

PSYCHOLOGICAL INTERVENTION FOR GRIEF IN CAREGIVERS OF ADULTS DIAGNOSED WITH INTELLECTUAL DISABILITIES

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Abstract

The objective of this pilot study was to adapt and provide preliminary data of the efficacy of an intervention aimed at family caregivers of adults with intellectual disability to provide them with different coping resources to better cope with their role as caregivers, as well as to reduce the psychological overload and pain associated with the diagnosis. A total of 24 caregivers participated, of which 14 were assigned to an intervention group (IG) and 10 to a control group (CG) through simple randomization. Variables of overload, mental health and feelings of grief produced by the diagnosis were measured. Linear models for repeated measures were used to evaluate the effect of the program. After the intervention, significant differences ($p < .5$) were found in the dimensions of emotional pain, relational loss and acceptance of loss, and feelings of grief brought on by the diagnosis. In conclusion, it is necessary that this type of program be given early to these caregivers in order to avoid the pathological and chronic grief into which they frequently end up.

KEY WORDS: *intellectual disability, loss, grief, caregivers, diagnosis, psychological intervention.*

Resumen

El objetivo de este estudio fue adaptar y aportar datos preliminares de la eficacia de una intervención psicológica para cuidadores familiares de adultos con discapacidad intelectual, con el fin de proporcionarles recursos de afrontamiento para sobrellevar su rol de cuidador y reducir la sobrecarga psicológica y el dolor que conlleva el diagnóstico. Participaron 24 cuidadores, de los cuales 14 fueron asignados a un grupo intervención (GI) y 10 a un grupo control (GC) mediante una aleatorización simple. Se midieron variables de sobrecarga, salud mental y sentimientos de duelo derivados del diagnóstico. Se utilizaron modelos lineales de medidas repetidas para evaluar el efecto del programa. Se encontraron diferencias estadísticamente significativas ($p < 0,05$) en las variables de dolor emocional,

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aceptación de la pérdida y en la experiencia actual del duelo, mostrando el GI una mejora tras la intervención. Como conclusión, es necesario que este tipo de programas se impartan de forma temprana en estos cuidadores con el fin de evitar el duelo patológico y crónico en el que terminan desembocando frecuentemente.

PALABRAS CLAVE: *discapacidad intelectual, pérdida, duelo, cuidadores, diagnóstico, intervención psicológica.*

Introduction

Intellectual disability (ID) encompasses a wide range of impairments in intellectual functioning and adaptive behaviour, as well as in conceptual, social and practical areas (American Psychiatric Association [APA], 2013). The global prevalence of ID is 0.05-1.55% (McKenzie et al., 2016) and in Spain a total of 282,412 people with a degree of impairment equal to or greater than 33% have been recorded (Institute for Older Persons and Social Services [IMSERSO], 2019).

However, ID also has a significant impact on the responsible caregiver (IMSERSO, 2019; Izuzquiza-Gasset and De La Herrán-Gascón, 2010). Becoming a caregiver for a person with a chronic illness often involves major lifestyle changes, with many negative implications (Gallagher and Whiteley, 2012; Matteucci et al., 2019; Oti-Boadi, 2017; Somanadham and Larkin, 2016; Spindler et al., 2017; Thompson et al., 2014; Viana-Tomaz et al., 2017). These include: a) significantly less time for leisure and personal self-care (Spindler et al., 2017; Viana-Tomaz et al., 2017); b) the loss or abandonment of employment due to incompatibility with caring responsibilities (Oti-Boadi, 2017; Spindler et al., 2017; Thompson et al., 2014); c) partial or total loss of social relationships (Oti-Boadi, 2017; Thompson et al., 2014; Viana-Tomaz et al., 2017); d) impaired family dynamics and couple relationships (Somanadham and Larkin, 2016; Spindler et al., 2017; Viana-Tomaz et al., 2017) and e) a greater risk of developing mental and physical health problems (high stress levels, depression, anxiety, high blood pressure, etc.) than the general population (Gallagher and Whiteley, 2012; Matteucci et al., 2019; Mora-Castañeda et al., 2023).

Primary caregivers, especially parents, are also likely to experience feelings of grief and loss when their family member is diagnosed with ID. Such news comes as a great emotional shock, dashing any hopes they may have had for their family member, and is accompanied by intense negative feelings such as sadness and pain (Fernández-Alcántara et al., 2015; Fernández-Alcántara et al., 2017; Ponte et al., 2012). Recent models such as the dual process model of grief (DPM) by Stroebe et al. (2017) suggest that these caregivers oscillate between processing and/or accepting the anticipated or imagined loss of the family member, and coping with the new situation. However, this oscillation, essential for dealing adaptively with the grieving process, is complicated by the challenges these caregivers face. From the

time of their loved one's diagnosis, life becomes a process of constant struggle (Stroebe et al., 2017). In fact, it has been found that these caregivers go through a grieving process characterised as cyclical, progressive, recurrent and persistent over time (Brown, 2013; Coughlin and Sethares, 2017), and which intensifies when their children do not reach hoped-for developmental milestones (Broberg, 2011; Brown, 2013).

Hence, the physical and psychological toll on these caregivers due to the grieving process and associated changes not only occurs at the time of the family member's diagnosis but carries over into later evolutionary stages (Balieiro-Takebayashi et al., 2019; Walker et al., 2020).

Few previous studies have analysed the effect of interventions aimed at caregivers. Such interventions (e.g., Bazzano et al., 2015; Dykens et al., 2014; Flynn et al., 2020; Jones et al., 2018; Lunsky et al., 2017) have mainly been mindfulness-based and targeted at parental caregivers of younger children with ID, with the exception of studies such as Lunsky et al. (2017), which was aimed at family caregivers of young people and adults with ID. In terms of outcomes, these interventions have shown that it is possible to improve the caregivers' short and long-term mental health and reduce their psychological distress. One limitation, however, is that these interventions did not specifically address feelings of grief and loss following the news of the diagnosis. Further research is also needed to test the efficacy of such interventions and compare them with other psychological treatments (Chua and Shorey, 2021; Osborn et al., 2021). Moreover, such interventions should be able to span different evolutionary stages, and not only focus on the aftermath of the news of the diagnosis (Chua and Shorey, 2021; Osborn et al., 2021).

In the overall context of grief interventions, Shear's (2010) therapy has proven effective in reducing complicated grief symptomatology associated with bereavement loss (Shear and Bloom, 2017). The 16-session intervention is based on the cognitive behavioural therapy model and includes motivational therapy techniques (Shear and Bloom, 2017). It focuses on addressing the processes that can sustain a maladaptive grieving process by supporting the bereaved person, helping them to process and accept the loss, rebuilding bonds and equipping them with adaptive strategies for moving on (Boelen et al., 2006; Shear and Bloom, 2017). Shear and Bloom's (2017) therapy has been used in research such as Bravo-Benítez et al. (2021), and was adapted for bereavement work with imaginal and in-vivo exposure techniques, cognitive restructuring, behavioural rehearsal and social skills training. The objectives of the intervention were to encourage acceptance of both the new situation and the consequences of the loss, to foster the bonds previously held with the family member, and to put in place strategies for participation in leisure activities to improve quality of life and psychological well-being (Bravo-Benítez et al., 2021). Bravo-Benítez et al. (2021) found this adaptation in their

programme to be effective in improving grief symptomatology in caregivers of people with dementia. However, to the best of our knowledge, no research has demonstrated this intervention's efficacy in grieving processes following a diagnosis of chronic illness or in the case of ID.

In light of this, a pilot study was designed with the following key objectives: to adapt and provide preliminary data on the efficacy of an intervention based on Shear's (2010) complicated grief therapy for family caregivers of adults with ID, to equip them with a range of coping resources linked to their caregiving role and to lessen the psychological burden and grief associated with the loss brought on by the diagnosis. The proposed hypothesis is based on the fact that the intervention will help caregivers to reduce the intensity of their feelings of pain associated with the diagnosis of their relative with intellectual disability, it will reduce their mental overload and improve their psychological well-being.

Primary caregivers of adults with ID were selected for this study because previous research has shown that the grieving processes associated with the diagnosis in this population persist even when the family member with ID is an adult (Brown, 2013; Coughlin and Sethares, 2017; Fernández-Ávalos et al., 2021). It is therefore necessary to evaluate the symptoms of grief at that moment in time, so as to later adapt and test the effectiveness of a psychological intervention to reduce their intensity (Chua and Shorey, 2021; Osborn et al., 2021).

Finally, this pilot study is based on a cognitive-behavioural group intervention programme, drawing on the psychological techniques used in Shear and Bloom's (2017) therapy, together with elements and techniques of acceptance and commitment therapy, strategies that have proven to work well in grief intervention (Bazzano et al., 2015; Dykens et al., 2014; Flynn et al., 2020; Jones et al., 2018; Lunskey et al., 2017).

Method

Participants

Participants are family caregivers of people with ID who belong to an association supporting people with ID in the province of Granada, Spain. Inclusion criteria were: a) being aged 18 or over and b) being the primary caregiver of an adult family member with an ID diagnosis, according to Diagnostic and statistical manual of mental disorders, DSM 5 (APA, 2013). Exclusion criteria were: a) having trouble attending and participating in the intervention programme and b) receiving psychological and/or psychiatric treatment at the time of programme delivery. The medical records of family members with ID were accessed to obtain information on their degree of disability.

Of the 45 family caregivers who voluntarily agreed to participate in the study, 32 fulfilled the inclusion criteria. Eight subsequently dropped out of the study during pre-assessment due to time constraints preventing their participation. As such, a total of 24 family caregivers of patients with ID were finally selected (Figure 1), and randomly assigned to one of the two groups by simple randomisation (1:1), using a sequence of computer-generated random numbers. The intervention group (IG) was made up of 14 family caregivers of adults with an ID diagnosis (five men and nine women) with a mean age of 68.28 years ($SD= 8.04$), while the control group (CG) was made up of 10 family caregivers of adults with an ID diagnosis (one man and nine women) with a mean age of 58.10 years ($SD= 8.50$).

Table 1 includes information on the caregivers' sociodemographic characteristics (descriptive statistics and effect sizes), such as age, gender, marital status, level of education, employment status, their relationship to the family member with ID and how frequently they lived together. Also included are the age and degree of disability of the family member with ID. No statistically significant differences were found between the groups for the variables described above, except for caregiver age where the mean score was higher in the IG.

Figure 1

Flowchart for the selection of participants

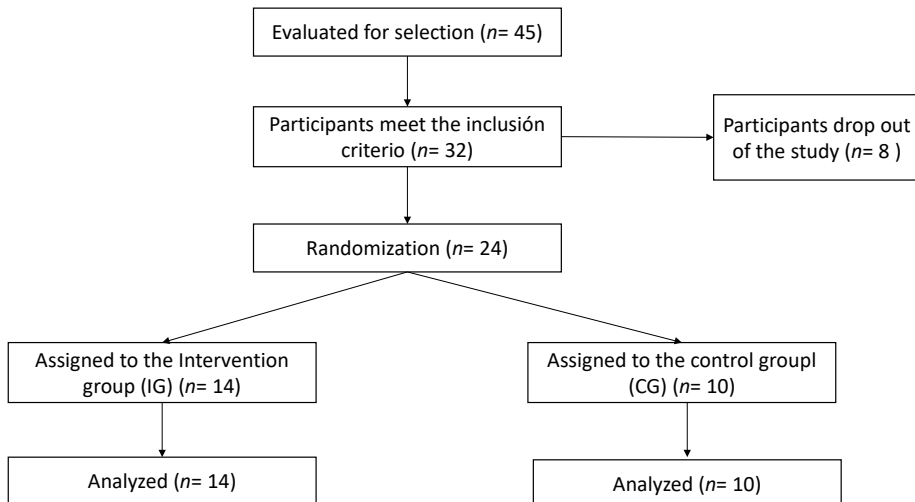


Table 1
Socio-demographic characteristics of the sample

Variables	IG (N= 14)	CG (N= 10)	t/χ^2	p	d
	$M(SD)$ o n (%)	$M(SD)$ o n (%)			
Age (years)	68.28 (8.04)	58.10 (8.50)	2.988	0.007*	1.235
Sex			2.057	0.151	0.293
Men	5 (35.7%)	1 (10%)			
Women	9 (64.3%)	9 (90%)			
Marital status			5.280	0.152	0.469
Married	13 (92.9%)	7 (70%)			
Single	0 (0%)	1 (10%)			
Divorced	1 (7.1%)	0 (0%)			
Widow/er	0 (0%)	2 (20%)			
Education level			4.920	0.085	0.453
Primary	11 (78.6%)	5 (50%)			
Secondary	3 (21.4%)	2 (20%)			
Universitary	0 (0%)	3 (30%)			
Employment situation			6.629	0.157	0.526
Employee	0 (0%)	2 (20%)			
Self-employed	2 (14.3%)	0 (0%)			
Unemployed	1 (7.1%)	2 (20%)			
Housework	4 (28.6%)	4 (40%)			
Retired	7 (77.8%)	2 (20%)			
Relationship with the family member with ID			2.469	0.291	0.321
Father	5 (35.71%)	1 (10%)			
Mother	8 (57.1%)	7 (70%)			
Sibling	1 (7.1%)	2 (20%)			
Frequency of days living with the family member with ID			3.624	0.163	0.389
Weekends	6 (42.9%)	1 (10%)			
Daily	6 (42.9%)	8 (80%)			
Less than 3 days a week	2 (14.3%)	1 (10%)			
Age of family member with ID	38.21 (6.93)	32.20 (9.28)	1.821	0.082	0.753
Diagnosis age of relative with ID	2.14 (4.65)	2.60 (3.37)	-0.264	0.794	-0.109
Family ID percentage	78.00 (22.47)	70.20 (14.85)	0.938	0.359	0.387

Notes: IG= Intervention group; CG= Control group; d = Cohen's d ; ID= intellectual disabilities. * p < .05.

Instruments

- a) *Zarit Caregiver Burden Scale* (ZARIT; Zarit et al., 1985), Spanish adaptation by Martín et al. (1996). This instrument measures caregiver burden. The ZARIT

- consists of 22 questions with 5 possible Likert-type answers (1= never to 5= almost always). The higher the scores obtained, the higher the perceived caregiver burden. The Spanish adaptation has shown adequate evidence of reliability and validity, with a high internal consistency ($\alpha = .91$) (Martín et al., 1996). In the present study, Cronbach's α was .904.
- b) *Goldberg General Health Questionnaire* (GHQ-28; Goldberg et al., 1997), Spanish adaptation by Lobo et al. (1986). This instrument assesses psychosocial health using four subscales: Somatic symptoms (Subscale A), symptoms of anxiety/distress and insomnia (Subscale B), symptoms of social dysfunction (Subscale C) and symptoms of depression (Subscale D). The GHQ-28 consists of 28 items (seven items in each subscale) with four Likert-type response options (different for each item). Higher scores reflect declining mental health. In terms of psychometric properties, the Spanish version used has a Cronbach's α of .93 (Lobo et al., 1986). In our study, Cronbach's α was .878.
- c) *Caregiver Grief Scale* (CGS; Meichsner et al., 2016), Spanish version adapted by Bravo-Benítez et al. (2021). This scale measures caregivers' manifestations of grief. It consists of 11 Likert-type items with five response options (1= strongly disagree to 5= strongly agree). The CGS includes four subscales reflecting different aspects of the caregiver's grieving process: Emotional pain (painful emotions surrounding the loss), Relational loss (losses associated with the relationship), Absolute loss (anticipation of a future without the person) and Acceptance of loss (acceptance of the ID diagnosis and open expression of grief). In psychometric terms, both the full scale and its subscales showed high levels of internal consistency, with Cronbach's α between .67 and .89 and high levels of construct validity. We used the Spanish version adapted by Bravo-Benítez et al. (2021), which has reliability values ranging from .55 to .85 (Emotional pain $\alpha = .62$, Relational loss $\alpha = .77$, Absolute loss $\alpha = .85$, Acceptance of loss $\alpha = .55$) and an overall Cronbach's α of .85. In our study, this adaptation showed adequate reliability values: emotional grief $\alpha = .84$, relational loss $\alpha = .91$, absolute loss $\alpha = .80$, acceptance of loss $\alpha = .91$, and an overall Cronbach's α of .926.
- d) *Texas Revised Inventory of Grief* (ITRD; Faschingbauer, 1981), Spanish adaptation by García-García et al. (2005). This instrument measures the intensity of a bereaved person's symptoms of grief. The ITRD consists of 21 items in total and divided into two subscales. The first assesses the bereaved person's behaviour and feelings in the immediate aftermath of the death, while the second assesses their present feelings about the loss. It consists of five Likert-type response categories (1= completely false to 5= completely true). Higher scores are indicative of greater grief symptomatology. In psychometric terms, the Cronbach's α coefficients of the two subscales were .75 and .86 respectively (Faschingbauer, 1981). In this study, the instrument was adapted to assess the family caregiver's grieving process in the past (Subscale 1), i.e. when they first

learned about their family member's ID diagnosis, and their present feelings about it (Subscale 2). We drew on previous examples in the literature where the TRIG has been adapted to assess grief following the loss of employment (Díaz et al., 2016) and in family members of people with acquired brain injury (López de Arróyabe & Calvete, 2005). In the present study this adaptation showed adequate reliability values ($\alpha = .89$ for Subscale 1 and $\alpha = .96$ for Subscale 2). In addition, Subscale 1 had an overall mean of 24.08 ($SD = 9.10$) while Subscale 2 had a mean of 44.37 ($SD = 15.19$). Appendix 1 shows the item statistics for this scale.

Procedure

Firstly, the study was approved by the Human Research Ethics Committee of the University of Granada, Spain (Ref: 445/CEIH/2017). The research proposal was then presented to the VALE association's management team (Granada, Spain). Once the centre's professional team had approved the proposal, family members fulfilling the inclusion criteria were invited to meet with the research team to be informed of the study's main features and objectives, with a view to seeking their collaboration. In the end, a total of 24 family members were selected to participate in the study and randomly assigned to the two groups. The voluntary participants were given an information document about the study and signed a written informed consent form. All participants completed the assessment tests in a single session, and in the same set order: sociodemographic data, Zarit scale, GHQ-28, CGS and TRIG. Participants received no payment for their participation. To preserve their anonymity, each participant was assigned an alphanumeric code.

Then, over a three-month period, family caregivers in the IG received 11 weekly face-to-face intervention sessions of one and a half hours each. The 14 family caregivers participating in the programme were subdivided into two groups of seven. The sessions for one IG subgroup were held in the morning and for the other in the afternoon. The intervention took place in the same premises as the pre- and post-assessment. Both the assessments and the intervention sessions were delivered by the same health psychologist, an expert in working with people with ID and their families/caregivers. CG participants continued to take part in the centre's regular activities (meetings, workshops and leisure outings with the rest of the family and professionals). At the end of the intervention, the post-assessment protocol was applied to both the IG and CG, in the same order as the pre-assessment. Each assessment lasted approximately one hour.

This is a pilot study using a quasi-experimental randomised design with participants assigned either to the intervention group (IG), which participated in a specific grief programme based on Shear and Bloom's (2017) approach together with acceptance and commitment therapy techniques, or to a control group (CG).

INTERVENTION PROGRAMME

The “Family Caregiver Grief Following a Diagnosis of Intellectual Disability” programme was based on a cognitive-behavioural paradigm. The psychological techniques used were imaginal exposure exercises, psychoeducation, storytelling and writing, self-report, task prescription and cognitive restructuring. Shear and Bloom's (2017) intervention model was used as a reference. Here, we adapted the intervention to the grieving process experienced by caregivers following their family member's ID diagnosis (Contreras, 2013; Meishcner and Wilz, 2018). The grief intervention strategies explored in the programme involved recognition, normalisation of grief, acceptance of the loss of the ideal child or family member and re-evaluation of the changes that had taken place (Centeno, 2013; Worden, 2004). Work on emotion identification and management mainly focused on elements and techniques of acceptance and commitment therapy (Mestre et al., 2017; Miró and Simón, 2012). Towards the end, the programme's closing sessions sought to foster the caregivers' subjective well-being and development through various cognitive-behavioural techniques, such as problem-solving, self-instruction, relaxation, and social and communication skills (Robles and Peralta, 2006; Vera and Roldán, 2009). Appendix 2 shows the content of each session of the intervention programme. At the end of each session, homework tasks were suggested and subsequent sessions began with a review of these tasks and/or questions from the previous session.

Data analysis

Quantitative data were analysed using the statistical software IBM SPSS for Windows, v. 26.0. Descriptive analyses were performed on means and standard deviations for quantitative variables and on frequencies for categorical variables. Differences between groups were analysed using the t-test (for independent samples) and the χ^2 test. Linear models for repeated measures (Wilks' lambda) were used to evaluate the effect of the programme. The two levels for the between-group factor referred to whether or not a participant had participated in the intervention programme (IG and CG), while the two levels for the within-subjects factor corresponded to the two evaluation windows (pre-intervention and post-intervention). In all cases, the assumptions of homogeneity of variances (Levene's test) were verified. The effect size was calculated using Cohen's *d*. Statistical significance was set at $p < 0.05$.

Results

First of all, Table 2 presents the results of the independent samples t-tests performed, establishing differences between the IG and CG for the variables measured at the time of pre-test in this pilot study.

Table 2
t test for independent samples at the time of pre-test

Variable (pre-test)	Group	<i>M</i> (<i>SD</i>)	<i>t</i>	<i>p</i>
Burden	Control	47.80(16.88)	0.936	.359
	Intervention	55.00(19.66)		
Somatic symptoms	Control	5.10(4.30)	1.233	.231
	Intervention	7.50(4.95)		
Anxiety/insomnia symptoms	Control	7.70(3.74)	0.008	.994
	Intervention	7.71(5.10)		
Symptoms of social dysfunction	Control	7.30(1.70)	-0.366	.718
	Intervention	7.00(2.15)		
Depressive symptoms	Control	2.10(3.60)	0.953	.351
	Intervention	3.64(4.10)		
Emotional pain	Control	8.50(4.06)	3.282	.003*
	Intervention	12.79(2.33)		
Relational loss	Control	6.60(3.37)	1.808	.084
	Intervention	9.29(3.73)		
Absolute loss	Control	11.00(3.83)	1.618	.120
	Intervention	13.00(2.22)		
Loss acceptance	Control	5.00(2.83)	2.574	.017*
	Intervention	7.79(2.45)		
Grief process - Diagnosis moment	Control	19.10(9.77)	2.516	.020*
	Intervention	27.64(6.91)		
Grief process - Current moment	Control	35.50(16.41)	2.739	.012*
	Intervention	50.71(10.86)		

Note: * $p < .05$.

Next, Table 3 presents the means, standard deviations, effect sizes (Cohen's *d*) and results obtained for between-group differences, assessment time and interactions between the different variables in our pilot study. Overall, the effect sizes (Cohen's *d*) are moderate to low.

For the Caregiver burden variable, significant differences were only observed in the Time factor, $F(1, 22) = 0.888$; $p = .036$. While the Time x Group interaction is not significant, the reduction in mean score in the IG (55.00-45.28) following the programme is worth noting.

In terms of the mental health variable, there are no significant differences for any of the factors (Time, Group, Time x Group). However, it should be noted that in all four IG subscales there is an overall decrease in mean scores, although significance is not achieved in the Time x Group factor.

With respect to the CGS subscales relating to caregiver grief, for the Time x Group interaction, we found statistically significant differences in the Emotional pain, $F(1, 22) = 36.716$; $p = .000$, Relational Loss, $F(1, 22) = 15.881$; $p = .001$, and Acceptance of Loss, $F(1, 22) = 14.646$; $p = .001$, subscales. With regard to the Emotional pain variable, these differences indicate a decrease in the intensity of emotions related to caregiver grief in the IG, and an increase or maintenance of emotional distress in the CG. For the Relational Loss variable, these differences

Table 3
Intervention group and control group results before and after the intervention

Variable	Grupo	M (DT) pre	M (DT) post	d	Factor	F	p
Burden	CG	47.80 (16.88)	44.40 (13.76)	0.041	T	0.888	.036*
	IG	55.00 (19.66)	45.28 (8.94)	0.077	T x G	1.000	.200
					G	0.142	.710
Somatic symptoms	CG	5.10 (4.30)	4.10 (3.34)	0.070	T	1.585	.222
	IG	7.50 (4.95)	5.07 (4.10)	0.065	T x G	1.450	.242
					G	0.572	.458
Anxiety/ insomnia symptoms	CG	7.70 (3.74)	4.50 (3.59)	0.001	T	0.013	.909
	IG	7.71 (5.10)	4.43 (4.62)	0.000	T x G	0.008	.928
					G	0.080	.780
Symptoms of social dysfunction	CG	7.30 (1.70)	6.20 (1.55)	0.054	T	1.193	.287
	IG	7.00 (2.15)	3.93 (3.02)	0.109	T x G	2.580	.123
					G	1.835	.190
Depressive symptoms	CG	2.10 (3.60)	1.80 (3.32)	0.014	T	0.294	.594
	IG	3.64 (4.10)	0.43 (0.65)	0.063	T x G	1.41	.248
					G	0.017	.898
Emotional pain	CG	8.50 (4.06)	9.20 (4.24)	0.012	T	0.252	.621
	IG	12.79 (2.33)	4.86 (2.07)	0.636	T x G	36.716	.000*
					G	0.069	.795
Relational loss	CG	6.60 (3.37)	9.10 (4.40)	0.073	T	1.657	.212
	IG	9.29 (3.73)	7.00 (2.88)	0.431	T x G	15.881	.001*
					G	1.249	.815
Absolute loss	CG	11.00 (3.83)	10.00 (4.45)	0.069	T	1.557	.226
	IG	13.00 (2.22)	10.21 (3.77)	0.111	T x G	2.611	.121
					G	0.367	.531
Loss acceptance	CG	5.00 (2.83)	5.10 (2.77)	0.044	T	0.977	.334
	IG	7.79 (2.45)	3.00 (1.30)	0.411	T x G	14.646	.001*
					G	0.028	.870
Grief process - Diagnosis moment	CG	19.10 (9.77)	19.30 (8.47)	0.129	T	3.907	.093
	IG	27.64 (6.91)	27.28 (7.65)	0.027	T x G	0.593	.450
					G	1.890	.184
Grief process - Current moment	CG	35.50 (16.41)	31.90 (12.34)	0.000	T	0.007	.935
	IG	50.71 (10.86)	35.36 (9.49)	0.278	T x G	8.103	.010*
					G	0.849	.367

Notes: CG= Control group (n= 10); IG= Intervention group (n= 14); T= Time; T x G= Time x G; G= Group *p< .05.

indicate a lower sense of loss of relationship with the family member with ID in the IG, and a greater sense of loss of relationship with the family member with ID in the CG. In the same vein, with regard to the Acceptance of Loss variable, the scores reveal greater acceptance of the diagnosis in IG caregivers, while in the CG it remains similar in both pre- and post-assessment. No significant differences were found in the other factors for either group. However, it should be noted that the significant differences found in the Emotional Distress and Acceptance of Loss subscales may not solely be due to the effect of the intervention. As shown in Table 2, there were already significant pre-test differences between the IG and CG on these subscales.

Finally, in terms of the TRIG scales, none of the factors (Time, Group, Time x Group) showed significant differences on the Diagnosis moment subscale. Meanwhile, for the Current moment, there were significant differences in the Time x Group factor, $F(1, 22) = 8.103$; $p = .010$. These differences reveal a reduction in feelings of grief due to the diagnosis in IG caregivers at the present time, in comparison to CG participants. Here again, it is difficult to infer that these significant differences are solely down to the intervention because, as shown in Table 2, there were already significant pre-test differences between the IG and CG on this subscale.

Discussion

The objectives of this pilot study were to adapt and provide preliminary data on the effectiveness of an intervention targeting family caregivers of adults with ID. It was designed to equip them with different coping resources to better deal with their caregiving role and reduce the psychological burden and distress associated with the diagnosis. The results suggest that participation in this programme leads to a reduction in the emotional distress associated with the grieving process and better acceptance of the ID diagnosis by family members.

Firstly, with regard to the diagnosis-related grief variable, the findings seem to indicate that participation in the programme reduces the dimensions of emotional distress, relational loss, acceptance of loss and ongoing feelings of grief stemming from the diagnosis. These results suggest a reduction in the frequency and intensity of grief-related emotions associated with loss and bonding, and greater acceptance of the diagnosis among caregivers. There is also a downward trend in the dimension assessing the anticipation of loss of a future without the family member (absolute loss). As such, all findings suggest that interventions using techniques and elements from Shear and Bloom's (2017) model and mindfulness exercises (Centeno, 2013; Mestre et al., 2017; Miró and Simón, 2012; Worden, 2004) may prove effective in managing the grieving process of these caregivers following a diagnosis of ID. In particular, the use of psychoeducational modules, emotional expression and management to encourage acceptance of the diagnosis, and skills training to improve communication with the family member with ID, may have made a positive contribution to these improvements (Bazzano et al., 2015; Dykens et al., 2014; Flynn et al., 2020; Jones et al., 2018; Lunsky et al., 2017). Group work may also have helped our participants to express their emotions more easily, by identifying with families in a similar situation (Bray et al., 2017).

With regard to the caregiver burden variable, we found no significant reduction, although there was a decrease in its mean score, in line with the findings of González-Fraile et al. (2019) and Magaña et al. (2015). Nor were there significant differences in the dimensions related to mental health (somatic, anxiety, social dysfunction and depression), although their means dropped slightly in the IG. Both caregiver burden and mental health effects are factors that begin at diagnosis and

persist over time, thereby cumulating in severe exhaustion and fatigue. It is therefore difficult to make significant improvements in a short period of time, as these problems have been ongoing for years (Acker, 2011; Balieiro-Takebayashi et al., 2019; Walker et al., 2020). However, despite no significant differences in these variables, the programme in this study demonstrates active coping strategies based on self-care to promote the improvement of the caregivers' physical and mental health, as well as coping with difficult situations while caring for family members with ID. Developing such coping mechanisms is important because, as previous studies of other populations have shown, caregivers who perceive their health positively seek medical care more infrequently and have less reliance on psychotropic drugs (Kiely et al., 2008).

In summary, this pilot study's intervention programme provides a range of benefits, including the following: a) working on the diagnosis-related feelings of grief in family caregivers; b) high levels of adherence to the programme, which can be extrapolated to caregivers in other populations; c) few material and professional resources are needed for its development and implementation; d) it encourages proactive changes in the caregiver's mental health and burden as well as in their manifestations of grief; e) it puts in place strategies for coping better with the caregiving role and dealing appropriately with critical situations that arise, and f) it develops bonds and support among the caregivers participating in the programme.

In terms of limitations, it should be noted that the sample was not large and therefore not representative. Furthermore, the participants were from a single centre, so it cannot be generalised to the population of family caregivers of people with intellectual disabilities. With this in mind, future studies should use stratified randomisation to minimise the differences between the study variables. A further limitation is that it was not possible to carry out follow-up evaluations to analyse how the reported outcomes evolve in the medium and long term. In addition, the CG did not receive any specific intervention, but instead engaged in the centre's usual activities. Furthermore, given the time elapsed between diagnosis and the present day, life experience may have contributed to the development of self-regulation and resilience skills in these caregivers, which could have influenced the results of our intervention. Hence, future studies using this intervention should involve newly diagnosed caregivers. Finally, our analysis did not factor in the influence on outcomes of different ID impairments. Future studies are therefore needed to examine how the characteristics of the family member with ID may influence the efficacy of the intervention.

To conclude, the grief intervention programme used in this pilot study showed an improvement in the grief symptomatology of these caregivers following their family member's ID diagnosis. Given the possibility of alleviating the intensity of grief symptoms associated with the diagnosis in these caregivers even when the family member is an adult, it is therefore recommended and necessary that such programmes are rolled out early with subsequent follow-up (Bray et al., 2017;

Whittingham et al., 2013), to prevent the cyclical and recurrent grief (Brown, 2013) typical of most caregivers.

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Appendix 1

Statistics of the items of the scale the Texas Revised Inventory of Grief adapted to caregivers of people with intellectual disabilities

Item	<i>M</i>	<i>SD</i>	<i>r</i> _c	<i>r</i> _m ²	α without item	Asymmetry	Kurtosis
1.1 After the diagnosis of his disability, it was difficult for me to relate to some people	2.75	1.54	.65	.71	.87	0.38	-1.46
1.2 After the diagnosis of his disability, it was difficult for me to concentrate on my work	3.38	1.69	.65	.69	.88	-0.36	-1.72
1.3 After the diagnosis of his disability, I lost interest in my family, friends and activities outside the home	2.46	1.32	.73	.70	.89	0.91	-0.34
1.4 Had a need to do things that he/she enjoyed doing before his/her diagnosis	2.92	1.47	.57	.57	.88	0.25	-1.21
1.5 After her diagnosis I was more irritable than usual	2.83	1.46	.51	.48	.89	0.22	-1.48
1.6 In the first three months after his diagnosis I felt unable to carry out my usual activities	3.54	1.53	.74	.94	.87	-0.64	-1.13
1.7 I felt angry because of the diagnosis of their disability	2.67	1.52	.68	.66	.87	-0.46	-1.23
1.8 After the diagnosis of his disability, it was hard for me to sleep	3.54	1.61	.76	.94	.86	-0.66	-1.23
2.1 I still feel like crying when I think about him/her before his/her diagnosis	3.17	1.52	.89	.96	.96	-0.06	-1.54
2.2 I still get sad when I think about him/her before his/her diagnosis	3.71	1.33	.84	.92	.96	-1.09	0.10
2.3 I can't accept your diagnosis	2.78	1.67	.76	.93	.96	0.24	-1.72
2.4 Sometimes I really miss how I was before my diagnosis	3.25	1.29	.72	.88	.96	-0.24	-0.76
2.5 It is painful for me to recall his memory of how he was before the diagnosis	3.30	1.30	.80	.93	.96	-0.47	-0.87
2.6 I often get lost thinking about him/her	4.08	1.38	.81	.95	.96	-1.57	1.22
2.7 I cry secretly when I think of him/her	3.33	1.61	.83	.91	.96	-0.46	-1.37
2.8 No one can ever fill the place that he/she has had in my life	4.42	1.14	.68	.72	.96	-2.47	5.78
2.9 I can't stop thinking about him/her	3.96	1.46	.83	.94	.96	-1.21	-0.00
2.10 I think it's not fair that I have this disability	4.00	1.41	.82	.85	.96	-1.31	0.43
2.11 The things and people around me still remind me of how I was before the diagnosis	2.50	1.14	.74	.80	.96	0.57	0.20
2.12 I am unable to accept your diagnosis	2.71	1.63	0.83	0.98	0.96	0.39	-1.50
2.13 Sometimes I feel the need for him/her to be with me in the same way that he/she was before the diagnosis	3.17	1.40	0.79	0.92	0.96	-0.22	-1.18

Note: *r*_c = Total items correlation corrected; *r*_m² = Squared multiple correlation.

Appendix 2

Objectives, theoretical content and techniques of the Family Caregiver Grief Following a Diagnosis of Intellectual Disability programme

Session	Objetives	Contents	Tecnicas
1	<ul style="list-style-type: none"> - Introduce and get to know the members of the group. - Provide adequate information about grief, its characteristics, emotions and processes involved, normalizing the suffering and the intense reactions of some emotions 	<ul style="list-style-type: none"> - Information on the grieving and loss processes related to the intellectual disability diagnosis of your family member 	<ul style="list-style-type: none"> - Socratic method - Psychoeducation
2	<ul style="list-style-type: none"> - Analyze what type of grief they had in the past and what they currently have - Analyze the changes produced after the diagnosis in personal, social and family areas 	<ul style="list-style-type: none"> - Recognition of grief due to the diagnosis of intellectual disability 	<ul style="list-style-type: none"> - Socratic Method, - Guided Discovery - Venting/emotional relief
3	<ul style="list-style-type: none"> - Work on the identification of thoughts and emotions in a general way. 	<ul style="list-style-type: none"> - Identification and expression of thoughts and emotions. 	<ul style="list-style-type: none"> - Psychoeducation - Meditation to name emotions - ABC self-registration - Group discussion
4	<ul style="list-style-type: none"> - Work on the identification and expression of thoughts and emotions related to the diagnosis, as well as the memories involved. 	<ul style="list-style-type: none"> - Identification and expression of thoughts and emotions related to the diagnosis of their family member with intellectual disability. 	<ul style="list-style-type: none"> - Psychoeducation - Meditation of difficult emotions - Exercise of visualization and guided imagination - ABC self-registration - Group discussion
5	<ul style="list-style-type: none"> - Work on the identification and change of cognitive distortions 	<ul style="list-style-type: none"> - Identification and modification of dysfunctional thoughts 	<ul style="list-style-type: none"> - Psychoeducation - Exposure in imagination - Cognitive restructuring - Self-registration
6	<ul style="list-style-type: none"> - Modify dysfunctional thoughts 	<ul style="list-style-type: none"> - Identification and modification of dysfunctional thoughts (Part II) 	<ul style="list-style-type: none"> - Psychoeducation - Exposure in imagination - Cognitive restructuring - Self-registration
7	<ul style="list-style-type: none"> - Work coping strategies 	<ul style="list-style-type: none"> - Expression of fears and 	<ul style="list-style-type: none"> - Psychoeducation

Session	Objetives	Contents	Tecniques
	<ul style="list-style-type: none"> - Work present and future fears or anxieties 	<ul style="list-style-type: none"> concerns in relation to care 	<ul style="list-style-type: none"> - Exposure in imagination - Cognitive restructuring - Self-instructions - Problem resolution
8	<ul style="list-style-type: none"> - Work on the feeling of guilt through forgiveness and self-compassion - Identify the positive aspects of caring for your relative (compare with the negative part worked on in the previous sessions) 	<ul style="list-style-type: none"> - Personal balance of care 	<ul style="list-style-type: none"> - Practice of mindfulness focused on forgiveness meditation - Practice how to deal with difficult emotions ("The seven steps of emotional balance") - Venting/emotional relief - Socratic Method
9	<ul style="list-style-type: none"> - Evaluate and promote the self-efficacy and self-esteem of family members (in relation to care and in general). - Work and reduce caregiver burden 	<ul style="list-style-type: none"> - Self-care (Part I) 	<ul style="list-style-type: none"> - Psychoeducation - Relaxation in theme imagination - Dynamics to reaffirm their self-esteem and self-efficacy - Metaphor of the jewel
10	<ul style="list-style-type: none"> - Promotion of healthy habits - Encourage pleasant activities - Teach to live in the present 	<ul style="list-style-type: none"> - Self-care (Part II) 	<ul style="list-style-type: none"> - Psychoeducation - Organizing tasks and setting personal goals - Practice mindfulness of breathing - Metaphor of the garden - Application and practice of mindfulness in daily life
11	<ul style="list-style-type: none"> - Improve the quality of family and couple life - Work on parenting guidelines for family members with intellectual disability 	<ul style="list-style-type: none"> - Attachment, overprotection and family dynamics 	<ul style="list-style-type: none"> - Social and communication skills - Psychoeducation - Debate and Socratic dialogue.