

Impact of ALS on Living and Working Arrangements: Results From a Real-World Point-in-Time Survey

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- To outline the impact of ALS on living and working arrangements, as reported by physicians, people living with ALS, and their care partners
- CONCLUSIONS
- ALS-related impacts to working arrangements may lead to loss of income for ALS families.
- The most frequently cited reason for changes in pALS working arrangements was impaired mobility, potentially highlighting a need for disability modifications to be more readily available in workplaces.
- Substantial caregiver burden is common and results indicate that specific responsibilities and the amount of care required may shift with disease progression.
- The full extent to which pALS are supported by cALS may not always be realized, even by the pALS themselves, potentially leading to under-recognition of caregiver burden among this group.
- These impacts to work and daily living highlight the high level of unmet need in ALS.

Introduction

- Amyotrophic lateral sclerosis (ALS) is a rare, degenerative neuromuscular disease, leading to progressive loss of muscle function, and ultimately death.¹
- The debilitating nature of the condition negatively impacts the working and living arrangements of people with ALS (pALS) and their care partners (cALS).
- A socioeconomic study from Germany found that the main components driving cost related to ALS were identified as health insurance expenditure, and loss of economic productivity among both pALS and cALS.²
- Significant costs are also seen to be related to increased caregiver assistance related to reduced ability to perform activities of daily living (ADLs).³
- Understanding both the degree of the effects of ALS on working and living arrangements, and the perception of these factors by both pALS and cALS, could be used to better inform healthcare decisions as well as improve the quality of care provided.

Results

- 142 neurologists (EU & UK: 110, US: 32) recorded data for a total of 880 pALS (EU & UK: 624, US: 256); 135 of these same pALS (EU & UK: 105, US: 30) and 82 cALS (EU & UK: 61, US: 21) provided self-reported data.
- Across the total pALS sample, the mean age was 61.7 years. 61.8% were male and 90.2% were White/Caucasian. The mean time since ALS diagnosis was 1.6 years (19.4 months).

Working arrangements

- Both pALS and cALS reported an impact of ALS on their working arrangements (**Figure 1**).
 - 46% of pALS reported that they had changed their working arrangements due to ALS, most frequently either reducing their working hours or stopping work entirely.
 - 37% of cALS reported that they had changed their working arrangements due to becoming a care partner, most frequently either reducing their working hours or adjusting to work from home.
- According to neurologists, the most frequent reason for work changes among pALS was impaired mobility (**Figure 2**). They reported that on average pALS experienced a change in employment status 1.3 years (16.1 months) after symptom onset.

Living arrangements

- Neurologists reported that 68% of pALS made one or more home modifications due to ALS (**Figure 3**). Notably, 14% of pALS had moved to an ALS-friendly house (e.g. bungalow, ground-floor apartment).
 - pALS were also asked to report home modifications they had made. When comparing physician and pALS responses only a low level of discordance was observed (less than a 5% difference for all modifications).
- cALS reported that they supported patients with a wide range of ADLs (**Figure 4**).
- Where both pALS- and cALS-reported perspectives were available, discordance was observed in the reporting of which ADLs required support (**Figure 5**). There was discordance in both directions but the majority of discordance related to cALS reporting more assistance provided to pALS than reported by pALS themselves.

Care burden

- Overall, cALS reported they provided a mean 53.1 (SD: 52.7) hours of care per week.
- The hours reported by cALS of individuals at different disease stages were as follows:

All cALS		King's staging				MiToS				
		1	2	3	4	0	1	2	3	4 ^a
n	77	8	6	30	33	43	10	8	4	12
Mean	53.1	26.5	40.5	41.2	72.6	40.9	50.0	88.0	84.5	65.5
SD	52.7	28.8	63.5	45.9	56.1	47.1	50.2	61.7	62.9	56.3

King's staging assesses any impact based on the number of affected regions, whereas MiToS assesses complete loss of independence in four key domains (bulbar, gross motor, fine motor, and respiratory function).
^a Previous analysis of this dataset⁶ found the reduction in non-professional caregiver hours in MiToS stage 4 to be offset by an increase in professional caregiver at this late stage of disease.

Financial burden

- Neurologists were asked to what extent they agreed or disagreed with several statements regarding the burden of ALS, considering all of the pALS they managed (5-item Likert-scale ranging from strongly disagree to strongly agree).
 - 73% of neurologists agreed or strongly agreed that pALS often express concerns to them about the financial burden of ALS.
 - Additionally, 74% of US neurologists agreed or strongly agreed that pALS often experience medical bankruptcy.

Strengths

- Physician, pALS and cALS perspectives were all sought.
- The real-world study design enables capture of data for pALS and cALS in general, independent of any therapeutic intervention or management strategy.

References: 1. Masrori P, Van Damme P. Amyotrophic lateral sclerosis: a clinical review. *Eur J Neurol.* 2020;27(10):1918-1929. 2. Schepelmann K, Winter Y, Spottke AE, et al. Socioeconomic burden of amyotrophic lateral sclerosis, myasthenia gravis and facioscapulohumeral muscular dystrophy. *J Neurol.* 2010;257(1):15-23. 3. Gladman M, Zinman L. The economic impact of amyotrophic lateral sclerosis: a systematic review. *Expert Rev Pharmacoecon Outcomes Res.* 2015;15(3):439-450. 4. Anderson P, Benford M, Harris N, Karavali M, Piercy J. Real-world physician and patient behaviour across countries: Disease-Specific Programmes - a means to understand. *Curr Med Res Opin.* 2008;24(11):3063-3072. 5. Stenson K et al. "Healthcare resource utilization at different stages of amyotrophic lateral sclerosis: Results from a real-world survey." *Journal of the Neurological Sciences* 452 (2023): 120764.
Disclosures: KS is an employee of and of and may hold stock and/or stock options in Biogen, USA. JM, JW, LE, NB, HI, OT are employees of Adelphi Real World and under contract with Biogen.

Methods

- Data were drawn from the Adelphi ALS Disease Specific Programme™ (DSP), a point-in-time survey of de-identified neurologists, pALS, and cALS in France, Germany, Italy, Spain, the UK, and the USA. The data were collected between July 2020 and March 2021.
- The DSP methodology has been previously published⁴ and was conducted according to the relevant regulations.
- Neurologists completed questionnaires on consulting pALS demographics, including employment status and living arrangements. These same pALS and their cALS, if applicable, were invited to complete questionnaires and answer questions from their perspectives.
- pALS disease stage was assessed using both King's and Milano-Torino staging (MiToS) systems, derived from their Revised Amyotrophic Lateral Sclerosis Functional Rating (ALSFRS-R) results.
- Descriptive statistics were reported throughout.

Figure 1. pALS- and cALS-reported changes to working arrangements

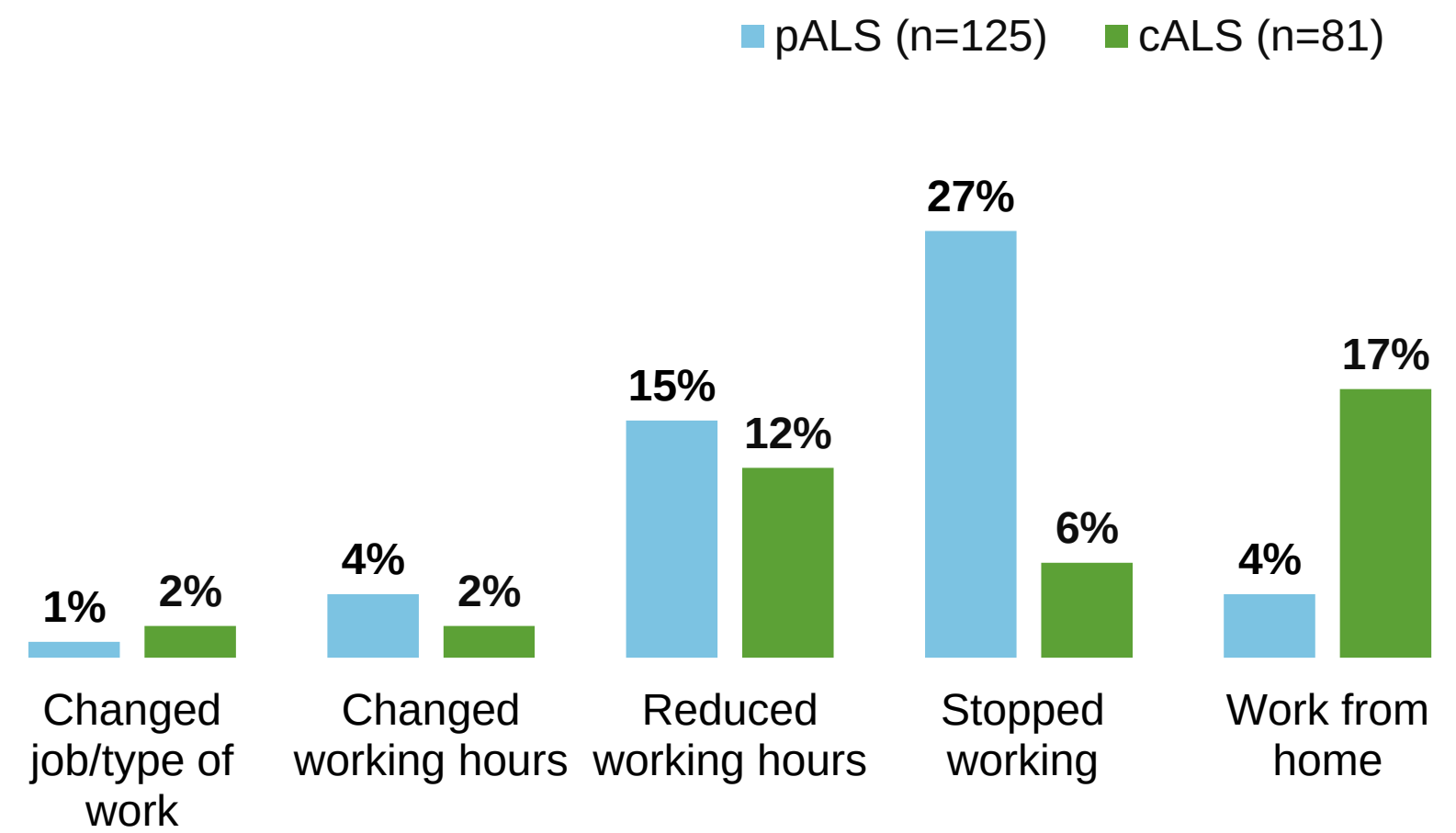


Figure 3. Physician-reported home modifications made by pALS

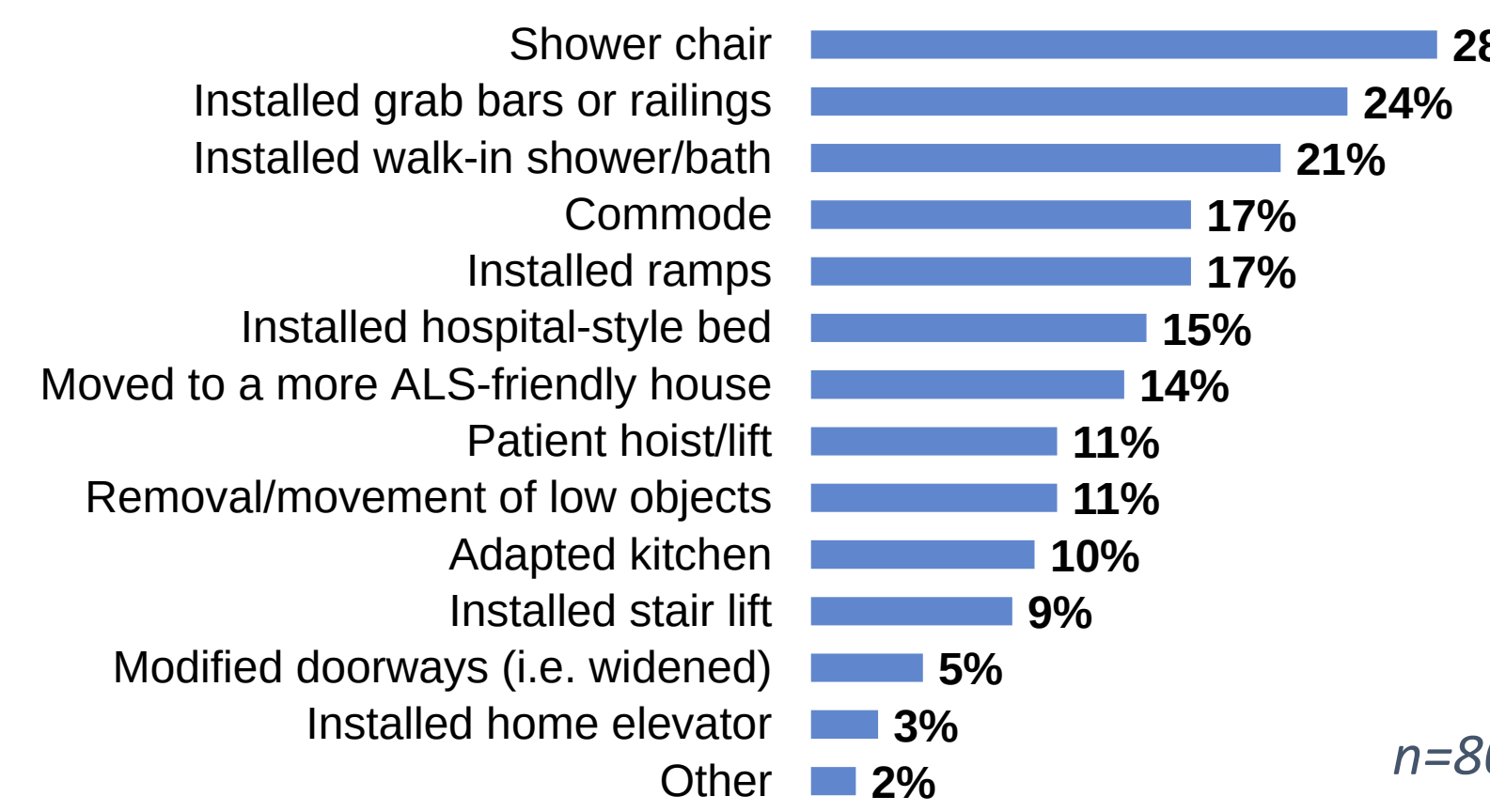


Figure 2. Physician-reported reasons for changes to pALS working arrangements

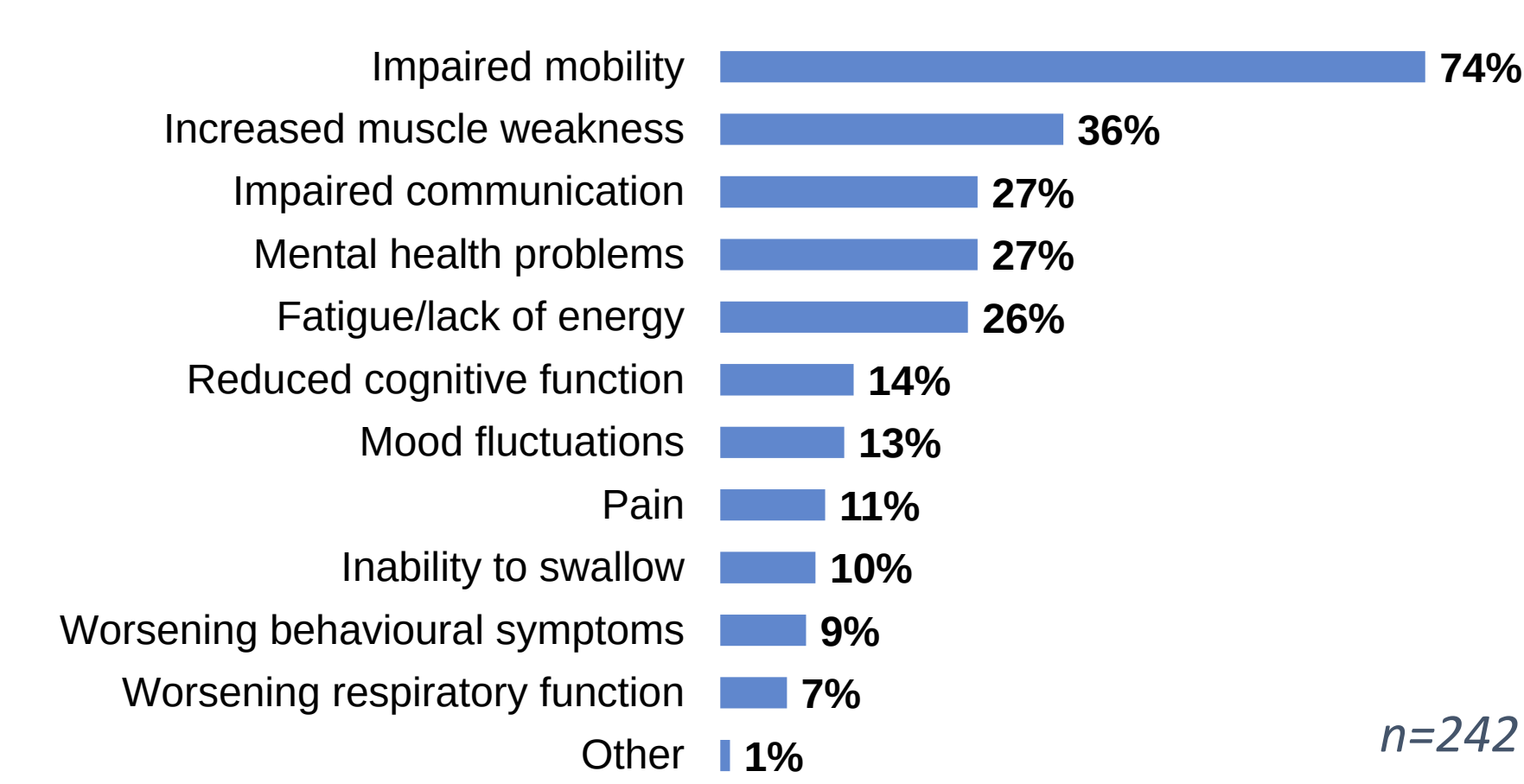


Figure 4. cALS-reported ADLs requiring support (top 10)

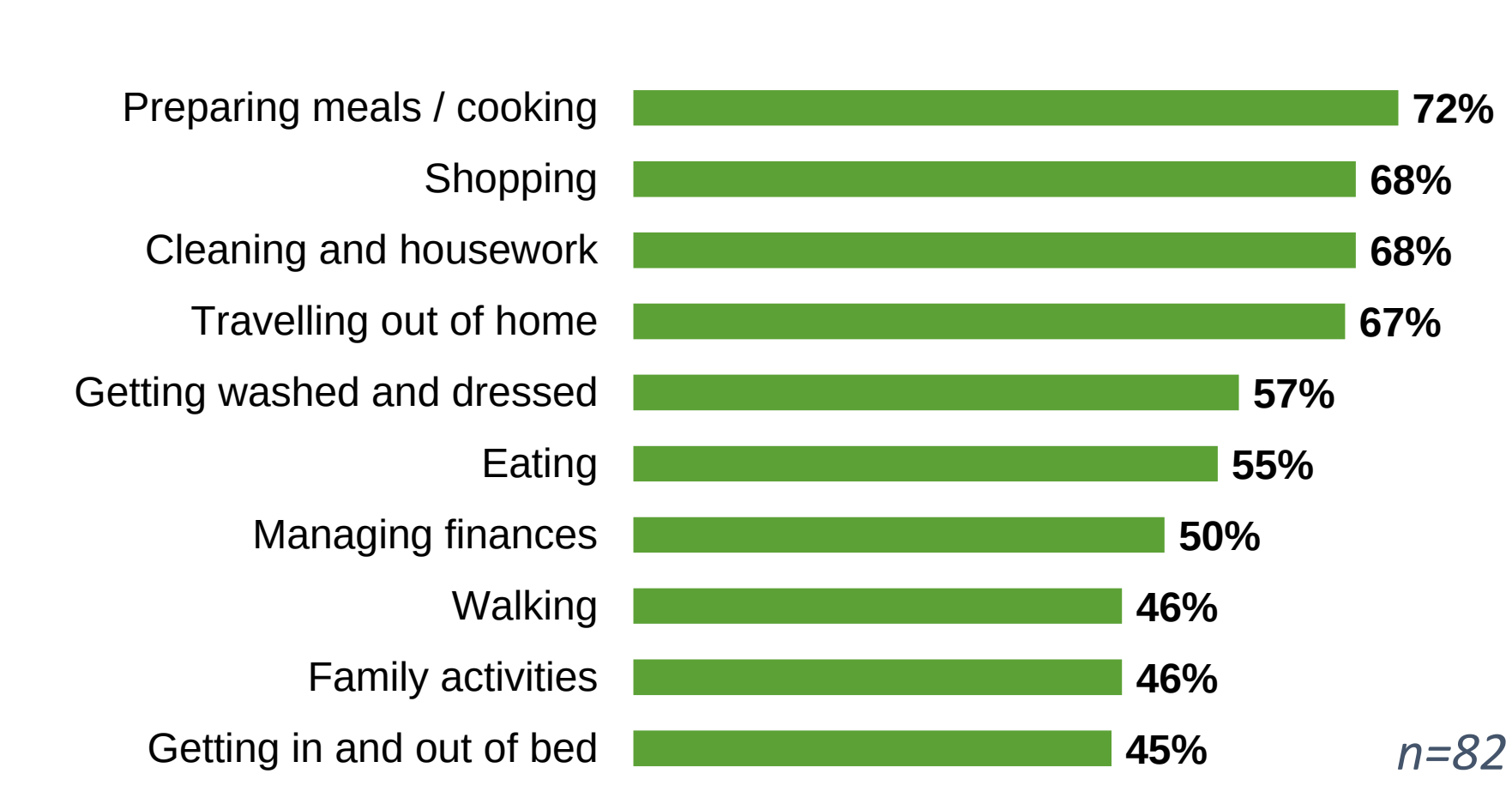
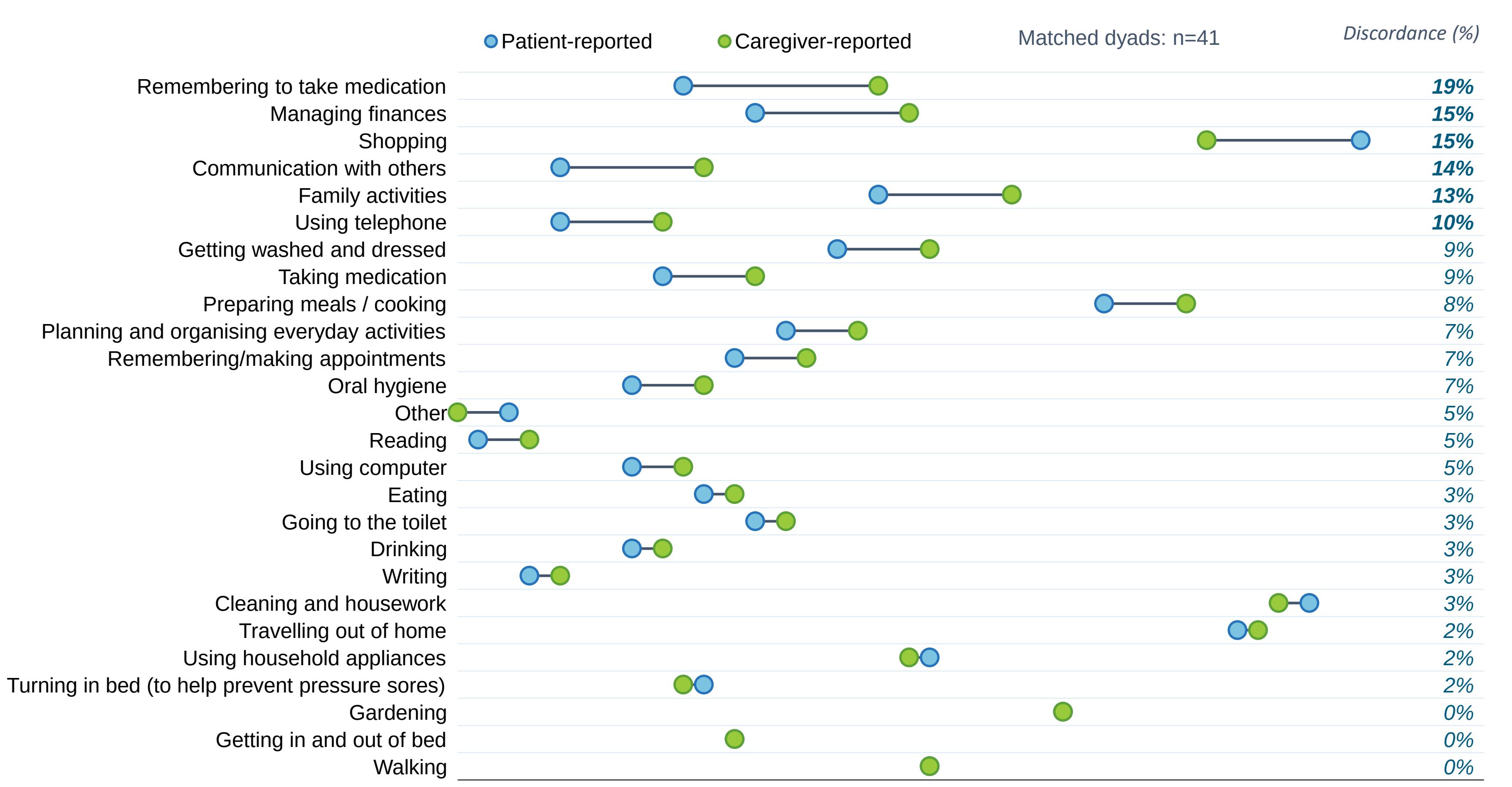


Figure 5. Concordance between pALS- and cALS- reported ADLs requiring support



Limitations

- The DSP is not based on a truly random sample of physicians and patients. While minimal inclusion criteria governed the selection of the participating physicians, participation is influenced by the willingness to complete the survey.