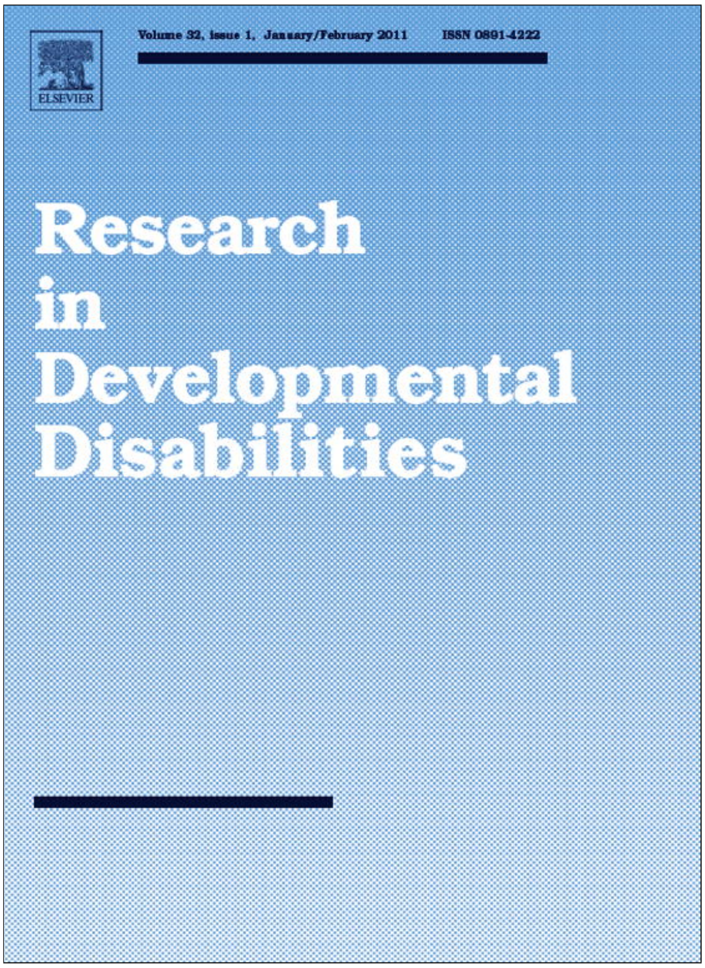
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Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder

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ABSTRACT

Few studies have been found that to assess the factors that explain higher levels of family burden in adults with intellectual disability (ID) and intellectual disability and mental disorders (ID–MD). The aims of this study were to assess family burden in people with ID and ID–MD and to determine which sociodemographic, clinical and functional disability variables account for family burden. The sample is composed of pairs of 203 participants with disability and their caregivers, of which 33.5% are caregivers of people with ID and 66.5% of ID–MD. Assessments were performed using scales of clinical and functional disability as the following instruments: Weschler Adult Intelligence Scale-III (WAIS-III), Inventory for Client and Agency Planning (ICAP), Psychiatric Assessment Schedule for Adults with Development Disability (PAS-ADD checklist), Disability Assessment Schedule of the World Health Organization (WHO-DAS-II) and family burden (Subjective and Objective Family Burden Inventory – SOFBI/ECFOS-II). People with ID–MD presented higher levels of functional disability than those with ID only. Higher levels of family burden were related to higher functional disability in all the areas ($p < 0.006–0.001$), lower intelligence quotient ($p < 0.001$), diagnosis of ID–MD ($p < 0.001$) and presence of organic, affective, psychotic and behavioral disorders ($p < 0.001$). Stepwise multiple regression showed that behavioral problems, affective and psychotic disorder, disability in participation in society, disability in personal care and presence of ID–MD explained more than 61% of the variance in family burden. An integrated approach using effective multidimensional interventions is essential for both people with ID and ID–MD and their caregivers in order to reduce family burden.

1. Introduction

Conservative estimates suggest a worldwide prevalence of intellectual disability (ID) of 0.9–1.7% (Maulick, Mascarenhas, Mathers, Dua, & Saxena, 2011) although higher rates are reported for low- and middle-income countries (Durkin, 2002). The burden and costs associated with intellectual disability, which comprises a broad array of different health conditions, has

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been widely recognized to be high, yet there is a large division between the availability of services and the health needs of affected individuals (Salvador-Carulla & Saxena, 2009). The service gap is particularly great in those suffering ID and co-occurring mental disorders (ID–MD) (Cooper, Smiley, Morrison, Williamson, & Allan, 2007a). The point prevalence of associated psychiatric disorders in ID is about 40% (including behavior problems) (Bailey, 2007; Cooper et al., 2007a; Deb, Thomas, & Bright, 2001) and an annual incidence of 8% has been reported (Smiley et al., 2007). Although people with ID can suffer from the whole spectrum of psychiatric disorders, some are notably more common than in the general population. Among the most commonly associated diagnoses are non-affective psychosis (Salvador-Carulla, Rodríguez-Blázquez, Rodríguez, Pérez-Marín, & Velasquez, 2000; Cooper et al., 2007b) and bipolar disorder (Cooper, Smiley, Morrison, Williamson, & Allan, 2007c). ID–MD is also frequently linked to problem behaviors, which have prevalence around 20% in this population (Deb et al., 2001; Holden & Gitlesen, 2004; Lowe et al., 2007).

The concept of family burden was imported to the study of ID from the mental health field. Studies assessing burden in families with children with autistic, physical and intellectual disability have found that heavier costs and other burdens develop in the course of raising such children than in raising children without special difficulties (Xion et al., 2010). However, fewer studies have looked at the families of adults with ID, even though the burden on families providing informal care for adults increased with the rise of psychiatric community services (Mandelbrote & Folkard, 1961). Some researchers have pointed out that less attention has been paid to burden in the informal care of people with ID–MD (Maes, Broekman, Dosen, & Nauts, 2003; Wodehouse & McGill, 2009).

Family burden is a complex construct, which includes very different domains ranging from family routines to number of caring hours, social support networks and out-of-pocket expenses. Therefore, a holistic view should include the understanding of family burden in biopsychosocial framework (World Health Organization [WHO], 2001). One study of unpaid caregivers of people with learning disabilities referring to intellectual disabilities in the United Kingdom found that 75% of caregivers of an adult with ID had been caring for more than 20 years, 26% reported not being in paid employment due to their responsibilities, and 48% spent 100 or more hours a week caring for that person (Emerson et al., 2010). However, 90% of those caregivers felt they were or were usually involved as much as they wanted to be in decisions about the care and treatment of the person they cared for. Care giving in mental disorder may also generate worry, shame and guilt. Researchers have reported that families can suffer from the stigma associated with the disorders of the persons they care for (Schene, 1990; Szmukler et al., 1996; Tessler & Gamache, 1995).

Caregivers of people with ID and ID–MD may perceive their personal situation as stressful and consider that they lack effective strategies or sufficient resources to cope (Lazarus & Folkman, 1984; Maes et al., 2003). Personal, family, and context factors are the modulators of parental stress in the degree of adaptation to the family situation (Kim, Greenberg, Seltzer, & Krauss, 2003; Maes et al., 2003; Orsmond, Seltzer, Krauss, & Hong, 2003), with older caregivers experiencing less family burden (Chou, Lee, Lin, Kröger, & Chang, 2009). People with ID plus mental and behavioral disorders generate higher levels of demand, more caring hours and a need for assistance with personal care (Greenberg, Seltzer, & Greenley, 1993; Heller, Miller, and Factor 1997; Pinquart & Sörensen, 2006; Winefield & Harvey, 1993). Our group recently evaluated family burden in three groups of support service users (ID, ID–MD and schizophrenia), demonstrating the highest level of burden in ID–MD users (Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & García, 2011).

Functional disability is usually defined as the difficulty or inability to independently perform basic activities of daily living or other tasks essential for independent living without assistance. People with ID presented higher levels of functional disability. Carr (2008) shows that people with ID had greater limitations in terms of autonomy; Määttä, Tervo-Määttä, Taanila, Kaski, and Iivanainen (2006) describe greater problems in verbal capacity and Bertoli et al. (2011) found that, in people with ID, problems with daily activities increase over time. Moreover, a number of problems arise in daily activities in people with MD, especially in those with severe mental problems (Viertiö et al., in press; Kurzban, Davis, & Brekke, 2010). So, the functional disability in people with ID–MD is expected to be greater.

According to the literature revision only, Heller and Factor (1991) have related social functioning of adults with ID and ID–MD to family burden, showing that worse social functioning of adults with ID–MD is related to higher levels of family burden. Fewer studies have related family burden to clinical and functional disability in adults ID and ID–MD.

Following on from the previous studies, we expected that family burden would be greater in ID–MD than in ID as a result of the additional factors of mental disorder and associated behavioral disorders and higher functional disability in the service user. Since there has been little study in this area and data are somewhat hazy, our aim was to provide additional information on the subject. In one single study, we have included the most important aspects from the limited literature available (sociodemographic and clinical factors and functional disability) that influence family burden. Therefore, the aims of the present study were to assess family burden in people with ID and ID–MD and to determine which sociodemographic, clinical and functional disability variables explain higher levels of family burden.

2. Material and methods

2.1. Design and procedures

This observational cross-sectional study was carried out in two institutions providing community care in the two largest cities in Spain, Barcelona and Madrid; the participating facilities provide care for adults with mild or moderate ID with or without MD. The ethical standards proposed for research in ID (Veenstra et al., 2010) were followed and the study was approved by the two centers' independent research ethics committees.

To recruit participants at each center, the head of the team responsible for coordinating the support service user's care sent a written explanation of the aims of the study to the family, requesting written informed consent from both the service user and the main caregiver. The participant and the caregiver were then referred to a trained psychologist, who gathered data for the study during two interviews, one with the participant and the other with the caregiver. Two trained psychologists, one in each center, carried out the interviews. At the time of data collection, the written informed consent of each participant (user and caregiver) was confirmed and aspects of confidentiality and data protection were explained.

2.2. Participants

We consecutively recruited, as described above, adults with mild or moderate ID with or without an associated mental disorder according to the International Classification of Diseases World Health Organization (ICD-10), [WHO], 2002), who lived in the community served by each center. Pairs of participants with ID and ID–MD and their main family caregivers were eligible to participate in this study.

The two participating centers were Parc Sanitari de Sant Joan de Déu (Barcelona) and the Carmen Pardo Valcarce Foundation (Madrid). The ID–MD group participants were included from occupational workshop and two specialist mental health units of Parc Sanitari Sant Joan de Déu. The ID group participants were included from the sheltered employment program and sheltered workshops of Carmen Pardo Valcarce Foundation. Inclusion criteria were living in the community, age between 18 and 65 years, and a diagnosis of ID or ID–MD.

A total of 217 participants with ID–MD ($n = 140$) and ID ($n = 77$) were enrolled, although only 203 family caregivers agreed to participate in the full test battery. Table 1 shows the description of participants with ID and ID–MD and family caregiver's characteristics (Table 1). No clinical differences were found between the 14 participants whose main family caregiver did not agree to complete all interviews, and who were therefore excluded from some analyses, and those who participated fully ($\chi^2 = 8.42$; g.ll = 5; $p = 0.134$).

Table 1
Description of participants with ID and ID–MD and family caregiver's characteristics.

Variables	Groups		Statistics	
Participants data				
	ID $N = 77$ n(%)	ID–MD $N = 140$ n(%)	χ^2	p Value*
Gender				
Man	51(66.2%)	80(57.1%)		
Woman	26(33.8%)	60(42.9%)	1.716	0.190
	Average (SD)	Average (SD)	Student-*t* test	p Value*
Age	29.17(7.29)	29.54(6.88)	−0.36	0.713
Functional disability (WHO-DAS-II)				
Comprehension and communication	1.77(0.73)	1.56(0.91)	1.63	0.104
Environment mobility	1.11(0.38)	1.83(0.99)	−7.30	<0.001
Personal care	1.47(0.62)	1.98(0.94)	−4.63	<0.001
Relationships with others	1.88(0.88)	2.22(1.03)	−2.30	0.022
Daily life activities	1.73(0.81)	2.20(1.04)	−3.48	0.001
Participation in society	1.45(0.51)	1.97(0.81)	−5.58	<0.001
Intellectual quotient	57.27(6.84)	54(6.65)	2.25	0.010
Caregivers data				
	n(%)	n(%)	χ^2	p Value*
Gender of caregivers				
Woman	59(86.8%)	111(82.2%)		
Man	9(13.2%)	24(17.8%)	0.685	0.408
Relationship with the adult (users)				
Mother	55(80.9%)	107(79.3%)		
Father	9(13.2%)	21(15.6%)		
Siblings	4(5.9%)	5(3.7%)		
Grandparents	0(0%)	2(1.5%)	1.67	0.643
	Average (SD)	Average (SD)	Student-*t* test	p Value*
Age of caregivers	58.51 (8.73)	59.30 (9.67)	−0.63	0.347

* $p < 0.05$ was considered significant.

2.3. Instruments

The following five tests or recording instruments were used to collect data reflecting family burden and sociodemographic, clinical and functional disability variables.

The Spanish version of the Weschler Adult Intelligence Scale, third edition (WAIS-III) (Weschler, 1999), was used to measure the service users' intelligence quotient (IQ). The IQ was assessed in the interview conducted with the participants (ID and ID–MD).

The remaining instruments, listed below, provided information about both service users and caregivers. The following instruments were assessed in an interview with the family caregiver.

The Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986) was used to collect records related to the diagnosis, personal data and functional limitations of each user. On this management instrument, adaptive behavior is measured on four scales (motor skills, social skills, personal life skills and community-living skills). The general independence scale provides information on services and support available to the individual. The Spanish version of the ICAP has shown high internal consistency (Cronbach alpha, 0.85) and good inter-rater reliability (Cohen kappa statistic, $>$0.75) (Montero, 1996).

The semi-structured subjective and objective family burden interview (ECFOS-II) was first developed for the analysis of family burden in schizophrenia (Vilaplana et al., 2007) and later adapted to ID (Martorell, Pereda, Salvador-Carulla, Ochoa, & Ayuso-Mateos, 2007). The instrument gives scores for caregivers' responses in nine modules referring to assistance with daily life activities, problematic behavior supervision, financial burden, impact on career's life, worries about patient's life, available help, career's health consequences and a global evaluation of burden. These modules can be used and interpreted independently as there is a score for each. The total ECFOS-II score was calculated in two phases. The sum of all the variables included in each module was calculated first, transforming that value into a score between 0 and 12. The second phase involved calculating the mean of the first eight modules to obtain a total score between 0 and 12. Higher scores indicate greater family burden (Marsà, 2010).

ECFOS-II has shown high internal consistency (Cronbach alpha, 0.88) and test–retest reliability (range, 0.61–1 for the different modules) in family caregivers of persons with ID (Vilaplana et al., 2007; Martorell et al., 2007).

The checklist of the Psychiatric Assessment Schedule for Adults with Development Disability (PAS-ADD) (Moss et al., 1998) was used in its the previously validated Spanish version (González-Gordon, Salvador-Carulla, Romero, González-Sáiz, & Romero, 2002). This semi-structured interview for psychiatric diagnosis in ID, whose feasibility has been analyzed in 14 European countries including Spain (Perry et al., 2010) consists of two sections. The first evaluates the presence or otherwise of stressful life events and the second comprises a total of 25 items with four response options. Three global scores are obtained related to affective, psychotic and organic-type problems. The affective score ranges from 0 to 28; the psychotic score ranges from 0 to 6 and the organic-type problems score ranges from 0 to 8. Scores over a determined threshold indicate a need for a more detailed psychologic evaluation. Inter-rater reliability, according to Perry et al., has ranged between 0.65 and 0.7. The agreement for case *vs.* non-case assessment was over 90%.

The Disability Assessment Schedule of the World Health Organization (WHO-DAS-II, 2000) assesses 36 items with a range of response of 0–5 (Garin et al., 2010). The six subscales include comprehension and communication, personal care, relationships with others, daily life activities, participation in society and functional difficulties associated with mobility within the environment. The reliability of the different subscales of the Spanish version ranged from 0.40 to 0.74 (interclass correlation coefficients) (Vázquez-Barquero et al., 2005).

2.4. Data analysis

Data were entered into SPSS v.17 for Windows (SPSS Inc., Chicago, IL) for statistical analysis.

The comparison of the two profiles of users (ID *vs.* ID–MD) and their caregivers were performed by Student t-test for quantitative variables and chi-square test for qualitative variables. The level of significance was set at $p < 0.05$. The Pearson correlation and Student t-test were used to compare the clinical, functional disability and sociodemographic variables by family burden and explore associations. Finally, a stepwise regression analysis was done to determine which sociodemographic, functional disability and clinical variables accounted for higher indexes of family burden. The stepwise method included in the one-to-one model the variables that explain part of the variance in overall family burden.

The variables included in the model were those we found to be significant in the previous analysis.

3. Results

No differences were found in the control variables (gender and ages of either users or caregivers between the two diagnostic groups) (Table 1) except for IQ being IQ higher in the ID group ($t = 2.25$; $p = 0.01$). The different areas of functional disability evaluated by the WHO-DAS-II were statistically higher in the ID–MD group in the following areas: mobility in the environment ($t = -7.30$; $p < 0.001$); personal care ($t = -4.63$; $p < 0.001$); relationships with others ($t = -2.30$; $p = 0.022$); daily life activities ($t = -3.48$; $p < 0.001$); and participation in society ($t = -5.59$; $p < 0.001$). With respect to clinical characteristics, statistically significant differences were found between ID and ID–MD participants in the three types of symptom of clinical severity: organic condition ($t = -6.542$; $p < 0.001$), affective disorders ($t = 10.769$; $p < 0.001$) and

Table 2
Relation between sociodemographic, clinical and functional disability variables to family burden.

Total family burden		
	Average (SD)	p Value*
Gender		
Men	3.28 (2.27)	0.237
Women	3.62 (2.03)	
Diagnosis		
ID–MD	4.17 (2.15)	<0.001
ID	2.02 (1.41)	
	Pearson's coefficient	p Value
Age of the participant	−0.006	0.929
Age of the mother	−0.046	0.474
Age of the father	−0.041	0.529
Organic diagnosis	0.501	<0.001
Affective diagnosis	0.609	<0.001
Psychotic diagnosis	0.491	<0.001
Behavioral disorders	0.591	<0.001
Comprehension and communication WHO-DAS-II	0.330	<0.001
Functional difficulties associated with mobility within the environment WHO-DAS-II	0.174	0.006
Personal care WHO-DAS-II	0.519	<0.001
Relationships with others WHO-DAS-II	0.312	<0.001
Daily life activities WHO-DAS-II	0.460	<0.001
Participation in society WHO-DAS-II	0.587	<0.001
Total punctuation WHO-DAS-II	0.588	<0.001
Intellectual quotient (IQ)	−0.242	<0.001

* $p < 0.05$ was considered significant.

Table 3
Clinical and functional disability variables associated with family burden.

Variables included in the model	B	p Value*
Affective disorder	0.055	0.028
Personal care WHO-DAS-II	0.160	<0.001
Participation in society WHO-DAS-II	0.092	<0.001
Psychotic disorder	0.341	<0.001
Behavioral disorders	0.037	<0.001
Presence ID–MD	0.494	0.025
R^2 adjusted = 0.616		

Variables excluded from the model: IQ, organic symptoms, communication and comprehension WHO-DAS-II, relationships with others WHO-DAS-II, daily life activities WHO-DAS-II and functional difficulties associated with mobility within the environment WHO-DAS-II.

* $p < 0.05$ was considered significant.

psychotic disorders ($t = -7.047$; $p < 0.001$). Those with ID–MD obtained the highest scores for PAS-ADD checklist items. The severity of behavioral problems, measured by the ICAP, was significantly greater ($t = -7.74$; $p < 0.001$) in people with ID–MD ($t = -3.70$) than in those people with only ID ($t = -3.31$).

In the comparison between caregivers, statistically significant differences were found in the mothers' working situation ($\chi^2 = 13.209$; $p = 0.004$), with the ID–MD having a higher percentage of retired mothers. A higher number of caregivers of individuals with ID–MD also dedicated a large number of hours a week to provide care (>28 h/wk for 76.7%) in comparison with the caregivers of participants with ID ($\chi^2 = 6.139$) ($p = 0.022$).

Table 2 shows the correlation coefficients for sociodemographic, clinical and functional disability variables in relation to higher family burden. People with ID–MD showed higher levels of family burden than people with ID ($p < 0.001$). A diagnosis of affective, organic and psychotic ($p < 0.001$) and presence of behavioral problems ($p < 0.001$) were related to higher levels of family burden. Moreover, higher scores in functional disability (WHO-DAS-II) showed higher family burden. Lower IQ was related with higher levels of family burden ($p < 0.001$).

Table 3 shows the clinical and functional disability variables associated with family burden. The model developed accounts for 61.6% of the variance in perception of caregiver family burden. The variable that explained the greatest amount of variance (37.6%) in the model was presence of affective disorder. When personal care (WHO-DAS-II) was included, the model explained an additional 11.5% of the variance in total of family burden, so that the two-variable model explained a total of 49.1% of the variance. The next variables included were as follows: participation in society (WHO-DAS-II) (which explained an additional 6.8% of the variance), psychotic disorders (explaining an additional 2.6% of the variance), behavioral disorders (an additional 2.2%), and presence of mental disorders associated with the ID (an additional 0.9%). With these additions, the six-variable model explained a total of 61.6% of the variance.

4. Discussion

This study explored the profile of family caregivers and the related factors of family burden in persons with ID and ID–MD using specialized services for persons with ID in the two largest cities in Spain. To our knowledge this is the first study to assess the clinical and functional disability variables together in the same study in relation to family burden in ID and ID–MD population.

The main results of our study show that clinical and functional disability variables and having MD associated (being in the ID–MD group) explain higher levels of family burden in comparison with only having ID. Specifically the clinical and functional disability variables that explain higher degrees of family burden in ID–MD were: presence of behavioral, affective and psychotic disorders and greater disabilities in the areas of participation in society and personal care.

The profile of people with ID and ID–MD is similar with respect to sociodemographic characteristics, although some differences emerged in their clinical and social functioning. People with ID–MD present more functional disability in several areas of the WHO-DAS-II than people with ID. Few studies have assessed the functional disability comparing ID and ID–MD. Consistent with our results, Bouras et al. (2004) found that people with ID and schizophrenia have lower functioning than those with ID alone.

Participants with ID–MD presented a high rate of affective, psychotic and behavioral disorders, as found in other studies on prevalence of mental disorders (Martínez-Leal et al., 2011; Maes et al., 2003; Hemmings, Tsakanikos, Underwood, Holt, & Bouras, 2008). We should stress that several differences emerged in the characteristics of these studies, although all the results are concordant. This finding was therefore expected, confirming the agreement between the clinical criterion (ICD-10) and the evaluation of symptoms using the PAS-ADD checklist.

In our study a low level of total family burden was found (lower than 5 considering the range is between 0 and 12), possibly due to the characteristics of the sample of users living in the community and having less severe functional disability. Another possible explanation might be that the sample consists of Hispanic families who, according to Jenkins (1988) and Seltzer et al. (1995), show greater acceptance of disability and/or mental disorder affecting those in their care and also to informal care patterns in severe mental illness in Spain (Salvador-Carulla, Costa-Font, Cabeses, McDaid, Alonso, & 2010). Moreover, Chou, Fu, Lin, and Lee (2011) found that older caregivers present lower levels of family burden, consistent with our results because the average age of the caregivers in our sample was around 60 years old.

We emphasize that the caregivers of people with ID–MD in this study perceived a greater family burden than the caregivers of those with ID only. Maes et al. (2003) and Emerson et al. (2010), found similar results in caregivers of child and adult with an ID–MD. The presence of behavioral problems, psychotic and affective symptoms increases the risk of having greater family burden. Other authors have found that either behavioral problems or psychotic symptoms contribute to explain higher rates of family burden both in people with ID and ID–MD (Maes et al., 2003; Matthews, Weston, Baxter, Felce, & Kerr, 2008; Kim et al., 2003). McIntyre, Blacher, and Baker (2002) also found greater family burden in people with behavioral problems.

Related to functional disability, the disability in participation in society and personal care are the main areas that contribute to higher family burden. Other authors indicate that disability in social contexts helps to explain family burden (Maes et al., 2003; Miltiades & Pruchno, 2001). When there is impairment in basic functions such as personal care, dependence is greater, with a negative effect on family burden. When persons do not engage in social interaction, or have greater communication difficulties, they may be more isolated, spending longer hours in the home, also generating greater family burden.

One of the possible limitations of the study is that some caregiver variables, which can mediate burden have not been included. Carers' coping strategies or attributional style, for example, have not been studied. Another limitation is that the nature of a cross-sectional study allows us to establish relationships between variables but not to identify longitudinal predictors of increased family burden. The final limitation that we would like to mention is that all the participants were enrolled at one of two centers and, as such, are possibly not representative of the whole population with ID or ID–MD.

Considering both clinical and functional disability aspects allows the development of community-based interventions with the aim of creating an appropriate network of social support, which can alleviate perceived global burden in caregivers of people with ID and ID–MD (Bax, 2000). The recently approved Spanish Dependency Law (BOE, 2006) considers caregivers' needs and tries to compensate for the time spent in the care of offspring or other dependents. Valuable initiatives would be the setting up of caregiver relief services (respite care), such as psychoeducation programs, mutual-help support groups, professional emotional and psychosocial support, as others have suggested (Cooper et al., 2007a; Hemmings et al., 2008). Interventions that address the reduction of the functional disability and symptoms of people with ID and ID–MD could also help to decrease the perceived family burden of the caregivers. Effective interventions based on the multidimensional approach proposed by the WHO (2001) and by the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002), which also address the abilities and difficulties of the people with ID, should be undertaken. It is first necessary to identify the support required by people with ID in their effort to acquire coping skills that facilitate social integration (Verdugo, Cordoba, Restrepo, Cardona, & Peña, 2009). Aspects such as social adjustment and communication skills are important for the personals ability to function in a social context, with consequent improvement in quality of life and reduction in caregiver burden.

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