

# Neurologists' Attitudes and Perceptions on Palliative care: A Canadian Perspective

Miranda M. Wan<sup>1</sup>, Nora Cristall<sup>1</sup>, Ronak Kapadia<sup>1</sup>, George Francis<sup>1</sup>, Lara Cooke<sup>1</sup>

<sup>1</sup>Department Of Clinical Neurosciences, University of Calgary

mmwan@ucalgary.ca



## BACKGROUND

- Many chronic neurologic conditions become palliative with substantial palliative care needs.<sup>1,2</sup>
- However, there is a significant gap in care delivery.<sup>3</sup>
- Neurologists are in a unique position as they are integral in providing patient centered care, understanding neurologic disease and illness trajectory, and how disease can affect patients' sense of self and values.<sup>3</sup>
- Little is known about neurologists' perceptions, approaches, and challenges in initiating care planning decisions and their attitudes and perceptions' towards palliative care for patients with progressive neurologic diseases.
- The aim of this study is to understand the attitudes and perceptions of Canadian neurologists on their approach to these conversations and palliative care

## METHODS

### Study Design

- Qualitative research design (*constructivist grounded theory*)
- This study was conducted between November 2022-April 2023 at a single Canadian academic center

### Participants & Data Collection

- Neurologists from one Division of Neurology were invited to participate in a 30 minute semi-structured interview.
- Interviews were conducted in English and occurred online or in-person and were recorded and transcribed.
- Initial purposive sampling was used. As data analysis commenced, theoretical sampling was used until saturation was reached and confirmed with additional interviews.
- An interview guide was developed from the previous literature that was edited based on case and conceptual memos generated by interviewers after each interview (MW and NC)<sup>4</sup>

### Data Analysis

- Two independent authors (MW, NC) conducted open coding and created a coding framework
- Each interview was independently analyzed by using this codebook and modified through an inductive process, to create axial codes across causal conditions, strategies, intervening conditions, and consequences. Selective coding was then conducted to develop substantive theoretical suppositions to support the axial codes (Figure 1)
- Member checking was conducted by the interviewer (MW)

## Main Question:

How do neurologists approach care planning and palliative care in patients with chronic neurologic conditions?

Background & previous experiences	Initiating & reassessing discussions	Ethical Implications	Understanding the role of the neurologist in palliative care
What does care planning mean? What does palliative care mean?	Tell me about a time you initiated a care planning discussion with your patient?	Can you tell me about a time you felt one of your patients was over-treated at end of life?	How does palliative care serve neurologic patients?
What previous training experiences have you had?	What role does prognosis play?		Tell me about a time you involved palliative care?

Table 1: Sample of interview guide questions used for semi-structured interviews.

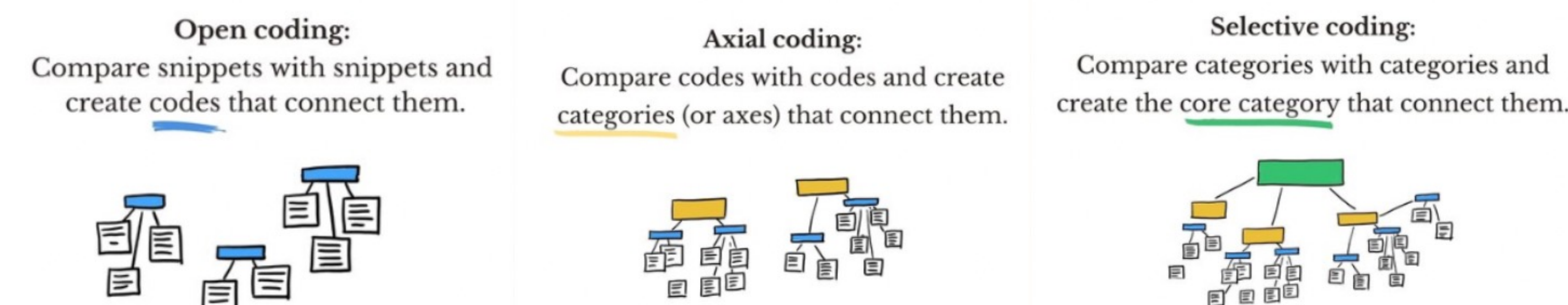


Figure 1: Schematic of the constant comparative method used in data analysis. <https://delvetool.com/guide>

## RESULTS

- Participants (10) represented a broad spectrum of neurologist experience & subspecialties (Table 2).

Type of Practice	Number of Years in Practice	Primary Neurology Subspecialty
Academic	0-5	Movement disorders
Academic	0-5	Stroke
Academic	0-5	Multiple Sclerosis
Community practice	6-10	General Neurology
Community practice & academic	11-15	Neuromuscular
Academic	11-15	Neuro-oncology
Academic	16-20	General Neurology
Academic	16-20	Multiple Sclerosis, General Neurology
Academic	>21	Neuromuscular
Academic	>21	Stroke

Table 2: Participant characteristics

## Theory:

Care planning and palliative care are high priorities for neurologists which are grounded in the fundamental principles of medical ethics of autonomy, non-maleficence, and beneficence.

*"Based on the prognosis and the benefit of the treatment, then we make a decision together in terms of what to do in terms of treatment."* Participant Alpha

*"We don't do palliative care for non-malignant disease, all that well."* Participant Golf

Because neurologic diseases can affect patients' independence and identity, and often have unclear prognoses, there are unique palliative care needs and neurologists' should have longitudinal involvement in their care.

*"A lot of the neurological diseases that we deal with are terminal or even if they're not terminal, they will change how people live. They will change the way they function in society as well."* Participant Alpha

Unfortunately, these needs remain unmet for patients. A number of barriers exist from a patient, provider, and health system perspective, such as misconceptions about palliative care, lack of provider experience or comfort, and resource availability.

*"I think it stems from [] the way people view illnesses. Where I trained, it's a bit more difficult for people to accept [illness]...they always feel like it's something that could be done and that drives things a lot."* Participant Foxtrot

*"We should be primary [providers], and we need to do better palliative care. What we don't get is we don't get access to the resources like the hospice type resources. We do reasonably well in the ward if someone's going to die in a few days, we don't do well when it's a month or six weeks."* Participant Delta

Opportunities to improve care exist with continuing education such as increasing educational opportunities for trainees and staff, collaboration with palliative care specialists, and health systems support, such as increasing public awareness to address misconceptions about palliative care and resource availability.

*"I think experience and time, mentors and models, and lots of those mentors and models are not in med[icine, such as] our allied health providers, social workers, and other people."* Participant Charlie

*"We just have this idea that life is going to go on and be great, but it's often not, [...], so I do think that it is terrible for families, patients, and the healthcare system. And so I would love it if society could have a much bigger, broader conversation about prolonging life."* Participant Echo

## DISCUSSION

- This theory is reflective of previous literature
  - Highlights the unique palliative care needs of neurologic patients and their families which are unmet and can lead to avoidable suffering.
  - Identifies a high priority area to advance care for neurologic patients
- What can we do?<sup>5</sup>
  - Educators - teach primary skills to trainees
  - Researchers - Build evidence base to improve quality & advocate for policy
  - Administrators - Models to demonstrate value to improved quality of care
  - Clinicians - Collaborate in a transformed integrated practice
  - Healthcare system leaders - Recognize need, innovate models of care
  - Patients and families - Share lived experiences

### Limitations

- Conducted at a single academic center in one country and homogeneity of clinical practice, self-selection bias for participants
- Relationship between the interviewer (resident) and interviewees (staff physicians) may have influenced responses. This was mitigated by having an additional interviewer who has no prior relationship with the interviewees.

### Future Directions

- Formal needs assessment of Canadian neurologists to prepare for design and implementation of tailored educational and point of care tools and strategies to enhance palliative care in our field.
- Continuing medical education opportunities & collaboration with palliative care providers

## CONCLUSION

To advance care for neurologic patients, neurologists must play a key role in the provision of care planning and palliative care.

Improving educational opportunities, increasing collaboration with palliative care specialists, and dedicated health system supports are required.

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