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EE515

Healthcare resource utilization and economic burden among caregivers of individuals with autism spectrum disorder caregiver: Findings from the 2024 5EU National Health and Wellness Survey

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Background

There are roughly five million people with autism spectrum disorder (ASD) in Europe, many of which need life-long care.[1]

Caregivers of individuals with ASD include formal (paid professionals) and informal (unpaid family members or friends) providers.[2]

Caregiving is known to negatively impact health, yet the economic burden on ASD caregivers remains largely under-researched.

Objective

The study is aimed to describe the sociodemographic profile and economic burden of caregivers to individuals with autism spectrum disorder (ASD) in the 5EU (France, Spain, Germany, Italy, UK).

Methods

We analyzed data from the 2024 5EU National Health and Wellness Survey, a cross-sectional survey designed to be representative of the adult population (≥18 years).

- Respondents were recruited through general population panels using quota-based sampling strategies.
- Participants self-identified as caregivers of either adults with ASD (CA) or children with ASD (CC).
- Information on caregiver demographics and healthcare resource utilization (HCRU) was collected.
- The economic burden was estimated using WHO-CHOICE unit cost data, with adjustments for inflation based on OECD consumer price index values.

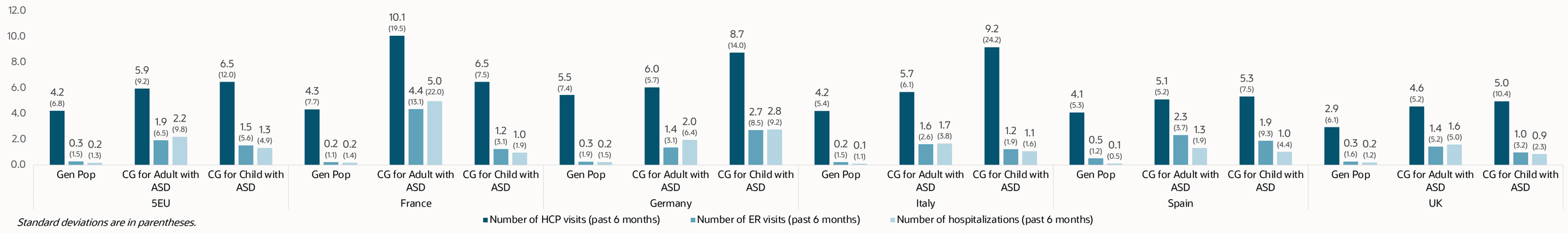
Results

- Across the 5EU, n=546 were CA and n=897 were CC, with all countries reporting more CC than CA.
- The UK had the highest count in both groups, while France had the largest difference between groups.
- Most caregivers were male (62.1% of CA and 52.8% of CC), although in France, Spain and the UK, female CC were more common (50.2%, 51.1%, and 51.8%, respectively).
- CA were more likely to be employed full-time, except in Italy.
- On average, CC had more HCP visits (6.5±12.1 vs 5.9±9.2 for CA) while CA had more ER visits (1.9±6.5 vs. 1.5±5.6) and hospitalizations (2.2±9.8 vs. 1.3±4.9).
- This trend reversed in France, where CA had more of all three HCRU types.
- CA accrued greater costs for ER visits (€ 288.78± € 880.55) and hospitalization (€ 9,585.18±€ 44,392.94) than CC.

Table 1. Demographic Characteristics

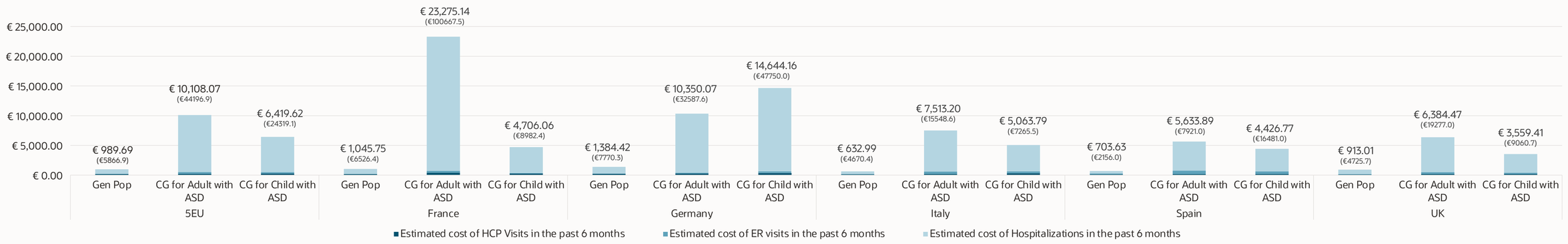
	5EU				France				Germany				Italy				Spain				UK			
	General Adult Population (n=60579)	CG for Adult with ASD (n=546)	CG for Child with ASD (n=897)	P-value	General Adult Population (n=14710)	CG for Adult with ASD (n=82)	CG for Child with ASD (n=207)	P-value	General Adult Population (n=14647)	CG for Adult with ASD (n=156)	CG for Child with ASD (n=194)	P-value	General Adult Population (n=9886)	CG for Adult with ASD (n=50)	CG for Child with ASD (n=64)	P-value	General Adult Population (n=6896)	CG for Adult with ASD (n=36)	CG for Child with ASD (n=94)	P-value	General Adult Population (n=14440)	CG for Adult with ASD (n=222)	CG for Child with ASD (n=338)	P-value
Sex																								
Male	50.3%	62.1%	52.8%	**<0.001**	47.0%	70.7%	49.8%	**<0.001**	52.0%	62.8%	59.8%	**<0.001**	52.0%	64.0%	71.9%	**0.002**	51.3%	63.9%	48.9%	0.288	50.5%	57.7%	48.2%	0.072
Female	49.7%	37.9%	47.2%		53.0%	29.3%	50.2%		48.0%	37.2%	40.2%		48.0%	36.0%	28.1%		48.7%	36.1%	51.1%		49.5%	42.3%	51.8%	
Age Category																								
18 to <25	7.4%	21.1%	13.8%	**<0.001**	8.2%	26.8%	14.0%	**<0.001**	7.3%	26.3%	23.2%	**<0.001**	5.8%	18.0%	6.3%	**<0.001**	7.2%	22.2%	13.8%	**<0.001**	8.2%	15.8%	9.8%	**<0.001**
25 to <35	16.1%	36.8%	22.9%		16.8%	47.6%	28.5%		15.1%	33.3%	25.3%		14.7%	32.0%	35.9%		13.0%	52.8%	20.2%		18.6%	33.8%	16.3%	
35 to <45	15.4%	19.6%	25.0%		14.7%	11.0%	26.6%		14.7%	24.4%	20.6%		15.9%	18.0%	20.3%		16.3%	13.9%	26.6%		16.0%	20.7%	26.9%	
45 to <55	16.8%	10.3%	22.4%		16.4%	7.3%	19.3%		14.9%	4.5%	13.9%		19.8%	16.0%	25.0%		23.2%	5.6%	26.6%		14.0%	14.9%	27.5%	
55 to <65	19.2%	7.1%	11.3%		17.3%	4.9%	6.3%		22.4%	5.1%	13.4%		17.8%	10.0%	4.7%		20.6%	2.8%	9.6%		18.2%	9.5%	14.8%	
65 and older	25.1%	5.1%	4.7%		26.7%	2.4%	5.3%		25.5%	6.4%	3.6%		25.9%	6.0%	7.8%		19.8%	2.8%	3.2%		25.1%	5.4%	4.7%	
Employment																								
Full-time	44.0%	61.2%	48.9%	**<0.001**	44.8%	58.5%	48.3%	**<0.001**	43.4%	70.5%	58.5%	**<0.001**	37.9%	40.0%	46.9%	0.09	51.2%	69.4%	46.8%	**<0.001**	44.3%	59.0%	44.7%	**<0.001**
Part-time or Self-employed	15.8%	17.9%	21.4%		11.3%	19.5%	19.3%		17.0%	11.6%	18.8%		20.9%	30.0%	25.0%		13.8%	19.5%	25.5%		17.1%	18.9%	22.5%	
Not employed	40.2%	20.9%	29.7%		43.9%	22.0%	32.4%		39.6%	17.9%	22.7%		41.2%	30.0%	28.1%		35.0%	11.1%	27.7%		38.6%	22.1%	32.8%	

Figure 1. Average Healthcare Resource Use in the Past 6 Months



Standard deviations are in parentheses.

Figure 2. Average Estimated Healthcare Resource Expenditure in the Past 6 Months



Costs displayed are total estimated costs which are the sum of cost of HCP visits, cost of ER visits and cost of hospitalizations, Standard deviations are in parentheses.

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Conclusion

Both CA and CC experience increased HCRU and economic burden underscoring the need for targeted interventions to alleviate financial strains and mitigate broader economic impact.

References

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