Patient and physician perspectives on the care and assistance needs in Huntington's disease

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BACKGROUND

- Huntington's disease (HD) is a rare, genetic, neurodegenerative and ultimately fatal disease that has a devastating impact on families across generations.[1,2]
- HD is characterised by a triad of cognitive, behavioural and motor symptoms leading to functional decline and progressive loss of independence.[2,3]
- As the disease progresses, most individuals with HD will require assistance with daily activities;[4] however, little is known about the type of care they require, as well as differences in care requirements across countries.

Objective

- To describe the assistance needs of people with HD across different countries.

METHODS

- A retrospective analysis was conducted using data from the Adelphi HD Disease Specific Programme, a cross-sectional study of neurologists or neuropsychiatrists in France, Germany, Italy, the UK and the US between July and October 2017.
  - Three questionnaires were created for different audiences: physicians, patients and care partners.
  - Care partners attending a consultation with the patient during the study period were also offered the chance to complete a form; however, only a small number of care partners (n=29) completed the survey. Therefore, data provided by care partners were not included in the analysis.
- This study utilises patient- and physician-reported information on care and assistance needs for individuals with HD.
- All data collected were reviewed and quality checked by Adelphi after the survey completion.
  - Physician-completed patient records with high levels of missing or inconsistent data were removed from the survey results.
  - There is an expectation that patient self-reporting will result in incomplete data; however, completed responses were retained wherever possible, resulting in a smaller number of observations for some analyses.
- As formal measures of severity may not be available for all patients, physicians were asked to subjectively describe the severity of each patient's HD on a scale of: Mild, Moderate, Severe and None of the above.

What does this mean for the HD community?

- Findings from this study suggest that having support from a team of different healthcare professionals (e.g. specialist doctors, occupational therapists, nurses) could help people with Huntington's disease (HD) access care for their individual needs.
- This study aimed to understand the needs of people with HD, including the support required.
- A survey looking at the assistance needs of people living with HD in the US and Europe found that the level of support needed depends on factors such as severity of disease, country of residence and available family support.
- The survey also found that a high proportion of people living with HD do not receive appropriate support.

Conclusions

- Assistance needs of people with HD vary with the severity of the disease, cultural differences, family support and other factors.
- The results of this survey show that a high proportion of individuals with HD are not receiving the level of assistance they require.
- A multidisciplinary group can help patients with HD and their families access appropriate care based on their individual needs.

RESULTS

Physician-reported patient demographics

- Of the total 1,050 patients included in the dataset, 555 (52.9%) were reported by their physician to have a care partner; physician-reported demographics of the 555 patients are reported in **Table 1**.

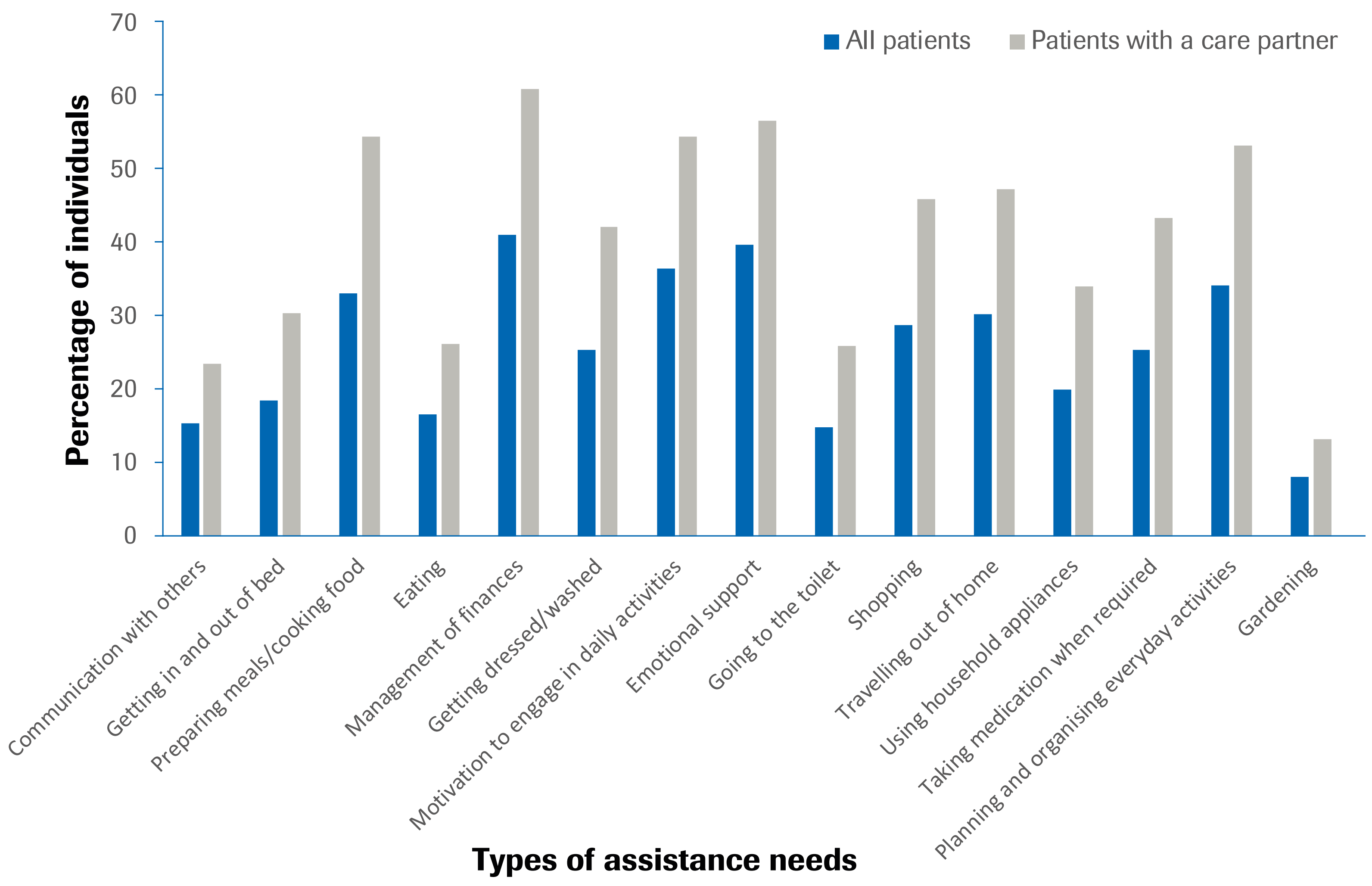
Table 1. Patient characteristics for those receiving assistance from any type of care partner (i.e. professional and non-professional)

	France	Germany	Italy	UK	US	Total
N	118	107	104	63	163	555
Age (years)						
Mean (SD)	59 (14.9)	48.2 (10.5)	53.1 (11.5)	56.2 (11.3)	52.5 (12.8)	53.6 (13.0)
Median	57.5	48.0	54.0	59.0	52.0	53.0
Gender						
Female (%)	48.3	52.3	37.5	34.9	39.9	43.1

Physician-reported types of assistance needs (Figure 1)

- Across all patients, the most common physician-reported type of assistance need was help with managing finances (41.1%), followed by emotional support (39.8%), motivation to engage in daily activities (36.5%), planning and organising everyday activities (34.3%) and preparing meals (33.2%).
- For patients with a care partner, assistance types were ranked in a similar order, although at higher rates (managing finances, 61.1%; emotional support, 56.8%; meal preparation, 54.6%; motivation to engage in daily activities, 54.6%; planning and organising everyday activities, 53.3%).

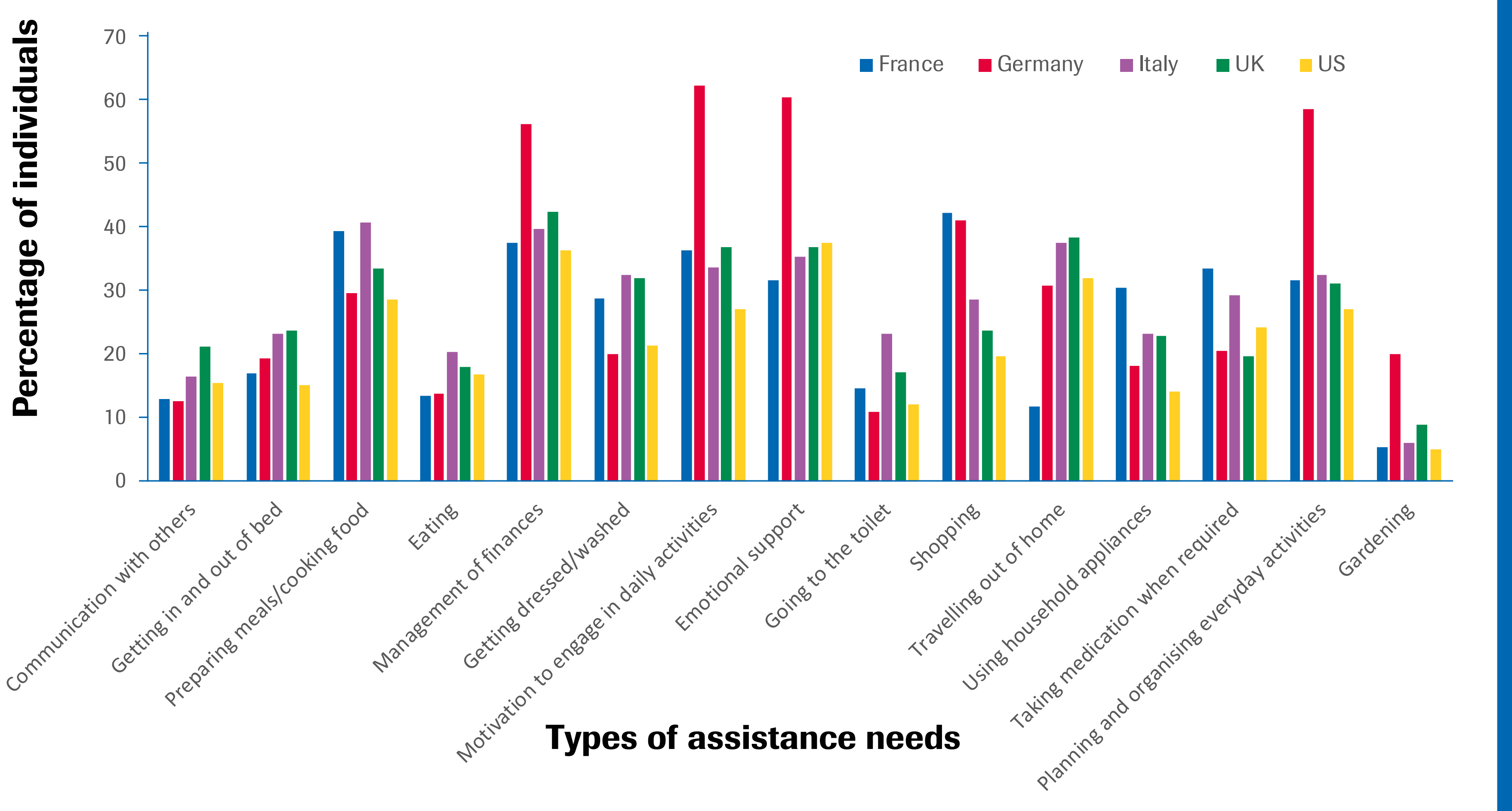
Figure 1. Types of assistance needs for total population of patients (n=1,050) and patients with a care partner (n=555)



Physician-reported types of assistance needs by country (Figure 2)

- The highest ranking type of assistance needed varied across countries (France: shopping, 42.4%; Germany: daily activities, 62.4%, Italy: meal preparation 40.9%, UK: finance management 42.6%, US: emotional support: 37.6%).

Figure 2. Types of assistance needs by country (%)



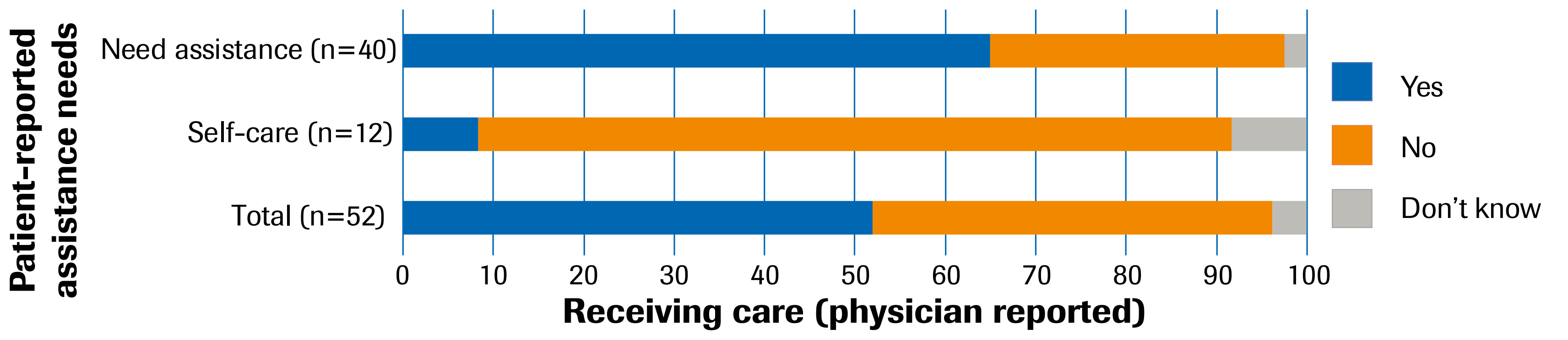
Physician-reported disease severity

- Physician-perceived disease severity distribution was similar in Italy, UK and US. Germany had the highest number of mild patients and France the highest number of severe patients.
- Patients with a care partner generally had more severe disease than patients without a care partner.
  - As severity increased, the proportion of individuals without a care partner decreased from 63.5% (Mild) to 9.1% (Severe), while those with a care partner increased from 28.3% (Mild) to 87.7% (Severe). The presence of a care partner is unknown for some patients who responded.

Patient-reported care and assistance needs

- There were 52 patients who reported their need for everyday help with HD-related difficulties; 40 (76.9%) patients reported needing assistance from a care partner, of which only 26 (65.0%) were reported by their physician to be receiving assistance **(Figure 3).**

Figure 3. Patients who reported caregiving needs (n=52) and percentage receiving assistance



Patient-reported assistance needs are based on responses to patient-completed form. Patients receiving care is based on responses in physician-reported form

Limitations

- Participants in the study may not reflect the general HD population as those who visit physicians more frequently may be more severely affected by the disease.
- Recall bias may have affected the responses to the questionnaires, a common limitation of surveys; however, the data for these analyses were collected at the time of each patient's appointment and this is expected to reduce the likelihood of recall bias.
- There was a small sample size of patients who reported whether they needed assistance and had data from their physicians on whether they received care (n=52).
- Despite such limitations, real-world studies play an important part in highlighting areas of concern that are not addressed in clinical trials.

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Abbreviations

HD, Huntington's disease; SD, standard deviation.

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