Collaboration between neurology and palliative care – how, when, where?

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Disclosure

- None

Learning objectives

- Understanding of the role of palliative care for neurological disease
- The aspects of palliative care important for neurologists
- The areas of collaboration with specialist palliative care
- Collaboration at the end of life
- Awareness of the increased role for the multidisciplinary approach in neurology

What happens in neurological disease?

- Progressive disease
  - Neurodegenerative disease: ALS, PD, MSA, PSP, Huntingtons, Alzheimer, other dementias,
  - High grade gliomas
  - Also young-onset progressive disease: muscular dystrophies, SMA
- Disabling
- No curative treatment
- Treatments may slow progression / help with symptoms
- Patients deteriorate and die

Neurological disease – variable prognosis

- Multiple sclerosis
  - Disease modifying treatments
  - Variable progression / prognosis
- Stroke
  - Sudden death
  - Progressive disability
  - Uncertainty
- Brain injury

Palliative care

An approach that improves the quality of life of patients and their families facing problems Associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

WHO 2002

Palliative care

- Holistic assessment
  - Physical
    - Symptoms
    - Mobility
  - Psychological
  - Social
  - Spiritual

Palliative care

- Palliative care approach
  - For all patients at all times
  - “Good care”
- Generalist palliative care
  - Frequently involved in providing palliative care
  - Requires training on communication skills and some expertise
- Specialist palliative care
  - Specialist training and specialist team
  - Complex issues
  - “neuro-palliative care”

Radbruch et al 2009

Early integration of care

- **Palliative care should be considered early in the disease trajectory, depending on the underlying diagnosis**

EAN/EAPC Consensus on palliative care

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Communication

- Communication should be
  - Open
  - Set goals and therapy options
  - Use structured models, SPIKES

- Early advance care planning encouraged
  - Especially if expectation of
    - Impaired communication
    - Cognitive deterioration

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Multidisciplinary team

- Patients should have
  - Multidisciplinary palliative care assessment
  - Access to specialist palliative care

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Carer support

- Needs of carers assessed regularly
- Support of carers – before and after death
- Professionals should reduce emotional exhaustion and burnout by
  - Education
  - Support
  - Supervision

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

End of life care

- Continued and repeated discussion
  - As continual changes
    - Physical
    - Cognitive
    - Preferences
- Encouragement of open discussion about dying process
- Encourage open discussion about the wish for hastened death

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Role of palliative care

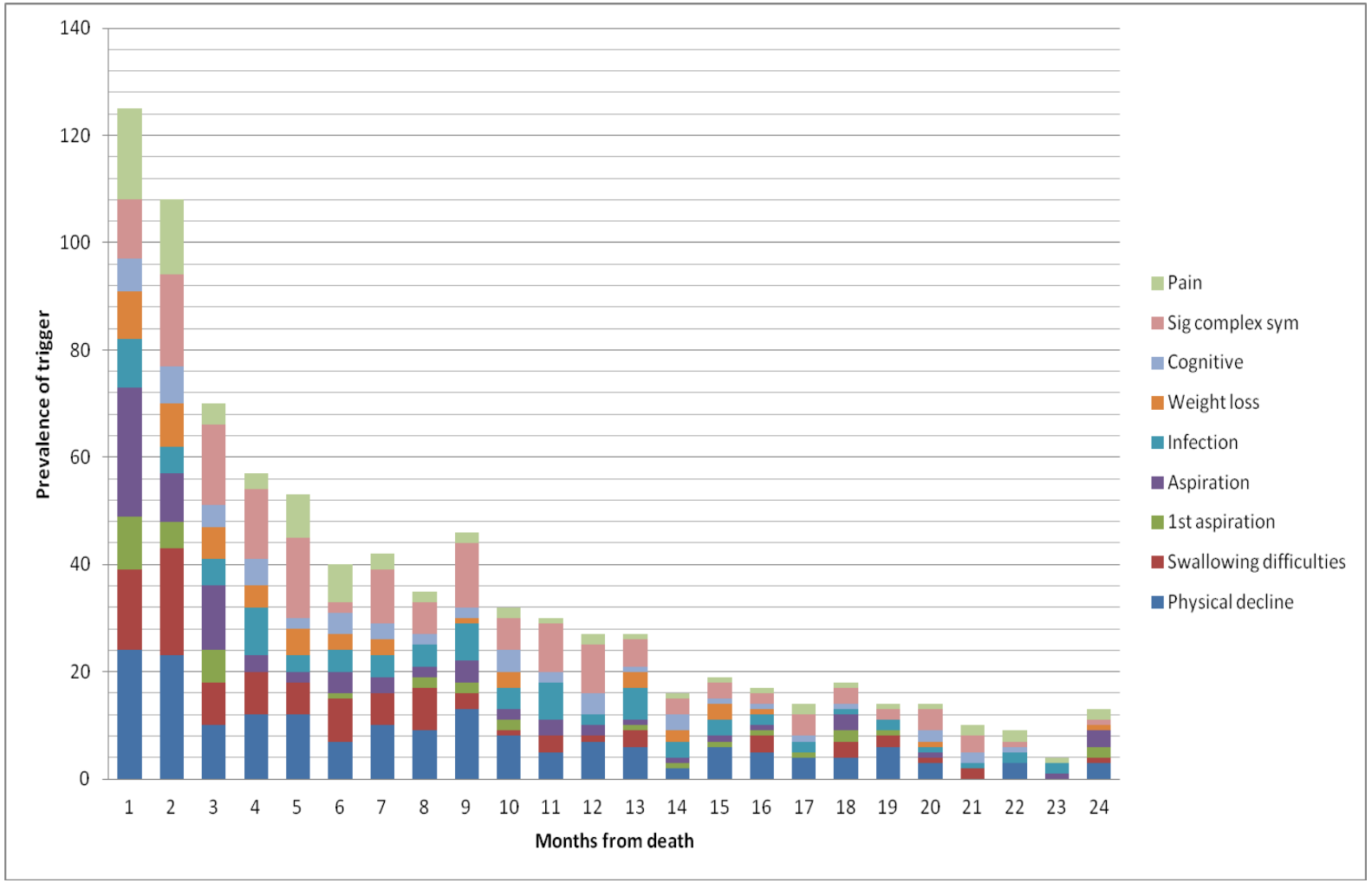
- May be from diagnosis
  - ALS
  - Severe stroke
- May be at times throughout the disease progression
  - Parkinson's disease
  - MSA / PSP / CBD
  - MS
  - Muscular dystrophies
- At the end of life
  - Any disease

Triggers for end of life care

- Generic for neurological care
  - Patient request
  - Family request
  - Dysphagia
  - Cognitive decline
  - Dyspnoea
  - Repeated infections
  - Weight loss
  - Marked decline in condition

Hussain et al 2014

Triggers in last 24 months before death



EURO-NEURO SURVEY

- 661 people responded
- Completions
  - 178 palliative care
    - 14 countries
    - Mean 11.7 years experience
  - 120 neurologists
    - 20 countries
    - Mean 19.2 years experience

Areas of collaboration

Strong/ moderate collaboration

	Neurology	Pall care
ALS	63%	70%
Cerebral tumour	68%	63%
PD	30%	27%
MS	34%	37%
Dementia	30%	39%
Stroke	34%	36%
HD	14%	36%

Areas of collaboration

	Neurology	Pall care
Joint clinics	24%	28%
Regular meetings	23%	19%
Joint ward rounds	13%	14%
Regular MDT meetings	31%	25%
Regular telephone	51%	49%

Areas for palliative care involvement

	Neurology	Pall care
Quality of life	85%	99%
Caregiver support	83%	96%
Complex decision making	76%	96%
Psychological issues	77%	96%
Information	68%	97%
Advance care planning	71%	90%
Physical symptoms	74%	94%

Barriers to collaboration

	Neurology	Pall care
Neurology not referring	-	43%
Palliative care not seeing neurology patients	14%	4%
No palliative care team	28%	-
Financial / resources	43%	20%
Patient / family refusal	10%	15%
GP continuing care alone	13%	17%

Where?

- Home
  - Collaboration with Family Doctor
- Hospital
  - Collaboration with other teams
- Hospice
- Nursing home
  - Elderly
  - Co-morbidities

Palliative care and neurology – the future

- Increasing collaboration
- At all levels
  - Neurology
    - Increased awareness of all neurology teams
    - Increased MDT working, including palliative care
    - Increased education of neurologists and palliative care

Palliative care and neurology – the future

- Specialist palliative care
  - Complex situations
    - Physical / psychosocial / spiritual
  - Ethical issues
  - Advance care planning
  - Specialist palliative care involvement
    - Multidisciplinary team approach
      - Physician - Specialist nurse
      - Psychosocial carer

Collaboration – how / when / who?

- Increased understanding of roles
- Increased contact
  - according to need
- From early in the diagnosis
- Particularly towards the end of life
- Increased education of all involved
- Aim to improve quality of life / quality of dying of patients and families

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