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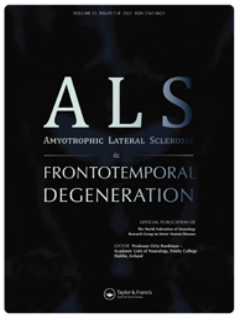

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RESEARCH ARTICLE

The involvement of palliative care with neurology – a comparison of UK, Switzerland and Italy

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Abstract

Objectives: To ascertain the involvement of palliative care with neurology services in the care of people with amyotrophic lateral sclerosis (ALS) in the United Kingdom, Italy and Switzerland, in particular the collaboration with and referral from neurology, the involvement in multidisciplinary team care and in the respiratory support of ALS patients. *Methods*: In 2019, two online surveys were undertaken of palliative care specialists, using specialist groups of the European Academy of Neurology, European Association of Palliative Care and the Association of Palliative Medicine for Great Britain and Ireland. *Results*: The respondents were specialist palliative care professionals, predominantly senior doctors, involved in the care of people with ALS. As the numbers of respondents from many countries were in single figures the analysis was restricted to the United Kingdom, Italy and Switzerland. The time of involvement varied, with early involvement commonest in the UK. Barriers to referral included neurologists not referring and financial issues, particularly in Switzerland. The reluctance of patients and families to see palliative care services was reported as less than 20% in all countries. Respondents were often involved in the care of people receiving noninvasive ventilation (NIV), in all countries. and with tracheostomy ventilation (TV), particularly in Italy. *Conclusions*: Palliative care services are often involved in the care of people with ALS, but the extent and timing of involvement varies. The use of clinical guidelines and education on palliative care for neurology services may encourage collaboration, for the benefit of people with ALS and their families.

Keywords: *Palliative care, amyotrophic lateral sclerosis, neurology, early referral, multidisciplinary team care, quality of life*

Introduction

Palliative care has been closely involved with people with amyotrophic lateral sclerosis (ALS, also known as motor neurone disease (MND)) for many decades. St Christopher's Hospice, opened by Dame Cicely Saunders in 1967 in south London, admitted people with ALS from the early days (1) and a review of these patients showed that palliative care was able to offer a great deal for these patients–symptom management, psychosocial care and evidence of a peaceful death (2,3). This collaboration between specialist palliative care services and neurology was found in a survey in 2019 in many European countries, when strong or

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moderate collaboration was reported by 63% of palliative care specialists and 70% of neurologists (4). Moreover, palliative care is now included in many guidelines on the care of people with ALS (5,6).

There is also increasing evidence that palliative care may improve the quality of life for people with chronic progressive neurological disease, such as ALS, and their families. A study in Italy, which included ALS patients, showed that a specialist palliative care team approach at home improved symptom management—in pain, bowel issues, sleep and dyspnea—and improved quality of life (7). Further studies of the multidisciplinary outpatient approach have shown improvement in symptom burden, emotional issues, non-religious spiritual issues and quality of life and there were positive effects for carers for symptom burden, emotional functioning, non-religious spiritual care, assessment of their own health and quality of life (8), reduced carer burden and improved quality of life (9).

Although palliative care services and neurology teams do seem to collaborate closely in the care of ALS patients, there is less evidence as to how this collaboration actually pertains to patients and their families. The earlier survey looking at the collaboration across neurological diseases did suggest that ALS and cerebral tumors were the areas where there was closest collaboration (4). This included joint outpatient clinics, multidisciplinary meetings, informal meetings and telephone calls. However, there was no specific information on the level and benefits of collaboration for ALS patients. This study aimed to look in greater detail at the collaboration between services for this specific group of patients.

Methods

Two surveys on ALS care were undertaken over the same time period. Originally these surveys were to have been undertaken independently, but due to the Covid-19 pandemic these plans were changed and the surveys were undertaken at the same time, when the infection rates were lower in the autumn of 2021. The surveys were designed by the authors, based on an earlier survey of palliative care collaboration with neurological services across Europe (4). All group members undertook the trial of the survey initially to ensure it was clear and small changes were made following this trial.

An online survey was organized by the European Academy of Neurology (EAN) Scientific Panel and the European Association for Palliative Care (EAPC) Reference Group on Neurology. This was sent to specialist palliative care services, using the links through the membership of these groups, and wider advertising within the EAPC website and congress.

The Survey asked for details of the service, the involvement in ALS care, the referral criteria and acceptance criteria for ALS, the extent of joint working with neurology services, the perceived barriers to collaboration, the other collaboration with other disciplines and the involvement of the service with patients requiring respiratory support. An initial Information Sheet was provided on the first page and consent was assumed when the participant started the survey.

A similar online survey was circulated in the United Kingdom through the Association for Palliative Medicine (APM), the members of which are primarily doctors working within specialist palliative care. The Survey was similar to the European study, with the addition of asking for an assessment of the expertise of both the individual and of the service in which they work, as the survey had been originally envisaged of the specialist palliative care services across the United Kingdom. Consent was assumed when the participant started the survey. Participants were encouraged to discuss with colleagues at their institution so that only one response was sent from each hospice.

The frequency of the responses was compared, but as the numbers were small no statistical analysis was undertaken. The results are shown in the Results for comparison and discussed in the Discussion.

Ethical approval for the study was obtained from the University of Kent Tizard Centre Ethics Committee (June 26th 2021).

Results

One hundred and twenty-six people completed the European survey, from 11 countries. It is impossible to estimate the total potential numbers who were eligible to complete the survey, but the EAPC alone comprises 60 organizations, all with memberships of up to several thousand. Of the participants, 92 were from Italy and 17 from Switzerland. In Switzerland, 381 emails were sent to the membership, giving a response rate of 5%. In Italy, the details were made available on the website on both the neurological and palliative care societies and the number of potential participants is over 3000, and a response rate cannot be calculated. The responses from other countries were only in single digit numbers and so it was decided that only these respondents would be included in this analysis.

Eighty-six people completed the UK Survey. The total membership of the APM is over 1000 but the potential hospices who could be involved number about 250, and so the response rate is potentially 34%.

Table 1. Participants involvement in palliative care.

	UK	Switzerland	Italy
N	86	17	92
Community	81%	58%	80%
In patient	76%	88%	75%
Hospital	69%	88%	62%
Out patients	80%	65%	67%
Day hospice	65%	12%	17%

Table 2. Multidisciplinary team membership.

	UK	Switzerland	Italy
N	86	17	92
Physicians	100%	100%	95%
Nurses	100%	100%	96%
Physiotherapist	81%	71%	72%
Occupational therapist	79%	41%	22%
Social worker	62%	71%	52%
Psychologist	37%	76%	75%
Spiritual care	77%	65%	35%
Speech and language therapist	20%	24%	24%

Table 3. Time of acceptance for referral.

	UK	Switzerland	Italy
n	86	17	92
At or soon after diagnosis	45%	65%	42%
When specific needs are seen	79%	53%	46%
When a new intervention is commenced	19%	24%	22%
At end of life	1%	18%	23%
Only in the terminal phase	3%	12%	23%

Table 4. Collaboration with neurology services.

	UK	Switzerland	Italy
n	76	17	92
Joint clinics	30%	24%	35%
Regular multidisciplinary team meetings	60%	29%	21%
Joint ward rounds	8%	0%	13%
Regular meetings	38%	24%	13%
Regular telephone discussions	53%	24%	48%

Table 5. Collaboration with other disciplines.

	UK	Switzerland	Italy
n	76	17	92
Neurology	86%	71%	83%
Gastroenterology	32%	47%	38%
Respiratory services	64%	82%	67%
Rehabilitation/disability teams	50%	35%	52%
ALS Society/Association	41%	35%	42%

Characteristics of the respondents and the services they provide

The majority of respondents were senior doctors—Italy: 69 senior doctors, five other medical practitioners, 11 nurses, five psychologists, one physiotherapist and one speech and language therapist; Switzerland 16 senior doctors and one junior doctor.; UK 68 senior doctors, 18 other medical practitioners. All were working in specialist palliative care. They generally were experienced in their roles—the years' experience in palliative care was 16.2 years (range 1–30 years) for the United Kingdom, 11.9 years (range 1–35 years) for Italy and 9.5 years (range 1–20 years) for Switzerland. They were involved in all areas of palliative care, including community, hospice and hospital (Table 1).

The respondents all were part of wider multidisciplinary teams within specialist palliative care and the membership of their teams is shown in Table 2. Nearly, all the teams, in all three countries, included medical and nursing members and a large majority included physiotherapists. There was variation in the involvement of social workers and psychologists, with psychologists more often involved in Switzerland and Italy, compared to the United Kingdom. In all three countries, speech and language therapists were only named in about 25% of the teams, even though ALS patients may have severe swallowing and speech issues.

Referral criteria for ALS patients

The time that referrals would be accepted and the palliative care team would become involved varied between the countries. In the UK referral, this was often at the time of diagnosis or of specific needs, and rarely at the end of life or only on the terminal phase (Table 3). In Switzerland, the teams were more often involved at diagnosis, but 18% were involved at the end of life and 12% stated that they were only involved in the terminal stages. In Italy, although referral at diagnosis was reported by 42%, involvement only in the terminal stages was reported by 23%.

The characteristics of collaboration between neurology and palliative care

All areas described collaboration with neurology services. In all three countries, this was often at joint clinic—UK 30%, Switzerland 24% and Italy 35% and by telephone call (Table 4). In the UK, 60% described regular multidisciplinary team meetings (MDT), but this was less common in the other countries. This may reflect the development of MDT approach for ALS care in the United Kingdom. There was also evidence of collaboration with other disciplines involved in the care network for ALS patients (Table 5). There were differences between the countries in which members of the MDT were involved, but this may

Table 6. Barriers to collaboration with neurology services.

	UK	Switzerland		Italy	
n	76	17	Unsure*	92	Unsure*
Neurology services reluctant to refer patients	16%	53%	18%	42%	24%
Palliative care team not able to see neurology patients	0%	12%	6%	13%	29%
Financial/resources	13%	29%	18%	16%	36%
General Practitioner (Family doctor) provides all care	3%	18%	41%	16%	29%
Differences in treatment discussion and options between services	NA	12%	65%	17%	47%
Patient/family reluctant to see palliative care services	20%	12%	29%	11%	33%

*Response not sure/not applicable.

Table 7. Involvement with ventilatory support.

	UK	Switzerland	Italy
n	76	17	92
Noninvasive ventilation			
Involvement at initiation	25%	24%	35%
Follow up at home	34%	24%	55%
Discussion of withdrawal at patient's request	96%	NA	NA
Withdrawal of ventilation at home	72%	35%	57%
Withdrawal of ventilation in inpatient unit	86%	53%	43%
Tracheostomy			
Involvement with patients with tracheostomy ventilation	37%	47%	76%

Table 8. Self-assessed expertise of ALS care.

	UK	Switzerland	Italy
N	86	17	92
Limited	3%	12%	20%
Somewhat	13%	24%	21%
Good	30%	47%	42%
Very good	41%	12%	14%
Excellent	12%	5%	3%

reflect the different organization of services within the differing healthcare systems.

Perceived barriers to referral and collaboration

There was evidence of barriers to referral (Table 6). There appeared to be fewer neurologists who do not to refer to palliative care in the United Kingdom—reported by 16%—than in the other countries, where this was stated in 53% in Switzerland and 42% in Italy. However, there was uncertainty in Switzerland and Italy in all the responses to these questions. Financial issues and resources were grouped together as a question and these seemed to be a larger barrier in Switzerland. There did not seem to be appreciable barriers from palliative care teams to be involved, differences in the discussion of treatment options between palliative care and neurology, or the wish of family doctors to provide all care. Patient and family reluctance was low in all three countries – UK 20%, Switzerland 12% and Italy 11%.

Involvement of palliative care in respiratory support

The involvement in the management of patients with respiratory support, from either noninvasive ventilation (NIV) or invasive ventilation with a tracheostomy (TV) varied between the countries. In the United Kingdom, there was involvement in care at home—reported by 34%—but the main involvement was during discussion and the withdrawal of ventilation, at the patient's request (Table 7). In Switzerland and Italy, there was a slightly greater involvement at home but less involvement in withdrawal. Many services were involved in the care of patients with TV, but this was commoner in Italy – UK 37%, Switzerland 47% and Italy 76%. This may reflect different attitudes to the use of TV in the countries, with a greater incidence of TV in Italy.

The self-assessment of the respondents' expertise in the management of ALS is shown in Table 8. In the United Kingdom, only 16% assessed their expertise as limited or somewhat and 53% assessed as very good or excellent. In Switzerland and Italy, they assessed themselves as limited or "somewhat"—36% and 41% respectively. However, overall, most services assessed themselves as good and above—UK 83%, Switzerland 64%, Italy 59%.

Discussion

The results from this study show that there is involvement of palliative care services seeing people with ALS and collaborating with neurology teams. Earlier studies had already shown this inter-speciality collaboration: in the UK 74% of hospices saw ALS patients in 2000 (10) and more recently in many European countries in 2019 where cerebral tumor and ALS were the commonest areas of collaboration between palliative care and neurology (4).

The respondents were mainly part of wider MDT. The role of MDT approach has been recommended in many guidelines (5,6) and has been show to be helpful, with an increased length of life seen in two studies in the United Kingdom and Ireland (11,12). The teams varied in the three countries, and this may reflect differences in the health systems. There would appear to be a particular difference in psycho-social care, with specialist palliative care social workers in the United Kingdom often providing psychosocial support for patients and support for their families, whereas in Italy and Switzerland the personal support is provided by a psychologist. However, in all three countries speech and language therapy (SLT) was poorly represented within the teams, with involvement in less than 25% of the teams. This is concerning as people with neurological disease have speech, swallowing and communication issues and SLT is an important member of the team to help in the assessment and management of these problems (13,14). The UK National Institute for Health and Care Excellence (NICE) Guideline recommended that a member of the MDT should have palliative care experience or be part of a wider specialist palliative care team which provides the ongoing management of the patient and family (6). This does appear to be occurring in the United Kingdom, at least in the teams which responded, as 60% of teams reported that they collaborated with neurology at a MDT meeting, whereas this was much lower in Switzerland (27%) and Italy (21%).

The time when services were able to take referrals for care did vary across the countries. In the United Kingdom, teams appear to be involved at diagnosis or in the earlier stages of the disease and rarely only at the end of life. This may again reflect the close involvement and expertise of these respondents, who were closely involved in the MDT care of people with ALS and were able to act on the NICE recommendations for early involvement and discussion of end-of-life issues early in the disease progression. However, this may not be totally representative of all palliative care services in the United Kingdom. In Italy and Switzerland, early involvement did occur, but there was frequently involvement in the later stages of disease progression—12% of Swiss respondents and 23% of Italian respondents stated that they only saw patients in the terminal phase. The earlier involvement has been recommended in guidelines (15) but in other areas reluctance to take people with ALS has been found. This may also reflect the differences in the healthcare systems in the three countries. In the United Kingdom, there is a smaller number of neurologists and collaboration with other services, including rehabilitation, palliative care and primary care, is common, with the increase multidisciplinary team approach maximizing the time provided by the neurologist. In Italy and Switzerland, there is a greater number of neurologists and there are specific ALS services, with teams that provide care from diagnosis until death (16). Thus, these teams may provide palliative care themselves and the collaboration with specialist palliative care may be less developed.

There was evidence of barriers to referral of people with ALS from neurology services to palliative care, and this was particularly in Switzerland (53%) and Italy (42%) compared to the United Kingdom (12%). The increased collaboration in the United Kingdom may reflect the increased expertise of the UK respondents and the increased collaboration and interaction with neurology, so that referrals are made more easily. In the other countries, there may also be financial issues, including restrictions in resources, reduced availability of palliative care and differences in the funding of healthcare, which may also affect referral. There may be aspects of the healthcare system that may reduce collaboration, related to funding of services or bureaucratic obstacles to collaboration.

The reluctance of patients and families was less than 20% and this is similar to the reports in the wider European study on all neurological disease where only 10% respondents reported that patients and families may not wish involvement (4). There has been much debate with palliative care as to whether the name itself, often associated with hospices and end of life care, is a barrier to the acceptance of referral by patients (17,18). Professionals have also been shown to be fearful of discussing palliative care[19] and there may be a need for further education of all involved—patients, families and professionals—so that there is a clear understanding that palliative care may be appropriate at any stage for a person with ALS.

All services had been involved with patients receiving NIV or TV. The use of NIV and TV vary between the three countries: UK NIV 28% (20), TV less than 1% (20,21); Italy NIV 14%, TV 40% (22); there are no figures for Switzerland but in Germany, which has similar access to ALS care NIV 21%, TV 9.5% (23). This was reflected in the responses as in Italy more respondents were seeing patients with TV. The decisions to commence TV are complex and may reflect sociocultural factors in decision making (21,24,25), but there are occasions when decision making is taken in emergency situations, without awareness of the implications of continuing deterioration and burden (26). In the United Kingdom, the services were particularly involved in the discussion of withdrawal of ventilation, at home or in the hospice. This may reflect the close involvement of these teams in the care for people with ALS, and the increased role of specialist palliative care in developing guidance for the withdrawal of ventilation, at the patient's request (26).

There are limitations to this study as the results rely on the responses to an open on-line questionnaire. It can be argued that the respondents may have a special interest in ALS care and are therefore not necessarily representative of the wider specialist palliative care services. This may certainly be so in the United Kingdom, where 53% assessed their expertise as very good or excellent. In Italy and Switzerland, only 17% assessed their skills as excellent or very good and about 40% had limited/somewhat expertise. There may also be concerns as to how non-English speakers complete a questionnaire, but the questions were kept as simple and clear as possible to reduce this risk. The low response from the majority of European countries was disappointing and it was not possible to obtain a broader a broader view of ALS care across but the inclusion of small numbers of respondents from many counties would have made it difficult to make any clear conclusions from such a mixed group, with a predominance of results from two countries. This may also reflect the differences in health care systems across Europe, which may affect the care and collaboration between services. The strengths of the study are the good response rate in the three countries, with a broad range of experience and views.

This study shows that palliative care services are often involved in the care of people with ALS, but the extent and timing of involvement varies between the three countries. These differences are complex and further research, across Europe, would be helpful to elucidate the most effective, and acceptable, ways to provide palliative care for people with ALS. These may be specific to the varying health and social care provided within each society. The inclusion of palliative care within clinical guidelines may encourage a collaborative approach. The EAN/EAPC consensus on palliative care (4) recommends training for all involved in neurological care—for neurologist in palliative care and palliative care specialists in neurology—and continuing education and collaboration would help to aid understanding and awareness of palliative care, and help people with ALS, and their families, maintain their quality of life and be cared for appropriately and safely.

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Author contributions

All authors were involved in the planning of the survey, the development of the survey instrument and the completion and approval of the final paper. DJO undertook the analysis of the results and prepared the draft paper, which was seen and commented on by all authors before submission.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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