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# Current collaboration between palliative care and neurology: a survey of clinicians in Europe

Professor David Oliver  
Tizard Centre  
Cornwallis North East  
University of Kent  
Canterbury  
Kent CT2 2NF  
UK  
[drdjoliver@gmail.com](mailto:drdjoliver@gmail.com)  
[+44 1634 846380](tel:+441634846380)  
[+44 7981 951701](tel:+447981951701)  
Corresponding author

Professor Gian Domenico Borasio  
Palliative and Supportive Care Service  
Lausanne University Hospital and University of Lausanne  
Lausanne, Switzerland

Dr Simone Veronese  
Fondazione FARO  
Turin, Italy

Professor Raymond Voltz  
Department of Palliative Medicine  
University Hospital Cologne  
Cologne, Germany

Professor Stefan Lorenzl  
Institute of Nursing Sciences and Practice  
Paracelsus Medical University  
Salzburg, Austria

Dr Nilay Heggul  
Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation  
King's College, London  
London, UK  
Education

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## **Abstract**

**Introduction:** The collaboration between palliative care and neurology has developed over the last 25 years and this study aimed to ascertain the collaboration between the specialties across Europe.

**Methods:** This online survey aimed to look at collaboration across Europe, using the links of the European Association for Palliative Care and the European Academy of Neurology.

**Results:** 298 people completed the survey – 178 from palliative care and 120 from neurology from over 20 countries across Europe. They reported that there was good collaboration in the care for people with amyotrophic lateral sclerosis and cerebral tumours but less for other progressive neurological diseases. The collaboration included joint meetings and clinics and telephone contacts. All felt that the collaboration was helpful, particularly for maintaining quality of life, physical symptom management, psychological support and complex decision making, including ethical issues.

**Discussion:** The study shows evidence for collaboration between palliative care and neurology, but with the need to develop this for all neurological illness, and there is a need for increased education of both areas.

## **Introduction**

Although palliative and hospice care is often associated with care of people with cancer, the role of palliative care in the care of people with progressive neurological disease has been increasingly adopted over the last 25 years, particularly amyotrophic lateral sclerosis / motor neurone disease (ALS/MND). Studies showed the many issues and symptoms experienced by ALS/MND patients could be managed effectively so that the majority of patients died peacefully [1,2].

More recently the European Association for Palliative Care (EAPC) and the European Academy of Neurology (EAN) collaborated in producing a Consensus Paper on neurological palliative care [3]. This outlined the main areas for collaboration: early involvement of palliative care, symptom management, carer support, communication and advance care planning, multidisciplinary team approach, end of life care including recognition of this phase, and education and training of professionals in both palliative care and neurology [3]. In the USA there has been development of Neuro-palliative care, with the additional training of neurologists who can then provide the fuller holistic approach [4,5].

The collaboration between palliative care and neurology has been studied to a limited extent. A UK survey showed that there were regular contacts between services for ALS/MND care – with 23% having regular contact with neurology services and 36% having contact with the MND Association [6]. The OPTCARE Neuro survey in the UK showed that, even in the centres which were about to undertake a trial intervention, the collaboration between the specialities was reported as good/excellent by only 36% of neurology and 58% of palliative care professionals [7]. Other studies have shown the benefits of multidisciplinary team working, with improvement in length of life for ALS/MND patients [8]. Moreover, guidelines have suggested increased palliative care involvement for MND [9,10,11], multiple sclerosis (MS) [12], Parkinson's disease (PD) [13] and glioma [14].

However, the number of people with progressive neurological disease receiving palliative care remains small. In the UK only 1.2% of surveyed neurological patients had contact with a palliative care team [15] whereas 88% of cancer patients have contact with palliative care during the disease progression [16]. Moreover, 5% of deaths of neurological patients are in a hospice and 18% at home, compared to 16% of cancer patient deaths in a hospice and 29% at home [17].

This study aimed to build on the collaboration between the EAPC and EAN to ascertain the level of collaboration between neurology and palliative care services by using an online survey of practitioners across Europe.

## **Methods**

An online survey was produced asking about the country of the person, their involvement with different disease groups, collaboration with the other discipline and their assessment of their competence in providing palliative care for people with neurological disease. There were two versions – for neurologists and for palliative care physicians – with appropriate differences according to the discipline.

Details of the survey were circulated to the membership of the EAPC and EAN. Members of the EAPC Reference Group on Neurology and the EAN Speciality Group on Palliative Care were also provided with the details and asked to disseminate among their contacts. Members of both groups, and the EAPC and EAN, were asked to circulate to their membership. This was repeated after one month and a total of two months was allowed for completion. Additionally, the Italian Society for Palliative Care (SICP) and the Italian Society of Neurology (SIN) both advertised the survey among their membership. The potential number of people who would have had access to the survey is unclear, as the circulation was by highlighted on the EAN and EAPC websites - the EAN represents 47 national associations and the EAPC has 60 national associations with large memberships. There was also targeted circulation to their special interest groups on palliative care - EAN Specialty Panel on palliative care has 25 members and the EAPC Reference Group on Neurology has 40 contacts.

Ethical approval for the study was obtained from the Ethics Committee of the Tizard Centre at the University of Kent, Canterbury, UK. At the start of the survey there was an explanation of the purpose of the study and how data would be handled. Continuation of the questionnaire was taken to show consent but participants could stop at any time if they wished.

The online survey was undertaken with SmartSurvey and a full analysis of the answers and the free text was available at the end of the survey period. The free text responses were analysed by two independent observers (DJO and NH) and the themes extracted.

## **Results**

661 people responded to the survey with 298 (45%) completed responses. Of these 178 were palliative care professionals from 14 countries, with a mean experience of 11.7 years, and 120 were neurologists from 20 countries, with a mean experience of 19.2 years. The commonest countries involved were: Italy (71 neurology and 142 palliative care; UK 9 / 9; Belgium 8 / 5; Croatia 0 / 6 ).

Their place of work of palliative care specialists was primarily in inpatients units, either hospice (68%), community (76%) and out-patients (52%). Neurologists were involved in hospital (67%), community based settings, including clinics (86%) or out-patients (64%).

The participants were members of wider team and the other disciplines within their teams are shown in Table 1. Although these teams were multidisciplinary, occupational therapy and speech and language therapy were less often within palliative care teams, and occupational therapy, social care and spiritual care were less often represented within neurology teams.

The neurological diseases where there was felt to be collaboration between the teams are shown in Table 2. Cerebral tumour and ALS/MND were the most common diseases with collaboration and for Huntington's disease, cortico-basal syndrome and myopathies there was the least collaboration.

The methods of collaboration are shown in Table 3. The commonest collaboration was by regular telephone contact and joint clinics. Regular meetings, such as multidisciplinary meetings involving both areas, were uncommon.

Barriers to collaboration identified by palliative care professionals included the reluctance of neurologists to refer patients to them (43%), financial or resource issues (20%) and the wish of family doctors to continue care so that they not involve them (17%). Only 15% of the palliative care professionals identified patient reluctance or refusal as a barrier. There were no comments added by participants.

Neurologists also identified barriers to collaboration, including the lack of palliative care services in their area (28%), palliative care services not accepting referrals for patients with neurological disease (14%), and financial or other resource issues (43%). Patient reluctance or refusal to see a palliative care team was viewed to be rare – 10%.

The main areas felt to be important for collaboration by both groups are shown in Table 4. There was general agreement that the most important areas where palliative care would be beneficial were supporting quality of life, caregiver support, psychological support and complex decision making. Advice on financial issues was felt to be of a lesser priority, although this was seen as more important within palliative care services.

The self-assessment of their expertise did show that there were concerns. Only 18% of palliative care professionals felt that they had expert or very good knowledge of neurology and 44% stated that their expertise was none, limited or somewhat. 16% of neurologists stated that their expertise in palliative care was very good or expert and 57% stated that their expertise was none, limited, or somewhat.

## **Discussion**

This survey shows that there is evidence of collaboration between palliative care specialists and neurologists across Europe. Moreover, this collaboration is seen as useful and helpful, particularly for areas that are complex in nature or require greater psychosocial support for patients and families. However, the main areas of collaboration are for cerebral tumours and ALS/MND with some collaboration for PD, MS, dementia and stroke, and little contact for Huntington's disease (HD) or myopathies. This may reflect differences in the understanding of probable prognosis of these diseases – as ALS and cerebral tumours may have a shorter prognosis and a clearer trajectory of deterioration compared to the longer, and often uncertain pattern, of deterioration for patients with PD and associated diseases, HD and myopathies.

The team approach would seem to be apparent in both areas, although there are differences. Palliative care teams are less likely to have speech and language therapists, which may be very important in the assessment of many patients with progressive neurological disease, who frequently have speech impairment or swallowing problems. Neurology teams have less social and spiritual support and this may be reflected in the neurologists seeing palliative care as providing this increased support for patients and families.

There are some barriers to this collaboration, although it would seem that patient and family reluctance to meet palliative care teams is not a major area of concern [18]. There may be differences across Europe in the availability of palliative care, especially teams who are involved with neurological disease. Although there is increasing interest in neurology, palliative care services may be reluctant to see people with progressive neurological disease due to concerns of staff of potential large numbers of patients who could be seen, and the pressure on resources. Other issues that increase this reluctance may be the trajectory of disease progression and prognosis being very variable – from months to years, with varying caring needs over these periods of time - the difficulty in identifying a dying phase, complexity of assessment and care, and the difficulties in accessing community services and equipment [19]. There are specific issues associated with the care of neurological disease including the variable timelines of progression, communication barriers, threats to personhood due to functional and cognitive change, and existential distress due to loss of autonomy, disability and fears of dying and death [20]. Financial and resource implications for collaboration will vary between countries and may need to be addressed locally.

The results also suggest that there may be reluctance on the part of neurologists to refer patients for palliative care. Many neurologists may be reluctant to discuss the diagnosis of a progressive disease or the possible deterioration [21]. There may be reluctance to discuss possible complications and the likely prognosis, including discussion of the likelihood of death [22]. This is despite evidence that good communication, with an empathic approach, is appreciated by patients and families [23] and the provision of information in a timely way, allowing an awareness of prognosis, may help in decision making and reduce patient anxiety [24].

The knowledge of both palliative care doctors and neurologists would seem to be an issue. This has been raised for many years and in 1996 the American Academy of Neurology Ethics and Humanities Subcommittee, in the USA, suggested that the principles of palliative care “are relevant to the management of almost all patients” [25]. Over 20 years ago research in the USA suggested that “neurologists have a duty to provide adequate palliative care” and made recommendations for the care of patients, in particular the ethical and legal issues of refusal of life sustaining treatment [26]. The need for education of neurologists in palliative care was emphasized in the care of dying patients, as it was found that many neurologists were very unclear about the ethical issues of withdrawing and withholding treatment and using analgesics at the end of life [21]. A recent online survey of consultants and residents in neurology in the Netherlands showed that discussions about these issues of withholding and withdrawing interventions or medication were often late in the disease progression in PD and MS but earlier in ALS and glioma [27]. Moreover, 75% of residents and 64% of consultants had received education and training in the discussion of these issues [27]. In 2014 it was found that in only 52% of training institutions included lectures on end of life care and palliative care and only 8% offered a clinical rotation in palliative care for neurologists [22].

Although there is evidence of increasing collaboration for cerebral tumours and ALS/MND the other progressive neurological diseases are largely ignored. There is increasing evidence of an important role for multidisciplinary team care and palliative care for neurological patients, with evidence of improved quality of life and often length of life [8]. Moreover, a randomized controlled trial of a

16week multidisciplinary palliative care intervention, using a waiting list method, did show that there were improvements in quality of life, and symptoms – pain, breathlessness, bowel issues and sleep [28]. This trial included ALS/MND, MS and PD and related diseases. Other Phase II trials have shown that short term palliative care interventions in for MS patients improved symptoms and caregiver burden in the group receiving palliative care, whereas there was deterioration in the control group [12]. The involvement of specialist nurses, who had received extra training in palliative care and support, was shown to reduce symptom burden but had no effect on quality of life or other outcomes [29].

The educational needs of both specialties were addressed in the EAN/EAPC Consensus Paper, which recommended education and training for both specialties in the other area of care. Palliative care services may also have limited knowledge of the specific issues of people with neurological disease and the availability and effectiveness of interventions and medications [3]. There may be little education in palliative care principles for neurological teams (neurologists in training and continuing medical education for those in practice) involved in care. There may also be a need for all professionals to be trained in communication skills, when coping with these complex issues, particularly when faced with variable cognition.

There are limitations to an online survey such as this. The respondents were those who had received or seen details of the survey within the communication outlets of the EAPC and EAN. This may bias the respondents to those with a particular interest in palliative care and neurology. Moreover, there was a large response from Italian neurologists, who responded more enthusiastically to the request for involvement in the study from the Italian Society of Neurology and the Italian Society of Palliative Care. This may have biased the figures, and a separate publication is planned looking at these Italian responses. However, there were responses from many different countries and the results may reflect an overall impression of the collaboration across Europe. This survey was limited to adult palliative care whereas the prevalence of neurological impairment in the paediatric population is higher, with reports of up to 75% [30]. The collaboration for this paediatric group is an area for further study.

This study shows some evidence of collaboration for some chronic progressive neurological disease but also a need for increased education and collaboration for all progressive disease groups, associated with severe disability and reduced life expectancy. There is increasing interest in developing collaboration including the use of triggers for referral [31], joint and close working in out-patient clinics [32], telemedicine [33] and the development of “neuro-palliative care” – with increased training of neurologists who could provide the ongoing care of patients with progressive neurological disease (4,5). Further research is needed to build an evidence base showing the effectiveness of palliative care in neurology and to ascertain the best model for this interaction.

### **Contributors**

Authors DO, GDB, SV, RV, SL and NH contributed to study design and implementation of the study and analysis of the dataset, provided critical feedback and revisions on the manuscript and approved the final version for submission.

### **Disclosure of conflicts of interest**

The authors declare no financial or other conflicts of interest

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## Competing interests

None declared

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**Table 1** Multidisciplinary team members

	Palliative care	Neurology
Doctor	90%	94%
Nurse	98%	99%
Psychologist	90%	79%
Physiotherapist	77%	79%
Social worker	73%	53%
Spiritual care	61%	43%
Occupational Therapist	27%	43%
Speech and language therapist	18%	68%

**Table 2** Collaboration for different neurological diseases

	Palliative care			Neurology		
	Strong /	Strong+moderate/	None	Strong /	Strong+moderate/	None
Cerebral tumour	36%	68%	13%	33%	63%	20%
ALS	31%	63%	14%	45%	70%	10%
Dementia	14%	30%	24%	9%	39%	25%
Stroke	13%	34%	31%	12%	36%	31%
MS	8%	34%	31%	9%	37%	30%
PD	7%	30%	27%	5%	27%	38%
MSA	3%	20%	45%	7%	32%	42%
PSP	3%	17%	49%	7%	31%	41%
HD	4%	14%	62%	7%	36%	35%
CBD	3%	14%	62%	5%	26%	42%
Myopathies	5%	10%	68%	9%	26%	40%

**Table 3** Modes of collaboration

	Palliative care	Neurology
Joint Out-patient Clinics	29%	24%
Multidisciplinary Team meetings	25%	29%
Informal Meetings	20%	21%
Ward rounds	15%	13%
Telephone calls	50%	50%

**Table 4** Areas where collaboration would be considered to be useful or expected

	Palliative care	Neurology
Quality of life	99%	85%
Physical symptoms	94%	74%
Psychological support	96%	77%
Complex decision making	96%	76%
Information	97%	68%
Caregiver Quality of life	94%	83%
Caregiver anxiety	95%	74%
Advance care planning	90%	71%
Practical problems	86%	68%
Coordination of care	75%	60%
Hospital admission	61%	60%
Finances	43%	26%