18. Pakenham KI, Cox S. The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment overtime. *Psychol Health.* 2012b;27(3):324–346.
 19. Pakenham KI, Cox S. The effects of parental illness and other ill family members on youth caregiving experiences. *Psychol Health.* 2015;30(7):857–878.
 20. Sieh DS, Meijer AM, Oort FJ, et al. Problem Behavior in Children of Chronically Ill Parents: A Meta-Analysis. *Clin Child Fam Psychol Rev.* 2010;13(4):384–397.
 21. Pakenham KI, Bursnall S. Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clin Rehabil.* 2006;20:709–723.
 22. Pakenham KI, Chiu J, Bursnall S, et al. Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *J Health Psychol.* 2007;12(1):89–102.

23. Cassidy T, Giles M. Further exploration of the Young Carers Perceived Stress Scale: identifying a benefit-finding dimension. *Br J Health Psychol.* 2013;18(3):642–655.
24. Pakenham KI, Cox S. Effects of Benefit Finding, Social Support and Caregiving on Youth Adjustment in a Parental Illness Context. *J Child Fam Stud.* 2018;27(8):2491–2506.
25. Cox S, Pakenham KI. Confirmatory factor analysis and invariance testing of the Young Carer of Parents Inventory (YCOPI). *Rehabil Psychol.* 2014;59(4):439–452.
26. Ireland MJ, Pakenham KI. The nature of youth care tasks in families experiencing chronic illness/disability: Development of the Youth Activities of Caregiving Scale (YACS). *Psychol Health.* 2010a;25(6):713–731.
27. Ireland MJ, Pakenham KI. Youth adjustment to parental illness or disability: The role of illness characteristics, caregiving, and attachment. *Psychol Health Med.* 2010b;15:632–645.
28. Fraser E, Pakenham KI. Evaluation of a resilience-based intervention for children of parents with mental illness. *Aust N Z J Psychiatry.* 2008;42(12):1041–1050.
29. Fraser E, Pakenham KI. Resilience in children of parents with mental illness: Relations between mental health literacy, social connectedness and coping, and both adjustment and caregiving. *Psychology, Health & Medicine.* 2009;14:573–584.
30. Coles AR, Pakenham KI, Leech C. Evaluation of an intensive psychosocial intervention for children of parents with multiple sclerosis. *Rehabil Psychol.* 2007;52:133–142.
31. Okuyama S. Development of Young carer psychological scale Japanese version. *International Journal of Brief Therapy and Family Science,* 2018;8(1):1–22.
32. Sieh DS, Visser-Meily JMA, Oort FJ, et al. Risk factors for problem behavior in adolescents of parents with a chronic medical condition. *Eur Child Adolesc Psychiatry.* 2012;21(8):459–471.
33. Gays M. Lifetime of caring: ACT schools-based young carers survey. Canberra: Marymead Child and Family Centre; 2002.
34. Siskowski C. Young caregivers: Effect of family health situations on school performance. *J Contin Educ Nurs.* 2006;22(3):163–169.

35. Farajzadeh A, Akbarfahimi M, Maroufizadeh S, et al. Psychometric properties of Persian version of the Caregiver Burden Scale in Iranian caregivers of patients with spinal cord injury. *Disabil Rehabil.* 2018;40(3):367–372.
36. Pakenham KI. The nature of sense making in caregiving for persons with multiple sclerosis. *Disabil Rehabil.* 2008;30(17):1263–1273.
37. Chattat R, Cortesi V, Izzicupo F, et al. The Italian version of the Zarit Burden Interview: a validation study. *Int Psychogeriatr.* 2011;23(5):797–805.
38. Negri L, Piazza G, Sartori RD, et al. The adult carer quality of life questionnaire (AC-QoL): comparison with measures of burden and well-being, and Italian validation. *Disabil Rehabil.* 2019;41(10):1207–1216.
39. Acquadro C, Conway K, Hareendran A, et al. Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. *Value Health.* 2008;11(3):509–521.
40. Tabachnick BG, Fidell LS, Ullman JB. *Using multivariate statistics.* Vol. 5. Boston (MA): Pearson; 2007.
41. Patton GC, Sawyer SM, Santelli JS, et al. Our future: a Lancet commission on adolescent health and wellbeing. *Lancet.* 2016;387(10036):2423–78.
42. The Kidscreen Group Europe. *The KIDSCREEN Questionnaires: Quality of life questionnaires for children and adolescents.* Lengerich: Pabst Science Publishers; 2006.
43. Ravens-Sieberer U, Auquier P, Erhart M, et al. The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Qual Life Res.* 2007;16(8):1347–1356.
44. Achenbach, TM. *Manual for the youth self-report and 1991 profile.* Burlington: University of Vermont, Department of Psychiatry; 1991.
45. Achenbach TM, Rescorla LA. *Manual for ASEBA School-Age Forms & Profiles.* Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families; 2001.

46. Frigerio A, Cattaneo C, Cataldo M, et al. Behavioral and Emotional Problems Among Italian Children and Adolescents Aged 4 to 18 Years as Reported by Parents and Teachers. *Eur J Psychol Assess.* 2004;20(2):124–133.
47. Marsh HW, Muthén B, Asparouhov T, et al. Exploratory structural equation modeling, integrating CFA and EFA: Application to students' evaluations of university teaching. *Struct Equ Modeling.* 2009;16(3):439–476.
48. Marsh HW, Morin AJ, Parker PD, et al. Exploratory structural equation modeling: An integration of the best features of exploratory and confirmatory factor analysis. *Annu Rev Clin Psychol.* 2014;10:85–110.
49. Hair Jr JF, Hult GTM, Ringle C, et al. A primer on partial least squares structural equation modeling (PLS-SEM). Sage publications; 2016.
50. Marsh HW, Hau KT, Grayson D. Goodness of fit evaluation in structural equation modeling. In Maydeu-Olivares A, McArdle J. *Contemporary psychometrics. A Festschrift for Roderick P. McDonald.* Mahwah NJ: Erlbaum; 2005. p. 275–340.
51. Berger R, Hänze M. Impact of expert teaching quality on novice academic performance in the jigsaw cooperative learning method. *Int J Sci Educ.* 2015;37(2):294–320.
52. World Health Organization. ICD-11: International statistical classification of diseases and related health problems. 11th revision ed. Geneva, Switzerland: WHO Publishing; 2018. [Updated 2019 April]. Available from <https://icd.who.int/browse11/l-m/en>
53. Pakenham KI. Children Who Care for Their Parents: The Impact of Parental Disability on Young Lives. In Marshall CA, Kendall E. *Disabilities: Insights from across fields and around the world.* Westport, CT: Praeger Publishers; 2009. p. 39–60.
54. Pedersen S, Revenson TA. Parental illness, family functioning, and adolescent well-being: A family ecology framework to guide research. *J Fam Psychol.* 2005;19:404–419.

55. Moffat AK, Redmond G. Is having a family member with chronic health concerns bad for young people's health? Cross-sectional evidence from a national survey of young Australians. *BMJ open*. 2017;7(1):e013946.
56. Alonso J, Buron A, Rojas-Farreras S, et al. Perceived stigma among individuals with common mental disorders. *J Affect Disord*. 2009;118(1–3):180–186.
57. Munizza C, Argentero P, Coppo A, et al. Public beliefs and attitudes towards depression in Italy: a national survey. *PloS one*. 2013;8(5):e63806.
58. Joseph S, Sempik J, Leu A, et al. Young carers research, practice and policy: an overview and critical perspective on possible future directions. *Adolesc Res Rev*. 2019:1-13.
59. Bursnall S, Pakenham KI. Too small for your boots! Understanding the experience of children when parents acquire a neurological condition. In Muenchberger H, Kendall E, Wright J. *Health and healing after traumatic brain injury: Understanding the power of family, friends, community and other support systems*. Santa Barbara, CA: Praeger Press; 2013. p. 87–100.
60. Thompson SC, Medvene LJ, Freedman D. Caregiving in the close relationships of cardiac patients: Exchange, power, and attributional perspectives on caregiver resentment. *Pers Relatsh*. 1995;2(2):125–142.
61. Williamson GM, Martin-Cook K, Weiner MF, et al. Caregiver resentment: Explaining why care recipients exhibit problem behavior. *Rehabil Psychol*. 2005;50(3):215.
62. Mazzuco S, Mencarini L, Rettaroli R. Similarities and differences between two cohorts of young adults in Italy: Results of a CATI survey on transition to adulthood. *Demogr Res*. 2006;15(5):105–146.
63. Eurostat. Share of young adults aged 18-34 living with their parents by age and sex - EU-SILC survey. 2019. [cited 2020 Jan 14]. Available from: https://ec.europa.eu/eurostat/web/products-datasets/-/ilc_lvps08.
64. Menniti A, Misiti M, Savioli M. Italian “stay at home” children: Attitudes and constraints. Rome, Italy: Institute for Population Research/National Research Council. (2000).

65. Guida E, Barello S, Corsaro A, et al. An Italian pilot study of a psycho-social intervention to support family caregivers' engagement in taking care of patients with complex care needs: the Engage-in-Caring project. *BMC Health Serv Res.* 2019;19(1):1–8.
66. Kline RB. *Methodology in the social sciences. Principles and practice of structural equation modelling.* 2nd ed. New York: The Guilford Press; 2005.

Table 1. YCOPI-R dimensions and themes.

YCOPI-R dimension	Theme
YCOPI-R, Part A	
• Caregiving Responsibilities	Refers to the psychological sense of duty or responsibility related to roles involved in contributing to family functioning
• Perceived Maturity	Refers to the “adult child” theme and how taking on adult roles within the family can foster a sense of independence and personal growth
• Worry about Parents	Refers to worry and hypervigilance about the parent’s safety and health and monitoring of their parent for signs of health changes
• Activity Restriction Global	Refers to the interference of the caregiving role in many areas such as leisure time and socializing
• Activity restriction Study/Work	Refers to the interference of the caregiving role with school and/or work
• Isolation	Refers to feelings of aloneness and difficulties in sharing caregiving experiences with others
YCOPI-R, Part B	
• Caregiving Guilt	Refers to relentless and inescapable caregiving, how young carers feel compelled to care for their parent and the associated guilt when they engage in non-caregiving activities
• Caregiving Isolation	Refers to the “hidden” nature of youth caregiving and difficulties talking about the parent’s illness or asking people for help
• Caregiving Confidence	Refers to the positive outcomes of youth caregiving; the enhanced self-efficacy through the development of new skills and knowledge
• Caregiving Discomfort	Refers to the distress and stigma associated with caregiving
• Caregiving Information/Support	Refers to young carers’ needs for support and information about their parent’s medical condition and treatment

Note. YCOPI-R = Young Carer of Parents Inventory. Adapted from Cox & Pakenham (2014).

Table 2. Descriptive data on participants' demographics, family structure, parental illness and caregiving context variables (N = 774).

Variable	Young carers (<i>n</i> = 386)			Non-carers (<i>n</i> = 388)		
	%	<i>M</i> (<i>SD</i>)	Range	%	<i>M</i> (<i>SD</i>)	Range
<i>Demographics</i>						
Age years		17.78 (3.60)	11-24		17.93 (4.09)	11-24
Gender: male	40.40			43.00		
Currently studying	87.00			80.70		
Currently working	29.50			27.1		
<i>Family structure</i>						
Family size		4.03 (1.06)	2-9		4.12 (1.35)	2-7
Number of older brothers		1.15 (.40)	1-3		1.07 (.33)	1-3
Number of older sisters		1.15 (.41)	1-3		1.05 (.23)	1-2
Single parent family	6.00			5.80		
<i>Parental illness</i>						
Ill mother	64.20					
Ill father	28.80					
Both parents	7.00					
Illness duration (years)		12.24 (12.84)	1-51			
Seriousness of illness		2.95 (.95)	1-5			
Parental functional difficulty		2.01 (1.10)	1-5			
Illness unpredictability		1.63 (.81)	0-4			
<i>Caregiving context variables</i> ^a						
Amount of help		2.95 (.81)	1-5			
Choice in helping		3.37 (1.32)	1-5			
Daily contact with ill parent	89.40					

Note. ^a Descriptive for caregiving tasks are reported in table 5.

Table 3. Exploratory structural equation modeling factor loadings of the Italian YCOPY-R Part A.

Factors and items	Factors					
	1	2	3	4	5	6
<i>Caregiving Responsibilities</i>						
20 Others expect me to help my parent(s)	.407	.018	-.029	-.038	.120	.120
21 My parent(s) expect me to help care for them	.530	-.023	.021	.049	.034	.061
22 My parent(s) relies on me to help them with household chores	.651	.004	.003	.086	-.018	.001
23 My parent(s) relies on me to do the shopping and budgeting	.699	.000	-.004	-.011	.047	-.059
24 I have to look after my other family members	.458	-.025	-.040	.110	.130	.025
25 My parent(s) relies on me for emotional support	.588	.086	.093	-.053	-.049	-.004
26 My parent(s) relies on me to make sure our family is organized	.693	.010	-.011	-.005	.001	.003
<i>Perceived Maturity</i>						
5 I know more about looking after a household than other people my age	.121	.583	.056	.122	-.036	-.075
6 I feel more like an adult than other people my age	.006	.970	-.041	.017	.001	.019
7 I am more grown-up and mature than other people my age	-.029	.832	.009	-.077	.037	.038
<i>Worry about Parents</i>						
1 I worry about my parent(s)	.022	.005	.729	-.095	-.003	.026
2 I always wonder if my parent(s) is/are safe	.013	-.013	.813	.021	.035	-.019
3 I worry about what will happen to my parent(s)	-.029	.011	.853	.029	-.010	.003
<i>Activity Restriction Global</i>						
8 Helping my parent(s) stops me from doing a lot of things that I want to do	.000	.054	-.011	.786	.024	.006
9 I miss out on a lot of activities because of my home responsibilities	.027	-.001	.059	.719	.133	.006
10 I feel as though I am missing out on things that other people my age are doing	.005	-.013	-.035	.545	-.010	.269
<i>Activity Restriction Study/Work</i>						
15 I sometimes miss school/work because I have to help my parent(s)	.011	.033	.002	-.037	.692	.004
16 Because of helping my parent(s) I sometimes feel too tired...	.025	.008	.018	.030	.820	-.007
17 I sometimes feel tired at school/work because I have been helping000	.002	.021	.031	.843	.008
18 Helping my parent(s) stops me from doing paid work	.015	-.028	-.029	.233	.503	.012
<i>Isolation</i>						
12 I wish that I had other people to talk to about my feelings and worries	.118	.019	.076	.070	-.104	.479
13 I sometimes feel alone	.024	-.040	-.006	-.103	.006	.864
14. Other people do not understand me and my situation	-.059	.107	-.004	.077	.047	.710

Table 4. Exploratory structural equation modeling factor loadings of the Italian YCOPI-R Part B.

Factors and items	Factors				
	1	2	3	4	5
<i>Caregiving Stigma</i>					
5 I find it hard explaining to my friends that my parent has an illness/disability	.798	.007	-.017	-.053	.001
6 I feel embarrassed about my parent's illness/disability	.433	-.039	.310	.036	-.059
10 I do not talk to my family about my concerns..., I do not want to upset them	.368	-.067	.039	.107	.143
11 I find it difficult to ask other people for help in my caring role when I need it	.402	.114	.170	.069	.031
<i>Caregiving Confidence</i>					
3 I am good at helping my parent and I always know what to do...	.052	.651	-.079	-.033	.118
14 I know exactly what to do to help my parent	-.080	.813	.049	.027	-.220
15 I am included in making decisions about my parent's illness/disability	.120	.432	.064	.050	.030
17 I am confident that I can care for my parent	.005	.710	-.212	-.032	-.003
<i>Caregiving Resentment</i>					
1 I wish that someone else could care for my parent	.042	-.032	.586	-.112	.087
2 I wish that I did not have to help my parent as much as I do	.109	.021	.647	-.034	-.071
16 I wish there was someone who was able to look out for me	-.067	.015	.609	.115	.073
<i>Caregiving Guilt</i>					
7 I feel guilty when I go out and have fun	-.010	-.032	.091	.784	-.040
8 When I am out with friends I feel that I should be at home instead	.121	.006	-.034	.855	.026
9 I feel guilty when I don't help out at home	-.061	.074	-.035	.348	.244
<i>Caregiving Information</i>					
13 I wish I had more information about my parent's illness/disability	-.036	-.019	.023	-.022	.953
18 I wish the doctors would talk to me and explain things...	.077	.025	.021	.074	.666

Table 5. Cronbach's alphas and descriptive data for the Italian YCOPI-R factors and other multi-item scales (N = 774).

Scale	N. of items	Young carers (<i>n</i> = 386)		Non-carers (<i>n</i> = 388)		Total <i>M</i> (<i>SD</i>)	<i>α</i>
		<i>M</i> (<i>SD</i>)	Range	<i>M</i> (<i>SD</i>)	Range		
YCOPI-R, Part A							
Caregiving Responsibilities	7	1.53 (.78)	0-3.9	1.34 (.79)	0-3.71	1.43 (.79)	.80
Perceived Maturity	3	2.46 (.91)	0-4	2.10 (1.01)	0-4	2.28 (.98)	.84
Worry about Parents	3	2.89 (.85)	0-4	2.84 (.91)	0-4.33	2.87 (.88)	.83
Activity Restriction Global	3	1.08 (.89)	0-4	.84 (.74)	0-3.67	.96 (.83)	.78
Activity Restriction Study/Work	4	.53 (.71)	0-3.50	.36 (.57)	0-3.25	.45 (.65)	.84
Isolation	3	1.75 (1.05)	0-4	1.56 (.94)	0-4	1.66 (1.00)	.73
YCOPI-R, Part B							
Caregiving Stigma	4	1.24 (.84)	0-4				.66
Caregiving Confidence	4	1.91 (.77)	0-4				.73
Caregiving Resentment	3	.90 (.78)	0-3.3				.64
Caregiving Guilt	3	1.44 (.89)	0-4				.70
Caregiving Information	2	2.11(1.17)	0-4				.80
Total caregiving tasks	28	1.25 (.52)	.07-2.96	1.12 (.53)	0-3		.89
Instrumental Care	7	1.14 (.72)	0-3.71	1.07 (.70)	0-3.57		.77
Social/Emotional Care	7	2.06 (.79)	0-4	1.87 (.86)	0-4		.85
Personal Care	8	.43 (.61)	0-3.88	.30 (.49)	0-3.50		.86
Domestic Care	6	1.53 (.67)	0-3.33	1.41 (.68)	0-4		.60
Total HRQoL	27	95.10 (15.64)	39-126	99.42 (12.78)	55-129	97.26 (14.44)	.91
Physical Well-being	5	14.96 (3.61)	5-23	15.79 (3.13)	6-23	15.37 (3.40)	.76
Psychological Well-being	7	25.89 (5.17)	8-35	27.13 (4.47)	10-35	26.51 (4.87)	.86
Autonomy & Parent Relations	7	25.65 (5.14)	10-35	26.68 (4.40)	11-35	26.16 (4.81)	.77
Peers & Social Support	4	14.87 (3.65)	4-20	15.83 (3.20)	4-20	15.35 (3.46)	.84
School Environment	4	13.76 (2.75)	5-20	13.97 (2.65)	4-20	13.87 (2.70)	.73
Internalizing Problems	31	15.75 (9.98)	0-53	12.91 (8.57)	0-39	14.32 (9.40)	.90
Externalizing Problems	32	10.31 (6.85)	0-41	8.91 (5.90)	0-30	9.61 (6.43)	.83

Table 6. Correlations among the Italian YCOPI-R factors, demographics, family structure, parental illness and caregiving context variables.

	YCOPI-R Part A						YCOPI-R Part B				
	1	2	3	4	5	6	7	8	9	10	11
<i>YCOPI-R, Part A (N = 774)</i>											
1. Caregiving Responsibilities											
2. Perceived Maturity	.30**										
3. Worry about Parents	.20**	.20**									
4. Activity Restriction Global	.39**	.24**	.05								
5. Activity Restriction Study/Work	.43**	.14**	.06	.56**							
6. Isolation	.24**	.24**	.05	.34**	.25**						
<i>YCOPI-R, Part B (n = 386)</i>											
7. Caregiving Stigma	.21**	.15**	.14**	.28**	.32**	.26**					
8. Caregiving Confidence	.12*	.24**	.20**	-.04	-.03	-.15**	-.06				
9. Caregiving Resentment	.22**	.07	-.02	.30**	.26**	.33**	.40**	-.10*			
10. Caregiving Guilt	.23**	.16**	.25**	.07	.10*	.14**	.30**	.06	.20		
11. Caregiving Information	.12*	.07	.17**	-.01	-.00	.06	.22**	.04	.18**	.29**	
<i>Demographics (N = 774)</i>											
Age	.01	.19**	.01	-.06	-.02	.12**	.04	.02	.04	-.02	.08
Gender: male	-.03	-.08*	-.16**	.03	.00	-.12**	-.16**	.06	-.10	-.13**	.01
Currently studying	-.08*	.13**	.03	-.03	-.06	.01	.04	.10	.01	-.07	.07
Currently working	-.07	-.20**	-.06	-.04	-.07	-.02	-.06	-.02	-.02	.03	.01
<i>Family structure (N = 774)</i>											
Family size	-.01	-.02	-.05	.07*	.08*	.01	-.09	.02	.01	.04	.05
Number of older brothers	-.10	-.11	-.15	.11	.07	-.07	-.15	.03	-.00	-.12	.02
Number of older sisters	.08	.05	.07	.14	.18*	.06	-.15	.16	-.13	.00	-.10
Single parent family	.08*	.03	-.01	.04	.08*	.10**	.04	.05	.06	.08	.03
<i>Parental illness (n = 386)</i>											
Ill mother	.09	.05	.10	-.06	-.08	.01	.02	.11*	-.11*	.13*	.09
Ill father	-.10*	-.08	-.04	.04	.05	-.06	-.07	-.06	.05	-.10	-.09
Both parents	.00	.05	-.12*	.04	.05	.08	.08	-.12*	.12*	-.07	-.01
Illness duration (years)	.01	.06	-.12*	.03	.10	.04	-.03	.15*	-.07	-.08	.00
Seriousness of illness	.15**	.14**	.07	.07	.19**	-.03	.21**	-.04	.09	.19**	.10
Parental functional difficulty	.15**	.08	.00	.11*	.16**	.06	.16**	.04	.19**	.11*	.15**
Illness unpredictability	.20**	.10*	.09	.19**	.26**	.11*	.35**	.00	.30**	.29**	.30**
<i>Caregiving context (n = 386)</i>											
Amount of help	.18**	.15**	.19**	.05	.02	-.10*	.03	.40**	-.09	.16**	.12*
Choice in helping	-.10*	.01	.06	-.12*	-.09	-.10*	-.08	.12*	-.15**	-.09	.10
Daily contact with ill parent	-.06	.03	-.01	.04	.06	.13*	.01	-.08	.06	-.05	-.06
Total caregiving tasks	.45**	.31**	.28**	.25**	.27**	.09*	.16**	.24**	.01	.19**	.10
Instrumental Care	.39**	.30**	.19**	.25**	.27*	.13**	.14*	.19**	.08	.11	.08
Social/Emotional Care	.35**	.26**	.38**	.09*	.10*	.03	.05	.28**	-.12*	.18**	.18**
Personal Care	.25**	.15**	.09*	.27**	.26**	.08*	.20**	.02	.10	.13*	.02
Domestic Care	.40**	.24**	.15**	.18**	.22**	.01	.09	.22**	.01	.15**	.00

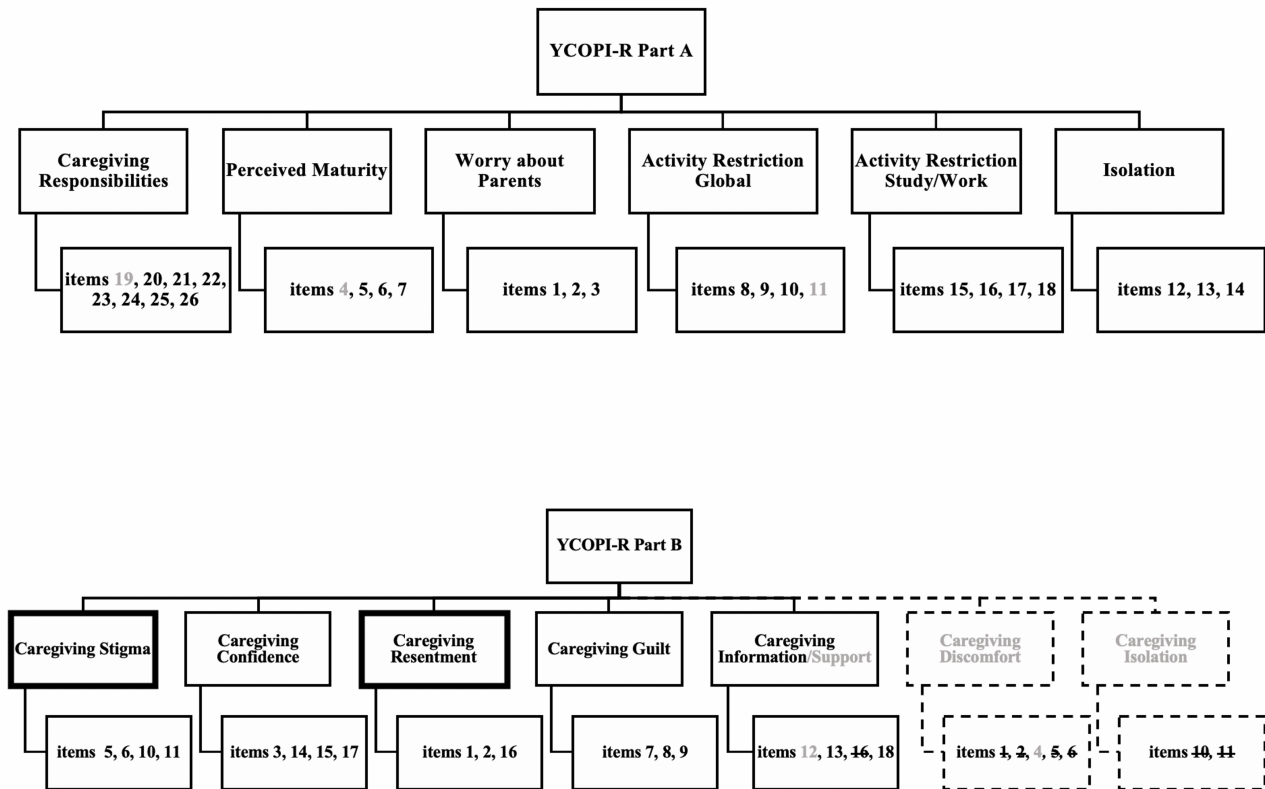
Note. * $p < .05$, ** $p < .01$.

Table 7. Linear regressions of Italian YCOPI-R Parts A and B factors predicting total HRQoL, internalizing and externalizing problems in the young carer subgroup (n = 386) and non-carer subgroup (n = 388).

Variable	HRQoL		Internalizing Problems		Externalizing Problems	
	Young carers β	Non-carers β	Young carers β	Non-carers β	Young carers β	Non-carers β
YCOPI-R, Part A						
Caregiving Responsibilities	-.018	-.030	.081	.070	.086	.017
Perceived Maturity	.002	.011	.032	-.004	.095	.020
Worry about Parents	.141**	.096*	-.011	.035	-.146**	-.103*
Activity Restriction Global	-.157**	-.097	.082	.040	.045	.037
Activity Restriction Study/Work	-.020	.030	.019	-.047	.003	.041
Isolation	-.417**	-.407**	.521**	.526**	.267**	.314**
YCOPI-R, Part B						
Caregiving Stigma	-.097*		.012		-.027	
Caregiving Confidence	.178**		-.083		-.068	
Caregiving Resentment	-.059		-.044		.008	
Caregiving Guilt	-.048		.108*		.005	
Caregiving Information	.070		-.084		-.044	
<i>F</i>	23.743**	15.897**	21.963**	27.323**	5.912**	9.401**
<i>R</i> ²	.40	.19	.38	.29	.12	.12

Note. * $p < .05$, ** $p < .01$. β = standardized beta coefficient.

Figure 1. Item and factor changes in the Italian YCOPI-R Part A and Part B compared to the original.



Note. Grey = discarded item or subscale; dotted line = factor not replicated in the Italian version; bold line = new factor emerged in the Italian version; strikethrough = items moved to another factor in the Italian version.