Journal of Child and Family Studies (2024) 33:515–526
https://doi.org/10.1007/s10826-023-02750-6

ORIGINAL PAPER

Grief Intervention Program for Caregivers to Individuals with Autism Spectrum Disorder (ASD): A Randomized Preliminary Trial

Jorge Bravo-Benítez[1] · Francisco Cruz-Quintana[1,2] · Elena Navarro[1,2] · María Nieves Pérez-Marfil[1,2]

Accepted: 28 November 2023 / Published online: 6 January 2024

Abstract

The aim of this study was to adapt and deliver a grief intervention program for family caregivers of individuals with ASD and assess its effectiveness in improving grief symptoms, distress, and emotional well-being. The intervention was adapted from Shear and Bloom's grief intervention program. The characteristics of the symptoms, along with uncertainty about how the disorder will progress, contribute to the cyclical nature of this grief. A total of 28 family caregivers of individuals with ASD took part. A series of self-report measures were used to assess grief, overload, resilience, post-traumatic growth, experiential avoidance, perceived health, and the benefits of caregiving. Findings indicate this program is effective in improving grief symptoms, overload, resilience, post-traumatic growth, and the quality of life of these caregivers. It is essential to develop and deliver interventions that address the feelings and manifestations of ambiguous grief in this type of caregiver, as there are currently no programs providing an effective response to this issue.

Keywords Ambiguous grief · ASD · Caregiver · Grief · Intervention program

Highlights

- In this study, a grief intervention program was adapted and delivered to family caregivers of children with ASD.
- We evaluated its effectiveness in improving grief symptoms, distress, and the emotional well-being of caregivers of children with ASD.
- Improvements in grief symptoms, overload, resilience, post-traumatic growth, and quality of life were achieved.
- Our study shows the importance of developing and implementing interventions to address the ambiguous grief of these caregivers.

There has been a dramatic increase in the number of children diagnosed with Autism Spectrum Disorder (ASD) in recent years (Chiarotti & Venerosi, 2020). Epidemiological studies carried out over the last 50 years show that its prevalence is on the rise (Seretopoulos et al., 2020).

ASDs are a construct encompassing a variety of neurodevelopmental mental disorders in which there is a particular combination of deficits in communication and social interaction, restrictive and repetitive behavior and interests, and/or sensory-behavioral problems associated with the early years (American Psychiatric Association, 2013; Lord et al., 2020). People with these disorders have complex care needs and require a range of integrated services, involving health promotion, personalized care, rehabilitation services, and partnership working with other sectors including education, employment, and social services (World Health Organization, 2021).

After receiving a diagnosis of ASD, there is a very painful process of assimilation. Experts refer to this as grief for the loss of a "typical child" (Mansell & Morris, 2004). Once this diagnosis is accepted, the complex care needs of this group (World Health Organization, 2021) require parents to make a series of adjustments and changes to family functioning strategies in order to support their child's proper development (Altiere & Von Kluge, 2009; Cridland et al., 2015).

✉ María Nieves Pérez-Marfil
nperez@ugr.es

[1] Mind, Brain, and Behavior Resarch Center (CIMCYC, Centro de Investigación Mente, Cerebro y Comportamiento), University of Granada, Granada, Spain

[2] Faculty of Psychology, University of Granada, Granada, Spain

The literature suggests that anxiety and depressive symptoms are common in parents of children with intellectual disabilities and developmental difficulties (Scherer et al., 2019). Specifically, a higher incidence of psychopathologies has been found in parents of children with ASD than in parents of children with other types of disabilities or those with age-appropriate development (Costa et al., 2017; Dabrowska & Pisula, 2010; Pottie & Ingram, 2008; Vasilopoulou & Nisbet, 2016). High levels of overload and physical and psychological health problems are evident (Gatzoyia et al., 2014; Giovagnoli et al., 2015; Karp and Kuo (2015); O'Halloran et al., 2013; Seguí et al., 2008). As well as the predominance of anxious-depressive symptomatology, which has a detrimental effect on their caregiving and overall symptomatology (Bitsika et al., 2013; Zablotsky et al., 2013; Zhou et al., 2019), feelings of grief, despondency, and sadness have been found to persist long after receiving the diagnosis (Ludlow et al., 2012). Caregivers' emotional responses, such as helplessness, confusion, bewilderment, and emotional distress, reflect the grief associated with unmet expectations and the loss of the ideal child (O'Brien, 2007; Mulligan et al., 2012). The loss of the "ideal child" has been identified as one of the causes of parental grief (Casey et al., 2012; Heiman, 2002) and the grief experience of an ASD diagnosis has been viewed as either a type of "chronic grief" (Olshansky, 1962) or "unresolved grief" (Rarity, 2007).

Various terms have been coined in the literature by different authors to describe the emotional dynamics and experiences of these families. Boss (1999; 2004) used the term "ambiguous loss" to describe an incomplete and uncertain loss that can occur when the child is physically present, but psychologically absent, or vice versa. Bruce and Schultz (2001) spoke of unresolved or "non-finite" grief, in reference to the feelings experienced by family members who suffer losses associated with disability, chronic illness, or accident. These families typically go through the different stages of grief several times or regress in their processing of the loss, especially when faced with developmental milestones that their children have not reached (Rarity, 2007). In the context of mental disability, the term chronic grief has been used to describe the feelings and experience of profound sadness shared by parents of children with these characteristics (Olshansky, 1962; Patrick-Ott & Ladd, 2010).

All of these authors cite the emotional experience of these parents. This experience is brought about by uncertain diagnoses and prognoses, the manifestation of some symptoms but not others, the seemingly typical development in the early years, and the difficulty children with ASD have in recognizing and expressing their emotions (O'Brien, 2007).

We were unable to find specific intervention programs which address ambiguous grief in family caregivers of individuals with ASD in the existing scientific literature (Altiere & Von Kluge, 2009). Interventions do exist for caregivers of people with intellectual disabilities, for example. Some are mindfulness therapies that focus on stress reduction (Bazzano et al., 2015; Dykens et al., 2014; Fitriani et al., 2021; Flynn et al., 2020; Jones et al., 2018; Lunsky et al., 2017; Zebrea et al., 2021), while others aim to provide support and psychoeducation about services, available resources, and personal self-care (Fitriani et al., 2021; Lunsky et al., 2017). The groups in these studies are heterogeneous. In some cases, they do not include a control group, or they focus on dealing specifically with the feelings of grief and loss brought on by the news of the diagnosis. Nor do they evaluate variables such as caregiver overload, grief caused by the diagnosis, resilience, and post-traumatic stress. These variables may be relevant to the assessment of these caregivers, as has been found in previous studies with other populations (Bravo-Benítez et al., 2021). Both the initial diagnosis and the ongoing responsibilities and daily demands placed on the caregiver mean that the family member faces many hurdles along the way, negatively impacting their quality of life (Bilgin & Kucuk, 2010).

The main aim of this study was to adapt, deliver, and assess the effects of a grief intervention program for family caregivers of individuals with ASD. This program has been tested in a sample of caregivers of people with dementia and the results showed the program to be effective in improving grief symptoms, caregiver burden, resilience, post-traumatic growth, and quality of life for family caregivers (Bravo-Benítez et al., 2021). It is hypothesized that caregivers who take part in the intervention program will significantly lower their levels of physical and mental distress compared to those who do not.

Methods

Participants

This study involved 28 participants (4 men and 24 women), all primary caregivers of children with ASD. The sample included users of two mental health clinics in the cities of Cadiz and Granada and members of an association for people with ASD in Cadiz, Spain. Inclusion criteria were: being a parent of an individual with ASD, being the primary caregiver, and agreeing to participate in an educational training program. Exclusion criteria were: caregivers with other dependents (aside from the individual with ASD), caregivers who delegated care of the family member to someone else, people diagnosed with a psychiatric disorder, and/or those who failed to perform the different tasks included in the program. The mean age of the family

caregivers was 42.71 years (range: 30-68); 85.7% were women and 14.3% were men. In terms of educational attainment, 10.7% had a primary education, 50% a high school education, and 39.3 % a higher education. Of the respondents, 75% were married, 14.3% divorced, 7.14% single, and 3.56% widowed. With respect to their employment status, 50% were in paid employment, 28.57 % were unemployed, and 21.4% were homemakers.

Participants were randomly assigned to two groups of 14 people each (Intervention Group (IG) or Control Group (CG)), depending on whether or not they took part in the intervention program. No significant differences were found between the CG and IG with regard to the sociodemographic variables, except for the monthly income variable ($t = 1.172$; $p = 0.0001$), with the CG having more disposable income than the IG (see Table 1). The children were between the ages of 6 and 12 years at the time of the study. They had been diagnosed between the ages of 18 and 132 months, and all had behavioral problems and were fully dependent. All of the children lived with their biological families and attended school Fig. 1.

Table 1 Differences in sociodemographic characteristics

Variables	Control group ($N = 14$)	Intervention group ($N = 14$)	t	p
	Mean (SD) or N (%)	Mean (SD) or N (%)		
Age	44.14 (6.94)	41.29 (9.38)	0.916	0.368
Gender				
Men	3 (21.4%)	1 (7.1%)	−1.063	0.297
Women	11 (78. 6%)	13 (92.9%)		
Level of education				
Primary education	1 (7.1%)	2 (14.3%)	1.790	0.085
Secondary education	5 (35.7%)	9 (64.3%)		
University education	8 (57.1%)	3 (21.4%)		
Employment status				
Employed	10 (71.4%)	4 (28.6%)	−1.426	0.166
Household chores	3 (21.4%)	3 (21.4%)		
Unemployed	1 (7.1%)	7 (50.0%)		
Monthly income				
The IPMW	0 (0%)	4 (28.6%)	4.172	0.001
Between one and two times the IPMW	3 (21.4%)	8 (57.1%)		
Between 2 and 3 times the IPMW	5 (35.7%)	1 (7.1%)		
More than 3 times the IPMW	6 (42.9%)	1 (7.1%)		

IPMW Interprofessional Minimum Wage

Measures

The battery of instruments used to assess the caregivers is outlined below. We conducted interviews to collect the participants' personal and sociodemographic data. This included: level of educational attainment, monthly household income, professional occupation, family relationship, number of relatives caring for the affected person, and any previous diagnoses of psychiatric illness.

The Caregiver Grief Scale (CGS) (Meichsner et al., 2016)

The CGS measures the different manifestations of grief symptomatology in caregivers. It consists of 5-point Likert-type scales grouped into 11 items, ranging from 1 (strongly disagree) to 5 (strongly agree). It showed high levels of internal consistency (Cronbach's α between 0.67 and 0.89) and high levels of construct validity, both for the different subscales and for the overall scale. This includes four factors that reveal different facets of caregiver grief: emotional pain (painful emotions related to loss), relational loss (losses associated with the relationship), absolute loss (anticipation of the future without the person), and acceptance of loss (acceptance and open expression of grief). The instrument has shown adequate reliability values in a Spanish sample of caregivers of people with dementia (emotional pain $\alpha = 0.62$, relational loss $\alpha = 0.77$, absolute loss $\alpha = 0.85$, acceptance of loss $\alpha = 0.55$) (Bravo-Benítez et al., 2021). The present study used a version that had been back-translated from English to Spanish, with reliability values ranging from $\alpha = 0.55$ to $\alpha = 0.85$ and an overall Cronbach's α of 0.85.

The Caregiver Burden Interview (CBI) (Zarit et al., 1980)

The CB assesses stress and subjective overload perceived by caregivers of dependent people. The test consists of 22 items on a 5-point Likert-type scale ranging from 1 (never) to 5 (almost always). It has an internal consistency of $\alpha = 0.91$ and a test-retest reliability of 0.96. For our study, we used the Spanish adaptation by Martín et al. (1996).

The Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003)

The CD-RISC is made up of 10 items on a 5-point Likert-type scale ranging from 0 (not true at all) to 4 (true nearly all of the time). This test has a high level of internal consistency with a Cronbach's α of 0.90. In our study we used the Spanish adaptation by Crespo et al. (2014).

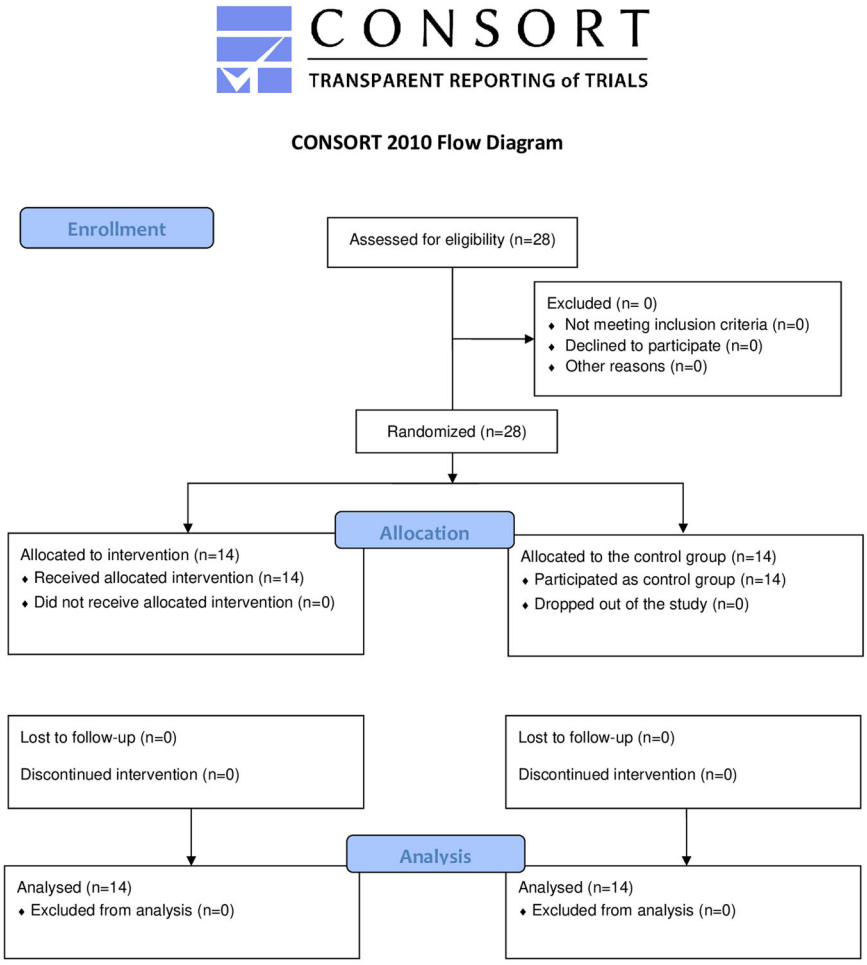

Fig. 1 depicts the CONSORT diagram for the study

The Acceptance and Action Questionnaire (AAQ-II) (Hayes et al., 2004)

This test measures experiential avoidance and psychological flexibility. It consists of 10 items on a 7-point Likert-type scale ranging from 1 (never true) to 7 (always true). It has a good level of internal consistency with a Cronbach's α of 0.88. It also has good construct validity, discriminant validity, and external validity. We administered the Spanish adaptation by Mairal (2004).

The Post-Traumatic Growth Inventory Short Form (PTGISF) (Tedeschi & Calhoun, 1996)

The Spanish adaptation by Castro et al. (2015) was used. This consists of 21 items assessing the perception of personal benefits in survivors of a traumatic event. It consists of a 6-point Likert scale ranging from 0 (no change) to 5 (very high degree of change), with higher scores indicating greater perceived change. This scale has a high level of internal consistency as measured by Cronbach's α (0.95).

Positive Aspects of Caregiving (PAC) (Tarlow et al., 2004)

The Spanish adaptation by Las Hayas et al. (2014) was used. This scale measures the benefits of caregiving and has good internal consistency scores. It consists of 11 items on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). The original version and its Spanish adaptation showed adequate reliability ($\alpha = 0.89$) (Las Hayas et al., 2014).

The SF-36 Health Survey (SF-36) (Ware & Sherbourne, 1992)

We used the Spanish adaptation by Alonso et al. (1995). This test contains 90 items and assesses perceived health. Internal consistency, as measured by Cronbach's α, ranges from 0.70 for the pain dimension to 0.90 for physical functioning. In terms of external validity, it was found to be significantly correlated with existing scales measuring similar constructs.

Intervention Program

The intervention was based on the guidelines from Shear and Bloom's grief intervention program (2017). The intervention was adapted to fit the study population, i.e., it was adapted to fit the grieving process associated with the illness of a family member. The following techniques were used: imaginal and in vivo exposure, cognitive restructuring, behavioral rehearsals, and social skills training. The main objectives were to promote acceptance of the consequences of the loss as well as the new situation, to strengthen bonds with their family member, and to encourage participation in tasks that would improve their satisfaction levels and quality of life.

The intervention program began with an introductory session. During this session the framework for the intervention was established, group members introduced themselves, the rules of the group were explained, participants were invited to talk about different aspects of their lives in relation to the theme, relevant information about the grieving process was provided, interests and life achievements were discussed, and an agenda was set.

The main focus of the following sessions was to work on grief symptomatology using the imaginal exposure technique and to measure the intensity of the symptoms using a pain monitoring diary. The most conflictive areas (hot spots) were then worked on more intensively to facilitate participants' emotional processing. Each of these sessions addressed a specific aspect of loss related to the unique characteristics of caring for a child with ASD.

In the penultimate session, participants held an imaginary conversation with their affected family member, in which they had the opportunity to imaginatively express and resolve issues that they had not communicated to their family member in real life. This helped to explore unresolved or outstanding aspects of the relationship and provided an opportunity to work on these areas during the session and bring them to resolution.

Longitudinal aspects of restoring well-being and a meaningful future for caregivers were addressed throughout the intervention program.

In the final session, participants shared what had and had not been achieved throughout the intervention, talked about feelings that had arisen during and at the end of the process, discussed unanswered questions, provided a recap of the intervention, and signed off from the program. Table 2 shows a diagram of the content of each session of the intervention program.

Table 2 Contents of the ten sessions of the intervention programme

Session number	Content
1	- Group rules and presentation
	- Psychoeducation: disenfranchised grief
	- Training in self-registration
2	- Description of the SUDS procedure (Subjective Units of Distress Scale)
	- Imaginal exposure
	- Working on rewarding activities
	- Working on goals
3	- Imaginal exposure
	- Working on personal resource management
	- Discussing avoided situations. Information
4	- Imaginal exposure
	- Discussing specific memories
	- Working on avoided situations
	- Working on rewarding activities and goals
5	- Imaginal exposure
	- Discussing specific memories
6 & 7	- Imaginal exposure
	- Working on avoided situations
	- Hot spots (remembering moments of exposure with high SUDS scores)
8	- Imaginal exposure
	- Discussing positive aspects in life
9	- Imaginal exposure
	- Role-playing and empty-chair technique with the affected family member
	- Anticipating and planning for painful dates/situations
10	- Imaginal exposure
	- Summary of the treatment
	- Identifying and dealing with feelings about the end of treatment. Encouraging acceptance of the new situation and developing the new bond
	- Discussing the potential for joy and satisfaction in life
	- Goodbye

Quality and Fidelity of the Intervention

To measure the fidelity of the content, its standardization, and the quality of the whole process, a detailed list of target objectives for each part of the various sessions was prepared and used by the psychologist in charge of the program. This checklist included a list of content that each participant was to work on during the different sessions, as well as the time available and method for working on this content (for example, participants were instructed to keep a pain monitoring diary). This list was completed 20 minutes before the end of each session and consisted of items to assess how the intervention had been delivered. These included the development of the objectives scheduled for that session, the adaptation of the content to the needs of the different participants, and the use of appropriate communication to ensure participants correctly understood the contents of each session.

Each item on the checklist was marked as "achieved" or "not achieved" to indicate whether or not the item had been accomplished during the course of the intervention.

Procedure

Our first step was to obtain approval for the study from the Research Ethics Committee of the University of Granada, Spain (Ref.: 359/CEIH/2017). We then contacted the management of the different centers and asked for their cooperation. Once approved, the study was disseminated through a variety of means.

Staff members at each center were informed of the research objectives and the participants were approached by the psychologist conducting the study. They were invited to a meeting at which the lead researcher provided information about the study and addressed their concerns. Those who expressed an interest in taking part then signed the informed consent form. Two groups, IG and CG, were formed based on whether the participants were part of the intervention program or not. Participants were randomly assigned to the different groups. The interviews then took place at the premises of the clinics and healthcare associations. The interviews were always conducted in the following order: the sociodemographic data interview; the Caregiver Grief Scale (CGS); the Caregiver Burden Interview (CBI); the Connor-Davidson Resilience Scale (CD-RISC); the Acceptance and Action Questionnaire (AAQ-II); the Post-Traumatic Growth Inventory Short Form (PTGISF); the Positive Aspects of Caregiving (PAC); and the SF-36 Health Survey. The length of the interviews varied, but on average they lasted around 45 minutes. Participants' names were not transcribed. Instead, each participant was assigned a numerical code to preserve their anonymity.

Due to the COVID-19 public health emergency, eight of the participants from the CG were interviewed by telephone.

Caregivers in the IG then received 10 one-and-a-half-hour intervention sessions once a week for two and a half months. After the intervention sessions were completed, both the IG and the CG repeated the assessment protocol in the same order as described above. The request for informed consent, the assessment sessions, and the delivery of the intervention program were carried out by a psychologist with experience and background in the field of grief.

Data Analysis

Data were analyzed using IBM SPSS for Windows, version 22.0. Descriptive analyses were performed and means, standard deviations, and frequencies were calculated. Between-group differences were analyzed using the *t*-test for independent samples and the χ^2 test. Linear models for repeated measures (Wilks' λ) were used to assess the impact of the program. In all cases, the assumptions of homogeneity of variances were taken into account (Levene's test). The effect size was calculated using Cohen's *d*. In addition, considering the large number of comparisons, the Benjamini–Hochberg Adjusted p-value was calculated for the Time x Group interactions. The statistical significance threshold was set at $p < 0.05$.

This study used a repeated measures quasi-experimental design with random allocation of participants to either the IG or the CG.

Results

The findings of the between-group comparison (see Tables 3 and 4) were then revealed. To perform the analysis, we used a general linear model of repeated measures with a 2×2 design. There were two levels for the inter-group factor, depending on whether or not study participants had taken part in the intervention program (IG or CG), and two levels for the intra-subject factor, corresponding to the two assessment points (time) (pre- and post-intervention). Table 3 shows the means, standard deviations, effect sizes (Cohen's *d*), and the findings obtained from the between-group differences, time of assessment, and the interaction of the variables. The dependent variables were the levels of caregiver grief (CGS), caregiver overload (CBI), resilience (CD-RISC), acceptance and action (AAQ-II), post-traumatic growth (PTGISF), positive aspects of caregiving (PAC), and perceived health (SF-36).

In the case of the caregiver grief scales, we found statistically significant differences in the CGS scales relating to Emotional Pain ($F(1,25) = 9.596$; $p = 0.005$), Relational Loss ($F(1,25) = 11.782$; $p = 0.002$), and Acceptance of Loss ($F(1,25) = 14.304$; $p = 0.001$) for the Time x Group interaction. In the first case, these differences indicated a decrease for the IG and, in the second and third cases, an increase for the CG and a decrease for the IG in the second assessment. There were also differences for the Group factor ($F(1,25) = 6.988$; $p = 0.014$) on the CGS Absolute Loss scale, indicating higher scores for the IG. Similarly, differences were found for the Zarit test in the Time x Group interaction ($F(1,25) = 41.411$; $p = 0.0001$), suggesting an increase in the second assessment for the CG, while a decrease was observed for the IG.

With regard to resilience (CDRISC), there were again statistically significant results in the Time x Group factor ($F(1,25) = 21{,}020$; $p = 0.0001$). These differences show that while there was a decrease for the CG in the second assessment, the IG saw an increase.

Focusing on the Acceptance and Action questionnaire (AAQ-II) scores, there were statistically significant results in the Time x Group factor ($F(1,25) = 5.794$; $p = 0.024$).

Table 3 Between-group differences on the scales of the measures assessed (means, standard deviation, effect sizes, F, Wilks' Lambda Effect and Benjamini–Hochberg Adjusted *p*-value)

Variable	Groups	*Mean (SD)* Pre	*Mean (SD)* Post	Effect size	Factor	*F*	*p*	*Benjamini–Hochberg Adjusted p-value*
CGS Emotional Pain	Control Intervention	10.00 (2.86) 11.36 (3.32)	10.50 (3.20) 8.79 (3.60)	0.17 0.74	Time Group Time x Group	4.364 0.025 9.596	0.047 0.875 0.005	0.040
CGS Relational Loss	Control Intervention	12.57 (2.82) 13.43 (2.31)	13.07 (3.00) 9.71 (3.47)	0.17 1.29	Time Group Time x Group	6.854 1.838 11.782	0.015 0.187 0.002	0.030
CGS Absolute Loss	Control Intervention	12.57 (10.21) 10.43 (3.72)	11.43 (3.69) 4.79 (2.39)	0.16 1.85	Time Group Time x Group	5.348 6.988 2.352	0.029 0.014 0.137	0.130
CGS Acceptance of Loss	Control Intervention	6.00 (1.88) 7.21 (2.33)	7.79 (1.85) 5.21 (2.22)	0.96 0.88	Time Group Time x Group	0.046 1.252 14.304	0.832 0.273 0.001	0.020
CBI	Control Intervention	65.86 (15.59) 72.43 (14.43)	72.14 (13.46) 60.29 (12.83)	0.43 0.89	Time Group Time x Group	4.183 0.264 41.411	0.051 0.611 0.000	0.010
CDRISC Total	Control Intervention	31.07 (5.85) 24.50 (8.78)	28.43 (7.37) 30.14 (7.27)	0.40 0.70	Time Group Time x Group	2.756 0.844 21.020	0.109 0.367 0.000	0.010
AAQII Total	Control Intervention	32.38 (6.96) 39.21 (9.07)	34.69 (9.03) 36.93 (7.31)	0.29 0.28	Time Group Time x Group	0.000 2.296 5.794	0.991 0.142 0.024	0.090
PTGISF Relating to Others Total	Control Intervention	6.86 (2.25) 4.86 (4.07)	5.79 (3.19) 6.21 (8.83)	0.39 0.21	Time Group Time x Group	0.019 0.218 1.355	0.892 0.645 0.255	0.170
PTGISF New Possibilities Total	Control Intervention	6.79 (2.97) 6.07 (3.15)	6.79 (3.67) 7.93 (5.36)	0 0.44	Time Group Time x Group	2.152 0.026 2.152	0.154 0.873 0.154	0.150
PTGISF Personal Strength Total	Control Intervention	6.93 (3.15) 7.57 (2.77)	6.64 (2.95) 9.00 (4.95)	0.10 0.37	Time Group Time x Group	0.942 1.535 2.120	0.341 0.226 0.157	0.160
PTGISF Spiritual Change Total	Control Intervention	2.86 (3.11) 2.14 (2.91)	3.29 (3.99) 4.57 (8.03)	0.12 0.44	Time Group Time x Group	1.617 0.036 0.792	0.215 0.851 0.382	0.200
PTGISF Appreciation of Life Total	Control Intervention	8.57 (2.56) 7.57 (2.10)	8.50 (2.56) 9.79 (6.45)	0.03 0.52	Time Group Time x Group	2.052 0.013 2.335	0.164 0.910 0.139	0.140
PTGISF Total	Control Intervention	32.00 (10.11) 28.21 (9.79)	31.00 (10.66) 31.50 (6.79)	0.10 0.40	Time Group Time x Group	1.384 0.228 4.867	0.250 0.637 0.036	0.110
PAC total	Control Intervention	46.64 (10.60) 42.14 (9.73)	44.86 (10.41) 48.50 (6.73)	0.17 0.77	Time Group Time x Group	2.831 0.017 8.982	0.104 0.898 0.006	0.050

CGS Caregiver Grief Scale, *CBI* Caregiver Burden Interview, *CD-RISC* Connor-Davidson Resilience Scale, *AAQ-II* The Acceptance and Action Questionnaire, *PTGISF* The Post-Traumatic Growth Inventory Short Form, *PAC* Positive Aspects of Caregiving

These results clearly show that, post-intervention, there was an increase for the CG and a decrease for the IG.

The results of the PTGISF revealed significant differences for the Time x Group factor on the Total PTGISF scale ($F(1,25) = 4.867$; $p = 0.036$). These show a decrease in scores for the CG in the second assessment while the same scores increased for the IG.

We also found significant differences in the positive aspects of caregiving, as assessed by the PAC instrument, for the Time x Group factor ($F(1,25) = 8.982$; $p = 0.006$).

Table 4 Between-group differences on the SF-36 scale of the measures assessed (means, standard deviation, effect size, F, Wilks' lambda effect and Benjamini–Hochberg Adjusted *p*-value)

Variable	Groups	*Mean (SD)* Pre	*Mean (SD)* Post	Effect size	Factor	*F*	*p*	*Benjamini–Hochberg Adjusted p-value*
SF36 General Health	Control Intervention	16.79 (2.39) 17.00 (2.28)	16.93 (1.82) 16.29 (1.94)	0.07 0.34	Time Group Time x Group	0.493 0.096 1.109	0.489 0.759 0.302	0.190
SF36 Physical Health	Control Intervention	28.50 (2.18) 26.86 (2.96)	26.50 (4.40) 27.86 (2.51)	0.61 0.37	Time Group Time x Group	0.758 0.019 6.825	0.392 0.891 0.015	0.080
SF36 Physical Role	Control Intervention	6.79 (1.76) 6.36 (1.82)	6.43 (1.95) 7.07 (1.59)	0.19 0.42	Time Group Time x Group	0.579 0.029 5.214	0.453 0.867 0.031	0.100
SF36 Emotional Role	Control Intervention	5.07 (1.21) 3.86 (1.29)	4.50 (1.45) 5.29 (0.91)	1.13 1.3	Time Group Time x Group	2.437 0.324 13.271	0.131 0.574 0.001	0.020
SF36 Social Function-ing	Control Intervention	6.29 (1.94) 6.07 (1.77)	6.21 (1.53) 5.93 (0.83)	0.05 0.11	Time Group Time x Group	0.101 0.259 0.011	0.753 0.615 0.916	0.210
SF36 Bodily Pain	Control Intervention	5.07 (2.30) 8.36 (2.53)	6.57 (2.98) 5.29 (1.73)	0.56 1.44	Time Group Time x Group	3.155 1.548 26.704	0.087 0.225 0.000	0.010
SF36 Vitality	Control Intervention	13.71 (2.49) 13.50 (1.65)	13.57 (2.71) 14.71 (1.44)	0.05 0.78	Time Group Time x Group	2.746 0.391 4.407	0.109 0.537 0.046	0.120
SF36 Mental Health	Control Intervention	19.64 (2.13) 17.21 (3.09)	19.43 (2.56) 19.64 (2.44)	0.09 0.88	Time Group Time x Group	5.076 1.727 7.232	0.033 0.200 0.012	0.07
SF36 PCS	Control Intervention	57.14 (3.13) 58.57 (4.71)	56.71 (3.47) 56.50 (3.55)	0.13 0.50	Time Group Time x Group	2.944 0.247 1.271	0.098 0.624 0.270	0.180
SF36 MCS	Control Intervention	43.64 (4.13) 41.00 (4.17)	44.71 (2.64) 45.21 (4.69)	0.32 0.95	Time Group Time x Group	2.903 0.812 8.211	0.100 0.376 0.008	0.060
SF36 Total	Control Intervention	74.29 (30.10) 102.93 (6.83)	101.50 (7.20) 104.07 (4.16)	1.46 0.21	Time Group Time x Group	13.579 11.233 11.478	0.001 0.002 0.002	0.030

SF The SF-36 Health Survey, *PCS* Physical Component Summary, *MCS* Mental Component Summary

These results indicated a pattern of change between the two assessment scores that was different for both groups, with CG showing a decrease and IG an increase.

With respect to the SF36 scales, statistically significant differences were found for Physical Health ($F(1,25) = 6.825$; $p = 0.015$), Physical Role ($F(1,25) = 5.214$; $p = 0.031$), Emotional Role ($F(1,25) = 13.271$; $p = 0.001$), Bodily Pain ($F(1,25) = 26.704$; $p = 0.0001$), Vitality ($F(1,25) = 4.407$; $p = 0.046$), Mental Health ($F(1,25) = 7.232$; $p = 0.012$), the Mental Component Summary (MCS) ($F(1,25) = 8.211$; $p = 0.008$), and the overall scale ($F(1,25) = 11.478$; $p = 0.002$) for the Time x Group interaction. Similarly, significant differences were observed for the Group factor in the overall SF36 scale ($F(1,25) = 11.233$; $p = 0.002$) and again for the Time factor in the Mental Health scales ($F(1,25) = 5.076$; $p = 0.033$) and overall SF36

($F(1,25) = 13.579$; $p = 0.001$). In all cases, these differences are explained by the fact that in the second assessment, the IG showed an increase in perceived health, while the CG showed a decrease (see Table 4).

Finally, the effect sizes for the IG are generally moderate, with high scores for the variables assessing caregiver grief, caregiver overload, the positive aspects of caregiving, resilience, and the various measures of perceived health, underlining the importance of the post-intervention changes.

Discussion

The main aim of this study was to adapt, deliver, and assess the effects of a grief intervention program for family caregivers of individuals with ASD. Overall, the program has helped reduce the symptoms associated with grief and the feelings of overload resulting from caregiving responsibilities. It has also been shown to improve empathy and resilience, the perception of benefit from the very act of caregiving, physical and emotional well-being, and the perceived health of participants.

The literature reviewed on this topic identifies three areas of significant concern for caregivers of individuals with ASD. One area relates to physical and mental health, another to the way care is delivered, and a final area to the grieving process and acceptance of loss.

In terms of physical and mental health, multiple studies have shown that parents of children with ASD tend to experience high levels of stress, anxiety, depression, and a lower quality of life than parents whose children have a more standard development (Costa et al., 2017; Giovagnoli et al., 2015; Karp and Kuo (2015); Vasilopoulou & Nisbet, 2016; Weiss and Thomson (2014)). The characteristics of our study sample, prior to delivery of the program, match the profile described in the literature reviewed. However, after delivery of the intervention program, improvements in mental health levels were noted, particularly in the perception of overall health for the group that took part in the program. We believe this is important because better caregiver physical and mental health also has a positive effect on the children's symptomology (Zhou et al., 2019). This finding is also encouraging in that it may have a direct protective effect. This is in light of the evidence in the literature that declining mental health in turn weakens social networks and contributes to the isolation, helplessness, and depression felt by family caregivers, leading to further mental and physical decline. Conversely, better mental health is often associated with greater and more satisfying social contact (Gariépy & Honkaniemi, 2016).

In the area of care, the levels of overload found in our study prior to delivery of the program are similar to and consistent with those found in previous studies (Gatzoyia et al., 2014; Giovagnoli et al., 2015; Han et al., 2021; Karp and Kuo (2015); O'Halloran et al., 2013). Our results show that the program reduces caregiver overload and improves the quality of the care provided. This is also in line with the recent study by Factor et al. (2022). This finding also seems important, as overload has been associated with the complexity and demands of caregiving, especially in the most severe cases, and with health, physical, and emotional problems in caregivers, particularly in situations where access to services and support is inadequate (World Health Organization, 2021). The literature shows that the daily demands of caregiving create many hurdles for the caregiver, negatively impacting their quality of life (Bilgin & Kucuk, 2010; O'Dea & Marcelo, 2022). It has been suggested that the stress of raising a child with these characteristics increases the parents' stress levels and makes them more likely to resort to maladaptive strategies to cope with these tense situations. Picci et al. (2015) also note that, in many cases, caregivers use maladaptive strategies to cope with the stress of caregiving, such as substance abuse, self-blame, avoidance, or attempts to deny reality by replaying stressful situations in their mind in a more positive but unrealistic way. First and foremost, our program has proven to be an effective vehicle for improving the well-being and quality of life of caregivers of children with these characteristics, significantly reducing their level of physical and mental discomfort. Secondly, in addition to the direct benefits to caregivers, these changes also impact the quality of care provided and the well-being of individuals with ASD. In other words, the program has a positive effect on the caregiver's empathetic capacity and resilience. On the one hand, these effects contribute to better quality care (more affectionate and more thorough) which, in turn, is associated with a reduction in the common behavioral problems of their family members. On the other hand, positive changes are also observed in their perception of resources and in their attitude and performance in the care of the family member. After participating in the program, participants feel that they have been equipped with more resources (knowledge and support) and are more mentally and physically prepared to handle the ups and downs of both the disorder and their caregiving role.

In the area of loss, the pre-program measures of grief were consistent with other studies showing the intense and persistent feelings of grief-related distress experienced by caregivers of individuals with ASD (O'Brien, 2007; Mulligan et al., 2012). After completing the intervention program, participating caregivers observed that their emotional distress had decreased significantly. A similar effect was found for feelings of loss and acceptance of reality, with significant improvements in feelings of loss and acceptance of reality of the loss. More specifically, after the program, significant decreases were observed in the symptoms associated with

grief and stress (emotional distress, feelings of relational loss, acceptance of loss, stress, subjective overload in performing the role of caregiver, and experiential avoidance). At the same time, we found an increase in factors that facilitate effective coping and adaptation to caregiving tasks (perception of the role of caregiver, the ability to adapt to adverse situations, and resilience). The program therefore has a positive impact on those aspects of caregiving that are very limiting for those carrying out this role.

We believe it is essential to devote more resources to researching and developing programs for caregivers that address grief symptoms throughout the caregiving process. In addition to the direct costs of living with ASD, the human and socioeconomic costs of not providing this group with adequate support are increasing, as highlighted previously (Buescher et al., 2014; Schofield et al., 2019). This is due to the fact that there are currently no programs offering effective solutions for the physical and mental health of caregivers that also address the grief process.

Study Implications

The benefits of this program are as follows: a) it addresses hitherto unmet needs associated with the grief processes of caregivers; b) high levels of adherence are achieved; c) it can be delivered to any caregiver, regardless of the severity of the affected person's symptoms; d) the program can be delivered with limited professional and material resources; e) it encourages proactive change in the coping mechanisms used to manage symptoms associated with grief and the caregiving role itself; f) it promotes changes that have repercussions at the personal, family, and societal levels; g) it supports and encourages actions targeted at the need for self-actualization; and h) it creates long-lasting supportive bonds between caregivers.

Study Limitations

Among the main limitations of this study is the heterogeneity of the sample, in relation to the characteristics of the person with ASD receiving care. To be specific, there were differences associated with the condition, e.g., the degree of cognitive impairment, the level of dependence, and the severity of the behavioral problems. There were also differences between the groups in terms of monthly income. Families in the CG had higher incomes than families in the IG. In terms of study design, it would also be interesting to take into account the different degrees of kinship existing between caregivers and care recipients, and to aim for an equal number of participants of each sex. Furthermore, there should be ongoing follow-up with participants to ensure that the positive changes achieved on completion of the program are sustained over time.

Conclusions

In conclusion, it is important to note the profound and significant impact that caring for someone with ASD has on caregivers' resources, finances, and physical and mental health. The nature of the symptoms, together with the uncertainty, the ongoing reminder of unmet milestones, and the unpredictability surrounding the evolution of the disorder, means that feelings of distress and grief are unrelenting. The provision of support tailored to the specific needs of caregivers is of the utmost importance. To this end, we believe that the following objectives need to be achieved: a reduction in caregiver overload, improving caregiver well-being and quality of life, and the delivery of interventions to help cope with the onset of grief.

Data availability

Files participants' dataset, syntax file and log files for analysis are all available in the Figshare repository in the following links: *Files participants's dataset: https://figshare.com/articles/dataset/Dataset/21355404 <https://figshare.com/articles/dataset/Dataset/21355404>* *log files for analysis: https://figshare.com/articles/dataset/Archive_of_analyses_/21357150 <https://figshare.com/articles/dataset/Archive_of_analyses_/21357150>* *Sytax file: https://figshare.com/articles/dataset/Sintaxis/21357219 <https://figshare.com/articles/dataset/Sintaxis/21357219>* *Explanatory note: https://figshare.com/articles/dataset/Explanatory_note/21357201 <https://figshare.com/articles/dataset/Explanatory_note/21357201>*

Acknowledgements The authors would like to thank all the participants who gave so generously of their time to make this research possible.

Author Contributions All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by J.B.-B., M.N.P.M. and F.C.-Q. The first draft of the manuscript was written by J.B.-B. and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Ethics Approval The study was approved by the Research Ethics Committee of the University of Granada, Spain (Ref.: 359/CEIH/2017).

Informed Consent All the participants signed the informed consent form.

References

Alonso, J., Prieto, L., & Anto, J. M. (1995). The Spanish version of the SF-36 Health Survey (the SF-36 health questionnaire): an

instrument for measuring clinical results. *Medicina Clínica*, *104*(20), 771–776. https://pubmed.ncbi.nlm.nih.gov/7783470/.

Altiere, M. J., & Von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of child and Family Studies*, *18*(1), 83–92. https://doi.org/10.1007/s10826-008-9209-y.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*, 5th Ed. American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596.

Bilgin, H., & Kucuk, L. (2010). Raising an autistic child: Perspectives from Turkish mothers. *Journal of Child and Adolescent Psychiatric Nursing*, *23*(2), 92–99. https://doi.org/10.1111/j.1744-6171.2010.00228.x.

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family*, *66*(3), 551–566. https://doi.org/10.1111/j.0022-2445.2004.00037.x.

Bravo-Benítez, J., Cruz-Quintana, F., Fernández-Alcántara, M., & Pérez-Marfil, M. N. (2021). Intervention Program to Improve Grief-Related Symptoms in Caregivers of Patients Diagnosed with Dementia. *Frontiers in Psychology*, *12*, 628750. https://doi.org/10.3389/fpsyg.2021.628750.

Bruce, E. J., & Schultz, C. L. (2001) *Nonfinite loss and grief: A psychoeducational approach*. Paul H Brookes Publishing.

Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA paediatrics*, *168*(8), 721–728. https://doi.org/10.1001/jamapediatrics.2014.210.

Casey, L. B., Zanksas, S., Meindl, J. N., Parra, G. R., Cogdal, P., & Powell, K. (2012). Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study. *Research in Autism Spectrum Disorders*, *6*(3), 1186–1193. https://doi.org/10.1016/j.rasd.2012.03.008.

Castro, M. C., Delgado, J. B., Alvarado, E. R., & Rovira, D. P. (2015). Spanish adaptation and validation of the posttraumatic growth inventory–short form. *Violence and Victims*, *30*(5), 756–769. https://doi.org/10.1891/0886-6708.VV-D-13-00165.

Chiarotti, F., & Venerosi, A. (2020). Epidemiology of autism spectrum disorders: a review of worldwide prevalence estimates since 2014. *Brain Sciences*, *10*(5), 274. https://doi.org/10.3390/brainsci10050274.

Connor, K. M., & Davidson, J. R. (2003). Development of a new resilience scale: the Connor-Davidson resilience scale (CD-RISC). *Depression and Anxiety*, *18*(2), 76–82. https://doi.org/10.1002/da.10113.

Costa, A. P., Steffgen, G., & Ferring, D. (2017). Contributors to well-being and stress in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *37*, 61–72. https://doi.org/10.1016/j.rasd.2017.01.007.

Crespo, M., Fernández-Lansac, V., & Soberón, C. (2014). Adaptación Española de la "Escala de Resiliencia de Connor-Davidson" (CD-RISC) en Situaciones de Estrés Crónico. *Behavioral. Psychology/Psicología Conductual*, *22*(2), 219–238. https://doi.org/10.1037/t62957-000.

Factor, R. S., Rea, H. M., Dahiya, A. V., Laugeson, E. A., & Scarpa, A. (2022). Pilot Study Examining Caregiver–Child and Family Functioning in PEERS® for Preschoolers. *Journal of Child and Family Studies*. https://doi.org/10.1007/s10826-022-02441-8.

Gariépy, G., & Honkaniemi, H. (2016). Social support and protection from depression: systematic review of current findings in Western countries. *The British Journal of Psychiatry*, *209*(4), 284–293. https://doi.org/10.1192/bjp.bp.115.169094.

Gatzoyia, D., Kotsis, K., Koullourou, I., Goulia, P., Carvalho, A. F., Soulis, S., & Hyphantis, T. (2014). The association of illness perceptions with depressive symptoms and general psychological distress in parents of an offspring with autism spectrum disorder. *Disability and Health Journal*, *7*(2), 173–180. https://doi.org/10.1016/j.dhjo.2013.10.008.

Giovagnoli, G., Postorino, V., Fatta, L. M., Sanges, V., De Peppo, L., Vassena, L., Rose, P. D., Vicari, S., & Mazzone, L. (2015). Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder. *Research in Developmental Disabilities*, *45-46*, 411–421. https://doi.org/10.1016/j.ridd.2015.08.006.

Han, A., Yuen, H. K., & Jenkins, J. (2021). Acceptance and commitment therapy for family caregivers: a systematic review and meta-analysis. *Journal of Health Psychology*, *26*(1), 82–102. https://doi.org/10.1177/1359105320941217.

Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., & Stewart, S. H. (2004). Measuring experiential avoidance: a preliminary test of a working model. *The Psychological Record*, *54*(4), 553–578. https://doi.org/10.1007/BF03395492.

Heiman, T. (2002). Parents of children with disabilities: resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, *14*(2), 159–171. https://doi.org/10.1023/A:1015219514621.

Karp, E. A., & Kuo, A. A. (2015). Maternal mental health after a child's diagnosis of autism spectrum disorder. *JAMA*, *313*(1), 81–82. https://doi.org/10.1001/jama.2014.11187.

Las Hayas, C., López de Arroyabe, E., & Calvete, E. (2014). Positive aspects of caregiving in Spanish caregivers of individuals with acquired brain injury. *Rehabilitation Psychology*, *59*(2), 193–202. https://doi.org/10.1037/a0035622.

Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature reviews. Disease primers*, *6*(1), 5. https://doi.org/10.1038/s41572-019-0138-4.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, *17*(5), 702–711. https://doi.org/10.1177/1359105311422955.

Mairal, J. B. (2004) Spanish adaptation of the Acceptance and Action Questionnaire (AAQ). *International Journal of Psychology and Psychological Therapy, 4*(3), 505-515. Retrieved from https://www.ijpsy.com/volumen4/num3/97/spanish-adaptation-of-the-acceptance-and-EN.pdf.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of services. *Autism*, *8*(4), 387–407. https://doi.org/10.1177/1362361304045213.

Martín, M., Salvadó, I., Nadal, S., Miji, L. C., & Rico, J. M. (1996). Adaptación para nuestro medio de la Escala de Sobrecarga del Cuidador (Caregiver Burden Interview) de Zarit. *Revista de Gerontología*, *6*, 338–346. https://doi.org/10.1157/13100841.

Meichsner, F., Schinköthe, D., & Wilz, G. (2016). The caregiver grief scale: development, exploratory and confirmatory factor analysis, and validation. *Clinical Gerontologist*, *39*(4), 342–361. https://doi.org/10.1080/07317115.2015.1121947.

Mulligan, J., Macculloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: a model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health*, *10*(4), 311–330. https://doi.org/10.1080/15332985.2012.664487.

O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations*, *56*(2), 135–146. Retrieved from http://www.jstor.org/stable/4541656.

O'Halloran, M., Sweeney, J., & Doody, O. (2013). Exploring fathers' perceptions of parenting a child with Asperger syndrome. *Journal of Intellectual Disabilities*, *17*(3), 198–213. https://doi.org/10.1177/1744629513494928.

Olshansky, S. (1962). Chronic sorrow: a response to having a mentally defective child. *Social casework*, *43*(4), 190–193. https://doi.org/10.1177/104438946204300404.

Patrick-Ott, A., & Ladd, L. D. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: a case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health*, *5*(1), 73–86. https://doi.org/10.1080/15401381003627327.

Picci, R. L., Oliva, F., Trivelli, F., Carezana, C., Zuffranieri, M., Ostacoli, L., Furlan, P. M., & Lala, R. (2015). Emotional burden and coping strategies of parents of children with rare diseases. *Journal of Child and Family Studies*, *24*(2), 514–522. https://doi.org/10.1007/s10826-013-9864-5.

Rarity, J. C. (2007). *Nonfinite grief in families with children on the autism spectrum*. (Publication n° 180195268). PhD Thesis, St. Mary's University, San Antonio, Texas, USA. ProQuest Dissertations & Theses Global.

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: a systematic review and meta-analysis. *PloS One*, *14*(7), e0219888. https://doi.org/10.1371/journal.pone.0219888.

Schofield, D., Shrestha, R. N., Zeppel, M. J., Cunich, M. M., Tanton, R., Veerman, J. L., & Passey, M. E. (2019). Economic costs of informal care for people with chronic diseases in the community: lost income, extra welfare payments, and reduced taxes in Australia in 2015–2030. *Health & Social Care in the Community*, *27*(2), 493–501. https://doi.org/10.1111/hsc.12670.

Seguí, J. D., Ortiz-Tallo, M., & De Diego, Y. (2008). Factores asociados al estrés del cuidador primario de niños con autismo: sobrecarga, psicopatología y estado de salud. *Anales de Psicología/Annals of Psychology*, *24*(1), 100–105. https://revistas.um.es/analesps/article/view/31841.

Seretopoulos, K., Lamnisos, D., & Giannakou, K. (2020). The epidemiology of autism spectrum disorder. *Archives of Hellenic Medicine*, *37*, 169–180. https://doi.org/10.1146/annurev.publhealth.28.021406.144007.

Shear, M. K., & Bloom, C. G. (2017). Complicated grief treatment: an evidence-based approach to grief therapy. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, *35*(1), 6–25. https://doi.org/10.1007/s10942-016-0242-2.

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Ruber, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, *26*(4), 429–453. https://doi.org/10.1177/0164027504264493.

Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress*, *9*(3), 455–471. https://doi.org/10.1002/jts.2490090305.

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. *Research in Autism Spectrum Disorders*, *23*, 36–49. https://doi.org/10.1016/j.rasd.2015.11.008.

Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care*, *30*, 473–483. https://doi.org/10.1097/00005650-199206000-00002.

Weiss, J. A., & Thomson, L. C. (2014). A systematic literature review of emotion regulation measurement in individuals with autism spectrum disorder. *Autism Research*, *7*(6), 629–648. https://doi.org/10.1002/aur.1426.

World Health Organisation. (2021). Available at: https://www.who.int/es/news-room/fact-sheets/detail/autism-spectrum-disorders. (accessed 1 January 2021).

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1380–1393. https://doi.org/10.1007/s10803-012-1693-7.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649.

Zhou, W., Liu, D., Xiong, X., & Xu, H. (2019). Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. *Medicine*, *98*(32), e16794. https://doi.org/10.1097/MD.0000000000016794.