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Sex and gender differences in health among informal caregivers of individuals with autism spectrum disorder and dementia/ Alzheimer's disease: evidence from an Italian study

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Summary. Long-term caregiving for a non-self-sufficient family member has been associated with high levels of chronic stress, which can pose significant risk to the mental and physical health of family caregivers (FCs). This study explores the impact of psychological stress on mental health outcomes (e.g., symptoms of depression), lifestyle behaviours, and perceived health, with particular attention to gender differences. We focused on two groups of FCs facing high caregiving burdens: those caring for individuals with dementia/Alzheimer's disease (DA) and those caring for individuals with neurodevelopmental disorders, including autism (ASD). Our analysis draws on data collected from 458 FCs (200 DA and 258 ASD), who participated in an online survey assessing both objective and subjective caregiving burden, psychological stress, depressive symptoms and perceived health status. The findings revealed that being female, caring for someone with DA (compared to those caring for people with ASD), and devoting more of caregiving hours per week were significant predictors of higher psychological stress levels. Participants showing the highest levels of stress were also those showing unhealthy lifestyles, more severe depressive symptoms and poorer perceived health. We suggest that the sex and gender-specific differences observed in this study may contribute to health inequalities among FCs. These findings underscore the need for targeted, sex/gender-sensitive interventions to address the unique health challenges faced by FCs. They also provide valuable insights for policymakers to design strategies that better support the well-being of FCs based on their specific needs and caregiving contexts.

Key words. Sex and gender differences, informal caregiver, autism spectrum disorder, dementia, Alzheimer's disease.

Introduction

Family caregivers (FCs) are the primary, long-term care providers for family members who are not-self-sufficient due to illness or disability. They are also referred to as informal caregivers to differentiate them from formal caregivers who are paid professional caregivers. Many studies have reported a link between the health status of FCs and their caregiving responsibilities. Caregiving stressor can indeed negatively impact health and consequently FCs are more likely than the general population to experience poor physical health, depression, anxiety, and disrupted sleep quality.[1]

In Italy the role of FC is not yet uniformly defined, making it particularly challenging to identify and address their health needs. Among the 13 million individuals aged 18-64 with care responsibilities, an estimated 2.8 million are FCs.[2] A significant proportion of FCs are middle-aged women who often have to give up work to devote themselves to care or have difficulty in reconciling work and care.

Over the next 20 years, the demand for caregiving is expected to rise due to the population aging, a prolonged decline in birth rates, and increased marital instability. These factors will contribute to a growing number of smaller families, often consisting of single individuals in older age.[3] In this context, Italian women are expected to face greater exposure and health risks compared to men, due to the high percentage of female caregivers,[4] coupled with the limited job opportunities available to women in Italy, a country with one of the lowest female employment rates in the EU.[5]

Indeed, women more frequently assume caregiving responsibilities than men, and this unequal distribution of caregiving duties may result in gender-related health disparities.[6] Consistent with this, sex and gender differences in mental and physical health measures have been observed to be more pronounced among FCs than in the general population. These disparities can be attributed to variations in stressors and access to social resources between female and male caregivers.[7] For instance, female FCs reported experiencing a greater physical and emotional burden while managing caregiving tasks during the COVID-19 pandemic compared to their male counterparts.[8] However, to date, sex and gender-specific health differences among FCs have not been consistently or comprehensively documented,[9,10] with most research focusing only on caregivers of individuals with dementia.[11]

In this study, we focused on two groups of FCs, those caring for individuals with dementia/Alzheimer's disease (DA) and those caring for individuals with neurodevelopmental disorders, including autism (ASD), with the aim of exploring the impact of psychological stress on

mental health outcomes, lifestyle behaviours, and perceived health.

Indeed, caregiving burden can be regarded as a form of chronic stress exposure that can prompt physical, emotional, and mental strain,[12,13] ultimately impacting various aspects of FC's life, including mental and physical health, cognitive function, self-efficacy, subjective well-being and quality of life, as well as social relationships and work-related outcomes.[14-17] Key stressors include the functional limitations and challenging behaviours of the care recipient, along with associated social and environmental demands. When faced with these stressors, caregivers evaluate whether these demands pose a potential threat and whether they have sufficient coping resources to manage them. If they perceive the demands as threatening and their coping capacity as inadequate, they experience stress. This stress appraisal often leads to negative emotional states, which, under severe circumstances, may directly contribute to the development of affective psychiatric disorders. Furthermore, negative emotional responses may trigger behavioural or physiological reactions, increasing the risk of psychiatric and physical illnesses.[13]

The current study provides novel insights that contribute to a deeper understanding of the determinants of health among caregivers. Specifically, we conducted a quantitative comparison of several health status indicators between two distinct caregiver populations – those caring for individuals with ASD and those caring for individuals with DA. While both groups manage caregiving for individuals who may exhibit significant cognitive impairments and behavioural disturbances (recognized predictors of elevated psychological stress in caregivers),[18,19] they differ substantially in terms of caregiver age (younger in the ASD group, older in the DA group) and kinship relation to the care recipient (primarily parents in the ASD group versus adult children or spouses in the DA group). Moreover, by recognizing stress as a key mediating factor in the relationship between caregiving and health, we analysed how varying levels of stress influence perceived health status, depressive symptoms, and lifestyle behaviours.

By investigating the relationship between caregiving burden, subjective stress, and health outcomes in an Italian sample of FCs – with a focus on sex/gender differences – our study aims to inform stakeholders on how to better support caregivers and reduce gender-based inequalities.

Methods

Participants and procedure

To ensure broader representation of the two FC groups (ASD and DA) at the national level, we relied on the support of family and patient associations as well as medical centres, which served as project partners.

Inclusion criteria

Both men and women, cohabiting or not with the care recipient, and belonging to various age groups and family relationships with the care recipient (e.g., father/mother, husband/wife, son/daughter, etc). Only primary caregivers were eligible to participate, defined as those with a principal role in the care of the non-self-sufficient family member. Non-self-sufficiency refers to the inability to care for oneself, as recognized by disability status requiring comprehensive, continuous long-term assistance (Italian Framework Law for Assistance, Social Integration, and the Rights of Persons with Disabilities). Both parents of children with disabilities were eligible to be included, as both are responsible for their child's care and assistance.

Participants voluntarily agree to take part after being fully informed about the study aims and about what it means for them to take part, and that they give consent before they enter the survey. This study was approved by the National Ethics Committee for the Experiments of Public Research Entities (Comitato Etico Nazionale per le sperimentazioni degli Enti Pubblici di Ricerca).

Caregivers' data were collected through an anonymous online questionnaire based on a Moodle® platform and were analysed. E-mail support was provided to the respondents if necessary.

Measures

The online questionnaire was composed by five sections:

1. socio-demographic data;
2. caregiving burden (5 measures): caregiving duration, cohabitation with the care-recipient, caregiving duties (number per week), time spent for caregiving (hours per week), caregiving responsibility sharing (sharing of caregiving responsibility with a person of trust);
3. support received (5 measures: institutional support – home care assistance, institutional support – residential, social support, psychological support, support of a care worker;
4. levels of perceived burden, stress and depressive symptoms;
5. lifestyles (4 measures: food habits, physical activity, smoking, alcohol consumption) and perceived general health (from poor to excellent).

Levels of perceived burden were measured using the 12-items Italian validated version[20] of the Zarit Burden Interview (ZBI)[21] and categorized as "none/mild" (score <11), "moderate" (score 11-20), and "severe" (score >20).

Stress levels were evaluated with the 10-item Italian validated version[22] of the Perceived Stress Scale (PSS), widely considered the gold standard instrument for measuring stress perception, i.e., the degree to which individuals perceived their life circumstances as unpredictable, uncontrollable, and/or overwhelming over the previous month.[23] Levels of stress were categorized as "low" (score <14), "moderate" (score 14-26), "high" (score >26).

The severity of depressive symptoms was assessed using the 9-item Italian validated version[24] of the Patient Health Questionnaire (PHQ), a self-administered reduced version of the PRIME-MD diagnostic instrument for common mental disorders.[25] Levels of depressive symptoms were categorized as "none/mild" (score <5), "mild" (score 5-9), "moderate" (score 10-14), "moderately severe" (score 15-19) and "severe" (score > 19).

Data analyses

Data from closed-ended questions with pre-coded response options were analysed descriptively using frequency distributions. Participants were categorized based on sex (women vs men; none selected the 'other' option) and the diagnosis of their relative (DA vs ASD). The Fisher's exact test was employed to compare the distribution of categorical variables between women and men, as well as between caregivers of individuals with DA and ASD.

To identify predictors of stress levels (dependent variable), a multiple linear regression model was conducted, incorporating sex, age, measures of objective burden and the support received as predictor variables.

Participants were then stratified based on their reported stress levels (high vs moderate vs low total score on the Perceived Stress Scale). Kruskal-Wallis test (for continuous variables, i.e., PHQ-9 depression score) and Fisher's exact test (categorical variables, i.e., lifestyles, perceived health) were used to examine whether participants' stress level was associated with depressive symptoms, unhealthier lifestyles, and poorer perceived health.

Results

Socio-demographic characteristics

The final sample consisted of 458 adults, both men (n=108; 23.6%) and women (n=350; 76.4%), reporting to be family caregivers of relatives with ASD (n=258; 56.3%) or with DA (n=200; 43.7%). Except for two (0.4%), all participants reported to be resident in Italy in the following geographical macro-areas: North (n=98; 21.4%), Centre (n= 222; 48.5%), South (n=120; 26.2%), and Islands (n=16; 3.5%).

Table 1 shows socio-demographic characteristics of participants stratified by sex and by diagnosis of care-recipient. Most participants reported being aged 31-64 years (31-49 years: 37.8% and 50-64 years: 46.3%). Statistical analyses showed differences between caregivers of people with ASD and caregivers of people with DA. Specifically, more caregivers of people with ASD (in comparison to the DA group) reported being aged 31-49 years (45.7% vs 27.5%), while fewer reported being older than 64 years (10.1% vs 18.5%). The majority of participants reported a high level of education (upper secondary education: 43.9%; university degree 38.0%) and to be employed (57.9%). However, women more often than men reported to be unemployed (22.6% vs 3.7%). They also more often reported to be single, separated, divorced or widowed (32.3% vs 18.5%). Supplementary Table 1 (available online in the Addenda section) shows further details on socio-demographic characteristics of participants.

Caregiving burden and support received

Table 2 shows the burden of caregiving and the level of support received. The majority of participants reported to have had caregiving duties from more than 5 years (67.9% of the sample), and to currently live with the care-recipient (77.1%). Almost half of the participants reported to carry out more than 20 caregiving duties/activities per week, and to spend more than 40 hours per week for caregiving (45.9% and 43.4%, respectively). Compared to men, women less often reported to share caregiving responsibility with an unpaid person of trust (69.4% vs 82.4%). The analyses revealed no other significant differences between men and women. By contrast, caregivers of people with ASD reported a higher level of caregiving burden compared to those caring for people with DA.

This difference was evident in several aspects:

1. caregiving duration (91.9% of the ASD group reported caregiving duration of more than 5 years compared to 37.0% of the DA group);
2. cohabitation with the care-recipient (90.3% of the ASD group reported to live with the care recipient compared to 60.0% of the AD group);
3. number of caregiving duties/activities per week (55.0% of the ASD group reported more than 20 duties/activities per week compared to 34.0% of the DA group);
4. time spent caregiving per week (48.8% of the ASD group reported more than 40 hours per week compared to 36.5% of the DA of group).

However, caregivers of people with ASD more often reported to share caregiving responsibility with a person of trust (82.2% vs 60.0%) (Table 2a).

Supplementary Table 2a (available only online in the Addenda section) shows further details on participants' caregiving burden.

Table 1. Socio-demographic characteristics of participants stratified by sex and by diagnosis of care-recipient

		TOT		Sex					Diagnosis of care-recipient				
				M		F		p	ASD		DA		p
		n	%	n	%	n	%		n	%	n	%	
Age	≤30 years	10	2.2	0	0.0	10	2.9	0.135	1	0.4	9	4.5	**0.000**
	31-49 years	173	37.8	39	36.1	134	38.3		118	45.7	55	27.5	
	50-64 years	212	46.3	49	45.4	163	46.6		113	43.8	99	49.5	
	>64 years	63	13.8	20	18.5	43	12.3		26	10.1	37	18.5	
Education	Primary education	8	1.7	3	2.8	5	1.4	0.162	1	0.4	7	3.5	**0.001**
	Lower secondary education	59	12.9	19	17.6	40	11.4		29	11.2	30	15.0	
	Upper secondary education	201	43.9	46	42.6	155	44.3		123	47.7	78	39.0	
	University degree	174	38.0	35	32.4	139	39.7		92	35.7	82	41.0	
	Other	16	3.5	5	4.6	11	3.1		13	5.0	3	1.5	
Employment	Employed	265	57.9	68	63.0	197	56.3	**0.000**	143	55.4	122	61.0	0.253
	Unemployed	83	18.1	4	3.7	79	22.6		56	21.7	27	13.5	
	Retired	110	24.0	36	33.3	74	21.1		59	22.9	51	25.5	
Marital status	Married/Cohabitant	323	71.0	88	81.5	235	67.7	**0.005**	202	78.3	121	61.4	**0.000**
	Single/Separated/ Divorced/Widowed	132	29.0	20	18.5	112	32.3		56	21.7	76	38.6	

Percentages are calculated as proportions within the total sample (TOT), separately within men (M) and women (F) and as proportion within caregivers of people with autism spectrum disorders (ASD) or with dementia/Alzheimer's disease (DA). p-column indicates whether a statistically significant difference exists between the distribution of categorical variables between M and F (Sex column) or between caregivers of ASD and DA (diagnosis of care-recipient column) (Fisher's exact tests, significant values in bold, $p < 0.05$).

Participants were also asked to report on the support received in their caregiving activities (Table 2b). The majority of respondents (70.5%) reported to receive support from public institutions, in particular home care assistance, rehabilitation services, and/or disability pension, while a much lower proportion (11.6%) reported to received support from public institutions in terms of accommodation in residential facilities for their care recipient. About one-third of the participants reported to receive social support from their informal social network (e.g., family or friends) or by a paid care worker. A very low proportion of participants (13.1%) reported to receive psychological support. Except for the variable "institutional support (home care assistance)", no differences were found between women and men regarding supports received, while participants in the DA group reported to receive less support than those in the ASD group in terms of home care assistance (56.0% vs 81.8%), accommodation in residential facilities (8.0% vs 14.3%), and social support (30.5% vs 46.5%). By contrast, caregivers of people with DA reported more often to be supported by a paid care worker in comparison with those of people with ASD (42.5% vs 31.4%). Supplementary Table 2b (available only online in the Addenda section) shows further details on supports received.

Mental health

Table 3 shows data collected on caregivers' mental health in terms of levels of perceived burden and stress and depressive symptomatology.

Most caregivers (307 out of 446 completing the ZBI, 68.8%) reported a severe perceived burden. There was a tendency (Fisher's exact test: p=0.055) for women to more frequently report severe perceived burden compared to men (71.7% vs 59.8%). Moreover, caregivers of people with ASD less often reported severe burden compared to those of people with DA (63.2% vs 76.0%).

Approximately half of the participants (245 out of 451 completing the PSS, 54.3%) reported moderate

Table 2. Caregiving burden (a) and support received (b) stratified by sex and by diagnosis of care-recipient

		TOT		Sex					Diagnosis of care-recipient				
				M		F		p	ASD		DA		p
		n	%	n	%	n	%		n	%	n	%	
a. Caregiving burden													
Caregiving duration	<20 months	27	5.9	5	4.6	22	6.3	0.330	3	1.2	24	12.0	**0.000**
	20 months - 5 years	120	26.2	23	21.3	97	27.7		18	7.0	102	51.0	
	>5 years	311	67.9	80	74.1	231	66.0		237	91.9	74	37.0	
Cohabitation with the care-recipient	No	105	22.9	20	18.5	85	24.3	0.240	25	9.7	80	40.0	**0.000**
	Yes	353	77.1	88	81.5	265	75.7		233	90.3	120	60.0	
Caregiving duties (number per week)	1-10 duties	154	33.6	36	33.3	118	33.7	0.938	65	25.2	89	44.5	**0.000**
	11-20 duties	94	20.5	21	19.4	73	20.9		51	19.8	43	21.5	
	>20 duties	210	45.9	51	47.2	159	45.4		142	55.0	68	34.0	
Time spent for caregiving (hours per week)	<20 hours	100	21.8	24	22.2	76	21.7	0.891	49	19.0	51	25.5	**0.026**
	20-40 hours	159	34.7	39	36.1	120	34.3		83	32.2	76	38.0	
	>40 hours	199	43.4	45	41.7	154	44.0		126	48.8	73	36.5	
Caregiving responsibility sharing#	No	126	27.5	19	17.6	107	30.6	**0.009**	46	17.8	80	40.0	**0.000**
	Yes	332	72.5	89	82.4	243	69.4		212	82.2	120	60.0	
b. Support received													
Institutional support (home care assistance)*	No	135	29.5	23	21.3	112	32.0	**0.040**	47	18.2	88	44.0	**0.000**
	Yes	323	70.5	85	78.7	238	68.0		211	81.8	112	56.0	
Institutional support (residential)**	No	405	88.4	94	87.0	311	88.9	0.608	221	85.7	184	92.0	**0.039**
	Yes	53	11.6	14	13.0	39	11.1		37	14.3	16	8.0	
Social support	No	277	60.5	68	63.0	209	59.7	0.575	138	53.5	139	69.5	**0.001**
	Yes	181	39.5	40	37.0	141	40.3		120	46.5	61	30.5	
Psychological support	No	398	86.9	98	90.7	300	85.7	0.195	223	86.4	175	87.5	0.781
	Yes	60	13.1	10	9.3	50	14.3		35	13.6	25	12.5	
Care worker	No	292	63.8	68	63.0	224	64.0	0.909	177	68.6	115	57.5	**0.019**
	Yes	166	36.2	40	37.0	126	36.0		81	31.4	85	42.5	

Percentages are calculated as proportions within the total sample (TOT), separately within men (M) and women (F) and as proportion within caregivers of people with autism spectrum disorders (ASD) or with dementia/Alzheimer's disease (DA). p-column indicates whether a statistically significant difference exists between the distribution of categorical variables between M and F (sex column) or between caregivers of ASD and DA (diagnosis of care-recipient column) (Fisher's exact tests, significant values in bold, $p < 0.05$).
#Sharing of caregiving responsibility with a (not paid) person of trust; *support received from public institutions (home care assistance, rehabilitation services, disability pension); **support received from public institutions (accommodation in residential facilities).

Table 3. Participants' mental health stratified by sex and by diagnosis of care-recipient

		TOT		Sex					Diagnosis of care-recipient				
				M		F		p	ASD		DA		p
		n	%	n	%	n	%		n	%	n	%	
Perceived burden (ZBI scores)	None/Mild burden	32	7.2	11	10.3	21	6.2	0.055	27	10.8	5	2.6	**0.001**
	Moderate burden	107	24.0	32	29.9	75	22.1		65	26.0	42	21.4	
	Severe burden	307	68.8	64	59.8	243	71.7		158	63.2	149	76.0	
Perceived stress (PSS scores)	Low stress	73	16.2	29	27.1	44	12.8	**0.000**	61	24.1	12	6.1	**0.000**
	Moderate stress	245	54.3	58	54.2	187	54.4		120	47.4	125	63.1	
	High stress	133	29.5	20	18.7	113	32.8		72	28.5	61	30.8	
Depressive symptoms (PHQ-9 scores)	None/Mild depression	101	22.5	34	31.8	67	19.6	**0.025**	67	26.7	34	17.2	0.050
	Mild depression	147	32.7	36	33.6	111	32.5		82	32.7	65	32.8	
	Moderate depression	107	23.8	23	21.5	84	24.6		53	21.1	54	27.3	
	Moderately severe depression	61	13.6	7	6.5	54	15.8		28	11.2	33	16.7	
	Severe depression	33	7.3	7	6.5	26	7.6		21	8.4	12	6.1	

Percentages are calculated as proportions within the total sample (TOT), separately within men (M) and women (F) and as proportion within caregivers of people with autism spectrum disorders (ASD) or with dementia/Alzheimer's disease (DA). p-column indicates whether a statistically significant difference exists between the distribution of categorical variables between M and F (sex column) or between caregivers of ASD and DA (diagnosis of care-recipient column) (Fisher's exact tests, significant values in bold, $p < 0.05$). PHQ: Patient Health Questionnaire; PSS: Perceived Stress Scale; ZBI: Zarit Burden Interview.

stress, and almost one-third (29.5%) severe stress. Women more often than men reported a severe level of stress (32.8% vs 18.7%). Caregivers of people with ASD reported to perceive less stress compared to those of people with DA (24.1% vs 6.1% reported low stress).

Most participants (355 out of 449 completing the PHQ-9, 79.1%) showed mild to moderate depressive symptomatology (22.5% none/mild depressive symptoms; 32.7% mild; 23.8% moderate). A lower proportion of respondents reported moderately severe and severe depression (13.6% and 7.3%, respectively). These levels of depression were more frequent in women than in men (moderately severe: 15.8% vs 6.5%; severe: 7.6% vs 6.5%). Caregivers of people with ASD more frequently reported both none/mild and severe depressive symptoms than caregivers of people with DA (none/mild; 26.7% vs 17.2%, severe: 8.4% vs 6.1%). Supplementary Table 3 (available only online in the Addenda section) shows further details on participants' mental health.

Lifestyle

Participants reported their lifestyle habits, namely food habits, smoking, alcohol consumption, and physical activity (Table 4). More than half of the participants reported having regular food habits (261 out of 451, 57.9%), and about 40% reported engaging in physical activity (173 out of 450 respondents, 38.4%). Furthermore, the majority reported neither smoking cigarettes (344 out of 451, 76.3%) nor consuming alcohol (324 out of 436, 74.3%). No significant differences were found between caregivers of people with ASD and those with DA disease, while some differences based on sex were observed. Specifically, women were more likely to report irregular food habits (44.9% vs 33.0%), although they reported less alcohol consumption compared to men (21.1% vs 31.4% reporting 1-3 drinks per day; 0.6% vs 4.8% reporting 4-6 drinks; 0.3% vs 1.0% reporting more than 6 drinks per day). Supplementary Table 4 (available only online in the Addenda section) shows further details on participants' lifestyle.

Perceived health

For which concern perceived health (Table 5), more than half of the participants (287 out of 457 respondents, 62.8%) reported poor (13.1%) or fair (49.7%) perceived health. About one-third (30.4%) reported good health, while only a small proportion reported very good or

Table 4. Participants' lifestyle stratified by sex and by diagnosis of care-recipient

		TOT		Sex					Diagnosis of care-recipient				
				M		F		p	ASD		DA		p
		n	%	n	%	n	%		n	%	n	%	
Food habits	Regular	261	57.9	71	67.0	190	55.1	**0.033**	145	57.3	116	58.6	0.848
	Irregular	190	42.1	35	33.0	155	44.9		108	42.7	82	41.4	
Physical activity	No	277	61.6	58	54.7	219	63.7	0.110	160	63.5	117	59.1	0.380
	Yes	173	38.4	48	45.3	125	36.3		92	36.5	81	40.9	
Smoking	None	344	76.3	84	77.8	260	75.8	0.795	193	76.0	151	76.6	0.983
	1-5 cigarettes	26	5.8	5	4.6	21	6.1		14	5.5	12	6.1	
	6-10 cigarettes	28	6.2	5	4.6	23	6.7		16	6.3	12	6.1	
	>10 cigarettes	53	11.8	14	13.0	39	11.4		31	12.2	22	11.2	
Alcohol consumption	None	324	74.3	66	62.9	258	77.9	**0.001**	183	74.7	141	73.8	0.987
	1-3 drinks per day	103	23.6	33	31.4	70	21.1		57	23.3	46	24.1	
	4-6 drinks per day	7	1.6	5	4.8	2	0.6		4	1.6	3	1.6	
	>6 drinks per day	2	0.5	1	1.0	1	0.3		1	0.4	1	0.5	

Percentages are calculated as proportions within the total sample (TOT), separately within men (M) and women (F) and as proportion within caregivers of people with autism spectrum disorders (ASD) or with dementia/Alzheimer's disease (DA). p-column indicates whether a statistically significant difference exists between the distribution of categorical variables between M and F (sex column) or between caregivers of ASD and DA (diagnosis of care-recipient column) (Fisher's exact tests, significant values in bold, $p < 0.05$).

excellent perceived health (6.1% and 0.7%, respectively). There was a tendency (Fisher's exact test: p=0.054) for women to report poor or fair perceived health more often compared to men (14.3% vs 9.3% and 51.9% vs 42.6%, respectively), and good and very good perceived health less often than men (27.8% vs 38.9% and 5.2% vs 9.3% respectively). Caregivers of people with DA reported excellent or very good perceived health less often than those of people with ASD (0.5% vs 0.8% and 2.5% vs 8.9%), while more often reported good or fair perceived health (32.5% vs 28.8% and 52.0% vs 47.9% respectively). Supplementary Table 5 (available only online in the Addenda section) shows further details on participants perceived health.

Stress levels and health

The multiple linear regression pointed out a significant effect of sex, diagnosis of care-recipient and time spent for caregiving on the stress total score, also adjusting for caregiver's age, caregiving duration, cohabitation with the care-recipient, caregiving responsibility sharing, caregiving duties, and support received (Table 6). Specifically, a significantly higher score was observed in women than in men (+2.55 points on average), and in caregivers spending 20 or more hours for caregiving than in those spending less than 20 hours per week (+2.22 points on average). On the contrary, a significantly lower score was observed in caregivers of ASD people than in those of people with Alzheimer (-2.33 point on average).

Finally, significant associations were found between the level of stress (high vs moderate vs low) and depressive symptoms, lifestyles and objective and perceived health status (Figures 1-3). Specifically, a significant difference was observed between caregivers with different stress levels (high vs moderate vs low) in:

1. mean PHQ-9 score (14.5 vs 8.6 vs 3.4 respectively; $p < 0.001$);
2. percentage reporting irregular food habits (54.6% vs 44.6% vs 12.3%; $p < 0.001$);
3. percentage reporting not engaging in physical activity (69.9% vs 62.1% vs 40.9%; $p < 0.001$);
4. percentage reporting poor/fair health (82.9% vs 62.9% vs 28.8%; $p < 0.001$).

Although a similar trend could be observed for smoking and alcohol consumption, the tests did not reach statistical significance. This could be due to the low frequency of participants reporting smoking and alcohol consumption (Table 5).

Table 5. Participants perceived health stratified by sex and by diagnosis of care-recipient

		TOT		Sex					Diagnosis of care-recipient				
				M		F		p	ASD		DA		p
		n	%	n	%	n	%		n	%	n	%	
Perceived physical health	Poor	60	13.1	10	9.3	50	14.3	0.054	35	13.6	25	12.5	**0.045**
	Fair	227	49.7	46	42.6	181	51.9		123	47.9	104	52.0	
	Good	139	30.4	42	38.9	97	27.8		74	28.8	65	32.5	
	Very good	28	6.1	10	9.3	18	5.2		23	8.9	5	2.5	
	Excellent	3	0.7	0	0.0	3	0.9		2	0.8	1	0.5	

Percentages are calculated as proportions within the total sample (TOT), separately within men (M) and women (F) and as proportion within caregivers of people with autism spectrum disorders (ASD) or with dementia/Alzheimer's disease (DA). p-column indicates whether a statistically significant difference exists between the distribution of categorical variables between M and F (sex column) or between caregivers of ASD and DA (diagnosis of care-recipient column) (Fisher's exact tests, significant values in bold, $p < 0.05$).

Table 6. Multiple linear regression on stress total score (Perceived Stress Scale; PSS)

	Variable	b	p	95% CI lower	95% CI upper
Sex	Men [Reference]	-	-	-	-
	Women	**2.55**	**0.003**	**0.87**	**4.23**
Age	<50 years [Reference]	-	-	-	-
	50-64 years	-0.89	0.260	-2.43	0.66
	>64 years	0.57	0.624	-1.71	2.84
Diagnosis of care-recipient	DA [Reference]	-	-	-	-
	ASD	**-2.33**	**0.019**	**-4.28**	**-0.39**
Caregiving duration	≤5 years [Reference]	-	-	-	-
	≥5 years	-1.40	0.143	-3.27	0.48
Cohabitation with the care-recipient	No [Reference]	-	-	-	-
	Yes	-0.94	0.350	-2.92	1.04
Caregiving responsibility sharing	No [Reference]	-	-	-	-
	Yes	-0.86	0.312	-2.54	0.81
Caregiving duties	1-20 duties per week [Reference]	-	-	-	-
	>20 duties per week	1.56	0.055	-0.03	3.15
Time spent for caregiving	1-19 hours per week [Reference]	-	-	-	-
	≥20 hours per week	**2.22**	**0.029**	**0.23**	**4.22**
Support received*	No [Reference]	-	-	-	-
	Yes	1.70	0.141	-0.57	3.97

CI: confidence interval; DA: dementia/Alzheimer's disease; ASD: autism spectrum disorders. Statistically significant results are highlighted in bold ($p < 0.05$ and 95% CI of the regression coefficient excluding the value 0). *At least one support (Table 2).

Discussion

Participants in our study were FCs of individuals with DA or ASD. Compared to caregivers in the ASD group, those in the DA group reported lower levels of objective burden across all measured indicators (including long-term caregiving, cohabitation with the care recipient, and the number of hours and tasks devoted to care). Nevertheless, they more frequently reported severe perceived burden and higher stress levels. Multiple linear regression analyses confirmed that caring for a person with DA is independently associated with increased caregiver stress, even after adjusting for all other covariates. This apparent incongruence may be explained by the lower levels of support more commonly reported by caregivers in the DA group. They were less likely to share caregiving responsibilities with others and more frequently reported insufficient institutional or social support compared to caregivers in the ASD group. Although a higher proportion of DA caregivers receive assistance from paid care workers, the limited availability of broader support networks may not be sufficient to alleviate their overall levels of stress and perceived burden.[26,27] Importantly, social isolation in itself constitutes an additional risk factor for caregiver health and well-being, as increasingly highlighted by the literature.[28,29]

Another possible explanation relates to the age of DA caregivers, who tend to be older than those in the ASD group – nearly 70% are over 50 years old, and about 20% are over 65. This trend is likely due to the fact that DA caregivers are often the spouse of the care recipient, resulting in a closer age proximity. This raises the hypothesis of a potential association between older age and higher levels of perceived burden and stress. However, this hypothesis was not supported by our regression analysis, which showed no significant effect of age on perceived stress after adjusting for other variables.

Conversely, caregiving burden was largely independent of the caregiver's sex across all parameters analysed, with the notable exception that women were less likely than men to report sharing caregiving responsibilities with a trusted individual. This lack of shared caregiving may help explain the higher levels of perceived burden and stress reported by women in our sample. Supporting this interpretation, a study examining time trends in health inequalities related to caregiving found that differences in health outcomes between carers and non-carers tended to diminish among those who shared care duties, but not among those providing care alone.[30]

Since women are predominant in caregiving roles and are more susceptible to the detrimental effects of stress,[31,32] we expect caregiving to have a more pronounced impact on women's health. This assumption is supported by our findings, as women were more likely than men to self-report greater depressive symptoms and poorer overall health following the assumption of caregiving responsibilities. This can be due to the heightened psychological stress levels experienced by women, which appears to be independent of the perceived caregiving burden (which was similar across genders).

Existing literature indicates that psychological stress among FCs has not been consistently quantified, and subjective caregiver burden has remained the primary metric for evaluating FCs' health.[33,34] Our findings show that psychological stress is significantly associated with depressive symptoms, unhealthy lifestyle behaviours, and poorer self-reported health. Although our data are based on self-reports and should be validated in larger studies including clinical assessments of caregivers' health status, we underscore the importance of integrating psychological stress evaluation alongside traditional measures of caregiver burden. This approach can help identify groups of caregivers that are at greater health risk, with particular attention to sex and gender differences.[35,36] Moreover, although numerous studies have established a link between chronic stress and indices of poor health, the exact mechanisms through which stress impacts health is still much discussed, and further research is warranted. Landmark studies have established a link between psychological stress, accelerated aging of immune system cells, and heightened health risks.[37,38]

Finally, we underscore the importance of early prevention of health problems in caregivers. Addressing the harmful effects of stress at an early stage, when health disturbances serve as 'alarm bells' for potential illness, is critical. Caregivers should also be encouraged to maintain healthy lifestyles. For instance, our findings show that women caregivers, despite generally adhering to regular diets, are more likely than men to exhibit irregular eating habits. In contrast, men consume alcohol more frequently than women, consistent with general population trends. This suggests that women, who are typically more attentive to dietary habits, may struggle to maintain this focus under the heightened stress of caregiving.[39]

Strengths and limitations

This study presents several strengths. First, we quantitatively compared multiple indicators of health status – including perceived stress – between two distinct populations of informal caregivers differing in socio-demographic characteristics, caregiving burden, and support received, allowing us to identify meaningful patterns and group-specific vulnerabilities. Second, we examined the impact of stress levels on a range of health-related outcomes, including self-rated health, depressive symptoms, and lifestyle behaviours, offering insight into potential mechanisms linking caregiving demands to health deterioration. Third, while some of our findings confirm

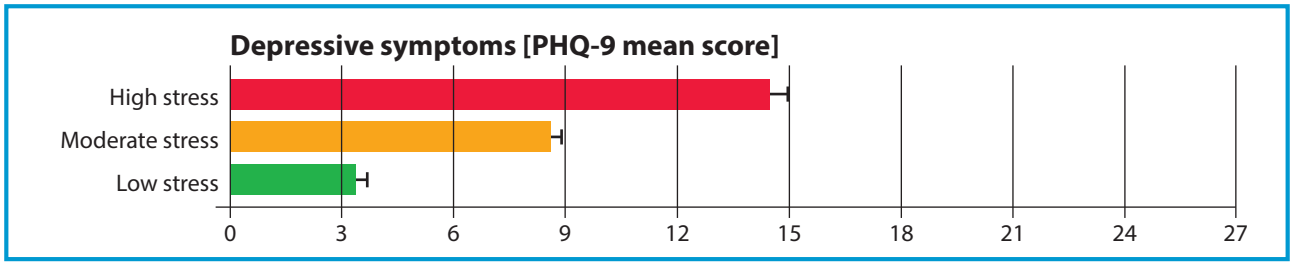

Figure 1. Depressive symptoms (PHQ-9 mean score and standard error) in the 3 groups of caregivers reporting high levels of stress (red bar, 16.2% of participants), moderate levels of stress (yellow bar, 54.3%), and low levels of stress (green bar, 29.5%). PHQ-9 range: 0-27.

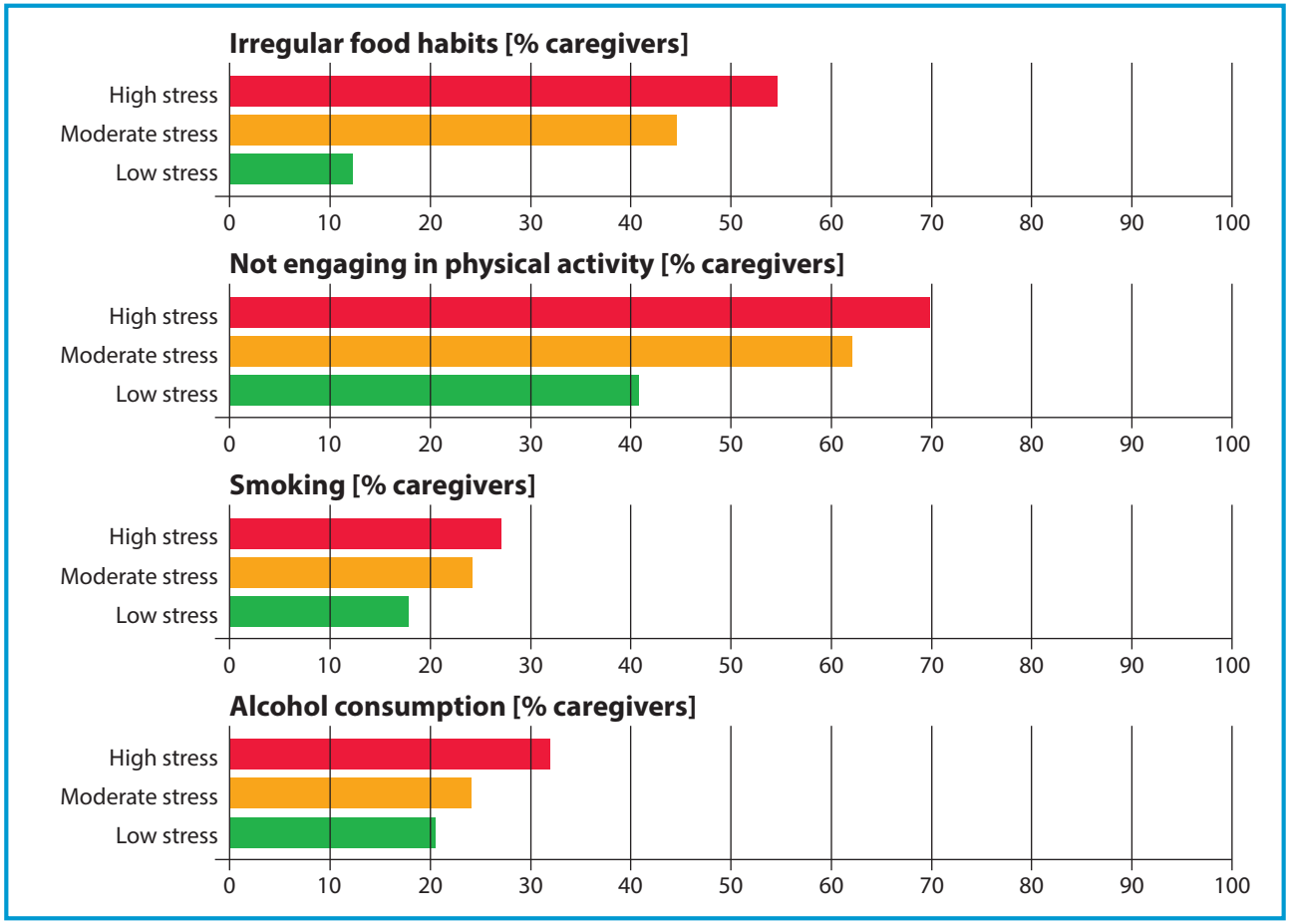

Figure 2. Percentage of caregivers reporting (from top to bottom) irregular food habits, not engaging in physical activity, smoking and alcohol consumption stratified in the 3 groups with high levels of stress (red bars, 16.2% of participants), moderate levels of stress (yellow bars, 54.3%), and low levels of stress (green bars, 29.5%).

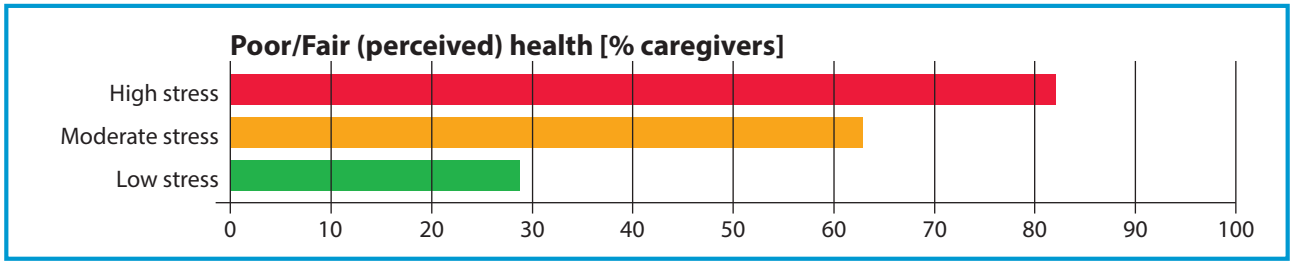

Figure 3. Percentage of caregivers reporting having Poor or Fair perceived health stratified in the 3 groups with high levels of stress (red bar, 16.2% of participants), moderate levels of stress (yellow bar, 54.3%), and low levels of stress (green bar, 29.5%).

existing literature (e.g., higher stress and depression levels among women), our results also offer novel contributions. In particular, they highlight the protective role of sharing caregiving responsibilities and the need for adequate institutional support – factors especially relevant to female caregivers, who are disproportionately affected by unemployment and high caregiving burden.

Nonetheless, several limitations must be acknowledged. First, our sample was obtained through convenience sampling via partner organizations, which may limit the generalizability of our findings. Second, the number of male participants was relatively low, potentially affecting the robustness of sex-stratified analyses. Moreover, due to the unbalanced distribution of male and female caregivers in our sample, it was not possible to perform inferential statistical analyses to assess sex differences within each group (DA and ASD). This limitation reduced our ability to explore potential sex-related differences in caregiving experiences across subgroups.

Third, the questionnaire was administered online, which may introduce self-selection bias; to mitigate this, participants were required to register on the platform and were provided with clear instructions. Fourth, data were entirely self-reported; however, quality checks on responses showed inconsistencies in fewer than 5% of cases. Finally, we did not collect socio-demographic or clinical data on the care recipients, due to ethical restrictions and the focus on caregivers' health regardless of care recipients' disease severity. This limits our ability to assess the role of care recipients' functional status in shaping caregiver outcomes.

Future research could address these limitations by including more diverse samples of caregivers – especially men. Collecting functional and diagnostic data of care recipients, where ethically feasible, would further clarify the relationship between care demands and caregiver outcomes. Observational and longitudinal studies are also needed to examine causal pathways and to support the development of targeted interventions and public health policies for this at-risk population.

Conclusions

Informal caregivers play a crucial role in ensuring the well-being of their loved ones, often over extended periods, while balancing personal, professional, and familial responsibilities. As such, informal caregiving is undoubtedly a valuable resource for both the individuals directly involved and society as a whole. Hence, it is crucial to question whether FCs may face health risks as a result of their caregiving responsibilities.[19]

Over the coming decades, the demand for caregiving is expected to increase due to population aging and declining birth rates. As a result, the need for caregiving will likely grow. This underscores the necessity for national policies that address not only the health of individuals requiring care but also that of their caregivers. Our findings emphasize the importance of psychological stress as a key indicator for gender-specific health prevention strategies.

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Key messages

- Caregiver stress is a significant risk factor for unhealthy lifestyle behaviours, more severe depressive symptoms, and worse self-perceived health.
- Sharing caregiving responsibilities and ensuring adequate institutional support – especially crucial for female caregivers, who are more likely to experience unemployment and a higher caregiving burden – can help mitigate the negative health impacts of caregiver stress.
- Caring for a person with dementia or Alzheimer's disease, compared to autism spectrum disorder, is linked to higher levels of caregiver stress, largely due to lower availability of support services.

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Authors' contribution statement. Marta Borgi conducted data analysis, results discussion, and writing; Antonio D'Amore contributed to questionnaire development, results discussion, and writing; Flavia Chiarotti performed the statistical analysis; Angela Ruocco, Elena Capuano, and Silvia Vitali collected data and assisted with manuscript preparation; Elena Ortona provided scientific support, and Marina Petrini coordinated the project, caregiver recruitment, results dissemination, and writing.

Ethical approval and informed consent. The study received approval from the Ethics Committee of the Istituto Superiore di Sanità in Rome, Italy, on June 28, 2021. Research was conducted in accordance with the WMA Helsinki Declaration. Caregivers' health data were collected via an anonymous online questionnaire. All data were analyzed in aggregate form, ensuring participants cannot be identified.

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