

The unmet needs of Elderly People with Multiple Sclerosis

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Introduction Up to 90% of people who are diagnosed with MS in their early 20s are likely to live with the disease for 50 or more years. Thus, they will have to manage MS-related disability (1,2) in addition to the normal age-related changes.

Objects To report the point of view of Elderly People with MS (EPwMS) and their caregivers about what they perceive as unmet needs and which resource they use to face them.

Methods A total of 58 over-70y subjects and their caregivers, followed as outpatients or as in-home patients by the Italian MS Society Rehabilitation Centre, Liguria, were enrolled and a questionnaire specifically designed to assess different needs was administered. Similarly, caregivers were asked to identify their needs. The questionnaire was composed of personal (PCN), health (HCN) and social care needs (SCN) questions.

Results

**Table 1 - Elderly people with MS (n=58)
Demographic and clinical characteristics**

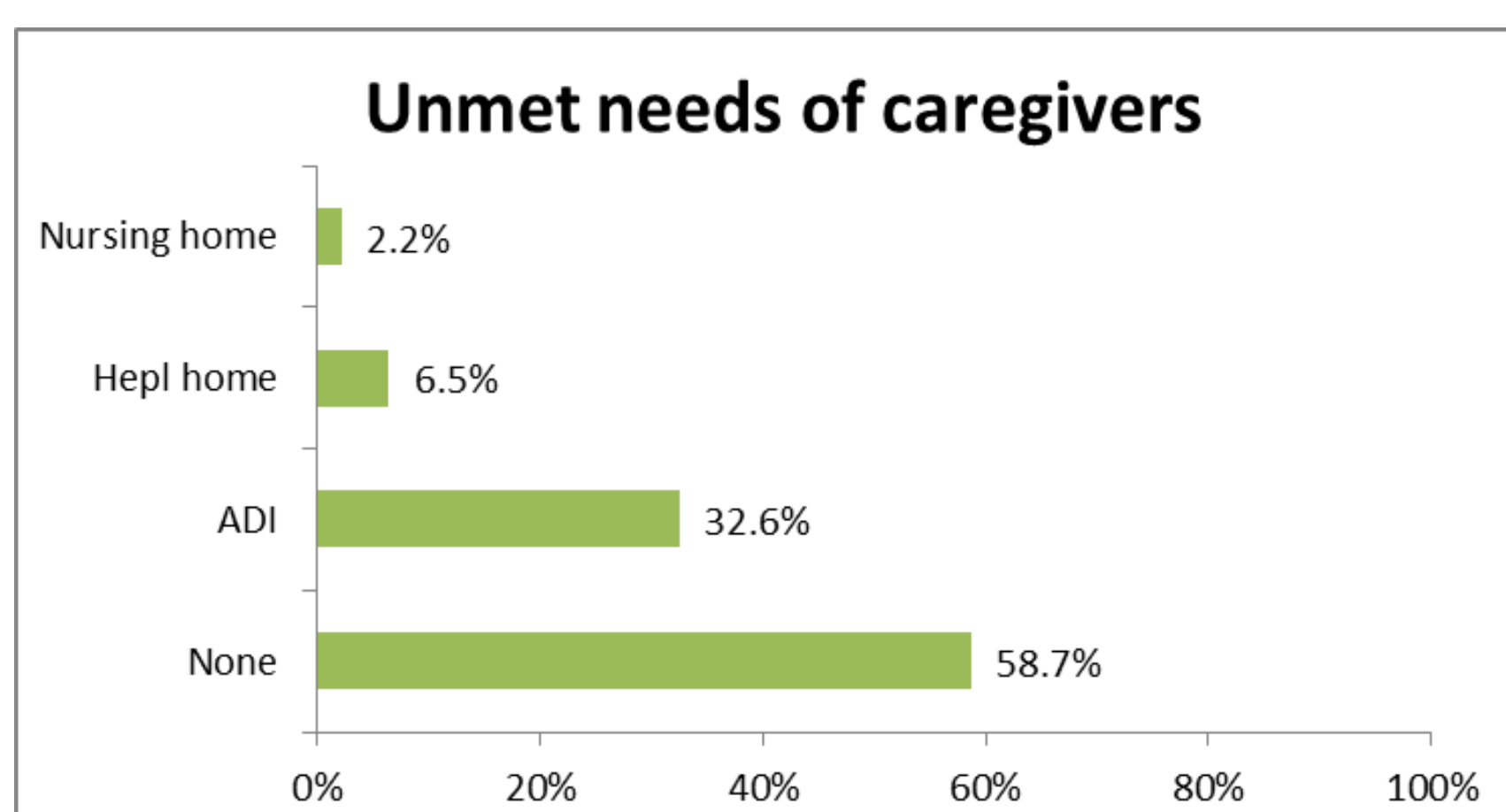
Age (years), mean (SD) range	75.6 (4.4) 70-89
Sex , %	Male 43.1% Female 56.9%
Education , %	Primary school 50.0% High school 34.5% University degree 15.5%
Duration of illness (years), mean (SD)	29.6 (13.9)
EDSS score , mean (SD) range	6.1 (1.4) 1-9
EDSS ≥ 7 , %	27.6%
GDS , mean (SD)	14.2 (6.6)
GDS class , %	Absent 29.3% Mild 34.5% Severe 36.2%
Ambulation status , %	Yes mobility 15.5% With aids 57.0% No mobility 27.5%
Caregiver presence , %	79.3%

GDS, Geriatric Depression Scale; EDSS, Expanded Disability Status Scale

Table 2 - Caregiver (n=46) characteristics

Age caregivers , (years), mean (SD)	65.7 (16.2)
Relation between patient and caregiver , %	Paid caregiver 17.4% Spouse/consort 69.6% Son/daughter 10.9% Other relatives 4.3%
CBI , mean (SD)	21.9 (14.6)

CBI, Caregiver Burden Inventory



- High frequency of depression (34.5% mild and 36.2% severe) and loss frequency of mobility

- The 79.3% of EPwMS had a caregiver (of these 82.6% is a informal caregiver)

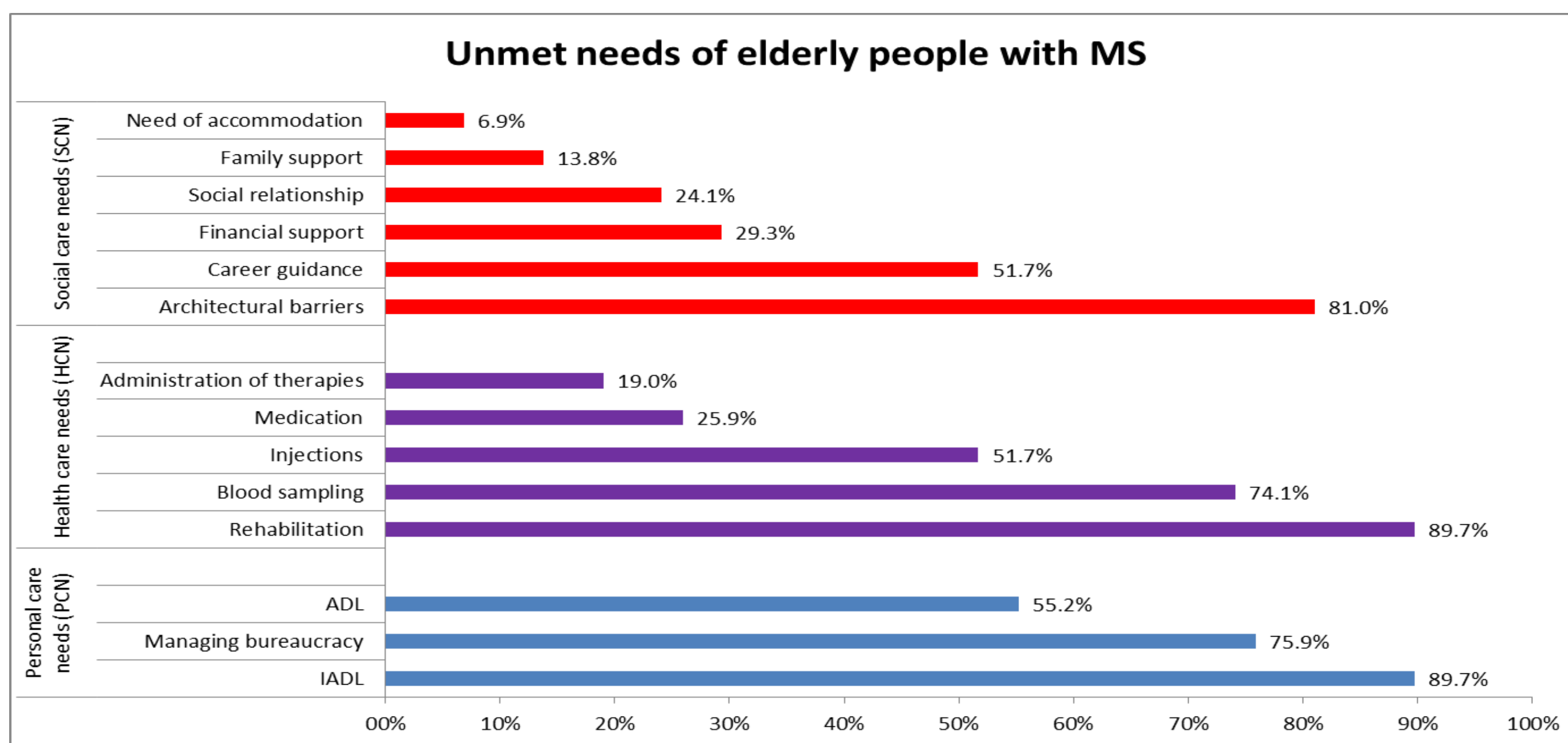
- 58.7% of the caregivers declared no needs

- Help for activity of daily living is the main needs reported by caregivers

PCN and HCN were the unmet needs **most frequent** reported by EPwMS

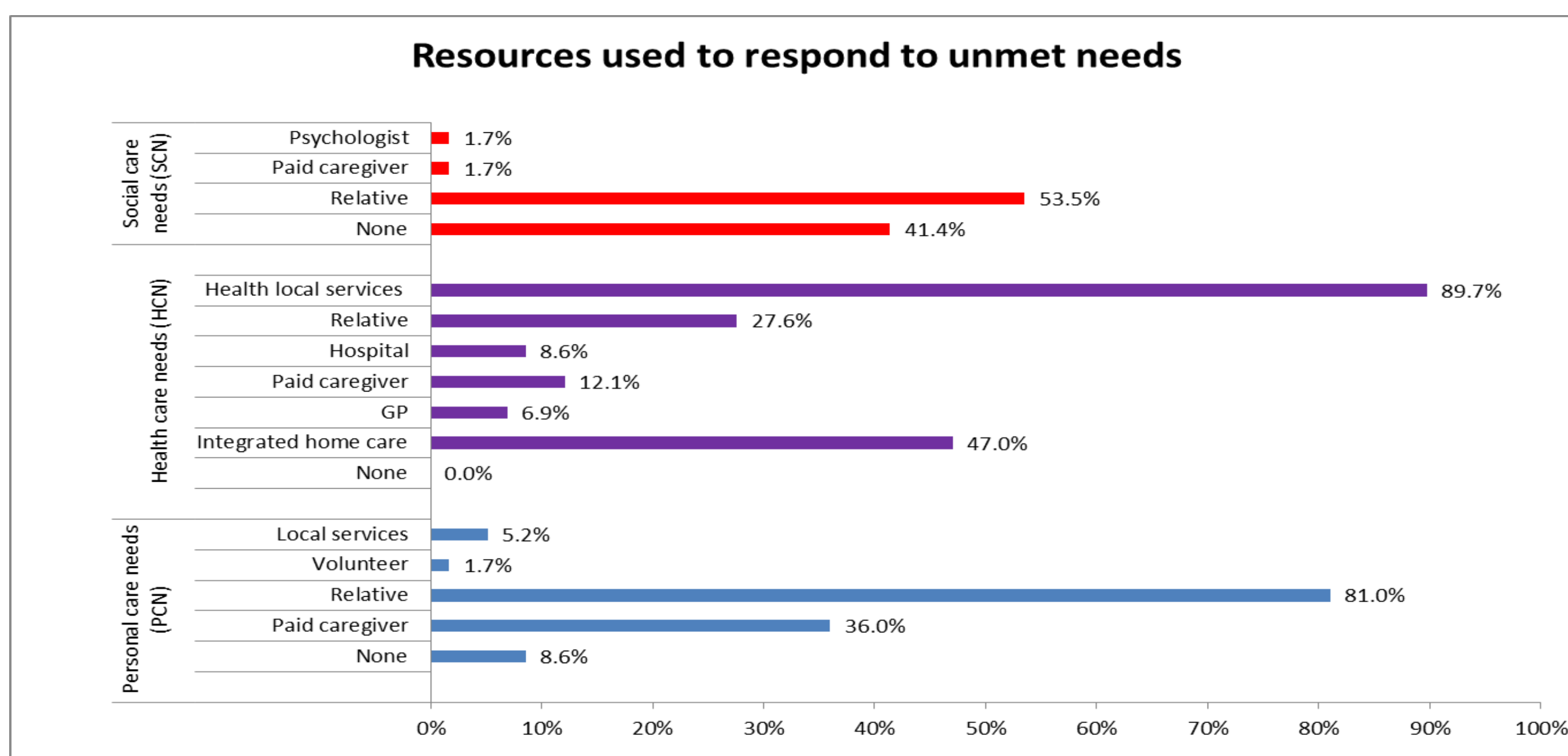
Needs most reported for categories were:

- **PCN**: lack of assistance in IADL and difficulties in managing bureaucracy
- **HCN**: rehabilitation and making easier blood
- **SCN**: legal support



Resources used to face the different need categories were:

- **PCN**: relatives and paid caregivers
- **HCN**: health local services and integrated home care
- **SCN**: relatives



Conclusion Most of EPwMS required mobility devices; moreover a large part of enrolled patients were depressed. Likely, the request of more rehabilitation reflects the wish to improve abilities maintenance and develop new strategies to manage limitations and functional losses. Besides, the need to obtain assistance to manage everyday tasks, including bureaucracy and legal issues, is a crucial point for both EPwMS and caregivers. While for PCN and HCN, specific resources are activated, for SCN often the potential resources are not identified.