

## *Supplementary Materials for*

# Gender and burden differences in family caregivers of patients affected by ten rare diseases

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**Table 1aS**

Family caregivers' Zarit answers to Item 7 "Do you feel fear for the future?" by family caregivers' sex

**Table 1bS**

Family caregivers' Zarit answers to Item 10 "Do you believe that taking care of your family member has adversely affected your health?" by family caregivers' sex

**Table 2S**

Family caregivers: burden by sex, occupation and age group

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Family caregivers: EQ5D answers to Item 4 "Do you feel pain and discomfort?" by patients' age

**Table 1aS**

Family caregivers' Zarit answers to Item 7 "Do you feel fear for the future?" by family caregivers' sex (p=0.007\*\*)

FCs sex	FCs number	"Never" n (%)	"Rarely" n (%)	"Sometimes" n (%)	"Very often" n (%)	"Nearly always" n (%)
M	53	4 (7.6)	5 (9.4)	21 (39.6)	7 (13.2)	16 (30.2)
F	146	2 (1.4)	8 (5.5)	36 (24.7)	43 (29.4)	57 (39.0)
Total	199	6 (3.0)	13 (6.5)	57 (28.6)	50 (25.1)	73 (36.7)

p: significance level of the Fisher's exact probability test: \*\* p<0.01; FC: family caregiver; M: males; F: females; n (%): absolute and percent frequency of FC responders each scale grade of the Zarit Item 7.

**Table 1bS**

Family caregivers' Zarit answers to Item 10 "Do you believe that taking care of your family member has adversely affected your health?" by family caregivers' sex (p=0.012\*)

FCs sex	FCs number	"Never" n (%)	"Rarely" n (%)	"Sometimes" n (%)	"Very often" n (%)	"Nearly always" n (%)
M	53	29 (54.7)	5 (9.4)	15 (28.3)	2 (3.8)	2 (3.8)
F	146	46 (31.5)	30 (20.5)	51 (34.9)	17 (11.6)	2 (1.4)
Total	199	75 (37.7)	35 (17.6)	66 (33.2)	19 (9.5)	4 (2.0)

p: significance level of the Fisher's exact probability test: \* p<0.05; FC: family caregiver; M: males; F: females; n (%): absolute and percent frequency of FC responders each scale grade of the Zarit Item 10.

**Table 2S**

Family caregivers: burden by sex, occupation and age group

FCs occupation	Zarit score	Male FCs age groups				Female FCs age groups			
		-39 y	40-54 y	55- y	Total	-39 y	40-54 y	55- y	Total
<b>Occupied</b>	n (%)	6 (85.7)	26 (86.7)	7 (46.7)	39 (75.0)	28 (58.3)	42 (52.5)	3 (17.6)	73 (50.3)
	mean (SD)	22.8 (6.9)	28.5 (14.1)	22.3 (16.6)	26.5 (13.7)	29.1 (12.7)	25.5 (11.4)	22.3 (17.1)	26.8 (12.1)
	median (min-max)	21.5 (14-32)	29 (10-60)	22 (0-46)	22 (0-60)	28 (6-56)	25 (7-59)	14 (11-42)	25 (6-59)
<b>Retired</b>	n (%)	0 (0)	0 (0)	8 (53.3)	8 (15.4)	1 (2.1)	7 (8.8)	8 (47.1)	16 (11.0)
	mean (SD)			25.0 (10.4)	25.0 (10.4)	16.0 (0)	34.7 (15.3)	27.9 (11.2)	30.1 (13.3)
	median (min-max)			22 (13-41)	22 (13-41)	16 (16-16)	31 (20-59)	29 (12-48)	28 (12-59)
<b>Homemaker</b>	n (%)	0 (0)	2 (6.7)	0 (0)	2 (3.8)	10 (20.8)	26 (32.5)	6 (35.3)	42 (29.0)
	mean (SD)		15.0 (1.4)		15.0 (1.4)	24.7 (10.1)	30.6 (13.3)	22.5 (11.5)	28.0 (12.6)
	median (min-max)		15 (14-16)		15 (14-16)	26 (7-42)	29 (8-56)	21 (9-44)	27 (7-56)
<b>Others</b>	n (%)	1 (14.3)	2 (6.7)	0 (0)	3 (5.8)	9 (18.8)	5 (6.3)	0 (0)	14 (9.7)
	mean (SD)	21.0 (0)	27.0 (4.2)		25.0 (4.6)	27.4 (10.2)	42.4 (10.9)		32.8 (12.5)
	median (min-max)	21 (21-21)	27 (24-30)		24 (21-30)	27 (16-46)	45 (29-56)		31 (16-56)
<b>Total</b>	n (%)	7 (100)	30 (100)	15 (100)	52 (100)	48 (100)	80 (100)	17 (100)	145 (100)
	mean (SD)	22.6 (6.4)	27.5 (13.6)	23.7 (13.2)	25.8 (12.7)	27.6 (11.7)	29 (13)	25 (11.9)	28.1 (12.4)
	median (min-max)	21 (14-32)	26 (10-60)	22 (0-46)	22 (0-60)	27 (6-56)	27 (7-59)	21 (9-48)	27 (6-59)

FC: family caregiver; y: years; Zarit: burden; others: never occupied or forced to leave work. SD: standard deviation; min-max: minimum-maximum.

**Table 3S**

Family caregivers: EQ5D answers to Item 4 “Do you feel pain and discomfort?” by patients’ age (p=0.003\*\*)

FCs caring for	FCs number	“No pain or discomfort” n (%)	“Mild pain or discomfort” n (%)	“Moderate pain or discomfort” n (%)	“Severe pain or discomfort” n (%)	“Extreme pain or discomfort” n (%)	Median category
Children	137	85 (62.0)	31 (22.6)	19 (13.9)	1 (0.7)	1 (0.7)	“No pain or discomfort”
Adults	56	20 (35.7)	23 (41.1)	9 (16.1)	3 (5.4)	1 (1.8)	“Mild pain or discomfort”
Total	193	105 (54.4)	54 (28.0)	28 (14.5)	4 (2.1)	2 (1.0)	

FC: Family caregiver.

n (%): absolute and percent frequency of FC responders to each scale grade of the EQ-5D Item 4.

p: significance level of the chi-squared test comparing FCs of child vs adult subjects with respect to Item 4: \*\* p&lt;0.01. Median category (of an ordinal variable): the category whose cumulative frequency is greater than (and nearest to) 50%.