

# From diagnosis to death: exploring the interface between neurology, rehabilitation and palliative care in managing people with long-term neurological conditions

Lynne Turner-Stokes, Nigel Sykes, Eli Silber, Ajeet Khatri, Lucy Sutton and Erica Young

**ABSTRACT** – This article reports a parallel survey of consultants working in the fields of neurology, rehabilitation and palliative medicine, and explores the interface between the three specialties in providing services for people with long-term neurological conditions. There was general agreement with respect to the core contributions offered by each specialty. However, there were also important areas of overlap which highlight the need for collaborative working practice, and for clinicians to respect the expertise of others in related areas. The survey highlighted a general shortfall in service provision for both palliative care and rehabilitation services for people with long-term neurological conditions, particular in the community. There was also a marked lack of coordination between services. Perhaps not surprisingly, each specialty reported greater ease of access to services within their own field, which further emphasises the need to work closely together.

**KEY WORDS:** neurology, palliative care, postal survey, rehabilitation, service coordination

## Introduction

The UK National Service Framework for Long Term Conditions<sup>1</sup> advocates life-long care for people with long-term neurological conditions (LTNC). It highlights the need for provision of specialist neurology, rehabilitation and palliative care services to support people throughout their illness and to the end of their lives.

In recent years, palliative care services have increasingly recognised the needs of non-cancer patients,<sup>2,3</sup> especially in rapidly fatal neurological conditions such as motor neurone disease (MND).<sup>4,5</sup> However, there are some major differences between the palliative care needs of people with LTNC and those of people with cancer.<sup>3,6,7</sup> In general, neurological conditions have a longer and more variable time course – it is often hard to determine exactly when a patient is entering the terminal stages of life. Symptoms are diverse, and many patients have complex disabilities

which include cognitive, behavioural and communication problems as well as physical deficits. For these reasons, guidelines increasingly recommend early referral to palliative care services.<sup>8,9</sup>

On the other hand, long-term disability management and symptom control in LTNC have always been a core element of many rehabilitation services – especially those based in the community and able to support people in their own homes. In addition, many neurology departments now have specialist nurses with specific experience in the management of specific neurological conditions, who also provide long-term support for patients and their families.<sup>10,11</sup>

In the context of current financial pressures on the NHS, an understanding of the interface between neurology, rehabilitation and palliative care is critical to ensuring that services work together to provide coordinated care for people with LTNC, rather than duplicating care provision and then competing for the scarce resources.<sup>1</sup>

The principal aim of this study was to explore the interaction between specialist palliative care and neurology/rehabilitation services, and the perceptions of consultants working in the three specialties regarding their relative roles in caring for people with long-term neurological conditions.

## Methods

### Study design

A cross-sectional postal survey using parallel questionnaires was sent out to consultants in neurology, rehabilitation and palliative medicine through their specialist societies.

### Questionnaire design

The three sets of questionnaires were developed by a multidisciplinary group led by the National Council for Palliative Care. The development group included specialists in neurology, rehabilitation and palliative care, as well as user and carer representatives. The questionnaire was customised for each of the three specialties, but designed on common core elements

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worded in exactly the same way, in order to provide reciprocal information.

An initial screening question filtered out those who did not run services for people with LTNC. The remainder of the questionnaire was divided into two principal parts:

- Part 1 described their service and the type of patients they treated:
  - the nature of the services and the types of LTNC that they managed
  - the professional disciplines with which they worked closely.
- Part 2 explored their interaction with the other service areas:
  - which core service elements their particular service offered

- which of the elements they regarded as ‘core service’ for each speciality
- how easily patients with LTNC could access the various services in their area.

In an open-ended question, respondents were also asked to provide qualitative responses describing any perceived gaps in the current specialist palliative care services for patients with LTNC.

**Questionnaire circulation**

After initial piloting, the questionnaires were approved by the relevant committees of the three UK specialist societies: the Association of British Neurologists (ABN), the Association for Palliative Medicine (APM) and the British Society of Rehabilitation Medicine (BSRM). Questionnaires were then

**Table 1. The percentage of physicians in each specialty who reported that they cared for the various groups of long-term neurological conditions.**

Long-term neurological conditions treated	Neurology (n=82)		Rehabilitation (n=47)		Palliative care (n=134)		$\chi^2$	df
	(n)	%	(n)	%	(n)	%		
<b>Sudden-onset conditions</b>							101.3	4
Yes	(53)	65	(42)	89	(23)	17		
Some	(18)	22	(3)	6	(33)	25		
No	(11)	13	(2)	2	(78)	58		
<i>Specific conditions</i>								
CVA	(58)	70	(39)	83	(32)	24	71.0	2
Other ABI	(46)	56	(38)	81	(22)	16	72.4	2
<b>Intermittent conditions</b>							112.4	4
Yes	(73)	89	(34)	72	(25)	19		
Some	(3)	4	(2)	4	(26)	20		
No	(6)	7	(11)	19	(83)	62		
<i>Specific</i>								
Relapsing-remitting MS	(64)	78	(35)	74	(35)	26	67.5	2
Epilepsy	(68)	83	(15)	32	(2)	1	154.2	2
<b>Progressive conditions</b>							23.7	4
Yes	(75)	91	(37)	79	(84)	63		
Some	(5)	6	(4)	9	(21)	16		
No	(2)	2	(6)	11	(29)	22		
<i>Specific</i>								
Progressive MS	(64)	78	(37)	79	(75)	56	14.8	2
Huntington's disease	(58)	70	(18)	38	(54)	40	21.6	2
MND	(66)	80	(29)	62	(92)	69	5.9**	2
Parkinson's disease	(69)	84	(15)	32	(66)	49	40.0	2
Progressive supra-nuclear palsy	(69)	84	(23)	49	(71)	53	26.5	2
Multi-system atrophy	(70)	85	(25)	53	(72)	54	24.1	2
<b>Stable conditions ± degenerative change</b>							114.5	4
Yes	(38)	46	(33)	70	(7)	5		
Some	(21)	25	(6)	13	(13)	10		
No	(23)	28	(8)	13	(114)	60		
<i>Specific</i>								
Cerebral palsy	(38)	46	(33)	70	(13)	10	69.9	
Post-polio syndrome	(38)	46	(29)	62	(3)	2	86.7	

ABI = acquired brain injury; CVA = cerebrovascular accident; df = degree of freedom; MND = motor neurone disease; MS = multiple sclerosis. All  $\chi^2$  tests significant to p <0.0001, except for motor neurone disease (p=0.05).

sent out by post in a single mail shot to all consultant members of those societies currently practising in England, Wales and Northern Ireland.

Consultants were asked to confer with their multidisciplinary teams in making their response, as well as with other medical consultant colleagues in their specialty. Those working in more than one centre with different service characteristics were invited to complete a questionnaire for each.

### Data handling and analysis

Data were entered into a spreadsheet (Microsoft Excel) and transferred to SPSS version 11.5 for statistical analysis. The majority of data were nominal or dichotomous. Chi-squared statistics were used to compare responses from the three groups, as in all cases the expected frequency of response was >5.

### Results

Individual responses rates for the three specialty groups were: neurology: 82/474 (17%), palliative care: 149/304 (49%), and rehabilitation: 53/198 (27%). Although respondents were invited to submit different responses for different services, only two such multiple responses were received.

All 82 (100%) of responding neurologists cared for people with LTNC, compared with 134/149 (90%) of palliative care

consultants and 47/53 (89%) rehabilitation physicians. These were taken as the group for further analysis, giving a total sample size of 263.

Fifty-nine neurologists (72%) reported that their service supported people with LTNC to the end of their lives; 53% 'occasionally', and 20% 'often'. A relatively smaller number (28 (60%)) of rehabilitation physicians provide this life-long support – 47% 'occasionally' and 13% 'often'.

### Types of LTNC covered by each group

The types of conditions covered are shown in Table 1. Chi-squared statistics are given for the three-way comparison between neurologists, rehabilitation and palliative physicians.

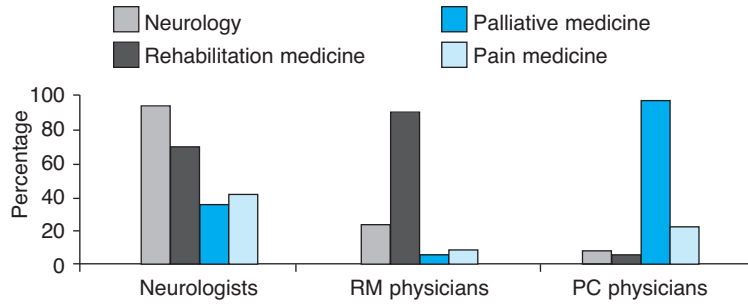
- Neurologists most commonly cared for intermittent and progressive conditions, and less commonly for sudden-onset and stable conditions with/without degenerative change – which were much more commonly cared for by rehabilitation physicians.
- Palliative physicians were most commonly involved with progressive conditions, but rarely with stable conditions such as cerebral palsy or post-polio. Approximately 60% of the palliative physicians had no involvement with people who had sudden onset conditions (such as brain injury, stroke etc) or people with intermittent conditions (epilepsy, relapsing-remitting multiple sclerosis (MS)).

**Table 2. The distribution of different disciplines in the multi-professional teams in each specialty.**

Long-term neurological conditions treated	Neurology (n=82)		Rehabilitation (n=47)		Palliative care (n=134)		$\chi^2$	df
	(n)	%	(n)	%	(n)	%		
<i>Specialty-trained medical staff</i>								
Neurology	(77)	94	(11)	23	(6)	4	180.9	2
Palliative medicine	(30)	37	(1)	2	(131)	98	166.0	2
Rehabilitation medicine	(58)	71	(42)	89	(3)	2	160.7	2
Pain medicine	(34)	41	(2)	4	(30)	22	23.6	2
<i>Specialty-trained nursing staff</i>								
Neurological	(76)	93	(14)	30	(7)	5	168.4	2
Palliative care	(16)	20	(2)	4	(129)	96	183.5	2
Rehabilitation	(28)	34	(40)	85	(3)	2	124.3	2
<i>Therapies</i>								
Physiotherapy	(77)	94	(47)	100	(103)	77	21.5	2
Occupational therapy	(73)	89	(46)	98	(94)	70	22.4	2
SLT	(75)	91	(44)	94	(31)	23	128.2	2
Psychology	(63)	77	(37)	79	(46)	34	49.7	2
Music/art therapy	(0)	0	(8)	17	(40)	30	30.4	2
<i>Support</i>								
Dietetics	(55)	67	(45)	96	(51)	38	51.9	2
Social work	(47)	57	(38)	81	(103)	81	16.6	2
Bereavement counsellor	(6)	7	(4)	9	(88)	66	94.3	2
Other counsellor	(10)	12	(13)	28	(40)	30	9.1**	2
Spiritual advisor	(1)	1	(11)	23	(98)	73	116.2	2

df = degree of freedom; SLT = speech and language therapy.  
All  $\chi^2$  tests significant to  $p < 0.0001$  except for 'other counsellor' ( $p=0.01$ ).

**Fig 1. Representation of specialty-trained medical staff on the multidisciplinary teams of the different groups of respondents.** Neurologists quite frequently had rehabilitation, palliative care and pain consultants working on their teams. In contrast, palliative care and rehabilitation consultants were rarely represented on each other's teams. PC = palliative care; RM = rehabilitation medicine.



- Palliative and rehabilitation physicians were involved to a broadly similar degree in patients with Huntington's, MND, Parkinson's disease, supra-nuclear palsy and multi-system atrophy – although rehabilitation physicians were more commonly involved in MS.

**Working relationships with other disciplines**

Table 2 shows the distribution of different disciplines represented within the respondents' multidisciplinary teams. As expected, doctors and nurses with trained in each specialty dominated in their respective groups. Neurologists were more likely to have rehabilitation doctors (71%) than palliative physicians (37%) as part of their team ( $\chi^2$  5.8, df 1 p=0.02). The palliative and rehabilitation physicians very rarely appeared to work on the same team. This striking finding is illustrated in Fig 1. Interestingly, neurologists in this group were about twice as likely to have a pain specialist on their team than palliative care physicians, although this may reflect the particular expertise of the latter group in this area.

All three disciplines worked closely with physiotherapists and occupational therapists. Neurologists and rehabilitation physicians worked more closely with speech and language therapists (SLTs), psychologists and dietitians than did palliative care consultants. As would be expected, however, the palliative

physicians were more likely than the other two groups to have bereavement counsellors and spiritual advisors on their teams.

**Core service elements**

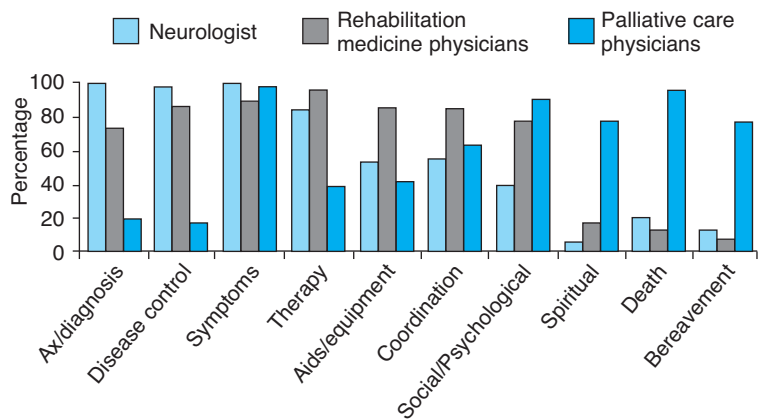
Respondents were asked to say what aspects of clinical practice were core elements of their service, from the list in Box 1. The response is illustrated in Fig 2.

- All three specialties believed that they had a major role in symptom management.
- Neurologists particularly provided assessment (Ax), diagnosis, disease control – and to a lesser extent therapy.
- Rehabilitation physicians majored in provision of therapy, aids and equipment, coordination of services and social/psychological support; although they often played a significant role in assessment and disease control.
- Palliative physicians focused mainly on social, psychological and spiritual support, and the management of death and bereavement.

Respondents were also asked to indicate which they believed were the core service elements for each of the three specialties, and the responses are illustrated in Fig 3.

**Box 1. Core elements of service for people with long-term neurological conditions.**

- 1 Assessment (Ax) and diagnosis
- 2 Control of disease progression and prevention of complications
- 3 Management of symptoms, eg pain, depression, breathlessness etc
- 4 Provision of therapy, spasticity management etc.
- 5 Provision of aids, equipment, eg aids to daily living, environmental control systems
- 6 Practical coordination of support services including NHS, voluntary, social services etc.
- 7 Social, psychological support
- 8 Spiritual support
- 9 Management of death
- 10 Aftercare, bereavement support



**Fig 2. Aspects of clinical practice that respondents in the different specialties regarded as core elements of their service.** Although there were areas of overlap between the specialty groups, the key roles for the different specialties were evident.

There was a reasonably high level of concordance between the different specialty groups about their relative roles, which largely reflected the elements of service offered, as described for Fig 2. Interestingly, however, neurologists did not perceive rehabilitation physicians to have a major role in assessment and diagnosis, whereas the rehabilitation doctors themselves saw this as a major part of their role. Similarly, neurologists perceived for themselves a greater role in therapy and symptom control than was accorded to them by the rehabilitation doctors. Palliative physicians tended to see symptom control as their primary domain, whereas the other two specialties saw a slightly lesser, although still prominent, role for them in this respect.

**Access to palliative care services for people with LTNC**

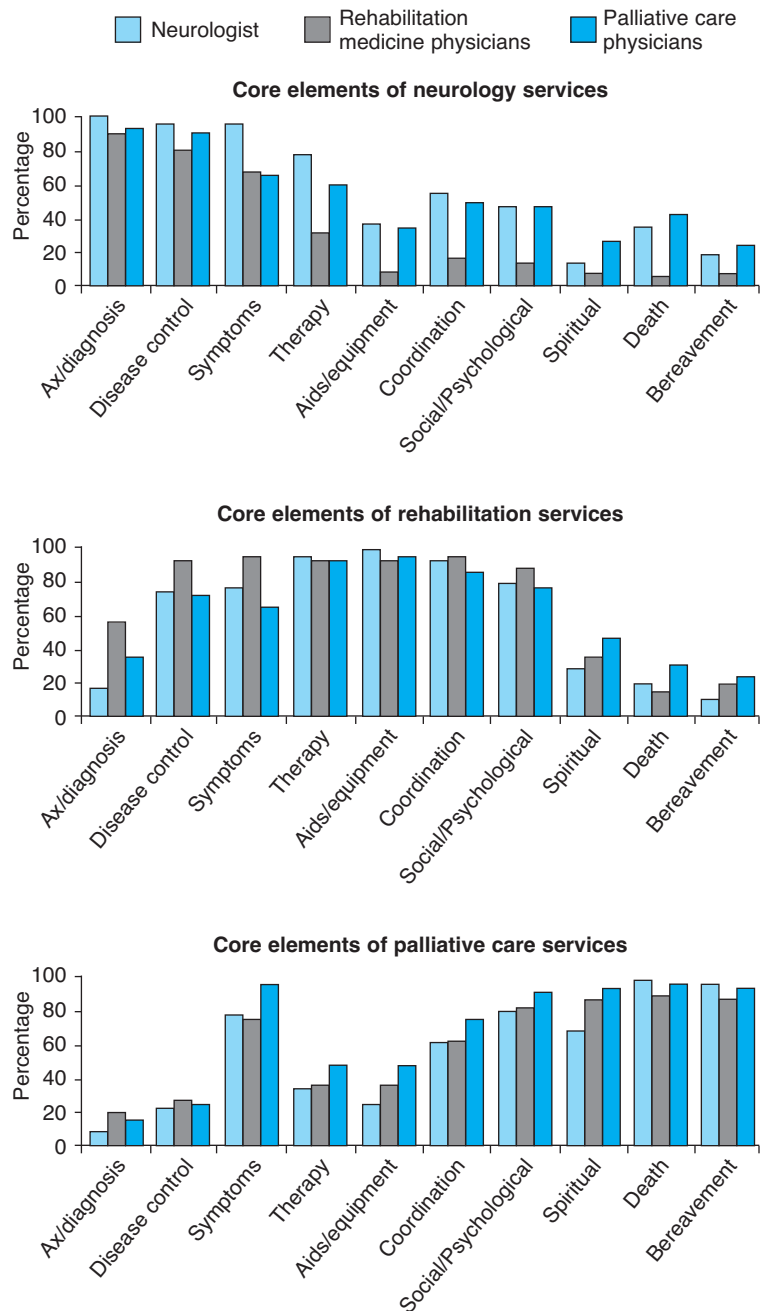
One hundred and sixteen (86%) palliative physicians perceived gaps in the provision of palliative care services for people with LTNC, compared with 56 (68%) neurologists and 34 (72%) rehabilitation physicians ( $\chi^2$  25.7 df 2,  $p < 0.0001$ ).

The ease with which the different disciplines could access each other's services for patients with LTNC is summarised in Table 3. Palliative physicians reported better levels of access to palliative care services for people with LTNC than were reported by the other two specialties:

- 88% of palliative physicians reported easy access to palliative care consultation and advice in hospital, while only 65% of neurologists and 62% of rehabilitation physicians reported such access ( $\chi^2$  26.3, df 6  $p < 0.0001$ ).
- Similarly, 77% of palliative physicians reported easy access to community palliative care services compared with only 31% of neurologists and 45% of rehabilitation physicians ( $\chi^2$  43.2, df 6  $p < 0.0001$ ).
- Hospice care was easily accessible to 68% of palliative physicians, but only 33% of neurologists and 44% of rehabilitation physicians ( $\chi^2$  40.4, df 6  $p < 0.0001$ ).

Similarly, rehabilitation physicians tended to report easier access to rehabilitation services than the other specialties.

- 84% of rehabilitation physicians reported that they could access specialist rehabilitation consultation easily for people in hospital with LTNC, compared with 47% of neurologists and 30% of palliative physicians ( $\chi^2$  40.8, df 6  $p < 0.0001$ ).
- Although 42% of rehabilitation physicians reported easy access to long-term community rehabilitation support



**Fig 3. Aspects of clinical practice regarded as 'core service' for each specialty.** Neurologists were seen by most as being the primary providers of assessment, diagnosis and management of the disease. Rehabilitation physicians were primary providers of therapy, equipment, social/psychological support and service coordination during the phase between diagnosis and death. Palliative care physicians were primary providers of terminal care, and the management of death and bereavement. All were involved in symptom management.

for this client group, the other disciplines reported less good access (12–16%) ( $\chi^2$  19.4, df 6  $p = 0.004$ ). Overall, nearly half the respondents from each specialty (43%) reported that they could only access community rehabilitation with difficulty, and another 28% reported variable access.



Whilst 61% of neurologists could access inpatient neurology services and 70% could access outpatient services, rehabilitation and palliative care physicians reported somewhat less easy access. However, these differences did not reach statistical significance ( $\chi^2$  6.9, df 6 p=0.32 and  $\chi^2$  8.2, df 6 p=0.22, respectively).

All three specialties agreed that closely coordinated care between palliative care services, neurology and rehabilitation was scarce. Again there was marked variability, but only about

25–30% reported easy access to well coordinated services, with similar proportions reporting difficulty and variable access.

**Gaps in palliative care provision for neurological patients**

Not all respondents made a comment in the qualitative section, but from the responses given (88 from palliative physicians, 52

**Table 3. The ease with which the different specialists can access each other's services for patients with long-term neurological conditions (LTNC).**

	Neurologists (n=80)		Rehabilitation (n=45)		Palliative care (n=130)		Total (n=251)	
	(n) %		(n) %		(n) %		(n) %	
<b>Palliative care (PC) services for people with LTNC</b>								
<i>PC consultation /advice for patients in hospital</i>								
Easily	(52)	65	(28)	62	(115)	88	(195)	76
With difficulty	(11)	14	(6)	3	(4)	3	(21)	8
Not at all	(4)	5	(4)	9	(0)	0	(8)	3
It varies	(13)	16	(7)	16	(11)	8	(31)	12
<i>Community PC services</i>								
Easily	(25)	31	(20)	45	(100)	77	(147)	59
With difficulty	(20)	25	(11)	25	(9)	7	(40)	16
Not at all	(5)	6	(5)	11	(4)	3	(14)	6
It varies	(25)	31	(8)	18	(17)	13	(50)	20
<i>Hospice care</i>								
Easily	(25)	33	(20)	44	(89)	68	(134)	54
With difficulty	(28)	35	(10)	22	(14)	11	(52)	21
Not at all	(0)	0	(4)	9	(2)	1	(6)	2
It varies	(22)	27	(9)	21	(25)	19	(56)	23
<b>Rehabilitation services for people with LTNC</b>								
<i>Specialist rehabilitation/ support for patient in hospital</i>								
Easily	(38)	47	(38)	84	(35)	30	(111)	46
With difficulty	(5)	31	(4)	9	(38)	32	(67)	28
Not at all	(1)	1	(1)	2	(4)	3	(6)	2
It varies	(17)	21	(2)	4	(39)	37	(58)	24
<i>Community long-term rehabilitation and support services</i>								
Easily	(12)	16	(19)	42	(16)	12	(47)	19
With difficulty	(34)	45	(20)	44	(53)	38	(107)	43
Not at all	(3)	4	(1)	2	(2)	1	(96)	2
It varies	(27)	35	(6)	13	(38)	29	(71)	28
<b>Neurology services for people with LTNC</b>								
<i>Neurological inpatient assessment</i>								
Easily	(49)	61	(21)	47	(46)	35	(117)	47
With difficulty	(20)	25	(11)	24	(36)	28	(67)	27
Not at all	(2)	2	(3)	7	(3)	2	(8)	3
It varies	(11)	14	(8)	18	(25)	19	(44)	17
<i>Neurological outpatient assessment</i>								
Easily	(56)	70	(27)	60	(58)	45	(141)	56
With difficulty	(14)	17	(12)	27	(28)	21	(54)	21
Not at all	(1)	1	(1)	2	(2)	1	(4)	2
It varies	(11)	14	(5)	11	(24)	18	(40)	16

NB. A slightly reduced number of respondents answered this section (total n=251).

from neurologists and 39 from rehabilitation physicians) seven key themes were drawn. The key elements from this section confirmed the findings from the quantitative results.

For each specialty the largest area of concern was lack of co-ordination, with the different services 'working in isolation'. From the palliative medicine perspective, this resulted either in very few referrals being made to them or the referrals being 'random' and poorly reflective of need.

Concerns were raised by neurologists and rehabilitation physicians about the lack of access to palliative care services for people with LTNC which included both:

- a shortage of palliative care facilities ('insufficient therapists in local hospice and palliative care teams to make it easy to manage physical disability', 'no access to palliative care apart from phone advice'), and
- a lack of willingness on the part of palliative care services to engage ('reluctance of specialist palliative care services to engage with non-cancer patients', 'unfocused messages from palliative care set-ups').

For their part, palliative physicians reported that their involvement with neurological patients was limited by lack of resources for staff and facilities ('can only support MND with current resources') or a 'need for more training in the care of neurological patients'.

Rehabilitation physicians saw palliative care as lacking in the necessary skills to manage neurological patients ('some hospices have difficulties with neurological as opposed to cancer patients') but all sides acknowledged that the time-scale for some long-term neurological conditions did not fit well with the characteristic pattern of working of specialist palliative care, which was much more attuned to rapidly declining cancer patients, eg 'the local service only accepts hospice admission two weeks from death', 'most hospices will not take LTNC patients until very last stages'.

Concerns were expressed by all three specialties about inadequate support for neurological patients in the community in terms of nursing and social care, rehabilitation support, and lack of appropriate residential placements, eg 'residential/nursing care, long term/medium term for younger patients with general nursing needs', 'sufficient packages of care in the community to meet needs'. Included in this category was a lack of respite care, which was not necessarily seen as the responsibility of specialist palliative care.

## Discussion

There are recognised limitations to this study. The response rates were low, especially for the neurologists and rehabilitation physicians. However, in the case of rehabilitation, this may partly reflect the instruction in the covering letter for rehabilitation consultants to collaborate in a single reply where more than one consultant worked in the same service, and also the fact that a substantial proportion of the membership of the BSRM do not run neurological rehabilitation services. The low overall response rates together with the high proportion (approximately 90%) of

responders engaged in the care of people with LTNC suggests that those who were motivated to respond did so only because they had an interest in the field of inquiry. Therefore, caution should be applied in relating these figures to the specialties as a whole. However, we believe that the responder group is likely to be reasonably representative of those consultants in the UK who are actively engaged in the management of people with LTNC, and the findings should be interpreted on that basis.

This survey demonstrated general agreement between the specialties about their relative roles in the interface between neurology, rehabilitation and palliative care. Neurologists were seen by most as being the primary providers of assessment, diagnosis and management of the disease. Rehabilitation physicians were primary providers of therapy, equipment, social/psychological support and service coordination during the period between diagnosis and death. Palliative physicians were primary providers of terminal care, and the management of death and bereavement.

However, there was also considerable overlap in the activities of each specialty and it is clearly important that the different professionals respect each other's role, not only in their primary areas of clinical practice but also in the overlapping areas – particularly those of symptom control and social/psychological support. For example, neurologists clearly saw themselves as key providers of therapy, spasticity management etc. It is important that rehabilitation physicians respect that, just as it is important for neurologists to recognise the diagnostic skills of rehabilitation physicians, who sometimes have the opportunity to observe patients at close quarters for longer periods to reach diagnoses that may have evaded earlier assessment.

By the same token it is also important for neurologists and rehabilitation physicians to embrace the involvement of palliative physicians at earlier stages, and take advantage of their experience in managing symptoms such as nausea, vomiting and breathlessness which can occur in relative early phases of the disease. In return, rehabilitation physicians may have useful experience in managing people with profound cognitive and communication deficits which it may be helpful to share with palliative physicians when approaching end-of-life decisions and symptom management in the later stages of illness.

With respect to service provision this survey highlighted a general shortfall, but there were also important differences in reported access to services, depending on which specialty respondents worked in. All found it easier to access services within their own field and this underlines the need for close collaborative working with colleagues who can smooth the patient's path into their services where appropriate. There were notable gaps, particularly in relation to community-based rehabilitation services and well coordinated service provision between the different specialties, and this is something that should be addressed as a matter of urgency. Collaborative training programmes, to ensure that doctors in training have proper exposure to each of the three areas, could help to establish better understanding and awareness of the different specialties. Similarly, specialist nurses may have a particular role to play in promoting cross-service coordination and liaison.

**Fig 4. Life circles: proposed model for the relationship of neurology, rehabilitation and palliative care in people with long-term neurological conditions.** In this model, the shading illustrates intensity of involvement for neurologists and palliative care physicians in acute and terminal care respectively. There is very close interaction between neurology and palliative care throughout the duration of rapidly progressive conditions, with relatively smaller role for rehabilitation medicine physicians. However, rehabilitation plays a major role in providing long-term care and support, often over many years, in the more slowly progressive or stable conditions. As the patient's condition becomes more advanced, rehabilitation and palliative care approaches often overlap – we have called this 'neuro-palliative rehabilitation'.

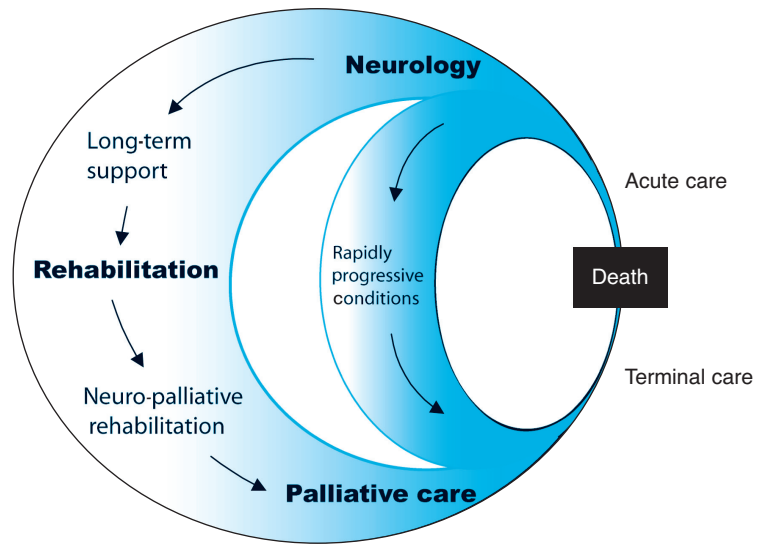


Figure 4 illustrates a proposed model for service interaction. People with rapidly progressive neurological conditions require closely coordinated neurology and palliative care services throughout the relatively short span of their condition. However, for people with more slowly changing conditions, the major role for neurology is in the early stages of diagnosis and treatment, and for palliative care in the late stages. For many years in between, rehabilitation services would provide the mainstay of support to coordinate services which help them to maximise their independence and autonomy, with input from neurology as required. Towards the later stages, the roles of rehabilitation and palliative care would become more closely intertwined in an approach which we have termed 'neuro-palliative rehabilitation'.

In conclusion, there are many exciting opportunities for these three specialties to work together, and by doing so to learn from each other, in order to improve the experience of patients and their families who live out their lives with a long-term neurological condition. Clinicians working within each field should be encouraged to seek out their counterparts in the other specialties and explore means of developing closer working practice.

### Acknowledgements

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