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The moderating role of age in the relationship between different stressors and the quality of life of the relatives of people with intellectual disabilities

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Abstract

Purpose The level of support needed for adaptive functioning and behavioral problems of individuals with intellectual disabilities (ID) can be a source of stress for caregivers. The aim of this study was to explore the moderating role of caregivers' age on the associations between these stressors and quality of life (QoL) of the family caregivers. As these sources of stress in people with ID can coexist, the triple interaction between stressors and age was also examined.

Methods 208 relatives (mean age = 50.98 years, SD = 12.86) of people with ID participated in the research. Participants answered a questionnaire with sociodemographic variables, measures of stressors (level of support for adaptive functioning of the people with ID and behavioral problems) and measures of QoL (WHOQOL-BREF).

Results The association between the level of support needed for adaptive functioning and lower QoL was only significant among older relatives, whereas the association between behavioral problems and lower QoL was only significant among younger relatives. A three-way interaction between behavioral problems, level of support needed, and age indicated that the association between the level of support for adaptive functioning and QoL in older relatives was greater when there were higher levels of behavioral problems.

Conclusions The role of caregivers' age in their QoL differs depending on the nature of the stressor, and an accumulation of stressors can have a particularly negative impact on older caregivers. Interventions should be adapted for caregivers of different ages and take into account the particular sources of stress they have to cope with.

Keywords Intellectual disabilities · Aging caregivers · Relatives · Adaptive functioning · Behavioral problems · Quality of life

It is estimated that one in every one hundred people in Spain has intellectual or developmental disabilities (ID/DD) [1, 2]. ID includes limitations in intellectual functioning, as well as adaptive behavior in the conceptual, social, and practical domains [3]. In Spain, as in most countries, almost all adult people with ID live with their families and are supported mainly by women, especially mothers [1, 4–6]. Care and support of a person with ID can have a major impact on family dynamics, as well as on social, economic, and health aspects of their lives [7–9]. Thus, family caregivers can experience psychological distress, including anxiety and depression [10] as well as a decline in their quality of life (QoL) [11–13]. However, not all family caregivers experience the same negative consequences. According to the transactional model of stress [14], psychological well-being will depend on personal characteristics (i.e., personality, age, education), aspects of the environment (such as characteristics of the person with ID), and the appraisal of available resources to cope with the demands of the situation.

One caregiver characteristic that can affect QoL is age. Because the life expectancy of people with ID has increased [15, 16], the need of support continues over time, sometimes extending throughout the life of the family caregiver [6, 17]. This makes the role of the caregiver's age especially relevant in the study of the problems associated with care.

Age has been considered a mitigating factor of distress in the general population [18, 19]. However, in this context,

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the few studies that have explored the role of caregivers' age have produced mixed results. Some have shown that older caregivers experience less burden [20–22], less psychological distress [18, 23, 24] and greater satisfaction with care and QoL [25, 26]. In contrast, other studies have found exactly the opposite, with older caregivers showing higher levels of distress, poorer QoL, and giving more negative appraisals of having a family member with ID [27–30]. Finally, other studies have observed no differences as a function of caregivers' age [17, 31].

Different hypotheses have been proposed to explain the role of age in family caregivers' distress. On the one hand, some authors suggest that the accumulation of demands after years of giving support wears them down, diminishing their physical and psychological resources and producing negative consequences [32, 33]. On the other hand, it has been considered that family caregivers develop various skills over the years as a result of different experiences and, thus, can adjust and improve their circumstances [34, 35].

An explanation that could account for the mixed results in the role of caregivers' age lies in the characteristics that people with ID may present, some of which can be important sources of stress. Which aspects of the person with ID act as stressors for the family caregiver? Two sources of stress—limitations of adaptive functioning and behavioral problems—have come to be viewed as the most important.

The limitation of adaptive functioning is one of the major characteristics of people with ID [3]. Adaptive functioning refers to the set of conceptual, social, and practical skills that have been learned by people in order to function in their daily lives and includes aspects such as mobility, communication, feeding, and hygiene [36]. A poorer ability to function in daily life activities implies a lower capacity for independent living and the need for greater support [37]. Thus, caregivers of people with lower adaptive functioning have more difficulties engaging in other activities, which curtails their social life and negatively affects their QoL [11]. Adaptive functioning deficit has been associated both with poorer QoL [38–40] and greater distress and burden for family caregivers [20, 41–43].

In addition to a deficit in adaptive functioning, people with ID can present behavioral problems. The presence of behavioral problems in the person with ID or DD, such as offensive, stereotyping, or disruptive behavior, has been considered a source of stress for family caregivers [41, 42, 44–46]. This factor is especially important considering that young people and children with ID have between 3 and 7 times more behavioral problems than typically developing youth [45, 47, 48], and that these behavioral problems can continue to exist during adulthood [49]. For this reason, behavioral problems have been considered a risk factor for family caregivers' QoL [38–40, 50] and psychological adjustment [29, 51, 52].

Overview of the current study

Care of a person with ID can continue throughout the life of the family caregiver, which may contribute to the deterioration of caregivers' QoL. Previous research has found contradictory results in the role of age and the consequences of care in caregivers, and it is, therefore, important to elucidate this role to design better interventions.

One factor that could help to clarify the mixed results in the role of age is the nature of the stressors that must be faced. Behavioral problems, such as non-cooperative, offensive, or repetitive habits, can produce great emotional exhaustion in the caregivers [53]. However, with time and experience, older caregivers may have learned to cope with these problems and may thus experience less distress than the younger caregivers [34, 35]. On another hand, supporting a person with a high level of dependency in different everyday activities also requires a physical performance that may be especially problematic for older caregivers, whose physical resources are lower [17, 54]. Therefore, the first objective of this study was to explore the moderating role of age for two potential sources of stress in caregiving (the level of support needed for adaptive functioning and behavioral problems) in family caregivers' QoL.

In addition, support needs and behavioral problems often coexist, and the impact of each type of stressor could be concomitantly affected by the other [55, 56]. Hence, we also examined a potential interaction between the level of support needed for adaptive functioning and behavioral problems. Furthermore, we examined a triple interaction between the two stressors (i.e., level of support needed for adaptive functioning and behavioral problems) and age. We hypothesized that the caregivers could present lower tolerance toward the limitations on adaptive functioning when the individual also presents severe behavioral problems. This effect could be particularly intense among older caregivers.

Methods

Participants

In Spain, it is estimated that over 277.472 people have a recognized ID [2]. These people usually live with their families, and are mainly supported by a female relative between 45 and 64 years old [1]. In this study, a total of 208 relatives participated, 50% via pencil-and-paper, 49.5% online, and 0.5% via telephone. Participants were from 16 Spanish autonomous communities (Basque Country 55%, Andalusia 7.9%, Catalonia 9.4%, Cantabria 8.4%, Castilla and León 3.5%, and others).

The inclusion criteria were: (1) being a relative caregiver of a person with ID (i.e., they should dedicate approximately a minimum of 20 h a week to the care of their relative or to related tasks); (2) living with the person with ID or maintaining ongoing contact with him/her. We excluded those participants: (1) of whom it was suspected that they did not correctly complete the questionnaire or did so randomly, or using stereotyped response patterns; (2) who lived with the person with ID but did not dedicate any time to his or her care; (3) where the dependent person they cared for has a disability other than ID (e.g., dementia, stroke, mental health) or autism; and (4) who did not reside in Spain.

Of the participants, 170 were women (81.7%). The participants' mean age was 50.98 years (SD = 12.86), ranging from 18 to 81. Concerning kinship, 80.3% of the participants were parents (mothers 68.8%, fathers 11.5%), 16.3% were siblings, and the remaining 3.4% were related in some other way, such as grandparents, uncles/aunts, or legal guardians. Regarding educational level, 49% of the sample had a university education, 2.5% vocational training, 28.9% secondary education, 19.1% primary education, and 0.5% had no formal education. Caregivers' most frequent employment situations were: full-time employed (32.4%), homemaker (25.1%), part-time employed (12.6%), and retired (13%). In most cases, the caregiver and the person with ID lived in the same household (85.6%). However, some caregivers reported caregiving only on certain days, for example, sharing tasks with other siblings (3.3%), whereas other family members mentioned that their relative with ID did not currently live in the same household but that they dedicated some time to his/her supervision and care (7.7%). The composition of the caregivers' sample is consistent with the distribution of the caregivers of people with disabilities in Spain [1, 57] except for education level, which was higher.

Regarding the people with ID, their average age was 24.55 years (SD = 14.99), with an age range between 0 and 63 years. Of these, 55.8% were men and 44.2% were women. The relatives of the people with ID reported that, in 48.6% of cases, their relative's ID was due to different genetic disorders: Down's Syndrome (16.3%), Fragile X Syndrome (7.7%), Rett's Syndrome (4.3%), Prader Willi Syndrome (1.4%), Angelman Syndrome (1%), as well as other disorders in which ID coexists with epileptic crises, such as Dravet's Syndrome (6.3%). In 38.9% of cases, the ID was due to different metabolic and acquired disorders (e.g., intrauterine infections, perinatal problems, anoxia in labor, phenylketonuria), and in 4.3% of cases, the causes were unknown. In 9.1% of cases, the cause of ID was cerebral palsy. The profiles of the sample were similar to those reported at the state level [1, 2].

Procedure

We contacted 20 associations for persons with ID from different regions of Spain and informed them about the purpose of the research. The participants could choose to answer the questionnaire online, on paper, or by telephone. Subsequently, approximately 40 further associations were contacted online, of which 20 shared the publication on their social networks. In addition, research information and instructions for participation were distributed on 20 websites about ID.

All the measures were completed by the family caregivers, including those related to the person with ID. The research was undertaken with the understanding and consent of each participant. Caregivers were informed of the purpose of the research and its ethical conditions. This investigation was approved by the Ethics Committee of the University of Deusto (Ref. ETK-08/15/16) in full accordance with the World Medical Association Declaration of Helsinki [58]. Participants received no financial compensation for participating in the study.

Measures

All of the family caregivers provided sociodemographic information about themselves and the person with ID, including age, gender, educational level and type of ID. Educational level was measured on a scale that ranged from 1 (*no formal education*) to 5 (*university education).*

QOL of the Caregiver–The World Health Organization QOL (WHOQOL-BREF) [59, 60] was used to assess the QoL of family members. The WHOQOL-BREF consists of 26 items that measure physical health, psychological health, social relationships, and environmental QoL. The items are rated on a 5-point Likert scale, ranging from 0 (*no, never*) to 4 (*always, totally*), such that higher scores indicate better QOL. The WHOQOL-BREF is a short version of the WHOQOL-100 [61, 62]. The Spanish adaptation [63] presents acceptable psychometric properties. Cronbach's alpha in the present study was .94 for the QoL scale.

Level of Support needed for Adaptive Functioning (Dyches, 2000 as cited in [64]). Eleven items were used to generally evaluate support needed in adaptive functioning. The objective of this scale was not to make a comprehensive evaluation of the adaptive skills of the person with ID, but to evaluate the amount of support people with ID need in their daily activities. The dimensions of adaptive behavior contained in the items include practical skills (e.g., personal care, life at home, health and safety), social skills (e.g., leisure or interaction with others), and conceptual skills (e.g., communication and self-direction) [36, 65, 66].

The items describe the degree of support needed in different domains, and caregivers rated them on a Likert scale ranging from 1 (*never or very rarely needs support*) to 4 (*always needs support*). Hence, the higher the score on this scale, the more support the person with ID needs to function in their daily life. The Spanish version was created using the translation and back-translation method [67]. This subscale has been used previously, obtaining adequate psychometric properties [64, 68]. Cronbach's alpha in the present study was .94.

Behavioral Problems–Independent Behavior Scales–Revised (SIB-R) [69]. We used items adapted from the Maladaptive Behavior scale of this questionnaire. The SIB-R is a list of items used to measure the independent behavioral skills of people with ID and DD from 3 months of age to adulthood. The eight items of the Problem Behavior scale were used dichotomously (yes/no) to observe the presence of different risk behaviors (e.g., self-injury, aggression, and disruptive behavior). Higher scores in this scale indicate more behavioral problems. The Spanish version was produced using the translation and back-translation method [67]. This questionnaire presents good psychometric properties for ID and DD [69, 70]. Cronbach's alpha coefficient in the present study was .80.

Data analysis

The IBM-SPSS-25 statistical program was used for the different analyses. A series of hierarchical multiple regression analyses were conducted to test the hypothesis that the association between the level of support needed for adaptive functioning and the caregivers' QoL will be stronger in older caregivers, especially when the persons with ID also present a high level of behavioral problems.

In the first step, demographic variables (caregiver's gender, level of education, and kinship with the person with ID) were regressed on relatives' QoL. In the second step, age, the level of support needed for adaptive functioning and the number of behavioral problems were entered in the model. In the third step, we entered a multiplicative term representing the interaction between the level of adaptive functioning and age, the interaction between the number of behavioral problems and age, and the interaction between the level of support needed for adaptive functioning and behavioral problems. In the fourth step, we entered the three-way interaction term (Age × Level of support needed for adaptive functioning × Behavioral problems). Following the standard procedure, we transformed the predictors into z-scores to maximize interpretability and to minimize potential problems with multi-collinearity [71].

Results

Table 1 shows the means, standard deviations, and correlation coefficients between the different variables of the study. QoL was negatively associated with stressors and positively associated with age and level of education. Table 2 presents the results of the hierarchical regressive analysis. In the first step, level of education was positively associated with QoL, whereas being a female and a parent of the person with ID were negatively associated with QoL. In the second step, age was positively associated with QoL, whereas the level of support needed for adaptive functioning was negatively associated with QoL. Behavioral problems were not significantly associated with QoL. In the third step, both the Age × Level of Support needed for adaptive functioning and the Age x Behavioral problem interaction terms were significantly associated with QoL. In the fourth step, the three-way interaction (Age × Level of support needed for adaptive functioning × Behavioral problems) was statistically significant.

Figures 1 and 2 display the plots for the two-way interaction terms. The graphic representations were made using the low (Mean − 1SD) and high values (Mean + 1SD) of stressors (level of support needed for adaptive functioning and behavioral problems) and age. To understand the form of these interactions, we conducted additional regression analyses, following procedures in which slope estimates are calculated and examined at high (Mean + 1SD) and low (Mean − 1SD) levels of moderator. In Fig. 1, we plotted the regression of QoL on the level of support needed for adaptive functioning for younger caregivers (Mean − 1SD) and older caregivers (Mean + 1SD). As can be observed in Fig. 1, there was a significant negative association between the level of support needed for adaptive functioning and the QoL of older caregivers ($\beta = -.32$, $p < .05$) but not of younger caregivers. Figure 2 displays the results for the number of

Table 1 Means, standard deviations, and correlation coefficients between variables

	M	SD	1	2	3	4
1. Age of the caregiver	50.98	12.86				
2. QoL of the caregiver (scale range: 0–104)	69.82	17.82	.18*			
3. Level of support (people with ID) (scale range: 1–4)	2.73	0.94	−.29**	−.22**		
4. Behavioral problems (people with ID) (scale range: 0–8)	2.27	2.25	−.26**	−.33**	.41**	
5. Level of education (scale range: 1–5)	3.78	1.25	−.39**	.23**	.20**	.02

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

Table 2 Multiple hierarchical regression analysis to evaluate age as a moderator of the relationship between stressors and QoL

Consequence: QoL	B	SE	β	t	Change in R^2
Step 1					
Gender	− 7.24	2.74	− .16	− 2.64*	R^2 = .09, *F* (3,199) = 6.33**
Education	4.32	.91	.31	4.75**	
Kinship	− 7.08	2.70	− .17	− 2.62*	
Step 2					
Age	5.58	1.32	.33	4.23**	ΔR^2 = .20, *F* (3,196) = 17.86**
LS	− 3.96	1.25	− .23	− 3.16*	
BP	− 2.06	1.30	− .12	− 1.58	
Step 3					
Age × LS	− 4.03	1.28	− .23	− 3.13*	ΔR^2 = .03, *F* (3,193) = 2.53
Age × BP	4.24	1.41	.25	3.00*	
LS × BP	− .96	1.16	− .05	− .83	
Step 4					
Age × LS × BP	− 3.09	1.14	− .22	− 2.71*	ΔR^2 = .03, *F* (1,192) = 7.37*

Kinship with the person with ID (1 = parent, 0 = other); Gender (1 = female, 0 = male)

LS level of support needed for adaptive functioning, *BP* behavioral problems

*$p < .05$, **$p < .001$

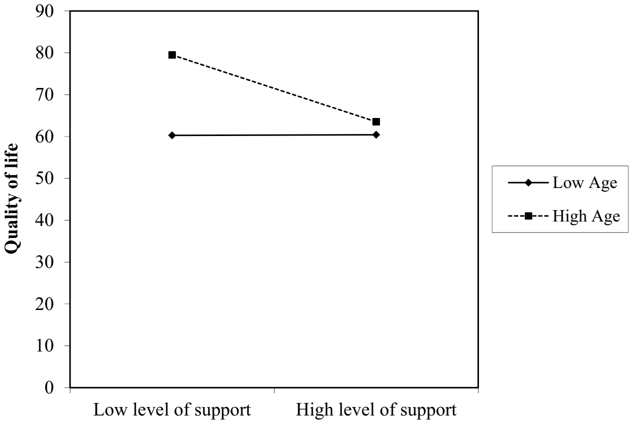

Fig. 1 Effect of the interaction between the level of support needed for adaptive functioning of the people with ID and caregivers' age on caregivers' QoL

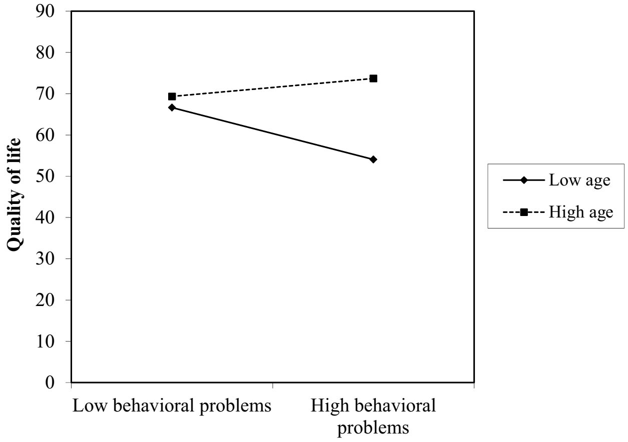

Fig. 2 Effect of the interaction between the number of behavioral problems of the people with ID and caregivers' age on caregivers' QoL

behavioral problems for and QoL. In this case, the pattern was the opposite, as the association between these variables was only statistically significant among younger caregivers (β = − .53, $p < .05$).

Figure 3 displays the three-way Age × Level of support needed for adaptive functioning × Behavioral problems interaction. We used the same procedure to examine the form of the three-way interaction. Additional regression analyses estimated slopes for younger (Mean − 1SD) and older caregivers (Mean + 1SD) and for high (Mean + 1SD) and low (Mean − 1 SD) levels of behavioral problems. These analyses indicated that the level of support needed for adaptive functioning was significantly associated with lower QoL for older caregivers when the person with ID presented either high (β = − .82, $p < .05$) or low behavioral problems (β = − .68, $p < .05$). Among younger caregivers, however, the association between the level of support needed for adaptive functioning and QoL was nonsignificant either for the high-behavioral problem group (β = .23, *ns*) or for the low-behavioral problem group (β = − .16, *ns*). This suggests that, for older people, the support needs are more determining than for young people, even if the number of behavioral problems is low.

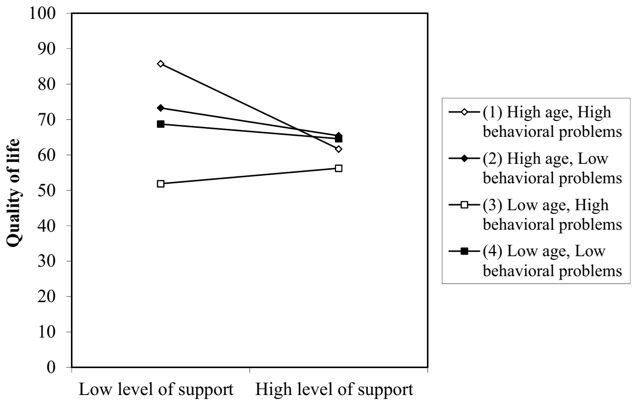

Fig. 3 Effect of the triple interaction between the level of support needed for adaptive functioning, the number of behavioral problems, and caregivers' age on caregivers' QoL

Discussion

Caregiving of people with ID can be a lifelong process, and caregivers' age may be a relevant factor for understanding the difficulties they experience [41, 54]. The studies that have explored the role of the caregivers' age on this stress process have obtained mixed results. However, most of them have ignored the characteristics and demands of the person with ID and the fact that several sources of stress may coexist. In this study, we examined whether the moderating role of caregivers' age may differ for each source of stress (e.g., behavioral problems and level of support needed).

The results indicate that the role of age is different depending on the nature of the stressor. The association between the level of support for adaptive functioning and QoL was only significant among older relatives, whereas the association between behavioral problems and QoL was only significant among younger relatives.

According to the adaptation hypothesis, people continue to learn and adapt as they grow older, expanding their coping repertoires and changing in ways that are functional [21, 34]. Therefore, after so many years, older relatives could become less affected by stressors such as behavioral problems, either because they have learned how to cope with them, for example, by accepting the situation, or simply because they have become accustomed to the situation. This finding is consistent with studies that have shown that older family caregivers of people with ID showed more acceptance of the way things were [34].

On another hand, family caregivers usually assist with personal care, mobility, household tasks, shopping, and transportation [72], tasks that require a physical performance and that can require a particularly great effort at advanced ages. For older caregivers, supporting a family member with ID may span over many decades, providing support at ages when they themselves would normally need such care [28, 41]. For this reason, support activities could also have a cumulative effect on long-term caregiving, resulting in an increased risk of poor health [54]. In addition, older caregivers may suffer from the increased incidence of chronic illnesses of later life. Being older usually implies physical deterioration and an increase in the caregivers' perceived functional impairment [17, 54, 73], which can greatly affect their caregiving ability and, therefore, their QoL. This support is especially intense in people with lower adaptive functioning skills. Thus, it is not surprising that this deficit in the person with ID has more negative consequences for older caregivers.

Furthermore, in this study, a three-way interaction between level of support needed, behavioral problems and age indicated that the negative association between support needed and QoL was more intense in older caregivers when the behavioral problems were high. This result is not surprising due to the cumulative effect that both stressors can have on family members, making the relationship with the person with ID and the provision of support especially difficult and stressful and having devastating consequences for older relatives.

All these results have important clinical implications as they highlight the importance of providing psychological care and support to family caregivers of persons with ID. Moreover, this support must be adapted to the different ages of caregivers. Among younger relatives, professional help could assist them to adapt psychologically and to learn how to face the stressors they will find throughout their life, with particular emphasis on the control of and ability to cope with behavioral problems. In the case of older caregivers, the results suggest that they may require additional support, especially when their relatives with ID present higher dependence. Due to the physical component of care, older family caregivers should be supported in everyday caregiving tasks, as well as with psychosocial and respite programs that can improve the outcomes of care [74].

Strengths, limitations, and future research

This research is not without limitations. First, all the measures were obtained from questionnaires, wherein participant honesty is essential to ensure reliable results. The most distressed family members are more likely to perceive the characteristics of their relative with ID more negatively. For future studies, it would be appropriate to complete information from professionals such as psychologists and monitors at the centers they attend. Second, we focused on caregivers' age and the characteristics of people with ID. However, according to the transactional model of stress [14], several other factors can influence the stress process. Thus, future studies should examine other variables of the caregivers as well as the availability of resources (i.e., social support, economic resources, etc.). Third, as this is a cross-sectional study, the relationships found between the variables are neither predictive nor causal. Therefore, a longitudinal study would be appropriate in the future, which would allow us to examine predictive associations between variables. Fourth, the sample used is a convenience sample that only represents caregivers who volunteered to take part in the research study. In fact, educational level was unusually high. Thus, the sample may represent only those with higher resources or fewer negative consequences of care. Finally, in the present study, the percentage of male participants was small. Although we controlled for gender in the analyses, it would be interesting to examine differences based on this and other characteristics of family caregivers.

This work also has strengths that should not be overlooked. First, we have studied the moderating effect of age on different stressors, and the triple interaction (Age × Level of support needed for adaptive functioning × Behavioral problems) rather than merely observing simple associations or differences between variables, as was the case in much of the previous research [23, 28]. In addition, the QoL of the family members has been the focus of the study. This global construct encompasses not only psychological but also physical, social, and environmental aspects, which are important consequences of care and much broader than mere psychological symptoms. Finally, the study of the role of caregivers' age is important, as the life expectancy of people with disabilities is rising, and parents have children increasingly later, so older relatives will be providing this support [15–17].

To conclude, the age of the family caregiver has a moderating effect on the relationship between stressors and their QoL. However, the pattern of this moderation is different depending on the stressor. Whereas behavioral problems deteriorate the QoL of younger caregivers, lack of functioning abilities deteriorates the QoL of older caregivers. Findings highlight the importance of support programs for caregivers, especially those at more advanced ages and in situations where more profound disabilities exist.

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Compliance with ethical standards

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

Informed consent All participants were informed and gave their consent before participating in the study.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

References

1. Instituto Nacional de Estadística (2008). *Encuesta sobre discapacidades, autonomía personal y situaciones de dependencia*. Resource document. Instituto Nacional de Estadística. Retrieved May 25, 2018, from http://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176782&menu=resultados&secc=1254736194716&idp=1254735573175.
2. IMSERSO (2016). *Base estatal de datos de personas con valoración del grado de discapacidad.* Resource document.Ministerio de Sanidad, Consumo y Bienestar Social. Retrieved May 25, 2018, from http://www.imserso.es/InterPresent1/groups/imserso/documents/binario/bdepcd_2016.pdf.
3. American Psychiatric Association. (2013). *DSM- V. Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
4. FEAPS (2015). *Informe sobre "El sobreesfuerzo económico que la discapacidad intelectual o de desarrollo ocasiona en la familia en España 2014"*. Retrieved May 25, 2018, from www.feaps.org/archivo/centrodocumental/doc_download/548-.html.
5. Lozano, M., & Pérez, I. (2000). Necesidades de la familia de las personas con retraso mental y necesidades de apoyo generalizado. In M. A. Verdugo (Ed.), *Familias y Discapacidad Intelectual* (pp. 199–225). Madrid: Colección FEAPS.
6. Cuskelly, M. (2006). Parents of adults with an intellectual disability. *Australian Institute of Family Studies: Family Matters, 74,* 20–25.
7. Baker, B. L., Blacher, J., Kopp, C. B., & Kraemer, B. (1997). Parenting children with mental retardation. In N. W. Bray (Ed.), *International review of research in mental retardation* (pp. 1–45). San Diego, CA: Academic Press.
8. Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., … Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics, 114*, 182–191. https://doi.org/10.1542/peds.114.2.e182
9. Parish, S. L., Rose, R. A., & Swaine, J. G. (2010). Financial well-being of US parents caring for coresident children and adults with developmental disabilities: An age cohort analysis. *Journal of Intellectual & Developmental Disability, 35,* 235–243. https://doi.org/10.3109/13668250.2010.519331.
10. Dave, D., Mittal, S., Tiwari, D., Parmar, M. C., Gedan, S., & Patel, V. (2014). Study of anxiety and depression in caregivers of intellectually disabled children. *Journal of Research in Medical and Dental Science, 2,* 8–13. https://doi.org/10.5455/jrmds.2014212.
11. Leung, C. Y. S., & Li-Tsang, C. W. P. (2003). Quality of life of parents who have children with disabilities. *Hong Kong Journal of Occupational Therapy, 13,* 19–24. https://doi.org/10.1016/S1569-1861(09)70019-1.
12. Lin, J. D., Hu, J., Yen, C. F., Hsu, S. W., Lin, L. P., Loh, C. H.,… & Wu, J. L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. *Research in Developmental Disabilities*, *30*, 1448–1458. https://doi.org/10.1016/j.ridd.2009.07.005.

13. Malhotra, S., Khan, W., & Bhatia, M. S. (2012). Quality of life of parents having children with developmental disabilities. *Delhi Psychiatric Society, 15,* 171–176.
14. Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. In W. D. Gentry (Ed.), *The handbook of behavioral medicine* (pp. 282–325). New York: Guilford.
15. Dieckmann, F., Giovis, C., & Offergeld, J. (2015). The life expectancy of people with intellectual disabilities in Germany. *Journal of Applied Research in Intellectual Disabilities, 28,* 373–382. https://doi.org/10.1111/jar.12193.
16. Ng, N., Sandberg, M., & Ahlström, G. (2015). Prevalence of older people with intellectual disability in Sweden: A spatial epidemiological analysis. *Journal of Intellectual Disability Research, 59,* 1155–1167. https://doi.org/10.1111/jir.12219.
17. Minnes, P., & Woodford, L. (2005). Well-being in aging parents caring for an adult with a developmental disability. *Journal on Developmental Disabilities, 11,* 47–66.
18. Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a National Study. *Journal of Health and Social Behavior, 49,* 301–316. https://doi.org/10.1177/002214650804900305.
19. Lawton, M. P., Kleban, M. H., & Dean, J. (1993). Affect and age: Cross-sectional comparisons of structure and prevalence. *Psychology and Aging, 8,* 165–175.
20. Chou, Y. C., Fu, L. Y., Lin, L. C., & Lee, Y. C. (2011). Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *International Psychogeriatrics, 23,* 562–572. https://doi.org/10.1017/S1041610210001225.
21. Hayden, M. E., & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35,* 364–372. https://doi.org/10.1352/00476765(1997)035%3c0364:spaapb%3e2.0.co;2.
22. Oh, H., & Lee, E. O. (2009). Caregiver burden and social support among mothers raising children with developmental disabilities in South Korea. *International Journal of Disability, Development and Education, 56,* 149–167. https://doi.org/10.1080/10349120902868624.
23. Kono, K., & Mearns, J. (2013). Distress of Japanese parents of children with intellectual disabilities: Correlations with age of parent and negative mood regulation expectancies. *Japanese Psychological Research, 55,* 358–365. https://doi.org/10.1111/jpr.12027.
24. Magaña, S. M., Ramírez García, J. I., Hernández, M. G., & Cortez, R. (2007). Psychological distress among Latino family caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services, 58,* 378–384. https://doi.org/10.1176/ps.2007.58.3.378.
25. Brown, R. I., Hong, K., Shearer, J., Wang, M., & Wang, S. Y. (2010). Family quality of life in several countries: Results and discussion of satisfaction in families where there is a child with a disability. In R. Kobler (Ed.), *Enhancing the quality of life of people with intellectual disabilities* (pp. 377–398). Dordrecht: Springer.
26. Seltzer, M. M., & Krauss, M. W. (1994). Aging parents with coresident adult children: The impact of lifelong caregiving. In M. M. Seltzer, M. W. Krauss, & M. P. Janicki (Eds.), *Life course perspectives on adulthood and old age* (pp. 3–18). Washington, DC: American Association on Mental Retardation.
27. Macias, M. M., Clifford, S. C., Saylor, C. F., & Kreh, S. M. (2001). Predictors of parenting stress in families of children with spina bifida. *Children's Health Care, 30,* 57–65. https://doi.org/10.1207/S15326888CHC3001_5.
28. Chou, Y. C., Lee, Y. C., Lin, L. C., Kröger, T., & Chan, A. N. (2009). Older and younger family caregivers of adults with intellectual disability: Factors associated with future plans. *Intellectual and Developmental Disabilities, 47,* 282–294. https://doi.org/10.1352/1934-9556-47.4.282.
29. Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging, 10,* 64–75. https://doi.org/10.1037/0882-7974.10.1.64.
30. Vogan, V., Lake, J. K., Weiss, J. A., Robinson, S., Tint, A., & Lunsky, Y. (2014). Factors associated with caregiver burden among parents of individuals with ASD: Differences across intellectual functioning. *Family Relations, 63,* 554–567. https://doi.org/10.1111/fare.12081.
31. Krauss, M. W., & Seltzer, M. M. (1993). Coping strategies among older mothers of adults with retardation: A life span developmental perspective. In A. P. Turnbull, J. M. Patterson, S. J. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families and disability: Participatory research in action in families who have a member with developmental disabilities* (pp. 173–182). Baltimore: Brookes.
32. Johnson, C. L., & Catalano, D. J. (1983). A longitudinal study of family supports to impaired elderly. *The Gerontologist, 23,* 612–618. https://doi.org/10.1093/geront/23.6.612.
33. Roberto, K. A. (1995). Family caregivers of aging adults with disabilities: A review of the caregiving literature. In K. A. Roberto (Ed.), *The elderly caregiver: Caring for adults with developmental disabilities* (pp. 3–18). Newbury Park, CA: Sage Publications.
34. Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities, 13,* 256–275. https://doi.org/10.1046/j.1468-3148.2000.00035.x.
35. Olson, D., McCubbin, H., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1983). *Families: What makes them work?*. Beverly Hills, CA: Sage.
36. American Association of Intellectual and Developmental Disabilities (AAID). (2011). *Discapacidad intelectual: definición, clasificación y sistemas de apoyo* (11th ed.). (M.A Verdugo, Trad.). Madrid: Alianza Editorial.
37. Felce, D., & Emerson, E. (2001). Living with support in a home in the community: Predictors of behavioral development and household and community activity. *Mental Retardation and Developmental Disabilities Research Reviews, 7,* 75–83. https://doi.org/10.1002/mrdd.1011.
38. Baghdadli, A., Pry, R., Michelon, C., & Rattaz, C. (2014). Impact of autism in adolescents on parental quality of life. *Quality of Life Research, 23,* 1859–1868. https://doi.org/10.1007/s11136-014-0635-6.
39. Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 120,* 395–411. https://doi.org/10.1352/1944-7558-120.5.395.
40. Rattaz, C., Michelon, C., Roeyers, H., & Baghdadli, A. (2017). Quality of life in parents of young adults with ASD: EpiTED cohort. *Journal of Autism and Developmental Disorders, 47,* 2826–2837. https://doi.org/10.1007/s10803-017-3197-y.
41. Haveman, M., Van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations, 46,* 417–425. https://doi.org/10.2307/585101.
42. Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental

disabilities. *Journal of Intellectual Disability Research, 51,* 109–124. https://doi.org/10.1111/j.1365-2788.2006.00829.x.

43. Hall, H. R., & Graff, J. C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34,* 4–25. https://doi.org/10.3109/01460862.2011.555270.
44. Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50,* 172–183. https://doi.org/10.1111/j.1365-2788.2005.00732.x.
45. Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation, 107,* 433–444. https://doi.org/10.1352/0895-8017(2002)107%3c0433:BPAPSI%3e2.0.CO;2.
46. Woodman, A. (2014). Trajectories of stress among parents of children with disabilities: A dyadic analysis. *Family Relations, 63,* 39–54. https://doi.org/10.1111/fare.12049.
47. Dekker, M. C., Koot, H. M., van der Ende, J., & Verhulst, F. C. (2002). Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology and Psychiatry, 43*(8), 1087–1098. https://doi.org/10.1111/1469-7610.00235.
48. Woodman, A. C., Mawdsley, H. P., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. *Research in Developmental Disabilities, 36,* 264–276. https://doi.org/10.1016/j.ridd.2014.10.011.
49. Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & Griffith, G. M. (2016). Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. *British Journal of Clinical Psychology, 56,* 16–32. https://doi.org/10.1111/bjc.12118.
50. Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability, 34,* 153–162. https://doi.org/10.1080/13668250902874608.
51. Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107,* 222–232. https://doi.org/10.1352/0895-8017(2002)107%3c0222:bpocwa%3e2.0.co;2.
52. Heller, T., & Factor, A. (1993). Aging family caregivers: Support resources and changes in burden and placement desire. *American Journal on Mental Retardation, 98,* 417–426.
53. Hastings, R. P., & Brown, T. (2002). Coping strategies and the impact of challenging behaviors on special educators' burnout. *Mental Retardation, 40,* 148–156. https://doi.org/10.1352/0047-6765(2002)040%3c0148:csatio%3e2.0.co;2.
54. Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1,* 24–30. https://doi.org/10.1111/j.1741-1130.2004.04004.x.
55. De Bildt, A., Sytema, S., Kraijer, D., Sparrow, S., & Minderaa, R. (2005). Adaptive functioning and behaviour problems in relation to level of education in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research, 49,* 672–681. https://doi.org/10.1111/j.1365-2788.2005.00711.x.
56. Mitchell, D. B., & Hauser-Cram, P. (2009). Early predictors of behavior problems. *Journal of Early Intervention, 32,* 3–16. https://doi.org/10.1177/1053815109349113.
57. Domínguez-Panchón, A. I., González-Fraile, E., González, A. B. C., Frade, M. R., Sánchez-Rial, M., Calo, M. N. F., … & Ventura, D. R. Estudio de eficacia de una intervención psicoeducativa para la reducción de la sobrecarga del cuidador principal de personas con discapacidad intelectual: análisis de línea base del estudio EDUCA-IV.*Informaciones Psiquiátricas, 227,* 67–88.
58. World Medical Association. (2002). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *Nursing Ethics, 9,* 105–109. https://doi.org/10.1191/0969733002ne486x.
59. Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research, 13,* 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00.
60. WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. *Psychological Medicine, 28,* 551–558.
61. Power, M., Bullinger, M., & Harper, A. (1999). The World Health Organization WHOQOL-100: Tests of the universality of Quality of Life in 15 different cultural groups worldwide. *Health Psychology, 18,* 495–505. https://doi.org/10.1037/0278-6133.18.5.495.
62. WHOQOL Group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. *Social Science and Medicine, 46,* 1569–1585.
63. Espinoza, I., Osorio, P., Torrejón, M. J., Lucas-Carrasco, R., & Bunout, D. (2011). Validación del Cuestionario de Calidad de Vida (WHOQOL-BREF) en adultos mayores chilenos. *Revista Médica de Chile, 139,* 579–586. https://doi.org/10.4067/S0034-98872011000500003.
64. Hsieh, P. C. (2011). *Contributions of leisure participation in predicting stress coping and quality of life among parental caregivers of children with developmental disabilities* (Doctoral dissertation, Indiana University). Resource document. ProQuest. Retrieved May 25, 2018, from https://search.proquest.com/docview/884789051?pq-origsite=gscholar.
65. American Association of Mental Retardation: Luckasson, R.; Coulter, D. L.; Polloway, E. A.; Reiss, S.; Schalock, R. L.; Snell, M. E.; Spitalnik, D. M. & Stark, J. A. (2004): *Retraso Mental: Definición, clasificación y sistemas de apoyo* (10th ed.). (M.A. Verdugo, & C. Jenaro, Trad.). Madrid: Alianza Editorial.
66. American Psychiatric Association. (2002). *DSM-IV-TR: Manual diagnóstico y estadístico de los trastornos mentales. Texto revisado*. Barcelona: Masson.
67. Acquadro, C., Conway, K., Hareendran, A., & Aaronson, N. (2008). Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. *Value in Health, 11,* 509–521. https://doi.org/10.1111/j.1524-4733.2007.00292.x.
68. Dodd, D. C. H., Zabriskie, R. B., Widmer, M. A., & Eggett, D. (2009). Contributions of family leisure to family functioning among families that include children with developmental disabilities. *Journal of Leisure Research, 41,* 261–286.
69. Bruininks, R. H., Woodcock, R. W., Weatherman, R. F., & Hill, B. K. (1996). *Scales of independent behavior revised.* Itasca, IL: Riverside.
70. Brown, L., Bundy, M. B., & Gore, J. S. (2010). Patterns of adaptive performance by individuals with autism spectrum disorders on the Scales of Independent Behavior-Revised (SIB-R). *International Journal on Disability and Human Development, 9,* 315–318. https://doi.org/10.1515/IJDHD.2010.035.
71. Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology, 51,* 115–134. https://doi.org/10.1037/0022-0167.51.1.115.
72. Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist, 46,* 344–356. https://doi.org/10.1093/geront/46.3.344.

73. Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in ageing family carers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 20,* 539–552. https://doi.org/10.1111/j.1468-3148.2007.00364.x.
74. Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and Developmental Disabilities, 53,* 329–345. https://doi.org/10.1352/1934-955653.5.329.