

Exploring the palliative care needs of service users with neurological conditions

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Sue Ryder Care Centre for Palliative
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University of Nottingham

Study Aim:

To explore the palliative and end of life care needs of adults with progressive long-term neurological conditions

Background

- Progressive long-term neurological conditions require palliation from diagnosis
- This study focuses on the most common conditions:
 - Multiple Sclerosis (MS),
 - Parkinson's disease (PD),
 - Motor Neurone Disease (MND),
 - Huntington's Disease (HD)

“a ‘silent minority’, who have fallen out of acute care follow-up and remain a collective mystery in terms of palliative care needs”

(Multiple Sclerosis Society, *MS and palliative care: a guide for health and social care professionals* 2006:2)

“Huntington’s Disease stands out as one of the most devastating illnesses, not only because of its neurodegenerative progression, but also because of its impact on families”

(Dawson et al. *Nursing and Health Sciences* 2004:123)

Study objectives

- To undertake a modified critical review of the evidence in palliative care.
- To identify the views, experiences and educational needs of health and social care professionals.
- To examine the accounts of service users for concerns and expectations of care at the end of life.

- To identify the experience and quality of life of informal carers
- To identify the range of patterns and circumstances of death and dying
- To gain understanding of issues for staff in the delivery of care to people with palliative and end of life care needs

Design

A multi-method design across three UK sites;

- 1) six neurological care centres run by Sue Ryder Care;
- 2) an independent inner city hospice – St. Joseph's, Hackney
- 3) an NHS specialist Huntington's disease out-patient clinic at the National Hospital for Neurology and Neurosurgery

Palliative Initiatives in Neurological Care (PINC)

To initiate the implementation of the three nationally recognised tools into the neurological care setting

- Gold Standards Framework (GSF)
- Liverpool Care Pathway (LCP)
- Preferred Place of Care (PPC)

www.suerydercare.org/getinvolved/pinccampaign.asp

Methods

- **Critical literature review**
- **Observation** of staff and service users (n=2 care centres)
- **Case studies** of service users and their informal carers (n=5)
- **Focus groups** with health and social care professionals (n=50)
- **Interviews** with bereaved informal carers (n=15)
- **Huntington's Disease Quality of Life Battery for Carers (HDQoL-C)** (n =200) (Aubeeluck and Buchanan,2005)
- **Audit** of deceased patients' notes (n=100)

To critically review evidence for the practice of palliative and end of life care for adults affected by progressive long-term neurological conditions

Five key domains:

- rehabilitative and palliative care
- services for families
- co-ordination of service delivery
- information and communication
- the dying phase

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HDQoL-C

- 10 to 20 minutes to complete
- contains 34 questions
- within four components:
 - 1) demographic & objective information,
 - 2) aspects of caring,
 - 3) satisfaction with life
 - 4) feelings about life

Audit

- Place of care and of death
- The presence of a record of an advance discussion or statement
- References to family care or involvement
- Interventions provided (including referrals to supportive care agencies)
- Do not resuscitate orders or similar and their proximity to death

Work to date:

- 6 Focus groups with contributions from 30 health and social care professionals
- The critical review is underway

The next stage:

- Provide a provisional report for SRC (March 07) to inform PINC development
- Start observation at 2 SRC centres
- Recruit service users and families to take part in case studies
- Continue with critical review

Conclusion

The study will enable a better understanding of:

- The delivery of palliative care
- The needs of service users and staff

Inform service providers to help them aim for best practice