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Healthcare for adults with long-term neurological conditions: European Academy of Neurology Members Survey

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ABSTRACT

Background The number of people living with long-term neurological conditions (PwLTNC) in Europe is on the rise and they experience a variety of complex symptoms, often requiring hospital admissions. This survey explored challenges healthcare professionals are encountering when providing care for PwLTNC. **Methods** A web-based survey was developed by the European Academy of Neurology (EAN) Scientific Panel on Palliative Care and disseminated by the EAN Scientific Department through the official mailing list, website and newsletter in the period 3 January 2024 to 27 February 2024. The United Nations' geoscheme for Europe was applied and differences between the North/West vs South/East/Greater European regions analysed.

Results A total of 153 EAN members (50% women, mean age 48 years) were participated. They expressed their dissatisfaction with the availability of long-term healthcare, including palliative care (60%), psychosocial (67%) and spiritual support (60%) offered to PwLTNC, their families and carers, the resources to provide healthcare for PwLTNC in medical emergencies and knowledge of acute medical staff about PwLTNC (45%). Dissatisfaction with the availability of resources needed to provide healthcare for PwLTNC, the psychosocial support offered to PwLTNC and the extent of advance care planning implementation was more frequently reported in South/East/Greater Europe compared with North/West Europe.

Conclusion This survey of the EAN members revealed dissatisfaction with long-term healthcare, including palliative care, offered to PwLTNC, their families and carers and pointed out healthcare disparities between the two European macroregions, with more critical figures in South/East/Greater Europe.

WHAT IS ALREADY KNOWN ON THIS TOPIC

Palliative care alleviates suffering among people with long-term neurological conditions (PwLTNC). However, existing evidence is predominantly drawn from high-income countries and a narow range of neurological disorders, limiting its broader relevance.

WHAT THIS STUDY ADDS

⇒ European neurologists reported substantial shortcomings in the provision of palliative care for PwLTNC. Notably, these gaps are particularly evident in South, East and Greater Europe, highlighting marked regional disparities.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings underscore an urgent need to provide equitable and holistic palliative care for PwLTNC. There is a clear need for future research to investigate unmet palliative care needs across diverse neurological conditions and geographical regions.

INTRODUCTION

Worldwide, conditions affecting nervous system are emerging as a leading group cause of overall disease burden and disability; accounting for 443 million disability-adjusted life years (DALYs) in 2021 (95% CI 378 to 521) and affecting 3.40 billion (95% CI 3.20 to 3.62) individuals (43.1%, 95% CI 40.5 to 45.9 of the global population). In Europe, the total number of DALYs attributable to neurological disorders in 2017 was 41.1 million (95% CI 36.7 to 45.9) and the total number of deaths was 1.97 million (95% CI 1.95 to 2.01). Due to the rapid ageing of



the European population, the burden of age-related neurological disorders is expected to further increase, and effective prevention, treatment and rehabilitation strategies are urgently needed.² A long-term neurological condition (LTNC) is defined as a disease of, injury or damage to the nervous system, which affects the individual and their family in one way or another for the rest of their life, including not only progressive neurological conditions but also acute-onset neurological conditions leaving significant persisting disability in affected individuals.³ People with LTNC (PwLTNC) experience physical, psychosocial and spiritual or existential suffering from the time of their diagnosis, often requiring hospital admissions and urgent care access.⁴ When presenting with medical emergencies, their complex symptoms demand more time and resources and higher staff knowledge and expertise.¹⁵

The WHO defines palliative care (PC) as 'An approach that improves the quality of life of patients (adults and children) and their families facing problems associated with life threatening illness. It prevents and relieves suffering through an early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial and spiritual'. An early PC involvement may help effectively manage the symptoms and enhance quality of life of PwLTNC, but they only rarely receive PC. Given constrained number of PC specialists and limited access to PC, training neurologists to provide primary PC and integrate it into routine neurological care has a potential to increase access to PC.

This web-based survey conducted by the European Academy of Neurology (EAN) Scientific Panel on Palliative Care aimed to explore the challenges neurologists practising in Europe are encountering when providing care for PwLTNC.

MATERIALS AND METHODS

In January 2023, six management group members of the EAN Scientific Panel on Palliative Care with an expertise in both neurology and PC (the authors KR, DO, SV, AS, MdV and LV), representing six European countries (Belgium, Croatia, Germany, Italy, Netherlands and United Kingdom), designed this study during an online management group meeting. The study protocol and survey content were drafted in English, and further refined through a series of online meetings and email communication. Each team member conducted independent review; KR compiled and integrated team feedback. All six authors approved the final version of the survey, which consisted of an invitation letter (explaining the purpose of the study and completion time), and a total of 18 questions: 6 multiple-choice questions targeting participants' demographic and professional characteristics and 12 questions with Likert scale ratings enquiring about views and experience on healthcare delivery for PwLTNCsee online supplemental file 1). Completion time was

approximately 10 min. Participants could review and modify their responses before survey submission. No personal information was collected. No incentives were offered for competition of the survey. The survey was developed using Survey Monkey (Momentive Europe UC—Dublin, Ireland), in accordance with the Checklist for Reporting Results of Internet E-Surveys (online supplemental file 2). It was disseminated by the EAN Scientific Department through the official mailing list, website and newsletter in the period from 3 January 2024 until 27 February 2024.

Statistical analysis

Statistical analysis was run using IBM SPSS V.25 (IBM Corporation, USA). Categorical variables were summarised as numbers and percentages, and continuous variables as means and SD. Countries were assigned to groups using 'Standard Country or Area Codes for Statistical Use' ('the M49 standard' prepared by the Statistics Division of the United Nations Secretariat) as follows:

Eastern Europe

Belarus, Bulgaria, Czech Republic, Hungary, Poland, Moldova, Romania, Russia, Slovakia, Ukraine.

Western Europe

Austria, Belgium, France, Germany, Liechtenstein, Luxembourg, Monaco, Netherlands, Switzerland.

Northern Europe

Denmark, Estonia, Finland, Iceland, Ireland, Latvia, Lithuania, Norway, Sweden, United Kingdom.

Southern Europe

Albania, Andorra, Bosnia and Herzegovina, Croatia, Greece, Holy See, Italy, Kosovo, Malta, Montenegro, North Macedonia, Portugal, San Marino, Serbia, Slovenia, Spain.

Greater Europe

Turkey, Cyprus, Armenia, Georgia, Kazakhstan, Azerbaijan. ¹⁰

The assignment of countries or areas to specific groupings was for statistical convenience only, did not imply any assumption regarding political or other affiliation of countries or territories and had been previously used in analysis of surveys of EAN members. ¹⁰ ¹¹

The differences in responses between EAN members practising in the North/West vs South/East/Greater European regions were tested using the χ^2 test. Statistical significance was set at p \leq 0.05, and Bonferroni correction was used for multiple comparisons, when applicable.

RESULTS

Hundred and fifty-three EAN members (50% women, mean age 48 ± 13 years) participated. Seven responders

Characteristics of the 146 participants in the survey currently or previously practising in Europe

Characteristic	Number (%)
Women	75 (51.4)
Age—years*	48.4 (13.0)
Working place University hospital Public hospital Research facility Outpatient service Private hospital Private practice	108 (74.0) 32 (21.9) 2 (1.4) 2 (1.4) 1 (0.7) 1 (0.7)
Special interest Movement disorders Multiple sclerosis Dementia Motor neuron disease/amyotrophic lateral sclerosis Stroke Neurocritical care Epilepsy Neuroepidemiology Neuroinfective diseases	36 (24.7) 35 (24.0) 29 (19.9) 29 (19.9) 25 (17.1) 14 (9.6) 13 (8.9) 3 (2.1) 2 (1.4)
Area of Europe Southern† Northern‡ Western§ Eastern¶ Greater**	63 (43.1) 34 (23.3) 27 (18.5) 17 (11.6) 5 (3.4)
*Mean (SD). †Italy n=31; Portugal n=9; Croatia n=7; Slovenia, Spair n=4; Bosnia/Herzegovina, Serbia n=1. ‡United Kingdom n=21; Denmark n=5; Latvia n=3; No Estonia, Finland, Swedon n=1	•

Estonia, Finland, Sweden n=1.

§Austria, Switzerland n=7; Belgium n=5; Germany n=4; France n=3; Netherlands n=1.

¶Poland n=5; Hungary, Moldova n=4; Romania, Ukraine, n=2.

who currently practise in Brazil (n=2), Djibouti Republic (n=1), Egypt (n=1), New Zealand (n=2)and Saudi Arabia (n=1) were excluded from the analysis. Only responses provided by participants currently practising in European countries (N=146) were analysed. Table 1 shows the characteristics of participants and the geographical distribution of their current or past countries of practice. 134 responders currently practice neurology (92%), while 12 (8%) have practised in the past.

Views about healthcare offered to PwLTNC

The majority of respondents indicated that, in their respective countries, PwLTNC receive timely diagnosis (61%), and timely treatment (55%), have unrestricted access to acute neurology clinics (61%) and are treated by neurologists when they experience acute emergencies (61%). However, 45% of surveyed EAN members perceived the knowledge the acute medical staff have about LTNC as unsatisfactory and the resources available to provide care for PwLTNC in the context of medical emergencies as insufficient. The majority of participants stated that psychosocial

and spiritual support are not offered to PwLTNC when they experience medical emergencies (67% and 60%, respectively). Moreover, 60% of respondents felt that the availability of long-term healthcare for PwLTNC is insufficient, and 51% that advance care planning (ACP) is not well established. Only 36% of surveyed healthcare professionals expressed their satisfaction with the collaboration between PC and nursing homes, and 46% with the collaboration between PC and primary care doctors (figure 1).

Differences across European regions

Significantly higher proportion of respondents practising in South/East/Greater Europe, compared with those practising in North/West Europe, expressed their dissatisfaction with the availability of resources needed to provide healthcare for PwLTNC in the context of medical emergencies (50% vs 38%; p<0.001), and with the psychosocial (78% vs 54%; p=0.002) and spiritual (72% vs 43%; p=0.001) support offered to PwLTNC when they experience acute medical emergencies. A higher percentage of respondents practising in South/East/Greater Europe than those practising in North/West Europe reported that there is no close collaboration between PC and general practitioners (34% vs 7%; p<0.001), and that ACP for PwLTNC is not well established (67% vs 29%; p<0.001). The two groups did not differ significantly with regards to their views whether PwLTNC receive timely diagnosis, timely treatment, unrestricted access to acute neurology clinics and are treated by neurologists when admitted with acute medical emergencies; whether acute medical staff possess satisfactory knowledge and awareness of PwLTNC, whether there is sufficient availability of and access to long-term healthcare, and whether nursing homes and PC collaborate closely (table 2).

DISCUSSION

This web-based survey explored the challenges EAN members encounter when providing healthcare for PwLTNC and revealed their dissatisfaction with the following:

- The availability of long-term healthcare.
- The psychosocial and spiritual support offered to PwLTNC, their families and carers.
- The extent of ACP implementation among PwLTNC.

All of the above are integral aspects of PC. In some countries, neuropalliative care for PwLTNC is delivered by neurologists with additional PC training and experience, within a multidisciplinary team setting.⁴ ⁴ In fact, alignment of treatment with the patient's needs, values and preferences, a core element of PC, should be routine aspect of care delivered by any health professional and in any care setting. 12

Traditionally, PC equated with hospice care and cancer. 13 14 While some of these principles may be translated to PwLTNC, the two disease groups differ

^{**}Turkey n=3; Armenia, Cyprus n=1.

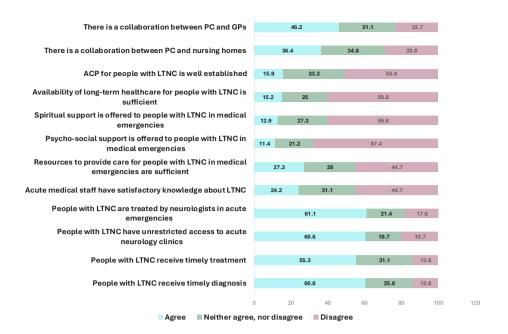


Figure 1 . Answers on the survey questions expressed as percentages. ACP, advance care planning; GP, general practitioner; PC, palliative care; PwLTNC, people with long-term neurological condition.

substantially. PwLTNC have unique PC needs, which are not limited to the end of life. 15 Evidence from clinical trials implicates that early integration of PC (coupled with other management strategies, including curative approaches) could enhance the quality of life (QoL) of PwLTNC, improve symptom management and increase patient and caregiver satisfaction. 16 17 For example, in the NE-PAL study (pilot, phase II randomized controlled trial, RCT), 50 PwLTNC (including those with amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease, multiple system atrophy and progressive supranuclear palsy) were randomised to receive either an immediate referral to the PC service (fast track) or a 16-week wait (standard track). After 16 weeks, fast-track participants had significant improvement in the QoL (measured by Schedule for the Evaluation of Individual Quality of Life Direct Weight, SEIQoLDW), pain, dyspnoea, sleep disturbance and bowel symptoms (on an 11-point numeric rating scale). 18 In a 6-month RCT with 76 pairs of people with multiple sclerosis (PwMS) and their caregivers, homebased PC approach significantly improved symptom burden measured by the Palliative care Outcome Scale-Symptoms-MS, compared with usual care. ¹² In another RCT with 103 PwMS and their caregivers, targeted consultations with multidisciplinary PC team yielded greater satisfaction, compared with standard care, while in a 26-week randomised trial with 52 PwMS (mean EDSS 7.7), already three multidisciplinary PC consultations reduced caregiver burden, costs to the health service, and pain (the Palliative

Care Outcome Scale). ¹⁹ ²⁰ In an RCT enrolling 210 people with Parkinson's disease and related disorders and 175 caregivers, participants receiving the PC intervention (outpatient integrated PC administered by a neurologist, social worker, chaplain and nurse using PC checklists, with guidance and selective involvement from a palliative medicine specialist), compared with participants receiving standard care, had better QoL (measured by the Quality of Life in Alzheimer Disease scale), reduced nonmotor symptom burden, motor symptom severity, higher rates and quality of advance directives, caregiver anxiety and caregiver burden (measured by Zarit burden interview) at 12 months. ¹³

Despite this, the role of PC for PwLTNC is still evolving and PC is rarely integrated in the care for PwLTNC: in the neurological patient experience web survey conducted by the Neurological Alliance (from 30 June 2014 until 17 September 2014, 6916 respondents with neurological disorders living in England), only 1% had regular contacts with PC.⁷ Similarly, a joint survey by the EAN, the European Association of Palliative Care (EAPC) and the Association of Palliative Medicine for Great Britain and Ireland (n=126 respondents) revealed that PC is involved in the care for people living with ALS when specific needs arise, but not necessarily from diagnosis.²¹

A key part in establishing neuropalliative care for PwLTNC is improving the education of neurologists, but in a recently conducted survey, only 3% of Italian Neurology residents (n=188 in total) reported that the neurology residency programme included education in

Table 2 Comparison of answers to the survey questions between neurologists from the two European macro-regions

*		Agree	Neither agree, ı disagree	nor Disagree	P χ² test
Do PwLTNC receive timely diagnosis?	North/West Europe n; %	37; 66.1%	10; 17.9%	9; 16.1%	0.216
	South/East/Greater Europe n; %	43; 56.6%	24; 31.6%	9; 11.8%	
Do PwLTNC receive timely treatment?	North/West Europe n; %	35; 62.5%	13; 23.2%	8; 14.3%	0.261
	South/East/Greater Europe n; %	38; 50%	28; 36.8%	10; 13.2%	
Is the access to acute neurology clinics for PwLTNC unrestricted?	North/West Europe n; %	34; 60.7%	9; 16.1%	13; 23.2%	0.549
	South/East/Greater Europe n; %	46; 60.5%	17; 22.4%	13; 17.1%	
Are PwLTNC admitted with acute medical emergencies treated by neurologists?	North/West Europe n; %	26; 47.3%	16; 29.1%	13; 23.6%	0.022
	South/East/Greater Europe n; %	54; 71.1%	12; 15.8%	10; 13.2%	
Is the knowledge and awareness about the LTNC among acute medical staff in your country satisfactory?	North/West Europe n; %	20; 35.7%	15; 26.8%	21; 37.5%	0.030
	South/East/Greater Europe n; %	12; 15.8%	26; 34.2%	38; 50.0%	
Are there sufficient resources to provide care for PwLTNC in the context of medical emergencies?	North/West Europe n; %	25; 44.6%	10; 17.9%	21; 37.5%	<0.001*
	South/East/Greater Europe n; %	11; 14.5%	27; 35.5%	38; 50.0%	
Is psycho-social support offered to PwLTNC, their families and carers in the context of medical emergencies?	n; %	12; 21.4%	14; 25.0%	30; 53.6%	0.002*
	South/East/Greater Europe n; %	3; 3.9%	14; 18.4%	59; 77.6%	
Is spiritual support offered to PwLTNC, their families and carers offered in the context of medical emergencies?	North/West Europe n; %	13; 23.2%	19; 33.9%	24; 42.9%	0.001*
	South/East/Greater Europe n; %	4; 5.3%	17; 22.4%	55; 72.4%	
Is there sufficient availability and access to long-term healthcare, including access to neurorehabilitation, for PwLTNC?	North/West Europe n; %	15; 26.8%	12; 21.4%	29; 51.8%	0.007
	South/East/Greater Europe n; %	5; 6.6%	21; 27.6%	50; 65.8%	
In general, is ACP for PwLTNC prior to the onset of changes in their decisional capacity well established in your country?	North/West Europe n; %	16; 28.6%	24; 42.9%	16; 28.6%	<0.001*
	South/East/Greater Europe n; %	5; 6.6%	20; 26.3%	51; 67.1%	

Continued

Table 2 Continued

Table 2 Continued							
*		Agree	Neither agree, n disagree	or Disagree	P χ² test		
Is there a close collaboration between palliative care and nursing homes?	North/West Europe n; %	25; 44.6%	23; 41.1%	8; 14.3%	0.007		
	South/East/Greater Europe n; %	23; 30.3%	23; 30.3%	30; 39.5%			
Is there a close collaboration between palliative care and GPs?	North/West Europe n; %	35; 62.5%	17; 30.4%	4; 7.1%	<0.001*		
	South/East/Greater Europe n; %	26; 34.2%	24; 31.6%	26; 34.2%			

Following Bonferroni correction, statistically significant differences were set at p<0.004 and are marked with *.

ACP, advance care planning; GP, general practitioner; PC, palliative care; PwLTNC, people with long-term neurological condition.

PC and only 18% had received ACP training. ²² In addition, clinicians often express concerns and reluctance to discuss PC, as its name itself, often associated with hospices and end of life care, may present a barrier to the acceptance of referral by PwLTNC. However, in a survey conducted jointly by the EAN and the EAPC in 2019, only 10% of 120 participating neurologists reported having experienced patient reluctance or refusal to see a PC team. ²¹ 23

Providing healthcare for PwLTNC is challenging. The management varies across different European countries and may be delivered by neurological services, neurorehabilitation, general medical services, geriatric medicine, primary care or PC. 16 Of note, along the disease trajectory, the integration of neurology, PC and rehabilitation competencies is key as well as the individualised care provided by each discipline. 12 In this survey, neurologists working in European countries, particularly those working in South/East/Greater Europe, expressed their dissatisfaction with the integration of care for PwLTNC. General PC for PwLTNC should be delivered, among others, by neurologists, while, on the other hand, management of more complex issues calls for collaboration with, and, if necessary, transfer to a specialist PC team. However, there is yet no consensus on how and when this should be initiated. Different 'triggers' for specialist PC referral have been proposed for PwLTNC. 15 17 24 However, the diversity of symptoms and illness trajectories PwLTNC may experience is challenging for a conventional model of PC, and a range of condition-specific triggers may be helpful. 15 There are specific challenges in caring for PwLTNC and these may affect the care provided. For instance, the variability in disease progression, communication and cognitive difficulties, threat to personhood and

existential distress, may all have profound effects on the caring team.¹⁶ In PwLTNC, cognitive impairment is highly prevalent and may occur early in the course of the disease —a prompt identification of cognitive impairment based on specialist assessment and early initiation of ACP are thus necessary.²⁴ In addition, proactive assessment of physical and psychosocial issues is recommended to reduce the need for crisis intervention (unplanned care).¹⁶

Second, the results of our survey highlighted healthcare disparities between the two European macroregions: participants practising in South/East/Greater Europe reported greater discontent with the availability of resources needed to provide healthcare for PwLTNC in the context of medical emergencies, with the psychosocial support offered to PwLTNC during acute medical emergencies, and with the practice of ACP, compared with participants practising in Nort/ West Europe. The two European macroregions are not homogeneous for economy or welfare. Of note, according to the WHO 2023 report, 63% of western and 26% of central and eastern European countries have a national PC plan, and it is possible that this contributes to the observed disparities. The report mentions the following barriers to PC implementation: a lack of awareness among policy-makers, health professionals and the public about what PC is, and the benefits it can offer to patients and health systems; cultural and social barriers, such as beliefs about death and dying; misconceptions about PC, such as that it is only for patients with cancer, or for the last weeks of life. Strategies to promote neuropalliative care particularly targeting PwLTNC living in East/South/Greater Europe are urgently needed.

^{*}A substantial number of participants practising in North/West Europe practised in the UK (21 out of 61, 34%), while among those practising in South/ East/Greater Europe, a high number practised in Italy (31 out of 85, 37%). In the sensitivity analysis (online supplemental file 3), the responses provided by participants practicing in Italy and United Kingdom did not impact inter-region differences regarding the expressed discontent with the availability of resources needed to provide healthcare for PwLTNC in the context of medical emergencies (49% vs 29%; p<0.001), with the psycho-social support offered to PwLTNC during acute medical emergencies (80% vs 47%; p=0.003), and with the extent of ACP being well established in PwLTNC (71% vs 29%; p<0.001).

This study has several limitations. Participation in the survey was overall low. As with all surveys, we cannot be certain that the responses provided by the participants are fully representative of all healthcare providers practising in Europe. Bias may have occurred due to varying response rates across the countries (eg, higher response rates from Italy and the United Kingdom). However, findings of the sensitivity analysis were consistent with the main analysis. Another limitation is that we did not address the views and experiences of PwLTNC and their caregivers, a key issue that should be the focus of future studies.

CONCLUSION

This survey of the EAN members revealed unsatisfaction with the availability of long-term healthcare, including PC, psychosocial and spiritual support offered to PwLTNC, their families and carers. The care offered to PwLTNC lacks integration, and ACP process is not well established. Moreover, the survey pointed out healthcare disparities between the two European macroregions, with more critical figures in South/East/Greater Europe.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval The study protocol and the survey were submitted to the European Academy of Neurology (EAN) Scientific Committee on 1 September 2023 and approved on 16 October 2023. This study presents research involving healthcare staff recruited as research participants by virtue of their professional role and does not include any identifiable personal information. Thus, a review by a Research Ethics Committee is not required. (REC; Governance Arrangements for Research Ethics Committees, paragraph 2.3.14). All data were handled in accordance with the General Data Protection Regulation (EU) 2016/679. Participants gave informed consent to participate in the study before taking part.

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REFERENCES

- 1 Steinmetz JD, Seeher KM, Schiess N, *et al.* Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *Lancet Neurol* 2024;23:344–81.
- 2 Deuschl G, Beghi E, Fazekas F, et al. The burden of neurological diseases in Europe: an analysis for the Global Burden of Disease Study 2017. Lancet Public Health 2020;5:e551-67.
- 3 Conditions NSFLT. National Service Framework: Long Term Conditions, 2005.
- 4 Kluger BM, Hudson P, Hanson LC, *et al*. Palliative care to support the needs of adults with neurological disease. *Lancet Neurol* 2023;22:619–31.
- 5 Mason S, Lewis J, Wren J. Tackling the burden of chronic ill health in emergency medicine. CJEM 2024;26:369–70.
- 6 WHO. Palliative care. 2023.
- 7 Alliance. tn. invisible patients. Available: https://www.neural. org.uk/assets/pdfs/2015-01-invisible-patients.pdf
- 8 Bock MA, Macchi ZA, Harrison KL, *et al.* Does a novel community-based outpatient palliative care intervention for Parkinson's disease and related disorders improve care? Qualitative results from patients and care partners. *Palliat Med* 2024;38:240–50.
- 9 Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004;6:e34.
- 10 Nations U. United Nations standard countries or area codes for statistical use (m49).
- 11 Habek M, Leys F, Krbot Skorić M, et al. Clinical autonomic nervous system laboratories in Europe: A joint survey of the European Academy of Neurology and the European Federation of Autonomic Societies: A joint survey of the European Academy of Neurology and the European Federation of Autonomic Societies. Eur J Neurol 2022;29:3633–46.
- 12 Solari A, Giordano A, Patti F, et al. Randomized controlled trial of a home-based palliative approach for people with severe multiple sclerosis. Mult Scler 2018;24:663–74.
- 13 Kluger BM, Miyasaki J, Katz M, et al. Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders: A Randomized Clinical Trial. JAMA Neurol 2020;77:551–60.
- 14 Turner-Stokes L, Sykes N, Silber E, *et al*. Long-term neurological conditions: management at the interface between

⁸Palliative Care, FARO, Turin, SP, Brazil

Features

- neurology, rehabilitation and palliative care. *Clin Med (Lond)* 2008;8:186–91.
- 15 McConvey K, Kazazian K, Iansavichene AE, et al. Triggers for Referral to Specialized Palliative Care in Advanced Neurologic and Neurosurgical Conditions: A Systematic Review. Neurol Clin Pract 2022;12:190–202.
- 16 Oliver DJ, Borasio GD, Caraceni A, et al. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. Eur J Neurol 2016;23:30–8.
- 17 Chang RS-K, Poon WS. "Triggers" for referral to neurology palliative care service. *Ann Palliat Med* 2018;7:289–95.
- 18 Veronese S, Gallo G, Valle A, et al. Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study. BMJ Support Palliat Care 2017;7:164–72.
- 19 Higginson IJ, McCrone P, Hart SR, *et al.* Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *J Pain Symptom Manage* 2009;38:816–26.

- 20 Bužgová R, Kozáková R, Bar M. Satisfaction of Patients With Severe Multiple Sclerosis and Their Family Members With Palliative Care: Interventional Study. Am J Hosp Palliat Care 2021;38:1348–55.
- 21 Oliver D, Baker I, Borasio GD, et al. The involvement of palliative care with neurology a comparison of UK, Switzerland and Italy. Amyotroph Lateral Scler Frontotemporal Degener 2023;24:256–62.
- 22 Bombaci A, Di Lorenzo F, Pucci E, et al. Education needs in palliative care and advance care planning of Italian residents in neurology: an online survey. Eur J Neurol 2024;31:e16376.
- 23 Oliver D, Borasio GD, Veronese S, et al. Current collaboration between palliative care and neurology: a survey of clinicians in Europe. BMJ Support Palliat Care 2020.
- 24 Hussain J, Adams D, Allgar V, et al. Triggers in advanced neurological conditions: prediction and management of the terminal phase. BMJ Support Palliat Care 2014;4:30–7.