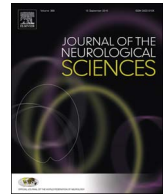




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## Challenges facing palliative neurology practice: A qualitative analysis

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## ABSTRACT

**Purpose:** This study aimed to develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness.

**Method:** The study was conducted at London Health Sciences Centre in Canada using grounded theory methodology. Qualitative thematic analysis was applied to focus group (health care providers physicians, nursing, allied health, trainees) and semi-structured interview (patient-caregiver dyads) data to explore challenges facing the delivery of palliative care in neurology.

**Results:** Specific characteristics of neurological disease that affect palliative care in neurology were identified: 1) *timelines* of disease progression, 2) *barriers to communication* arising from neurologic disease, 3) *variability across disease progression*, and 4) *threat to personhood* arising from functional and cognitive impairments related to neurologic disease. Moreover, three key challenges that shaped and complicated palliative care in neurology were identified: 1) *uncertainty* with respect to prognosis, support availability and disease trajectory, 2) *inconsistency* in information, attitudes and skills among care providers, care teams, caregivers and families, and 3) *existential distress* specific to neurological disease, including emotional, psychological and spiritual distress resulting from loss of function, autonomy and death. These challenges were experienced across groups, but manifested themselves in different ways for each group.

**Conclusions:** Further research regarding prognosis, improved identification of patients with palliative care needs, developing an approach to palliative care delivery within neurology and the creation of more robust educational resources for teaching palliative neurology are expected to improve neurologists' comfort with palliative care, thereby enhancing care delivery in neurology.

## 1. Introduction

Palliative care's indications extend beyond cancer; the need for effective palliative care in progressive neurological illnesses has increasingly been emphasized both in current research [1–3] and in the policy statements of the governing bodies of post-graduate medical education. Both the Royal College of Physicians and Surgeons of Canada [4] and the Accreditation Council for Graduate Medical Education [5] require that neurology residents receive education in palliative care. However, there is great variability in the training and preparedness of neurology trainees regarding how to approach palliative care in neurology [6,7].

Progressive neurological illnesses differ significantly from cancer, creating distinct challenges for healthcare providers [3]. Data suggests that hospice referrals occur less frequently and later in the disease

trajectory for patients with neurological disease [2,8,9]. Disease trajectory, symptom burden, and the variety and types of functional and cognitive impairments associated with life-limiting neurologic disease suggest that conventional approaches to palliative care cannot be straightforwardly applied in neurology [2,10]. The symptom burden of patients living with neurologic disease often includes cognitive, emotional and psychological impairment, speech and communication impairment, difficulties with mobility, limited respiratory and swallowing functions, and a wide range of unpredictable impacts on social, family and work life [2]. Moreover, since the course of many neurological diseases lead to significant dysfunction, many patients require timely and effective planning regarding goals of care, substitute decision-makers, advance care planning and end-of-life decisions followed by palliative care delivery designed to meet their needs [2]. While existing palliative care resources provide indispensable support for the clinical

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neurologists and their patients, more study is needed to identify the specific challenges faced by patients with neurologic disease, best practices for timely and effective support of these patients and their caregivers, and best approaches for including training in palliative neurology for neurology residents [2,3].

Using a qualitative approach, the goal of our study is to develop a conceptual understanding of the process and challenges of providing palliative care in the setting of neurological illness. The study results will help delineate the challenges facing palliative care in neurology.

## 2. Method

The study was conducted between November 2013 and March 2015 at a single large Canadian academic medical centre with active clinical services in neurology and neurosurgery. For this exploratory study, we used grounded theory methodology. Grounded theory is a research methodology designed to construct novel theory via a rigorous analysis of research data [11]. In the grounded theory approach, data collection and data analysis occur concurrently, each influencing the other in an iterative fashion.

Data collection took place via a combination of focus groups and individual or dyadic interviews. Participants were either health care providers or patient-caregiver dyads [3]. Health care provider participants were sampled purposively to ensure that all participants cared for seriously ill patients (inpatient and outpatient) living with neurological disease. Providers cared for a variety of neurological diseases including, but not limited to amyotrophic lateral sclerosis, muscular dystrophies, stroke, neuro-oncology and traumatic brain injury. Four focus groups were formed: A) palliative care physicians either as palliative care specialists [4] or neurologists providing palliative care [2], B) neurology [6] and general palliative care [2] residents, C) nurses who care for patients with advanced and end-stage neurological illness (4 nurse practitioners, 1 registered nurse); and D) allied health care providers (3 speech language pathology, 3 occupational therapy, physiotherapy) who care for patients with advanced and end-stage neurological illness. These participants were chosen as they represent different facets of the multidisciplinary care required to support people living with serious neurologic illnesses. Participants were identified using an email invitation directed at each group of potential participants and via in person discussions with the team leads for each target group. Focus groups were led by two of the authors (MC, TG) and based on a pre-determined framework guided by open-ended questions designed to elicit participants' experiences with providing palliative care for individuals with neurological illnesses, and to elaborate the challenges they faced (Appendix A). Focus groups were typically 90 min long.

In addition to data from health care providers, we also sought the perspectives of patients and their caregivers, to enrich our understanding of the challenges of palliative care in neurology. For patients and caregivers, we chose a dyadic interview approach to data collection in order to represent the needs of the two individuals most affected by the neurologic disease. Potential participants were identified through direct invitation [1] or via referral from other physician sources [2]. Participants represented both inpatients [1] and outpatients [2] and all participants were being followed by a palliative care physician, in addition to a neurologist. Both patients and caregivers were interviewed together, except in one case in which the patient was no longer able to participate in an interview. In this case, the caregiver was interviewed alone. All three semi-structured interviews were led by TG, based on a semi-structured interview guide (Appendix B). Focus groups and semi-structured interviews were recorded and transcribed verbatim without participant identifiers.

### 2.1. Qualitative data analysis

Data were analysed using the constant comparative approach that characterizes grounded theory. Rigorous and iterative review of the

data was completed starting with line by line coding (MC, TG). All transcripts were examined in detail and key themes were identified and listed. The themes identified were compared across focus groups and interviews, and memos were created to identify the preliminary coding categories and to identify the range of data that each thematic category contained. Thematic categories were re-examined and refined throughout the course of the study and relationships between categories were further explored to elevate the level of analysis from categorical to conceptual and improve the depth and meaning of the data. Qualitative analysis software was used to support data analysis (NVivo 10 for Windows).

### 2.2. Consent

The study was approved by the Western University Health Sciences Research Ethics Board. Written informed consent was obtained from all participants.

## 3. Results

While it is clear that there are substantial overlaps between general palliative care and palliative care in neurology, respondents frequently highlighted specific challenges arising for patients with neurological disease. Specific characteristics of neurological disease that affect palliative care in neurology were identified: 1) *timelines* of disease progression, 2) *barriers to communication* arising from neurological disease, 3) *variability across disease progression*, and 4) *threat to personhood* arising from functional and cognitive impairments related to neurologic disease.

### 3.1. Features specific to neurologic disease

#### 3.1.1. Timelines

Timelines for disease progression are often longer and more uncertain in neurological disease, as compared to oncological diseases, regardless of whether disease onset is acute or progressive. As one respondent reported, additional challenges for clinicians arise from:

“the degree of uncertainty around patients with strokes and things like that. Again, with cancer, if someone has stage 4 cancer, [...] not that they can 100% predict life expectancy, but the prognosis is fairly certain and you can give people a general timeline.”  
(trainee)

Uncertainty about timelines is a challenge not just for clinicians, but also impacts patient understanding of the disease and its life-limiting trajectory:

“Something, I think, that's really problematic [for patients and families] is the understanding of the progression of the disease, and it's hard because the trajectory is unknown. We don't know the length of time. There is not, like cancer, okay, you've got your cancer here and this is what the five year survival rate is going to be [...] I find that a lot of them [patients and families] just don't understand that yes, this is probably a disease that will take your life.”  
(nurse)

The uncertain timelines of neurologic illness also complicates caregiver understanding and attitudes towards neurologic disease and palliative care:

“It's a bit of a crap shoot. I mean really if she got it [progressive supranuclear palsy] when she was 60, there's a trajectory I think associated with it. [...] Well, [the physician] thought that my mom had probably had it for seven years before we went through all these machinations. So, there is no projected end date for Mom and it's more like MS [multiple sclerosis].”  
(caregiver)

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