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Highlights

Family impact in intellectual disability, severe mental health disorders and mental health disorders in ID. A comparison

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► The interaction of ID and mental health problems results in a higher degree of burden on families than when both conditions are presented separately. ► The impact in caregivers to people with schizophrenia is higher than the one detected in caregivers to people with ID. ► Needs of caregivers to people with ID should be addressed specifically in order to effectively support families.

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Family impact in intellectual disability, severe mental health disorders and mental health disorders in ID. A comparison

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ABSTRACT

Family impact (or family burden) is a concept born in the field of mental health that has successfully been exported to the ambit of intellectual disability (ID). However, differences in family impact associated with severe mental health disorders (schizophrenia), to ID or to mental health problems in ID should be expected. Seventy-two adults with intellectual disability clients of the Carmen Pardo-Valcarce Foundation's sheltered workshops and vocational employment programmes in Madrid (Spain), 203 adults diagnosed with schizophrenia from four Spanish Community Mental Health Services (Barcelona, Madrid, Granada and Navarra) and 90 adults with mental health problems in ID (MH-ID) from the Parc Sanitari Sant Joan de Déu Health Care Site in Sant Boi de Llobregat, Barcelona (Spain) were asked to participate in the present study along with their main caregivers. Family impact experienced by caregivers was assessed with the ECFOs-II/SOFBI-II scale (Entrevista de Carga Familiar Objetiva y Subjetiva/Objective and Subjective Family Burden Interview). In global terms, results showed that the higher family impact was found between caregivers to people with MH-ID. The interaction of both conditions (ID and mental health problems) results in a higher degree of burden on families than when both conditions are presented separately. There was also an impact in caregivers to people with schizophrenia, this impact being higher than the one detected in caregivers to people with intellectual disability. Needs of caregivers to people with disability should be addressed specifically in order to effectively support families.

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1. Introduction

The term 'family burden' has been introduced to describe the adverse consequences of taking care of severely disturbed psychiatric patients (Treadley, 1946). More recently, the term 'impact' has been proposed as an alternative to 'burden', assuming that taking care of a relative with disability has not only adverse costs for the family, but also positive consequences (Blacher & Hatton, 2001; Blacher, Baker, & MacLean, 2007; Hastings, Beck, & Hill, 2005).

Although initial studies tended to focus on the figure of the main caregiver, it has broadened to also include burden associated with the rest of the family members (Schene, Tessler, & Gamache, 1966). Family burden is usually divided into objective and subjective burden (Hoening & Hamilton, 1966), being objective burden related to observable and concrete

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demands, while subjective burden is related to the emotional costs and the extent to which family members perceive they are carrying a burden.

When considering people experiencing severe mental disorders like schizophrenia, it is long acknowledged that the raise of psychiatric community services has increased burden on families (Mandelbrote & Folkard, 1961). Less attention has been paid to the case of people with ID to date (Wodehouse & McGill, 2009). However, the progressive recognition of their rights and values, the process of de-institutionalization undergone in the last few decades and recent changes in family structures have contributed to the growing interest in the situation of families taking care of a member with ID. Likewise, the acceptance of the biopsychosocial model as a framework for understanding disability (World Health Organization [WHO], 2001) has highlighted the importance of the family's role due to the links between biological, psychological and social dimensions that such a model introduces. Thus, family burden (or family impact) is a concept born in the field of psychiatric disorders that has been successfully exported to the ambit of ID.

Nevertheless, such a multidomain, complex and global concept should be understood more deeply and differences in the burdening genesis should be addressed in order to better analyse the concept and therefore design more effective interventions. Apart from impacting families' mental health and quality of life (Aznar & Castañón, 2005; Emerson, Robertson, & Wood, 2004; Floyd & Gallagher, 1997; Gallagher, Phillips, Oliver, & Carroll, 2008; Hassall, Rose, & McDonald, 2005; Hastings, Daley, Burns, & Beck, 2006), family burden has been acknowledged to influence the outcomes of the disability condition (Falloon, 1985; Perlick, Stastny, Mattis, & Teresi, 1992; Perlick, Rosenheck, Clarkin, Raue, & Sirey, 2001; Perlick et al., 2004), generating a circular relationship between quality of life in both individuals and their families.

However, very few comparative studies of diverse disabling conditions have been undertaken. It has been stated (Maes, Broekman, Došen, & Nauts, 2003) that caregiving to people with mental health disorders and intellectual disabilities has a higher impact on families than the sole condition of intellectual disabilities. The underlying hypothesis of challenging behaviours accounting for most of family burden has already been stated (Emerson et al., 2001). Moreover, autism has been found to cause more stress to caregivers compared to other diagnosis such as Down syndrome (Blacher & McIntyre, 2006). Regarding economical costs, children without disabilities and children with autism, physical disabilities and mental

disabilities have been compared (Xiong et al., 2011), finding significant differences in raisings expenses.

Differences in burden associated with mental health disorders, burden associated with ID, or the interaction of both (MH-ID) should also be expected, highlighting which models of services should be designed to address the needs of families and therefore pursue a better communitarian framework of services.

2. Materials and methods

2.1. Participants

Participants were recruited from three different settings throughout Spain. The ID group was gathered within workers of the Carmen Pardo-Valcarce Foundation's sheltered employment programme and clients of sheltered workshops in the same Foundation. The Pardo-Valcarce Foundation provides community care services for over 450 persons with ID in Madrid (Spain), including educational and vocational services. The ID group consisted of 72 participants with a mean IQ of 58.92 (range: 36-73, SD = 7.63) as measured by the Wechsler Adult Intelligence Scale-III (WAIS-III). Individuals from the ID group had a mean age of 28.61 years (range: 20-55 years, SD = 5.84) and 59.7% were male. Participants with any prior or present psychiatric diagnosis or with behavioural problems were previously excluded from the group internal reports measured by means of the PAS-ADD interview (Moss et al., 1993) and ICAP (Bruinninks, Hill, Weatherman, & Woodcock, 1986; Montero, 1996). The schizophrenia group ($n=203$) data were provided by the scientific association PSICOST and were originally gathered from individuals with ICD-10 diagnosis of schizophrenia from four Community Mental Health Sites [Barcelona (Gavà Mental Health Care Site [MHCS]), Madrid (Salamanca MHCS), Granada (MHCS La Loja) and Navarra (MHCS Burlada)]. Participants had a mean age of 37.97 years (SD = 8.29) and 71.6% were male. The group of mental health disorders in ID (MH-ID) was recruited from the Parc Sanitari Sant Joan de Déu Health Care Site in Sant Boi de Llobregat, Barcelona (Spain) and was defined as individuals meeting both criteria of IQ < 70 and ICD-10 diagnosis of a comorbid psychiatric disorder (WAIS-III and PAS-ADD respectively). It consisted of 90 participants with a mean IQ of 53.53 (range: 45-73, SD = 7.06). Participants had a mean age of 30.77 years (range: 17-54 years, SD = 8.29) and 45.6% were male. As for ICD-10 disorders diagnosed: schizophrenia, schizotypal or delusional disorders (F20-F29), $n=26$ (28.9%); mood (affective) disorders (F30-F39), $n=11$ (12.2%); neurotic, stress-related or somatoform disorders (F40-F48), $n=22$ (24.4%); disorders of adult personality or behaviour (F60-F69), $n=16$ (17.8%); others; $n=15$ (17%). All participants were informed about the project and letters were sent to their relatives. Afterwards, they were asked for their informed consent.

2.2. Instrument

Burden experienced by caregivers was assessed with the ECFOS-II/SOFBI-II scale (*Entrevista de Carga Familiar Objetiva y Subjetiva/Objective and Subjective Family Burden Interview*). The SOFBI-II scale is a survey tool that has been elaborated by the PSICOST Group in order to assess family burden. The interview was initially aimed at principal caregivers to people with schizophrenia who lived in the community (Vilaplana et al., 2007); however, the scale has recently been validated for people with ID (Martorell, Pereda, Salvador-Carulla, Ochoa, & Ayuso-Mateos, 2007). Developed and expanded from the FBIS-F

73 Family Burden Interview *Schedule – Short Form*, the SOFBI has an introductory section plus 7 modules which evaluate different
74 domains of family burden (a final optional descriptive module is also included):

- 75
76 1) The *introductory section* includes 11 questions related to completion and caregiver **characteristics**.
77 2) *Module A* records assistance with the activities of daily living, the subjective burden (worries and distress) related to this
78 assistance and the objective burden (frequency and time of care **provided**).
79 3) *Module B* records supervision of behavioural problems and related burden, again both subjective and **objective**.
80 4) *Module C* gathers information on out-of-pocket expenses related to care and daily **living**.
81 5) *Module D* explores the impact of care on the functioning of the primary caregiver life domains (work, social relationships,
82 **leisure**).
83 6) *Module E* rates subjective burden (such as worry about well-being, quality of life, future of the person with ID...) **experienced**
84 **by the primary caregiver**, assessed using a self-reported 7-item scale.
85 7) *Module F* provides information on the dedication to care and replacement of the primary caregiver by other **carers**.
86 8) *Module G* provides information on the impact on the caregiver's health: health status, use of health services and days lost
87 at work related to these health problems.

88 Each of these modules is quantified via yes/no questions or Likert combined numerical and verbal scales. A total score can
89 be obtained in order to estimate the total level of burden.

90 2.3. Statistical analyses

91 Mean total scores and mean scores for each SOFBI module were computed using the Statistical Package for the Social
92 Sciences (SPSS version 15). Relationship between age and gender and total and module scores were explored for each
93 diagnostic group using *t*-tests and chi-square tests. One-way ANOVA (followed by *post hoc* comparisons between pairs of
94 groups) was performed to test the differences in total mean scores and modules scores for the three diagnostic groups.

105 3. Results

106 3.1. Within-group analyses

107 For both ID and MH-ID, we explored whether level of burden was related to age or gender (see Table 1). Comparisons were
108 not performed for the schizophrenia group due to unavailability of matched data.

109 Regarding gender, results of *t*-tests and chi-square showed no significant differences of burden between males and
110 females neither in the ID group (module A: $t = 1.20$, $P = 0.23$; module B: $t = 0.66$, $P = 0.51$; module D: $t = 1.25$, $P = 0.22$; module
111 E: $t = 1.30$, $P = 0.20$; module F: $\chi^2 = 0.54$, $P = 0.46$; total: $t = 0.62$, $P = 0.54$) nor in the DD group (module A: $t = -0.72$, $P = 0.47$;
112 module B: $t = 0.70$, $P = 0.49$; module D: $t = 1.40$, $P = 0.17$; module E: $t = 0.18$, $P = 0.86$; module F: $\chi^2 = 0.03$, $P = 0.86$; module G:
113 $\chi^2 = 0.51$, $P = 0.47$; total: $t = 0.97$, $P = 0.34$).

114 When considering age, two sub-groups were defined attending to their median (ID group: median = 27; dual diagnosis
115 group: median = 30). Significant differences arose in module E in the ID group ($P < 0.05$), showing less family burden in the
116 eldest group, but not in the rest of the modules (module A: $t = 1.73$, $P = 0.09$; module B: $t = 1.36$, $P = 0.18$; module D: $t = 0.34$,
117 $P = 0.74$; module E: $t = 2.14$, $P = 0.04$; module F: $\chi^2 = 0.00$, $P = 0.99$; total: $t = 0.24$, $P = 0.81$). No significant differences were
118 found for the MH-ID group (module A: $t = 1.54$, $P = 0.13$; module B: $t = 1.82$, $P = 0.07$; module D: $t = 1.55$, $P = 0.12$; module E:
119 $t = 1.75$, $P = 0.08$; module F: $\chi^2 = 0.00$, $P = 0.99$; module G: $\chi^2 = 0.40$, $P = 0.53$; total: $t = 1.44$, $P = 0.15$).

Table 1
Burden scores (mean and standard deviation) for diagnosis groups, gender, age and IQ.

	Module A	Module B	Module D	Module E	Module F	Module G	Total
ID group							
Gender							
Male (n = 43)	1.18 (1.10)	0.17 (0.40)	0.84 (1.37)	5.85 (2.92)	2.79 (5.13)	0.00 (0.00)	1.66 (1.43)
Female (n = 29)	1.55 (1.48)	0.24 (0.51)	1.31 (1.87)	6.78 (3.09)	3.72 (5.65)	0.00 (0.00)	1.86 (1.33)
Age							
<27 (n = 38)	1.57 (1.42)	0.27 (0.51)	1.09 (1.82)	6.92 (3.05)	3.16 (5.36)	0.00 (0.00)	1.78 (1.20)
>27 (n = 34)	1.06 (1.04)	0.13 (0.35)	0.96 (1.32)	5.45 (2.79)	3.18 (5.37)	0.00 (0.00)	1.70 (1.57)
MH-ID group							
Gender							
Male (n = 41)	3.70 (2.37)	2.67 (1.83)	4.73 (2.58)	10.16 (1.93)	6.15 (6.07)	3.22 (5.38)	5.22 (1.93)
Female (n = 49)	3.38 (1.90)	2.97 (2.17)	5.50 (2.59)	10.24 (2.28)	6.37 (6.05)	2.45 (4.89)	5.60 (1.76)
Age							
<30 (n = 46)	3.20 (1.89)	3.21 (2.04)	5.56 (2.54)	10.58 (1.79)	6.26 (6.06)	3.13 (5.33)	5.70 (1.91)
>30 (n = 44)	3.88 (2.30)	2.44 (1.94)	4.72 (2.62)	9.81 (2.37)	6.27 (6.06)	2.45 (4.90)	5.15 (1.74)

ID, intellectual disability group; MH-ID, mental health in intellectual disability group.

Table 2

Impact differences between groups (modules A, B, D and E). Mean scores, standard deviations and results of ANOVA and *post hoc* tests.

SOFBI module	Diagnosis group	Mean	SD	$F_{2,362}$	Post hoc [#] (Games–Howell)
Module A: activities of daily life	ID	1.33	1.27	44.39 ^{***}	MH-ID > ID, Schz
	Schz	1.63	1.70		
	MH-ID	3.53	2.12		
Module B: behavioural problems	ID	0.20	0.44	53.11 ^{***}	MH-ID > ID MH-ID > Schz Schz > ID
	Schz	1.27	1.75		
	MH-ID	2.83	2.02		
Module D: life domains	ID	1.03	1.60	71.91 ^{***}	MH-ID > ID MH-ID > Schz Schz > ID
	Schz	2.03	2.54		
	MH-ID	5.15	2.60		
Module E: worries	ID	6.23	3.00	55.22 ^{***}	MH-ID > ID, Schz
	Schz	6.60	3.17		
	MH-ID	10.20	2.12		
Total	ID	1.74	1.38	81.80 ^{***}	MH-ID > ID MH-ID > Schz Schz > ID
	Schz	3.28	2.01		
	MH-ID	5.43	1.84		

ID, intellectual disability group; Schz, schizophrenia group; MH-ID, mental health in intellectual disability group.

[#] Only significant differences between groups are depicted ($P_s < 0.001$).^{***} $P < 0.001$.

Table 3

Impact differences between groups (modules F and G). Percentages and chi-square test.

SOFBI module	ID	Schz	MH-ID	χ^2
Module F: help from other carers	Yes: 73.6%	Yes: 72.9%	Yes: 47.8%	19.62 ^{***}
	No: 26.4%	No: 27.1%	No: 52.2%	
Module G: health problems	Yes: 0%	Yes: 10.8%	Yes: 23.3%	21.35 ^{***}
	No: 100%	No: 89.2%	No: 76.7%	

ID, intellectual disability group; Schz, schizophrenia group; MH-ID, mental health in intellectual disability group.

^{***} $P < 0.001$.

120 3.2. Between-group analyses

121 Results for one-way ANOVA showed significant differences in total score of family burden between diagnostic groups,
 122 $F_{2,362} = 81.80$, $P < 0.001$. Results of Games–Howell *post hoc* tests for unequal variances showed that the MH-ID condition
 123 presented the highest degrees of family burden, followed by the schizophrenia group and being the ID condition the least
 124 burdening.

125 When taking specific modules into account, all of them were significantly higher for the MH-ID group. However,
 126 significant differences between schizophrenia and ID module scores were found in modules B and D (module B is expected,
 127 regarding challenging behaviours were excluded in the ID group), with no significant differences in modules A and E (see
 128 Table 2 for more details).

129 Results for chi-square analysis showed significant differences in module F and G scores between diagnostic groups
 130 ($P < 0.001$, see Table 3 for more details). The MH-ID group had significantly less replacement by other carers and a significant
 131 higher impact on caregiver's health. The schizophrenia group, though significantly less than the MH-ID group, also aroused
 132 health problems on the carer whereas the ID group did not.

133 4. Discussion

134 Taking care of a sibling with MH-ID burdens families in a higher degree than taking care of someone with schizophrenia
 135 or ID. People not familiar with ID may tend to think that it is the ID condition the origin of family burden, concluding
 136 therefore that the arising of a mental health problem would not impact carers that much.

137 As Reiss, Levitan, and Szyszko (1982) stated when illustrating the diagnostic overshadowing effect, intellectual disability
 138 overshadows the individual and extensively their families, applying the perceptual heuristic of seeing the effect of mental
 139 health disorders smaller than real because of being presented besides an already existing disability (Jopp & Keys, 2001). Our
 140 data suggest that when a mental health problem ensues, families are highly impacted, independently of a previous diagnosis
 141 of ID. Even more, we can conclude that the sole condition of ID, though generating family impact, is less significant than the
 142 one caused only by psychiatric symptoms, concluding that the interaction generates a higher impact than when presented
 143 separately.

144 As results highlight, families taking care of someone with ID are worried about the future of their relative (module E) and
 145 have to spend some of their time helping him or her with activities of daily living (module A). This should obviously be taken
 146 into account when designing supports and policies for caregivers to people with ID, but it should be considered that this
 147 situation is highly impacted by the apparition of psychiatric symptoms, something very common between people with ID

(Borthwick-Duffy, 1994; Campbell & Malone, 1991; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Menolascino & Fleisher, 1991). For Spanish population see Salvador-Carulla, Rodriguez-Blazquez, Rodriguez, Perez-Marin, and Velazquez (2000).

Derived from the research on the care for elderly people, two main explaining theories have been proposed to understand the process of familiar adaptation and its evolution over the life span: the *wear and tear hypothesis* and the *adaptational hypothesis*. The first states that both physical and psychological depletion should be expected for caregivers in the long term, as their – physical and psychological – resources get progressively exhausted (Johnson & Catalano, 1983). On the other hand, the later suggests that the familiar adjustment to the caregiver role improves over time (Townsend, Noelker, Deimling, & Bass, 1989), more in view with the actual resilience theories. That the arousal of psychiatric symptoms in a family system would better suit the *wear and tear hypothesis*, while ID carers would probably suit the *adaptational theory*. First, while ID is early diagnosed (commonly in childhood), the usual onset of mental illness in adolescence implies a later diagnosis. Second, the course of ID is more stable than the course of mental illness. Moreover, results from the within-groups analysis stress this assumption. For instance, significant differences found in module E when considering age in the ID group show that the higher level of burden is associated with the youngest group. Reduction of the caregiver's motives of concern as age increases could be understood as a result of an adaptation process. Concerns about the future are equally present in schizophrenia and ID (module E), and the amount of time and concerns aroused by activities of daily living (module A) as well as replacement by other carers (module F) are the same for both groups. But, aligned with the *wear and tear hypothesis*, taking care of someone with schizophrenia has a significantly higher impact on his or her life domains (module D) as well as on the carer's health (module G).

As time passes and distance increases from the de-institutionalization process, the role of the family in caring for individuals with disability will become even more pronounced as central to the biopsychosocial model of mental health care. Actual policies, as the recently approved Spanish Dependency Law, reflect the importance of caregivers as part of the care system of people with disability and therefore more research is needed in order to understand their needs and supports.

Finally, a limitation of this study should be noted. It should be pointed out that our participants only present mild-to-moderate ranges of intellectual disability; therefore, our conclusions are not generalizable to ID groups with more support needs.

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