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Being a Young Carer in Portugal: The Impact of Caring on Adolescents' Life Satisfaction

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Abstract: Caring for an ill or disabled relative can present significant challenges that may exceed the personal resources of the caregiver. Young carers (YCs) often take on this role, providing support to family members or friends, which can have far-reaching effects on various aspects of their lives. This study involved 235 adolescents, 106 YCs and 129 non-carers (NCs), who completed questionnaires assessing life satisfaction, social support, family functioning, academic functioning, and caring activities. Group effects measured with MANOVA and MANCOVA (controlling for age effects), showed YCs to have higher amounts of caregiving activities than NC (as expected) but lower satisfaction with life. Hierarchical regressions also found that, for YCs, academic functioning, social support and the negative impact of caregiving predicted satisfaction with life; and that the negative impact of caregiving on YCs is explained by their family functioning and the amount of their caregiving activities. For NCs, only academic functioning, social support and family functioning predicted satisfaction with life. In conclusion, caregiving has a negative impact on YC's life satisfaction, but this effect is determined by their social support, academic functioning and negative impact of caring, which in turn depends on their familiar functioning and amount of caring activities.

Keywords: young carers; informal carers; life satisfaction; social support; family functioning; academic functioning; caring activities

1. Introduction

Caring for individuals with disabilities presents a range of challenges that can exceed the carer's personal resources [1], leading to potentially significant negative impacts (physical, psychological, social and economic) on the lives of the carer and person being cared for. Young carers (YCs) are defined as young people who provide informal (unpaid) care, assistance, or support to family members or friends. These family members are usually parents or grandparents, but can also be siblings or other relatives [2]. YCs often take on substantial caregiving responsibilities, assuming roles that would typically be associated with adults [3]. Although the age range of YCs varies in the literature - a YC can be as young as 5 years old up to the age of 26 [4, 5] – a typical distinction is between carers under 18 and young adult carers up to age 25 [6]. However, research to date has mostly focused on adolescent YCs [4]. While around 6-8% of adolescents may be classed as YCs [7], this group remains largely hidden [8] with their specific needs and challenges often overlooked in research and policy in most countries [6].

1.1. Negative Consequences of being a Young Carer

Reports of worse physical and mental health are recurring themes in the YCs literature. The impact on their physical health can be demonstrated by YCs' complaints of tiredness, exhaustion, poor sleep, headache, back pain, physical exertion, and injuries, suffering from their own illnesses and impacts on diet and exercise [3, 4, 9-11].

Caring responsibilities can have significant implications for the mental health of YCs [3, 4, 12, 13]. Indeed, a systematic review conducted by Fleitas Alfonzo, Singh, Disney, Ervin and King [13] revealed a consistent association between being a YC and experiencing poor mental health including depression, anxiety, and other emotional problems. Those challenges can include worry, anger and resentment towards the cared-for relative [11, 14-18], as well as emotional consequences like sadness and disappointment [19]. Additionally, YCs may experience feelings of guilt of not doing enough to help [14], and often find themselves overwhelmed and exhausted [3, 14, 16]. The impact on mental-well being can extend to difficulties with sleeping and eating, self-harm, substance use, and suicidal ideation [14]. YCs can suffer from self-mutilation, peer rejection and bullying [3, 11, 14, 20-22]. Moroever, these challeneges are associated with lower levels of self-esteem, life satisfaction, happiness and well-being [14, 22-25] and lower quality of life [26] compared to NCs. Disturbingly, research indicates these consequences can manifest as young as 10 to 11 years old [22], with YCs showing poorer health and less happiness with their lives than their non-carer peers. Furthermore, these impacts on mental health appear not to be limited to the period of caregiving, but can persist even four years later, as revealed by a longitudinal study by King, et al. [27].

Additionally, caring responsibilities can significantly hinder academic engagement and performance in YCs [17, 18, 28]. This can arise from difficulties concentrating in class, struggling to meet deadlines, having limited time to complete homework, and school absenteeism due to caregiving obligations [29], as well as poorer educational aspirations and outcomes [22]. The combination of these two roles (caring and learning) may create an overwhelming burden for these young people [30], which may be reflected in feelings of lack of control over their life expectations, leading to conflicts, particularly when faced with contradictory or incompatible needs [19].

1.2. Positive Consequences of being a Young Carer

Despite the challenges they face, not all YCs have difficulties in health, wellbeing or education: for some it is likely that the experience of caring is beneficial to them and can lead to maturity and competence [31]. Research emphasizes the existence of positive consequences associated with being a caregiver [16, 17, 32], such as advanced coping mechanisms, maturity and responsibility [11, 33-36], and caring can help them develop multiple skills and values such as compassion and empathy [3, 16, 37, 38], skills for managing challenging situations and resilience [34, 37, 39, 40], independence and autonomy [17], knowledge and skills about health and advocacy [17], social skills, interpersonal relationships, proximity to the person cared for [3], self-efficacy, self-confidence, tolerance, self-esteem [17], setting priorities and seeking out services of family and community support.

Several studies have demonstrated that YCs can derive value from their caregiving role and ability to support loved ones. Such studies have shown YCs often report feelings of satisfaction, pride, protection and gratification [41], along with a sense of fulfilment [14] or accomplishment [42], and a strong sense of purpose [30]. Aditionally, caregiving can foster closer relationships between the YCs and the person(s) for whom they care. These positive aspects can moderate the relationship between 'caregiver burden' and YCs' mental health and wellbeing [14]. Similarly, Gough and Gulliford [42] concluded that YCs are often particularly resilient and use a benefit-seeking orientation to form a sense of satisfaction and accomplishment from their roles, along with having practical coping strategies and a strong sense of agency and connectedness that also promoted better outcomes for YCs. Benefit finding was shown to directly enhance better mental wellbeing, and also indirectly influence wellbeing by promoting better coping and reducing feelings of helplessness [43].

1.3. Influencing Factors

The association between the amount of caring activity and measures of wellbeing and mental health appears to be complex, which is not surprising given that a straightforward linear relationship should not be assumed according to Joseph, Sempik, Leu and Becker [31]. Instead, this relationship is likely to be influenced by various factors. Joseph, Sempik, Leu and Becker [31] acknowledge that research on this topic has tended to overlook moderating factors and lacks theoretical sophistication. It is essential to recognize that caring occurs within a cultural context and is shaped by diverse support systems across schools, communities and helping professions [44]. Therefore, how caring activity relates to health and wellbeing is expected to be dependent on multiple and intrerelated factors.

1.3.1. Socio-demographic Factors

Research shows that being a YC and its impacts depend on a range of factors, such as age and gender [12, 14, 45-47], living arrangements and financial status [14, 45, 48], ethnicity [47, 49], who is the ill/disabled relative being supported [12, 14, 25], the nature of the illness or disability [12, 14, 46], the level of dependency and the need for assistance [14, 18], and family structure and support [18]. Being a YC can become 'damaging' when it is persistent in the long-term and excessive, with responsibilities that are disproportionate to the capabilities of a child's age or maturity level, as caring for longer durations and from a younger age [16, 47, 50]. Girls and older YCs also tend to have higher caring demands and responsibilities [14] and are more likely to report issues with their mental health [14, 45, 47, 51]. Age also influenced the degree to which YCs were aware of their role in the family structure, with adolescents being more aware than younger children of how their caring responsibilities changed their lives [14].

Research suggests that the negative mental health outcomes of caring are more likely when YCs provide personal care, including more intimate forms of care [14, 52] and emotional caring tasks [14] that were perceived as more burdensome than instrumental caring tasks involving household chores. In general, a dose-response relationship between care and mental health was observed [27, 51], with stronger effects for those who provide daily and more intensive care [27]. Bou [14]'s review also found YCs burden to be directly correlated with stress and inversely related with carers' quality of life and life satisfaction, and Pakenham and Cox [53] emphasise that higher caregiving responsibilities have both direct and indirect adverse effects on YCs' mental health. Only after YCs had stopped being carers did many of them realize that their own needs had been neglected, preventing them from taking the opportunity to ask for help or to self-care and for self-compassion [9]. In fact, various limitations to YCs' self-care were observed [40].

1.3.2. Social Support

Social support and quality of relationships play an important role in moderating carers' health and wellbeing [19, 54, 55]. The availability of social resources has been found to be highly predictive of YCs' adjustment and positive outcomes [3, 35]. Pakenham, Chiu, Bursnall and Cannon [32] observed that social support increases the level of YCs' satisfaction with life, being the strongest and most consistent predictor of their social adjustment. However, YCs may reduce their involvement in social activities either because of stigma or because of extra burden in the form of perceived stress [56], dedicating less time to personal development, socializing with friends and other social and leisure activities [18], enhancing social isolation, social stigma and bullying experiences [14, 18]. YCs report of feeling 'different' and misunderstood by their peers, withdrawing from their circle of friends, and hiding their caregiving identity [29]. Self-stigma seems to hinder peer relationship formation as YCs were often weary of exchanging confidences about their circumstances due to privacy concerns or fear of illness-related stigma [14] and may conceal the conditions of their relatives from others as they do not want to be identified as 'young carers' [57]. Thus, for some YCs, caring hindered the development of friendships through sacrificed social opportunities, or not feeling "like their age", contributing to loneliness, as YCs are prone to isolation from peers and services due to their caring demands [14].

Guggiari, Fatton, Becker, Lewis, Casu, Hoefman, Hanson, Santini, Boccaletti, Nap, Hlebec, Wirth and Leu [45] found associations between receiving support and visibility from their school and YCs' health related quality of life; moreover, YCs who reported that their school knew about their carer role also reported fewer mental health issues [45] and, when YCs did seek support, they better adjusted to caring [14]. These associations seem to be complex, as the disclosure about their caring role and YCs social support appears to be related, and YCs recognise that identifying as a YC could help them gain recognition for their roles and get the support they need [14].

Support from schools and teachers play an important role in YCs' wellbeing and development, and while many YCs seemed to enjoy going to school as it provides them with a break from caring and the possibility to socialise [28], some of them face bullying and harassment [14]. YCs' relationships with teachers varied too, with some feeling supported and accommodated, and others perceiving teachers as insensitive to their caring situations and its impact on their studies, or misunderstanding their difficulties [11]. In general, evidence suggests that, even if not all YCs inform their school and teachers of their caring role [30], when YCs did confide in teachers, their academic performance and enjoyment of education improved [14]. Though, wellbeing, social support and satisfaction of adolescents' basic psychological needs at school (ie, autonomy, competence, and relatedness) do not have a linear relation [58].

To understand the YCs experience, family variables must be acknowledged. In general, the way families function can provide an important source of emotional and material support for their members [59], attending the way family members communicate, relate, make decisions and solve problems [60]. An adaptive family functioning predicts a positive development of young people, namely in terms of mental health, self-esteem and life satisfaction; and on the contrary, problems in this functioning condition the adjustment of young people and are related to symptoms of depression and anxiety [61]. The family is, therefore, a privileged space for learning of significant dimensions of interaction, adaptation and communication, where positive or negative emotions and affections give meaning to the feeling of being and belonging [62]. And even if several sources of stress can contribute to the burden felt by families (for example, illness or disability) [63], families may deal with the stressful events and circumstances in order to solve problems through effective use of different resources, both internal, such as open communication or mutual support, and external, such as social support [64]. Surprisingly, YCs' family functioning has not been a main issue in YCs research and support [38, for an exception]. Yet, when they felt supported and acknowledged by their family members, including their care recipient, YCs reported that caring improved their family closeness and their relationship with the person(s) for whom they provide care; otherwise, they viewed their caring negatively [14]. Moreover, recognition for the caring role and support in caring, including relatives and the cared-for person, predicted better wellbeing [19].

1.4. The Present Study

It is essential to recognize that caregiving can present both challenges and opportunities for positive development. To empower YCs and help them overcome their vulnerabilities, it is necessary to better understand the psychological appraisal factors that influence their caregiving experiences. By considering the primary stressors of caregiving, such as the amount of cargiving, and also taking into account contextual factors such as academic and family functioning, it is possible to gain insights into the effects of caregiving responsibilities on the wellbeing and mental health of YCs [44]. Examining the subjective experiences of caregiving, beyond just intensity or quantity, is also important for understanding its impact on children and young people. By doing so, it is possible to better understand how these factors shape the relationship between the caring role and other relevant life outcomes, which may not be as previously assumed in some past studies [31].

Recognizing the prevailing focus on measuring negative mental health outcomes (e.g., depression, anxiety and other mental or emotional problems) among YCs, the present study sought to instead consider positive indicators and mediating factors. Specifically, the study had two objectives: (1) to test how YCs compare to their peers without caring roles in terms of life satisfaction, and (2) to develop a model that helps to explain what contributes to satisfaction with life for YCs (comparing to NC), taking into account the social support received, their family and academic functioning, the amount of caring activities they perform and, for caregivers only, the subjective impact of being a caregiver. Additionally, we also aim to (3) understand predictors of negative impact of caring on YCs.

2. Materials and Methods

2.1. Participants and data collection procedure

Data collection on YCs took place between April and June 2023 in seventeen Portuguese schools within the funded pilot-project Jovens Cuidadores[1] (POISE 39-4639-FSE-000681) in the municipality of Vila Nova de Gaia, an urban area in the north of Portugal, after Ethics Committee approval was confirmed from the correspondence authors' affiliation university. Following school directors contacts, the schools that agreed to participate received the project team that went to students' classes. In total, 419 screening/presentation sessions were conducted, where YCs general information and project's aims were explained. Some preliminary data on YC status was also collected, as all students were invited to individually write their answers on two questions about (i) the existence of ill/disabled relative(s) at their family and (ii) the care they provided. From the 9015 participants on YC screening/presentation sessions, 951 students (10.6%) privately disclosed their YC status, and N=106 agreed to participate in data collection, after legal representatives were contacted and formal consent was provided, along with YC status confirmation, by interviewing both the YC and their legal representatives, either at school, online or at their home, according to their preference. Only then, online questionnaire were sent to the young carers.

Data collection on noncarers (NC) took place in two schools, selected for convenience from the global sample. In those schools, informed consent forms were delivered by the time of the screening/presentation sessions, both to YCs and NCs. Paper-and-pencil questionnaires were then provided only to authorized noncarers students (N=129). Prior to completing the survey, all participating adolescents were informed about the study aims, confidentiality issues, and the voluntary nature of participation. Completing the survey took approximately 25 minutes and was administered during school classes for the noncarers and online for YC.

In total, 235 adolescents (89 boys and 140 girls), aged between 13 and 18 years-old (*M* = 15.18 *SD* = 1.19) participated in the study. 106 participants (35 boys and 71 girls) were identified as young carers, while 129 participants (54 boys and 69 girls) were noncarers. Within the YC group, adolescents were attending the 7th grade (2.8%) to 12th grade (8.5%), although were mainly from the 9th grade (42.5%). Regarding the NC group, most adolescents were also attending the 9th grade (71.3%), although some of them were from the 10th (10.9%) and the 11th (17.8%) grades. Table 1 provides further information on the characteristics of the sample, including adolescents' parents education and family structure.

Table 1. Sociodemographic characteristics of the sample (*N* = 235).

	Young Carers (*n* =106)		**Noncarers (*n* =129)**		**Total Sample (*n*=235)**	
Age (years) M(*SD*), min-max	15.51 (1.30), 13-18		14.90 (1.01), 14-18		15.18 (1.19), 13-18	
Gender	*n*	%	*n*	%	*N*	%
Masculine	35	33.02	54	41.86	89	37.87
Feminine	71	66.98	69	53.49	140	59.57

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[1] The "Projecto Jovens Cuidadores" was led by Portincarers - Associação Cuidadores de Portugal, the first national association of carers to work with and for young carers in Portugal. The project was funded by Portugal Inovação Social - partnerships for impact and by Vila Nova de Gaia City Council (C.M.VNG) social investor, having the collaboration of the Portuguese Sports and Youth Institute (IPDJ, North Regional Directorate). The project aimed to identify and support young carers in different areas, such as assessing their needs, providing psychological support and promoting their leisure time, involving young carers, their families, schools, local institutions and authorities. The project team has a solid academic background, with members ranging from senior researchers to junior beginning researchers. Part of this team carried out this study in parallel with their commitments to supporting young carers.

Missing	0	.00	6	4.65	6	2.55
Grade M(*SD*), min-max	9.73 (1.14), 7º-12º		9.47 (.78), 9º-11º		9.58 (.97), 7º-12º	
7th to 9th Grade	53	50	92	71.32	145	61.71
10th to 12th Grade	53	50	37	28.68	90	38.29
Mother's Education						
Basic Education	49	46.23	39	32.30	88	37.45
Medium Education	23	21.70	31	24.03	54	22.98
High Education	25	23.58	38	29.46	63	26.81
Missing	9	8.49	21	16.28	30	12.77
Father's Education						
Basic Education	56	52.83	42	32.56	98	41.70
Medium Education	23	21.70	33	25.58	56	23.83
High Education	14	13.21	28	21.71	42	17.87
Missing	13	12.26	26	2.16	39	16.60
Family Structure						
Single-parent family	18	16.98	12	9.30	30	12.77
Nuclear family	33	31.13	86	66.67	119	56.40
Blended family	15	14.15	7	5.43	22	9.36
Extended family	36	33.96	15	11.63	51	21.70
Missing	4	3.77	9	6.98	13	5.53

Attending to YCs' specific characteristics, as presented in Table 2, most of them cared for their parents (41.5%) or grandparents (34.9%), with 14.1% caring for more than one person. Their caring role exist for M=4.6 years (SD=3.468), with the more frequent situation of being a YC for 3 to 6 years (46.0%). Most YCs spent 7 to 14 hours a week caring (28.3%) or less (24.5%), but a significant proportion exceed this time caring for their ill/disabled relative(s) (15.1%). Almost a third were not able to quantify the amount of caring per week (32.1%). Accordingly, and attending to the intensity of caring tasks as addressed by MACA-YC18 (Joseph *et al.*, 2009), most YCs (67.9%) show high (37.7%) or very high (30.2%) amounts of caring values, with almost one third showing low (9.4%) to moderate (22.6%) caring intensity, reflecting the heterogeneity of the YCs reality.

Table 2. Young Carers caring characteristics (N=106).

	n	%
Cared person		
Parent or similar (mother, father, stepmother, or stepfather)	44	41.5
Grandparent or grandgrandparent	38	35.8
Sibling	16	15.1
Other relative	8	7.5
Number of cared persons		
One person being cared	91	85.8
More than one person being cared	15	14.1
Years of caring role: M(SD)=4,55 (3,468), 0-16 years		
Up to 2 years	35	33.0
3 to 6 years	43	40.6
7 years or more	28	26.4
Amount of caring tasks (MACA-YC18)		
Low (00 – 09 points)	10	9.4

Moderate (10 – 13 points)	24	22.6
High (14 – 17 points)	40	37.7
Very high (18 – 36 points)	32	30.2
Hours on caring tasks per week		
Less than 7h/week	26	24.5
7 a 14h/week	30	28.3
Over than 14h/week	16	15.1
Missing	34	32.1

2.2. Measures and data analysis procedures

2.2.1. Socio-demographic and caring characteristics

The Socio-Demographic Questionnaire was designed in order to collect data related to gender, age, education grade, household composition and structure, and mother's and father's education, as an indication of socioeconomic status. Additionally, specific information related to YC role was collected: cared person(s), number of cared persons, years of caring role, and number of hours on caring tasks per week.

2.2.2. Satisfaction with Life

Satisfaction with life was assessed using the Portuguese version of the Brief Life Satisfaction Scale (BLSS) [65, 66], a unidimensional self-report measure consisting of 6 items that use a Likert response scale of 7 points, between 0 – Terrible to 6 – Fantastic, that allows access to satisfaction with the lives of adolescents. Each item focuses on a specific dimension of adolescent's life that is considered appropriate for this developmental stage (e.g., family, friends, or school: *I describe my experience with school as*). Higher values represent more satisfaction with life. The scale shows good internal consistency with a Cronbach's alpha coefficient of .809.

2.2.3. Satisfaction with Social Support

The Portuguese version of the Scale of Satisfaction with Social Support (SSSS)[67] is a self-report measure comprising 12 items, aiming to assess adolescent's satisfaction with social support. The SSSS enables measurement of the perceived needs or sense of social support and the relation of these perceptions with children and adolescents' health and well-being. Answers were given according to a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree), where adolescents reported to which degree they agree with the affirmation. The items are organized in two dimensions: Satisfaction with Social Support (six items) (e.g., *I am satisfied with the number of friends I have*) and Need for Activities connected to Social Support (six items) (e.g., *I would like to participate in more activities developed by organizations (e.g., sport clubs, scouts*)). The mean of the 12 items was computed to obtain the total score of adolescents' satisfaction with social support. Higher values represent more satisfaction with social support. Cronbach's alpha yielded acceptable consistency results for the total score of the SSSS (α = .810).

2.2.4. Family Functioning

To assess family functioning, the Portuguese version of the Systemic Clinical Outcome Routine Evaluation (SCORE-15)[64, 68] was used, which consists of a self-report questionnaire utilising 15 items that assess various aspects of family functioning that are sensitive to therapeutic change, divided into three dimensions: Family resources (e.g., *We are good at finding new ways of dealing with difficulties*), Communication in the family (e.g., *My family often doesn't get along tell the truth with each other*), and Family Difficulties (e.g., *We feel very unhappy in our family*). The answers are marked according to the five-level Likert scale (1 = Describes us very well; 2 = Describes us well; 3 = Describes us in part; 4 = Describes us poorly; and 5 = Describes us very poorly). The lower the value of the total score, the better the family functioning [64, 68]. With regard to the psychometric characteristics of this instrument, there is good internal consistency both for the total scale (α= 0.905), and for factor 1 (α = 0.885), factor 2 (α= 0.805) and the factor 3 (α = 0.823).

2.2.5. Academic Functioning

To assess academic functioning, a composite measure of 9 items was developed (research version, Meireles & Marques, 2023), including main indicators of adolescents' academic accomplishment and of their ability to fulfil academic behavior. Items include a self-report on adolescent grades, punctuality and assiduity, homework attainment and home studying, along with willingness to go to school and ability to concentrate in class. Items are scored on a 5-point Likert-type scale (0 = Very Insufficient, 1 = Insufficient, 2 = Sufficient, 3 = Good, 4 = Very Good), following terms regularly used in the school context to evaluate adolescent students' performance. Higher values represent better academic functioning. Cronbach's alpha yielded acceptable consistency results for the total score (α = .851).

2.2.6. Caring Activities

To assess the provision of care by young people, the Portuguese translation of the Multidimensional Assessment of Caring Activities (MACA-YC18) [34] was used, which assesses the total amount of caring activities carried out by a young person. The MACA-YC18 is a self-report questionnaire consisting of 18 items, scored on a 3-point Likert-type scale (0 = Never, 1 = Sometimes, and 2 = Often) and distributed into 6 subscales: (i) subscale "Domestic Tasks" assesses the degree to which the young person engages in activities such as cleaning, cooking, washing dishes or clothes (e.g. *You clean your own room*); (ii) the "Household Management" subscale assesses the degree of involvement in activities to keep the house running, such as shopping, cleaning the house and lifting heavy objects (e.g. *you take responsibility for buying food*); (iii) the "Personal Care" subscale assesses the degree of involvement in caring activities, such as helping the person to dress and undress, wash and use the bathroom, help with mobility and provide health care such as administering medication or changing dressings (e.g. *You help the person you care for to take a bath or shower*); (iv) the "Emotional Care" subscale assesses the extent to which the young person offers company and emotional support to the person being cared for, watching over them, supervising them and taking them for walks (e.g. *Do you pay attention to the person you care for to make sure that she is fine*); (v) the subscale "Care for Siblings" assesses the extent to which the young person is responsible for taking care of siblings alone or with a parent present (e.g. *You take care of your brothers or sisters alone*); and (vi) the "Financial/Practical Management" subscale assesses the extent to which the young person helps out financially and takes on practical adult responsibilities such as working part-time (e.g. *You work part-time to contribute money at home*). MACA-YC18 scores are to be sumed up, with higher values reflecting more caring activities. The original version of the MACA-YC18 has good psychometric characteristics with acceptable internal consistency for the different subscales: Cronbach's alpha coefficient of 0.898 (personal care), 0.756 (care for siblings), 0.597 (domestic tasks), 0.702 (emotional care), 0.651 (household management), 0.593 (financial/practical management), and 0.780 (full scale) [34]. For the present study, internal consistency both for the total scale (α= 0.855), and for subscales were similar to original values with 0.845 (personal care), 0.841 (care for siblings), 0.649 (domestic tasks), 0.812 (emotional care), 0.574 (household management), 0.682 (financial/practical management).

2.2.7. Subjective impact of caring

The Portuguese translation of the Positive and Negative Outcomes of Caring (PANOC-YC20) [34] was also used, in order to assess the subjective cognitive and emotional impact of the act of caring in the YCs. The PANOC-YC20 is a self-report questionnaire composed of 2 subscales (positive and negative), each consisting of 10 items, scored on a 3-point Likert scale (0 = Never, 1 = Sometimes, and 2 = Often). The positive subscale assesses the extent to which the young person positively experiences the role of caregiver (e.g. *I feel good about myself when caring for someone*). In turn, the negative subscale assesses the extent to which the young person negatively experiences their role as a caregiver (e.g. *When caring, I have to do things that make me upset*). The original version of the PANOC-YC18 has good internal consistency with a Cronbach's alpha coefficient of .906 for the positive subscale and .918 for the negative subscale [34]. For the present study, internal consistency was also good, both for the positive (α = .827) and the negative (α = .860) subscales.

2.2.8. Data analysis procedures

Statistical analyses were performed using IBM SPSS version 26.0, assuming an alpha level of .05. Descriptive statistics were conducted for both groups (young carers and noncarers). Given the significant percentage of missing values (>5%) in the sample (17%), and after analysing the pattern of missing values, a Multiple Imputation was conducted (20 imputations). As the variations along the multiple imputations did not seem significant, it was decided to use the original sample in the subsequent analyses. Preliminary multivariate analyses of variance were then conducted to test for gender differences for all variables in the study. As gender differences were not found, this variable was not controlled for in the subsequent analyses. On the contrary, age was (positively) correlated with both family functioning and the amount of caring activities performed, thus it was controlled in the analyses involving these variables.

To examine the effects of group, a multivariate analysis of variance (MANOVA) was performed to verify whether young carers and noncarers differed regarding satisfaction with life, satisfaction with social support and academic functioning. A multivariate analysis of covariance (MANCOVA) was performed to verify whether young carers and noncarers differed regarding family functioning and the amount of caring activities performed, controlling for age. Effect sizes for all analyses were estimated with partial eta squared statistic (η^2), considering $\eta^2 < .01$ as a low effect, $.01 < \eta^2 < .06$ as a medium effect, and $.06 < \eta^2 < .14$ as a large effect [69].

Afterwards, a hierarchical regression analysis was performed to assess whether social support, family functioning, academic functioning, amount of caring activities performed, and subjective impact of caring (included only in the YC group), were significant predictors of satisfaction with life in adolescent young carers (YC) and noncarers (NC). Also, a hierarchical regression analysis was performed to assess whether social support, family functioning, academic functioning and amount of caring activities performed, were significant predictors of negative impacts of caring in the YC group.

3. Results

3.1. Differences between young carers and noncarers on satisfaction with life, social support, family functioning, academic functioning and amount of caring activities

To examine these differences, a MANOVA of the scores of satisfaction with life, social support, and academic functioning as the dependent variables was performed to examine the effects of group (YC vs NC). Significant main effects were found for group, Wilks' lambda = 0.79, F (5, 133) = 6.892, $p < .001$, partial $\eta2 = .206$.

A MANCOVA was also performed, to examine the effects of group (YC vs NC), having family functioning and amount of caring activities as dependent variables, controlling for age. Significant main effects were found, Wilks' lambda = 0.83, F (2, 206) = 7.593, $p < .001$, partial $\eta2 = .069$. In addition, significant main effects were found for satisfaction with life, F(1, 137) = 4.85, $p < .05$, partial $\eta2 = .034$; and for amount of caring activities, F(1, 209) = 15.14, $p < .001$, partial $\eta2 = .068$. No significant main effects were found for social support, academic functioning and family functioning (Table 3).

Table 3. Mean (M) and standard deviation (SD) results regarding young carers and noncarers.

	Young Carers	**Noncarers (*n* =129)**	**Between group differences**

	(*n* =106)					
	M	SD	M	SD	*F*	p
Satisfaction with life	4.66	.88	4.93	.66	5.10	**.045**
Amount of caring activities	15.95	5.59	12.05	6.75	15.14	**<.001**
Social support	3.41	.72	3.64	.69	3.55	.061
Family functioning	2.26	.82	2.02	.77	2.17	.142
Academic functioning	3.85	.61	3.83	.61	.04	.841
Negative impact of caring	3.40	3.48				

3.2. Family functioning, academic functioning, social support, amount of activities and negative impact of caring as predictors of Satisfaction with life in YC

A hierarchical regression analysis was then conducted to examine which variables - family functioning, academic functioning, social support, amount and negative impact of caring - represent the strongest predictor of YC's satisfaction with life. The first step in the hierarchical regression included the variable age as predictor, the second step included the family functioning, academic functioning, and social support as predictors, and the third step included amount of caring activities and negative impact of caring (see Table 4). When all variables were entered in the regression equation, 53.4% of variance of satisfaction with life was explained, with academic functioning (β = .31, $p < .01$), social support (β = .36, $p < .01$), and negative impact of caring(β = -.38, $p < .01$) emerging as significantly predicting the satisfaction of life, after controlling for age (β = .11, $p > .05$).

Table 4. Hierarchical regression for family functioning, academic functioning, satisfaction with social support, negative impact of caring and amount of caring activities as predictors of life satisfaction in adolescent young carers (YC), controlling for age (N = 57).

	β	**95% CI**	***t***	**R²**	**Δ R²**
Step 1					
Age	-.042	-.24 .18	-.31	.002	-.016
Step 2				.343	.249***
Age	.04	-.15 .20	.33		
Family functioning	-.34**	-.56 to -.11	-2.97		
Academic functioning	.26*	.04 to .69	2.26		
Social support	.32**	.11 to .66	2.78		
Step 3				.534	.479***
Age	.11	-.07 .24	1.11		
Family functioning	-.15	-.36 .06	-1.41		
Academic functioning	.31**	.15 .72	3.06		
Social support	.36***	.19 .68	3.57		
Negative impact of caring	-.38**	-.16 - .04	-3.20		
Amount of caring activities	-.18	-.07 - .01	-1.66		

Legend: * p < .05; ** p < .01; *** p < .001; CI – Confidence Interval.

3.3. Family functioning, academic functioning, social support, and amount of activities as predictors of negative impact of caring in Young Carers

A hierarchical regression analysis was conducted afterwards to examine which variables - family functioning, academic functioning, social support, and amount of caring activities - represent the strongest predictor of negative impact of caring in YCs. The first step in the hierarchical regression included the variable age as predictor, the second step included the family functioning, academic functioning, and social support as predictors, and the third step included the amount of caring activities (see Table 5). When all variables were entered in the regression equation, 33% of variance of negative impact of caring was explained, with family functioning ($\beta = .30$, $p < .05$), and the amount of caring activities ($\beta = .38$, $p < .01$) emerging as significantly predicting the negative impact of caring, after controlling for age ($\beta = .10$, $p > .05$).

Table 5. Hierarchical regression for family functioning, academic functioning, satisfaction with social support and amount of caring activities as predictors of negative impact of caring in YCs, controlling for age (N =57).

	β	95% CI	*t*	R²	Δ R²
Step 1					
Age	.17	-.28 1.25	1.27	.029	.011
Step 2				.21	.14*
Age	.14	-.33 1.11	1.10		
Family functioning	.39**	.49 to 2.33	3.07		
Academic functioning	.17	-.43 to	1.36		
Social support	.14	2.24	1.12		
		-.51 to			
		1.78			
Step 3				.33	.27***
Age	.10	-.40 .94	.82		
Family functioning	.30*	-.53 -.06	-2.47		
Academic functioning	.20	-.19 2.28	1.70		
Social support	.16	-.32 1.81	1.41		
Amount of caring activities	.38**	.09 .40	3.12		

Legend: * p < .05; *** p < .001; CI – Confidence Interval.

3.4. Family functioning, academic functioning, social support, and amount of activities as predictors of Satisfaction with life in Noncarers

A hierarchical regression analysis was then conducted to examine which variables - family functioning, academic functioning, social support, and amount of activities - represent the strongest predictor of noncarer's satisfaction with life. The first step in the hierarchical regression included the variable age as predictor, the second step included the family functioning, academic functioning, social support as predictors, and the third step included the amount of caring activities (see Table 6). When all variables were entered in the regression equation, 46% of variance of satisfaction with life was explained, with academic functioning ($\beta = .27$, $p < .05$), social support ($\beta = .28$, $p < .01$), and family functioning ($\beta = -.31$, $p < .05$) emerging as significantly predicting satisfaction of life, after controlling for age ($\beta = .06$, $p > .05$).

Table 6. Hierarchical regression for family functioning, academic functioning, satisfaction with social support and amount of caring activities as predictors of life satisfaction in adolescent noncarers (NC), controlling for age (N = 82).

	β	95% CI	*t*	R²	Δ R²
Step 1					
Age	-.042	-.24 .18	-.31	.000	-.012

Step 2				.45	.42***
Age	.07	-.07 .16	.75		
Family functioning	-.26*	-.46 to -.04	-2.36		
Academic functioning	.30**	.10 to .55	2.85		
Social support	.29**	.09 to .47	2.85		
Step 3				.46	.42***
Age	.06	-.08 .15	.63		
Family functioning	-.31*	-.53 -.06	-2.47		
Academic functioning	.27*	.06 .53	2.46		
Social support	.28**	.09 .46	2.91		
Amount of caring activities	.08	-.01 .03	.81		

Legend: * p < .05; *** p < .001; CI – Confidence Interval.

4. Discussion

Young carers have been studied for the last few decades with growing contributions to supportive policies and practices [18] and, in different countries and continents, similar findings have been published on the prevalence and challenges these young people face when caring for their ill/disabled relatives and friends [31, 70]. Available data suggest that, for each 100 adolescents, 6 to 8 will be young carers, some of them in need for community and professional support [31]. This may represent the presence of 2-3 YCs in every classroom, no matter what country or socio-economic development is considered. However, no major research exists on Portuguese YCs as far as we are aware [71, 72].

Demographic and socio-economic challenges in Portugal would suggest that there will be significant numbers of children and young people in Portugal who would be considered to be young carers if they were visible or identified. These demographic changes include: longer life expectancy and an aging population, growing numbers of single-parent families, parental age rising, along with the growing prevalence of chronic and mental health conditions, 95% of whom live in family settings [73], along with cultural aspects placing the family as a central role in the caring system. Portuguese health professionals have acknowledged the existence of young carers in the past [71, 72, 74], even if only the Madeira Island reality was addressed, and no data were ever collected directly on Portuguese YCs. Though, the study reported in this paper may represent the first significant research on Portuguese young carers, and offers a contribution to raising awareness on this group's needs, being the simple recognition of Portuguese YCs' existence an important outcome in itself.

Our study inquired more than 9000 Portuguese adolescents with more than 900 students privately disclosing their experience of caring for their ill or disabled relatives. This represents groundbreaking preliminary data on the need for recognizing and identifying Portuguese young carers wherever they may be found, and researching and advocating for their needs. The data presented here suggest a higher proportion of Portuguese YCs than in some other countries where there is an established record of research and policy responses to young carers [75, 76].

This study represents an early contribution to acknowledging the reality of Portuguese YCs. The results also offer insights into the factors that support better outcomes for YCs in terms of their wellbeing, life satisfaction and specific developmental challenges. Indeed, addressing YCs' life satisfaction, considering their social support, family and academic functioning and their experiences and meanings of caring activities, is a relevant contribution to the understanding of the impact of their experiences on YCs' outcomes. Our findings confirmed our initial hypothesis of YCs' lower satisfaction with life than NCs, as expected [77]. This result supports existing concerns for the wellbeing of YCs and the implications of caring on their health and opportunities, as have already been revealed [14, 22-26, 77]. YCs tend to experience feelings of worry and hypervigilance associated with their caring tasks [78, 79], and being a carer is consistently associated with poorer mental health outcomes, such as depression, anxiety and other mental or emotional symptoms [13]. Moreover, having mental health problems is strongly associated with reduced satisfaction with life, being perhaps the strongest predictor of it [80].

Caregiving experience has been shown to have significant impacts on YCs' wellbeing. The range of personal detriments incurred by substantial and continuous care affects YCs' physical and mental health [3, 4, 9-11, 14, 39]. The impact has also been reported on children's social exclusion and school difficulties [19, 31, 33], which can impair their development and wellbeing [18, 31]. It is important to emphasize that our research shows lower life satisfaction for young carers than their noncarer peers; and that YCs' academic functioning, their satisfaction with social support and the negative subjective impact of caregiving predicts their satisfaction with life, highlighting the important role of social support for YCs' wellbeing that has already been documented [32, 33, 35]. YCs often experience lack of support and recognition for their particular role, mostly when they themselves are not aware of their caring identity and/or their proximal environments don't know about their caring role [19, 79]. Our research shows that this lack of recognition and support makes young carers less satisfied with their life, especially when teachers and peers don't know or don't understand their situation, more likely to misinterpret their behaviors, leaving YCs more socially isolated and emotionally lonely [11]. On the other hand, being acknowledged, identified and understood by others as carers, and being in receipt of appropriate support from peers and school staff, have a significant impact on YCs' satisfaction with life [11].

Schools, and support in schools, have a key role to play in improving YCs' satisfaction with life – school can be a protective factor. Our results suggest that, besides the subjective experience of caring, YCs' life satisfaction is dependent on whether they are able to maintain a satisfactory role as a student/pupil. Assuming their caring role demands a lot of time and energy from the YCs and, thus, leaves them with less time for their student role and performance, young carers can experience role overload [70]. Alternatively, when their caring role does not impose an excessive role strain, and they are able to retain their willingness and ability to go to school and concentrate in class, along with achieving desired grades, punctuality, assiduity and home studying, then their life satisfaction increases. This is consistent with studies that point to the negative emotional consequences (extreme outbursts of anger, sadness, and disappointment) that YCs experience, especially when they are not able to complete educational assessments on time or to quality [39]. Not surprisingly therefore, our results show that adolescents' role as a student makes a contribution to their life satisfaction, regardless of whether they assume a caring role. Life satisfaction refers to a comparative process in which individuals evaluate their lives against their own self-imposed standards [81], and it includes different dimensions, such as family, friends, and school [82]. In adolescence, meeting the basic psychological needs at school appears to be associated with well-being and life satisfaction [58, 83, 84], which highlights the importance of this context and role in adolescents' lives [85]. Thus, support from schools and teachers play an important role in YCs' wellbeing and development, and many YCs seemed to enjoy going to school as it provides them with a break from caring, the possibility to socialize, enjoy and learn [28].

Although no predictive effect of family functioning on life satisfaction was observed, after caring variables were considered and controlled, family variables are shown to have an important effect, along with the amount of caring activities reported, on the *negative* impact of caregiving, which in turn, also predicts YCs' life satisfaction. Thus, the negative impact of caregiving on YCs can be partially explained by their family functioning and the amount of their caregiving activities performed. Family functioning has been neglected in the YCs' literature, but Bou´s [14's] study showed that when YCs felt supported and acknowledged by their family members, including the care recipient, YCs reported that caring improved their family closeness and their relationship with the care recipient; otherwise, YCs viewed their caring negatively [14]. Moreover, recognition for the caring role and support in caring, including from relatives and the person receiving care, predicted better well-being [19]. Thus, low family resources, low communication in the family, and family difficulties are very important given their predictive force for the *negative* impact of caring. This result emphasizes the protective role of family functioning. An adaptive family functioning predicts a positive development of young people, namely in terms of mental health, self-esteem and life satisfaction; and on the contrary, problems in family functioning condition the adjustment of young people and are related to symptoms of depression and anxiety [61].

Noncarers have significant variability in the domestic and familial tasks performed, as would be expected. For noncarers, academic functioning, social support and family functioning, but not the amount of activities they undertake, predicted satisfaction with life. In conclusion, caregiving tasks and meaning have a negative impact on YCs' life satisfaction but not on NCs, as we could expect [27, 51]. A YC may be responsible for domestic tasks (e.g., cleaning, cooking, or laundry), household management (e.g., shopping and household repairs), financial management (e.g., helping to pay bills or working part-time), personal care (e.g., helping the person to feed, dress and undress, bath and perform daily hygiene, or administer food and medication), emotional support (e.g., supervision or companionship) and sibling assistance (e.g., caring for siblings alone or with a parent present) [34]. These tasks have a significant impact on YCs´ lives [31, 86] especially when they are cumulative, as is the case with our sample: the greater the number of tasks, the greater the negative impact of caring.

Whatever the type of care (involvement in household chores or more intimate care), the relationship with the person being cared for, and the emotional and physical demands of care, provided on a daily basis, are aspects that are associated with more stress and, therefore, a greater impact of care on life satisfaction. Thus, this result emphasizes the need to address this set of variables when designing programs to promote YCs' life satisfaction. Furthermore, the predictive value of subjective meaning of their caring activities, but not of the amount of caring tasks per se, highlights the need for a more reflexive and psychological approach to YCs' experiences, over and above the caring tasks objectively reported.

Besides the negative consequences of caring on YCs' mental and physical health, the caring role may have positive consequences for YCs [16, 17, 32] including maturity and competence [31]. Thus, programs targeting the promotion of YCs life satisfaction should also address the positive consequences of caregiving [11, 33-36], and specially helping them to develop self-compassion and empathy [3, 16, 37, 38], feelings of fulfilment [14] or accomplishment [42], and a sense of purpose [30] – all positive adaptations and positive subjective feelings of caring. Not only can caring have positive outcomes, but these can be improved through the principles of positive psychology. Furthermore, promoting and increasing life satisfaction, self-compassion, fulfillment and flourishing should also play a powerful role in reducing the negative impact of caregiving [14], which in turn, is shown to predict YCs' satisfaction with life. As Gough and Gulliford [42] state, the benefit-seeking orientation as the process of deriving positive growth from adversity, may lead YCs to be particularly resilient and form a sense of satisfaction and fulfillment in their roles, along with practical coping strategies and a strong sense of agency and connection that also promote better outcomes for YCs. Benefit discovery has been associated with better mental well-being both directly and indirectly through better coping and less helplessness [43]. Coming to know and support YCs is not only about identifying and overcoming their vulnerabilities, in order to equal them with noncarers young people. In fact, it is an unique chance to face this caring role as a positive opportunity for growth and development, all over the life span, and in different relational context, both across the family development path, and throughout the positive and mutually rewarding and healthy caring relationships one (should) come to build wherever s/he lives, involving identity, relatedness and competence central issues worthing to further acknowledge.

5. Conclusions

This article may represent the first study of Portuguese young carers. It is methodologically complex to research hidden and invisible groups, especially when they are children who are carers, with the associated complex ethical, informed, and parental consent requirements. Moreover, in the Portuguese context, this is made more challenging when the awareness of young carers amongst publics and professionals, including policy makers, teachers, and communities, is low. Young carers themselves often do now see or identify themselves as 'carers' but rather as children living with parents and other family members who may have some illness or condition which requires the child to "help at home".

Identification and recruitment challenges have been reported and there is no dominant view as to what constitutes the best approach to finding YCs, or to 'count them' [87]. Internationally, YCs have been identified through national census, large surveys and longitudinal studies, and through children self-identifying as young carers. This poses a challenge for a country such as Portugal – in its infancy regarding YCs' research and policy development. What should ideally come first: awareness raising and support activities for YCs, or research on (or with) YCs? Following Hanson, et al. [88] we would suggest that awareness raising directed at key groups (such as healthcare workers, teachers, social workers etc) without solid research evidence as to the extent and nature of young caring, is not likely to prove to be effective. Our strategy, in this research and outside, was to systematize and spread knowledge about YCs to help with awareness raising amongst publics, academics and policy makers, which helps to put Portuguese YCs' 'on the map' and also helps to establish a research agenda. Projecto Jovens Cuidadores acted as a multilevel pilot structure involving all these institutions, helping to raise awareness and identifying YCs needs and characteristics.

The research presented here illuminates the experiences of YCs in Portugal, bringing them out of the shadows. It shows the factors that are associated with young carers' (positive) satisfaction with life, and those that are associated with negative impacts and outcomes. This provides a foundation for the development of policy and practice in Portugal. Policy and interventions should be designed to accentuate the positive and reduce or mediate the negative factors. We can also learn from international advances in policy and practice. Young carers research in Portugal is in its infancy, as is the development of policy and practice. There is a long way to go, but we have made a start.

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References

1. Chiao, C. Y., H. S. Wu, and C. Y. Hsiao. "Caregiver Burden for Informal Caregivers of Patients with Dementia: A Systematic Review." *Int Nurs Rev* 62, no. 3 (2015): 340-50.
2. Dearden, Chris, and Saul Becker. "Young Carers in the Uk: The 2004 Report." Loughborough University, https://repository.lboro.ac.uk/articles/online_resource/Young_carers_in_the_UK_the_2004_report_/9470903 (
3. Aldridge, Jo, and Saul Becker. "Punishing Children for Caring: The Hidden Cost of Young Carers." *Children & Society* 7, no. 4 (1993): 376-87.
4. Lacey, Rebecca E., Baowen Xue, and Anne McMunn. "The Mental and Physical Health of Young Carers: A Systematic Review." *The Lancet Public Health* 7, no. 9 (2022): e787-e96.

5. Williams, Janet K., Lioness Ayres, Janet Specht, Kathleen Sparbel, and Mary Lou Klimek. "Caregiving by Teens for Family Members with Huntington Disease." *Journal of Family Nursing* 15, no. 3 (2009): 273-94.
6. Becker, S. "Special Issue Information." *International Journal of Environmental Research and Public Health*, no. Special Issue "Young Carers: Research, Policy and Practice" (2023).
7. Leu, Agnes, Marianne Frech, and Corinna Jung. "“You Don't Look for It”—a Study of Swiss Professionals’ Awareness of Young Carers and Their Support Needs." *Health & Social Care in the Community* 26, no. 4 (2018): e560-e70.
8. Barbabella, F., L. Magnusson, L. Boccaletti, G. Casu, V. Hlebec, I. Bolko, F. Lewis, R. Hoefman, R. Brolin, S. Santini, M. Socci, B. D'Amen, Y. de Jong, T. Bouwman, N. de Jong, A. Leu, D. Phelps, E. Guggiari, A. Wirth, V. Morgan, S. Becker, and E. Hanson. "Recruitment of Adolescent Young Carers to a Psychosocial Support Intervention Study in Six European Countries: Lessons Learned from the Me-We Project." *Int J Environ Res Public Health* 20, no. 6 (2023).
9. Nagl-Cupal, M., M. Daniel, M. M. Koller, and H. Mayer. "Prevalence and Effects of Caregiving on Children." *J Adv Nurs* 70, no. 10 (2014): 2314-25.
10. Robison, Omef, G. Inglis, and J. Egan. "The Health, Well-Being and Future Opportunities of Young Carers: A Population Approach." *Public Health* 185 (2020): 139-43.
11. Becker, Fiona, and Saul Becker. "Young Adult Carers in the Uk: Experiences, Needs and Services for Carers Aged 16-24." 2008.
12. Chevrier, B., A. Untas, and G. Dorard. "Are We All the Same When Faced with an Ill Relative? A Person-Oriented Approach to Caring Activities and Mental Health in Emerging Adult Students." *Int J Environ Res Public Health* 19, no. 13 (2022).
13. Fleitas Alfonzo, Ludmila, Ankur Singh, George Disney, Jennifer Ervin, and Tania King. "Mental Health of Young Informal Carers: A Systematic Review." *Social Psychiatry and Psychiatric Epidemiology* 57, no. 12 (2022): 2345-58.
14. Bou, Camille. "Factors Associated with the Quality-of-Life of Young Unpaid Carers: A Systematic Review of the Evidence from 2003 to 2019." *International Journal of Environmental Research and Public Health*, no. 6 (2023).
15. Cohen, D., J. A. Greene, P. A. Toyinbo, and C. T. Siskowski. "Impact of Family Caregiving by Youth on Their Psychological Well-Being: A Latent Trait Analysis." *J Behav Health Serv Res* 39, no. 3 (2012): 245-56.
16. Charles, Grant, Tim Stainton, and Sheila Marshall. *Young Carers in Canada: The Hidden Costs and Benefits of Young Caregiving*, 2012.
17. Aldridge, Jo, Dan Clay, Caitlin Connors, Naomi Day, and Marina Gkiza. "The Lives of Young Carers in England: Qualitative Report to Department for Education." *Loughborough: Loughborough University Young Carers Research Group* (2016).
18. Johanson, P., Hanson, E., Hlebec, V., Sirk, K., Mrzel, M., Boccaletti, L., Manattini, A., Alves, B., Teixeira, A. R., &; Centola, F. . "Innovative School Education Methodologies and Tools for Guaranteeing Social Inclusion of Young Carers (Edy-Care-Project) [E-Book]. Edy-Care Project." ed EDY-CARE project, 2017.
19. Wepf, Hannah, and Agnes Leu. "Well-Being and Perceived Stress of Adolescent Young Carers: A Cross-Sectional Comparative Study." *Journal of Child and Family Studies* 31, no. 4 (2022): 934-48.
20. Choudhury, Dipak, and Huw Williams. "Strengthening the Educational Inclusion of Young Carers with Additional Needs: An Eco-Systemic Understanding." *Educational Psychology in Practice* 36, no. 3 (2020): 241-56.
21. Warren, Janet. "Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks?" *Children & Society* 21, no. 2 (2007): 136-46.
22. Lloyd, Katrina. "Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring among 10 and 11 year Old School Children." *Journal of Happiness Studies* 14, no. 1 (2013): 67-80.
23. Hamilton, Myra Giselle, and Elizabeth Adamson. "Bounded Agency in Young Carers' Lifecourse-Stage Domains and Transitions." *Journal of Youth Studies* 16, no. 1 (2013): 101-17.
24. Lakman, Yana, and Heather Chalmers. "Psychosocial Comparison of Carers and Noncarers." *Child & Youth Services* 40, no. 2 (2019): 200-19.
25. Thomas, Nigel, Tim Stainton, Sonia Jackson, W. Cheung, Samantha Doubtfire, and Amanda Webb. "'Your Friends Don't Understand': Invisibility and Unmet Need: In the Lives of 'Young Carers'." *Child & Family Social Work* 8 (2003): 35-46.
26. De Roos, Simone A., Alice H. De Boer, and Sander M. Bot. "Well-Being and Need for Support of Adolescents with a Chronically Ill Family Member." *Journal of Child and Family Studies* 26, no. 2 (2017): 405-15.
27. King, Tania, Ankur Singh, and George Disney. "Associations between Young Informal Caring and Mental Health: A Prospective Observational Study Using Augmented Inverse Probability Weighting." *The Lancet Regional Health – Western Pacific* 15 (2021).
28. Becker, Saul, and Joe Sempik. "Young Adult Carers: The Impact of Caring on Health and Education." *Children & Society* 33, no. 4 (2019): 377-86.

29. Saragosa, Marianne, Melissa Frew, Shoshana Hahn-Goldberg, Ani Orchanian-Cheff, Howard Abrams, and Karen Okrainec. "The Young Carers&Rsquo; Journey: A Systematic Review and Meta Ethnography." *International Journal of Environmental Research and Public Health* 19, no. 10 (2022): 5826.
30. Skufca, Laura and Hartman O'Connell, Ian "Staying the Course: How Dual Responsibilities Create Challenges for Student Caregivers.", ed AARP Research. Washington, DC: AARP Research, 2020.
31. Joseph, Stephen, Joe Sempik, Agnes Leu, and Saul Becker. "Young Carers Research, Practice and Policy: An Overview and Critical Perspective on Possible Future Directions." *Adolescent Research Review* 5, no. 1 (2020): 77-89.
32. Pakenham, Kenneth I., Jessica Chiu, Samantha Bursnall, and Toni Cannon. "Relations between Social Support, Appraisal and Coping and Both Positive and Negative Outcomes in Young Carers." *Journal of Health Psychology* 12, no. 1 (2007): 89-102.
33. Aldridge, Jo, and Saul Becker. "Punishing Children for Caring: The Hidden Cost of Young Carers." *Children & Society* 7 (2007): 376-87.
34. Joseph, S., S. Becker, F. Becker, and S. Regel. "Assessment of Caring and Its Effects in Young People: Development of the Multidimensional Assessment of Caring Activities Checklist (Maca-Yc18) and the Positive and Negative Outcomes of Caring Questionnaire (Panoc-Yc20) for Young Carers." *Child Care Health Dev* 35, no. 4 (2009): 510-20.
35. Cassidy, T., and M. Giles. "Further Exploration of the Young Carers Perceived Stress Scale: Identifying a Benefit-Finding Dimension." *Br J Health Psychol* 18, no. 3 (2013): 642-55.
36. Cohen, Carole A, Angela Colantonio, and Lee Vernich. "Positive Aspects of Caregiving: Rounding out the Caregiver Experience." *International journal of geriatric psychiatry* 17, no. 2 (2002): 184-88.
37. Fives, Allyn, Danielle Kennan, John Canavan, and Bernadine Brady. "Why We Still Need the Term 'Young Carer': Findings from an Exploratory Study of Young Carers in Ireland." *Critical Social Work* 14, no. 1 (2013).
38. Becker, Saul, Jo Aldridge, and Chris Dearden. *Young Carers and Their Families*. Oxford: Blackwell Science, 1998.
39. Stamatopoulos, Vivian. "The Young Carer Penalty: Exploring the Costs of Caregiving among a Sample of Canadian Youth." *Child & Youth Services* 39 (2018): 1-26.
40. Moore, Tim, Helen Bourke-Taylor, Natalie Greenland, Stewart McDougall, Luke Robinson, Ted Brown, and Leah Bromfield. "Young Carers and Educational Engagement: Quantitative Analysis of Bursary Applications in Australia." *Health & Social Care in the Community* 30 (2021).
41. Moore, Tim, and Morag McArthur. "We're All in It Together: Supporting Young Carers and Their Families in Australia." *Health & Social Care in the Community* 15, no. 6 (2007): 561-68.
42. Gough, Gemma, and Anthea Gulliford. "Resilience Amongst Young Carers: Investigating Protective Factors and Benefit-Finding as Perceived by Young Carers." *Educational Psychology in Practice* 36, no. 2 (2020): 149-69.
43. Wepf, Hannah, Stephen Joseph, and Agnes Leu. "Pathways to Mental Well-Being in Young Carers: The Role of Benefit Finding, Coping, Helplessness, and Caring Tasks." *Journal of Youth and Adolescence* 50, no. 9 (2021): 1911-24.
44. Kavanaugh, Melinda S, Vivian Stamatopoulos, Donna Cohen, and Lixia Zhang. "Unacknowledged Caregivers: A Scoping Review of Research on Caregiving Youth in the United States." *Adolescent Research Review* 1 (2016): 29-49.
45. Guggiari, E., M. Fatton, S. Becker, F. Lewis, G. Casu, R. Hoefman, E. Hanson, S. Santini, L. Boccaletti, H. H. Nap, V. Hlebec, A. Wirth, and A. Leu. "Visibility as a Key Dimension to Better Health-Related Quality of Life and Mental Health: Results of the European Union Funded "Me-We" Online Survey Study on Adolescent Young Carers in Switzerland." *Int J Environ Res Public Health* 20, no. 5 (2023).
46. Johansson, Pauline, Lennart Magnusson, Licia Boccaletti, Valentina Hlebec, Bruno Alves, Ana Teixeira, Francesca Centola, and Elizabeth Hanson. "Innovative School Education Methodologies and Tools for Guaranteeing Social Inclusion of Young Carers (Edy-Care-Project)." Paper presented at the The 3rd International Young Carers conference, Online, May 3-6, 2021 2021.
47. Frank, Jenny, and Julie McLarnon. *Young Carers, Parents and Their Families: Key Principles of Practice: Supportive Practice Guidance for Those Who Work Directly with, or Commission Services for, Young Carers and Their Families*: Children's Society, 2008.
48. Metzing-Blau, Sabine, and Wilfried Schnepp. "Young Carers in Germany: To Live on as Normal as Possible – a Grounded Theory Study." *BMC Nursing* 7, no. 1 (2008): 15.
49. Wayman, Sarah, Phil Raws, and Helen Leadbitter. "There's Nobody Is There–No One Who Can Actually Help?" *Children's Society: London, UK* (2016).
50. Boumans, N. P. G., and E. Dorant. "A Cross-Sectional Study on Experiences of Young Adult Carers Compared to Young Adult Noncarers: Parentification, Coping and Resilience." *Scand J Caring Sci* 32, no. 4 (2018): 1409-17.
51. Tseliou, F., M. Rosato, A. Maguire, D. Wright, and D. O'Reilly. "Variation of Caregiver Health and Mortality Risks by Age: A Census-Based Record Linkage Study." *Am J Epidemiol* 187, no. 7 (2018): 1401-10.

doi:10.20944/preprints202309.0076.v1

52. Gates, M. F., and N. R. Lackey. "Youngsters Caring for Adults with Cancer." *Image J Nurs Sch* 30, no. 1 (1998): 11-15.
53. Pakenham, K. I., and S. Cox. "The Effects of Parental Illness and Other Ill Family Members on Youth Caregiving Experiences." *Psychol Health* 30, no. 7 (2015): 857-78.
54. George, Emma S., Milica Kecmanovic, Tanya Meade, and Gregory S. Kolt. "Psychological Distress among Carers and the Moderating Effects of Social Support." *BMC Psychiatry* 20, no. 1 (2020): 154.
55. Anjos, Karla Ferraz dos, Rita Narriman Silva de Oliveira Boery, Rafael Pereira, Larissa Chaves Pedreira, Alba Benemérita Alves Vilela, Vanessa Cruz Santos, and Darci de Oliveira Santa Rosa. "Association between Social Support and Quality of Life of Relative Caregivers of Elderly Dependents." *Ciência & Saúde Coletiva* 20 (2015).
56. Isaksen, Lise Widding. "Toward a Sociology of (Gendered) Disgust: Images of Bodily Decay and the Social Organization of Care Work." *Journal of Family Issues* 23, no. 7 (2002): 791-811.
57. Chikhradze, Nino, Christiane Knecht, and Sabine Metzing. "Young Carers: Growing up with Chronic Illness in the Family - a Systematic Review 2007-2017." *Journal of Compassionate Health Care* 4, no. 1 (2017): 12.
58. Meireles, A., S. Marques, M. M. Peixoto, M. Sousa, and S. Cruz. "Portuguese Adolescents' Cognitive Well-Being and Basic Psychological Needs During the Covid-19 Outbreak: A Longitudinal Study." *Appl Psychol Health Well Being* 14, no. 3 (2022): 881-98.
59. Belsey, Mark A. *Aids and the Family: Policy Options for a Crisis in Family Capital*: United Nations, Department of Economic and Social Affairs New York, 2005.
60. Walker, Roz, and Carrington Shepherd. *Strengthening Aboriginal Family Functioning: What Works and Why?*: Australian Institute of Family Studies Melbourne (AUST), 2008.
61. Francisco, Rita, Sara Loios, and Marta Pedro. "Family Functioning and Adolescent Psychological Maladjustment: The Mediating Role of Coping Strategies." *Child Psychiatry & Human Development* 47, no. 5 (2016): 759-70.
62. Alarcão, Madalena, and Maria Filomena Gaspar. "Imprevisibilidade Familiar E Suas Implicações No Desenvolvimento Individual E Familiar." *Paidéia (Ribeirão Preto)* 17 (2007): 89-102.
63. Dunning, Melissa J, and Rebecca Giallo. "Fatigue, Parenting Stress, Self-Efficacy and Satisfaction in Mothers of Infants and Young Children." *Journal of Reproductive and Infant Psychology* 30, no. 2 (2012): 145-59.
64. Vilaça, Margarida, Bruno de Sousa, Peter Stratton, and Ana Paula Relvas. "The 15-Item Systemic Clinical Outcome and Routine Evaluation (Score-15) Scale: Portuguese Validation Studies." *The Spanish Journal of Psychology* 18 (2015): E87.
65. Costa, Pedro JC, Richard A Inman, and Paulo AS Moreira. "The Brief Multidimensional Students' Life Satisfaction Scale (Bmslss): Further Evidence of Factorial Structure, Reliability, and Relations with Other Indicators of Subjective Wellbeing." *Applied research in quality of life* 17, no. 6 (2022): 3541-58.
66. Huebner, ES. "Brief Life Satisfaction Scale." *Documento electrónico: http://www. cla. sc. edu/PSYC/pdfdocs/huebslssbrief. doc* (1997).
67. Gaspar, Tania, José Luis Pais Ribeiro, Margarida Gaspar Matos, Isabel Leal, and Aristides Ferreira. "Psychometric Properties of a Brief Version of the Escala De Satisfação Com O Suporte Social for Children and Adolescents." *The Spanish Journal of Psychology* 12, no. 1 (2009): 360-72.
68. Stratton, Peter, Julia Bland, Emma Janes, and Judith Lask. "Developing an Indicator of Family Function and a Practicable Outcome Measure for Systemic Family and Couple Therapy: The Score." *Journal of family therapy* 32, no. 3 (2010): 232-58.
69. Cohen, Peter A, and Lakshmi S Dacanay. "Computer-Based Instruction and Health Professions Education: A Meta-Analysis of Outcomes." *Evaluation & the Health Professions* 15, no. 3 (1992): 259-81.
70. Leu, Agnes, and Saul Becker. "A Cross-National and Comparative Classification of in-Country Awareness and Policy Responses to 'Young Carers'." *Journal of Youth Studies* 20, no. 6 (2017): 750-62.
71. Marote, Ana Sofia Filipe, Carla Andreia Pinto, Marlene da Rocha Vieira, Maria do Céu Aguiar Barbiéri-Figueiredo, and Pedro Miguel Nunes Pedrosa. "Children as Carers: An Integrative Review." *Revista latino-americana de enfermagem* 20 (2012): 1196-205.
72. Pinto, Andreia Carla, Ana Sofia Filipe Marote, Pedro Miguel Nunes Pedros, and Maria do Céu Barbieri-Figueiredo. "Crianças Como Cuidadores: Uma Investigação Sobre a Perspetiva Dos Enfermeiros Da Região Autónoma Da Madeira Da Madeira." *Revista de Enfermagem*, no. 9 (2016).
73. Instituto Nacional de Estatística, INE. "Censos 2021: Resultados Definitivos, Principais Indicadores." ed INE. Lisboa: INE, 2021.
74. Marote, ASF, ATLS Eduardo, CA Pinto, MR Vieira, and PMN Pedrosa. "Crianças Como Prestadoras De Cuidados." *Redes de Conhecimento em Enfermagem de Família* (2010): 148-57.
75. Aldridge, Jo. "Where Are We Now? Twenty-Five Years of Research, Policy and Practice on Young Carers." *Critical Social Policy* 38, no. 1 (2017): 155-65.

76. Di Gessa, Giorgio, Baowen Xue, Rebecca Lacey, and Anne McMunn. "Young Adult Carers in the Uk—New Evidence from the Uk Household Longitudinal Study." *International Journal of Environmental Research and Public Health* 19, no. 21 (2022): 14076.
77. Haugland, Bente Storm Mowatt, Mari Hysing, and Børge Sivertsen. "The Burden of Care: A National Survey on the Prevalence, Demographic Characteristics and Health Problems among Young Adult Carers Attending Higher Education in Norway." *Frontiers in Psychology* 10 (2020): 2859.
78. Ali, Lilas, B Hedman Ahlström, Barbro Krevers, and Ingela Skärsäter. "Daily Life for Young Adults Who Care for a Person with Mental Illness: A Qualitative Study." *Journal of psychiatric and mental health nursing* 19, no. 7 (2012): 610-17.
79. McDougall, Emma, Moira O'Connor, and Joel Howell. "“Something That Happens at Home and Stays at Home”: An Exploration of the Lived Experience of Young Carers in Western Australia." *Health & Social Care in the Community* 26, no. 4 (2018): 572-80.
80. Lombardo, Patrick, Wayne Jones, Liangliang Wang, Xin Shen, and Elliot M Goldner. "The Fundamental Association between Mental Health and Life Satisfaction: Results from Successive Waves of a Canadian National Survey." *BMC public health* 18, no. 1 (2018): 1-9.
81. Pavot, William, and Ed Diener. "Review of the Satisfaction with Life Scale." *Psychological assessment* 5, no. 2 (1993): 164.
82. Huebner, E Scott, Shannon M Suldo, Laura C Smith, and Caroline G McKnight. "Life Satisfaction in Children and Youth: Empirical Foundations and Implications for School Psychologists." *Psychology in the Schools* 41, no. 1 (2004): 81-93.
83. Eryilmaz, Ali. "A Model for Subjective Well-Being in Adolescence: Need Satisfaction and Reasons for Living." *Social Indicators Research* 107 (2012): 561-74.
84. Leversen, Ingrid, Anne G Danielsen, Marianne S Birkeland, and Oddrun Samdal. "Basic Psychological Need Satisfaction in Leisure Activities and Adolescents’ Life Satisfaction." *Journal of Youth and Adolescence* 41 (2012): 1588-99.
85. Tian, Lili, Huan Chen, and E. Scott Huebner. "The Longitudinal Relationships between Basic Psychological Needs Satisfaction at School and School-Related Subjective Well-Being in Adolescents." *Social Indicators Research* 119, no. 1 (2014): 353-72.
86. Hendricks, Bailey A., Melinda S. Kavanaugh, and Marie A. Bakitas. "How Far Have We Come? An Updated Scoping Review of Young Carers in the U.S." *Child and Adolescent Social Work Journal* 38, no. 5 (2021): 491-504.
87. Untas, Aurélie, Eléonore Jarrige, Christel Vioulac, and Géraldine Dorard. "Prevalence and Characteristics of Adolescent Young Carers in France: The Challenge of Identification." *Journal of Advanced Nursing* 78, no. 8 (2022): 2367-82.
88. Hanson, Elizabeth, Francesco Barbabella, Lennart Magnusson, Rosita Brolin, Miriam Svensson, Stecy Yghemonos, Valentina Hlebec, Irena Bolko, Licia Boccaletti, and Giulia Casu. "Research and Innovation for and with Adolescent Young Carers to Influence Policy and Practice—the European Union Funded “Me-We” Project." *International Journal of Environmental Research and Public Health* 19, no. 16 (2022): 9932.