




## Original Article

# Trainee Distress When Faced with End-of-Life Care in Neurology: A Qualitative Analysis

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**ABSTRACT: Objective:** To identify sources of distress experienced by trainees when providing neuropalliative care and to explore the perceived and unperceived educational needs of trainees learning to deliver neuropalliative care. **Method:** This study is a post hoc analysis of a qualitative investigation performed at a single Canadian academic center with active clinical services in palliative medicine, neurology, and neurosurgery. Grounded theory methodology was used to explore trainees' perspectives when learning neuropalliative care. This study used focus groups, using open-ended questions, to elicit participants' experiences providing neuropalliative care as well as to explore the challenges in neuropalliative care. **Results:** Qualitative analysis identified multiple sources of distress for trainees in neuropalliative care and broad themes emerged: 1) a *lack of experience and knowledge*, 2) the *emotional toll* of learning neuropalliative care, and 3) *prognostic uncertainty* in neuropalliative care. **Conclusion:** Our results suggest that palliative neurology curricula should focus not only on symptom management but also on strategies for improving communication about prognosis and managing clinical uncertainty. Improving trainee comfort and confidence in neuropalliative care throughout the illness trajectory may alleviate sources of distress during training and increase quality of care.

**RÉSUMÉ : Détresse des stagiaires en neurologie face aux soins de fin de vie : une analyse qualitative. Objectif :** Identifier les sources de détresse ressenties par les stagiaires lors de la prestation de soins neuro-palliatifs ; explorer les besoins éducatifs perçus et non perçus de ces mêmes stagiaires en matière d'apprentissage et de prestation de soins neuro-palliatifs. **Méthode :** Cette étude constitue une analyse *post hoc* d'une enquête qualitative réalisée dans un seul centre universitaire canadien disposant de services cliniques actifs en médecine palliative, en neurologie et en neurochirurgie. La méthode de la théorie ancrée (*grounded theory methodology*) a été utilisée pour explorer les perspectives des stagiaires lors de leurs activités d'apprentissage en matière de soins neuro-palliatifs. Il est à noter également que cette étude a fait appel à des groupes de discussion et à des questions ouvertes afin de recueillir l'expérience des participants et d'explorer les défis que posent les soins neuro-palliatifs. **Résultats :** L'analyse qualitative a permis d'identifier de multiples sources de détresse chez les stagiaires en soins neuro-palliatifs. À ce sujet, de grands thèmes ont émergé : 1) *un manque d'expérience et de connaissances* ; 2) *le poids émotionnel lié à l'apprentissage des soins neuro-palliatifs* ; 3) *l'incertitude pronostique dans les soins neuro-palliatifs*. **Conclusion :** Nos résultats suggèrent que les programmes de neurologie palliative devraient se concentrer non seulement sur la prise en charge des symptômes mais aussi sur des stratégies visant à améliorer la communication des pronostics et à gérer l'incertitude clinique. Il se peut ainsi que l'amélioration du confort et de la confiance des stagiaires à l'égard des trajectoires des patients malades atténue leurs sources de détresse en cours de formation et augmente la qualité des soins prodigués.

**Keywords:** Clinical neurology; End-of-life; Medical education; Palliative care; Palliative neurology; Prognosis

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## Introduction

Many neurological and neurosurgical conditions have trajectories that could benefit from a palliative approach to care. Patients requiring neuropalliative services often have complex and variable illness trajectories that require prognostic discussions, which are challenging for both neurologists and families.<sup>1</sup> Increasingly, there is evidence that incorporation of neuropalliative care is beneficial throughout the illness trajectory and can be

implemented from the time of diagnosis.<sup>2–4</sup> Neuropalliative care is not solely indicated at the end-of-life. There is a consensus that neurologists should have adequate training in essential palliative care skills, which include advanced care planning, communicating challenging news, managing chronic pain and complex symptoms, and addressing psychosocial concerns faced by patients and families when confronted with serious neurological illness.<sup>4</sup> In fact, graduate medical education programs now

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**Table 1:** Examples of neurology competencies related to palliative care, taken from the Royal College of Physicians and Surgeons of Canada Neurology Competencies document (June 2019)

Competency
2.3. Establish goals of care in collaboration with patient and their families, which may include slowing disease progression, treating symptoms, achieving cure, improving function, and palliation
2.3.1. Identify and discuss the need for advance care plans
2.3.2. Facilitate discussions regarding palliation and end-of-life care
2.4. Establish a patient-centred management plan
2.4.1. Develop, implement and monitor patient-centred care plans, including prognostication for
2.4.1.1. outpatients with acute presentations and/or chronic neurologic conditions
2.4.1.2. hospitalized patients with acute illness, or acute exacerbations of chronic illness
2.4.1.7. symptom management
2.4.1.8. end-of-life care
1.1. Communicate using a patient-centred approach that encourages patient and family trust and autonomy, and is characterized by empathy, respect, and compassion
1.2. Optimize the physical environment for patient comfort, dignity, privacy, engagement, and safety
1.4. Respond to a patient's non-verbal behaviours to enhance communication

mandate that neurology trainees receive education in palliative care (Accreditation Council for Graduate Medical Education, Royal College of Physicians and Surgeons of Canada), reflecting the growing importance of learning to apply palliative principles within neurology (Table 1).

Despite recent advances in palliative care education, neurologists often feel challenged when facing complex neuropalliative situations.<sup>5</sup> Indeed, clinical uncertainty has been shown to be a source of distress even for experienced neurologists.<sup>1</sup> Distress is known to take an emotional and psychological toll on healthcare providers and thus impacts the quality of palliative care delivery in neurology.<sup>6</sup> Evidence suggests that most healthcare professionals do not receive adequate training and guidance on how to respond to their own feelings when faced with providing care for serious illness.<sup>7</sup> Palliative care education tends to focus on knowledge, rather than attitudes, and often does not allow for trainees providing palliative care to reflect on their own experiences.<sup>8</sup> While previous studies have identified that trainees feel unprepared and overwhelmed to face complex serious illness,<sup>8-12</sup> there is limited knowledge of the specific sources of distress.

Better understanding sources of distress encountered by trainees when caring for patients and families living with a neuropalliative conditions can help guide the curriculum reform needed to better equip neurology and neurosurgery postgraduate trainees to provide high-quality palliative care. This study is a post hoc qualitative analysis of a previous study that explored the challenges facing palliative neurology practice in which trainees were interviewed as a portion of data collection.<sup>5</sup> During the grounded theory analysis of the larger study, it became apparent that trainees experienced distress when faced with end-of-life care in neurology. The objective of the present study is to explore these sources of distress in greater detail

and to determine the perceived and unperceived educational needs of trainees in neuropalliative care.

## Methodology

This qualitative study was completed between November 2013 and March 2015 at a single Canadian academic center with an active Neurology and Neurosurgery residency program. We used grounded theory methodology for data analysis starting with line-by-line coding (K.K., M.C., T.E.G) and identification of key themes within the transcripts. Comprehensive details regarding qualitative data analysis and the grounded theory methodology are described elsewhere.<sup>5</sup> Full approval for this study was obtained from the Western Health Sciences Research Ethics Board. All participants provided written informed consent.

Data were collected via two focus groups with resident neurology (total six trainees, years 2–5 of 5 years) and palliative medicine trainees (total two trainees, year 3 – final year). Trainees had clinical experience in a variety of settings including inpatient, outpatient, and emergency departments. Trainees participated on a voluntary basis and were identified using an email invitation for participation in a focus group. The focus groups were part of a larger study exploring the challenges facing palliative neurology practice, and trainees were interviewed as a portion of data collection.<sup>5</sup> Because we explored the data content in the trainee subgroup of a larger study, analysis occurred subsequent to rather than simultaneously with data collection and a total of two focus groups were performed specifically with trainees. Focus groups were led by two of the authors (M.C., T.E.G.) and were typically 90 minutes long. The open-ended questions used to stimulate discussion regarding participants experiences can be found in a previously published manuscript.<sup>5</sup>

## Results

Both neurology and palliative medicine trainees identified similar sources of distress when facing neuropalliative care. Therefore, the data were analyzed as a single group of trainees regardless of background training. Qualitative analysis identified multiple sources of distress with the following broad themes: 1) trainees were concerned that they had a *lack of experience or knowledge* required to care for people with neuropalliative conditions; 2) trainees identified a high *emotional toll* associated with caring for people with neuropalliative conditions during their training; and 3) trainees viewed *prognostic uncertainty* as a barrier to trainee participation in neuropalliative care.

### Lack of Experience or Knowledge

Trainees stated that the focus of neuropalliative care is to provide a framework for addressing issues at the end-of-life in neurology, to maximize comfort, and to ease transitions at the end-of-life. They overwhelmingly identified a *lack of knowledge* regarding how to approach clinical situations and a *lack of experience* in clinical neuropalliative care as major sources of distress.

“... a way of doing a values history [to determine a patient's beliefs, preferences, and values for care] because no one really goes through that. We're just expected to get one, so maybe having some sort of clinical tools that are available to us or a teaching session in terms of how to get a values history from someone.”

"I think sometimes as residents we are thrown into these situations without previous experience. I think some sort of training or a palliative course . . ."

Feeling unprepared to participate stemmed from a lack of guidance on how to approach patients and families at the end-of-life. Trainees felt unprepared to initiate conversations about a poor prognosis or other sensitive issues, and they felt that their own lack of knowledge about illness trajectories made it more difficult to initiate discussions at end-of-life.

" . . . sometimes you just don't know how far you should talk, or what is at that end-of-life in terms of how it goes, how much you should discuss with the patients because maybe you feel they're near end-of-life but we can't really predict how long they will live."

Trainees wished to have more structured guidance regarding an approach to end-of-life care situations in neurology before caring for patients and families in a clinical setting.

" . . . I think we've been given handouts in terms of just having to have that palliative discussion, certain phrases and things to use, which are very helpful, especially when you are just starting off because it's a very uncomfortable conversation to have, particularly when you haven't done it before and you have no training."

Because trainees perceived themselves as having a lack of knowledge and confidence in their skills, they were worried about conveying inappropriate or inaccurate information during family conferences.

"there's also the comfort level in your own ability to predict what's happening. So when you're early on, you don't want to say death and dying because what if you're wrong, like I'm not sure they're death and dying, nobody mentioned it at rounds or whatever, but do I know they're really dying?"

True knowledge gaps regarding specific community services contributed to this lack of confidence.

"But we don't know what they have or what they could have in terms of support in terms of people [home care] coming into the house, nursing support at home, managing their needs as they grow in the community without having to come into hospital each time . . . And we don't know what we can offer"

Trainees did not feel comfortable identifying their lack of experience in neuropalliative care to fellow medical team members, and as such, they felt unable to reach out for support, leaving them with a feeling of isolation. However, trainees also developed confidence over time and were able to express more comfort in approaching neuropalliative care in the latter half of their training.

"I think the difference is mostly just more experience with the way neurologic diseases go . . . But when you're doing neurologic palliative care, because the diseases that we deal with can be quite different and have different trajectories and the whole different prognostication process, then you're still uncomfortable with the idea of talking about end-of-life."

"I think when you first start out you're so worried about causing harm. You're so worried about saying something that the family and the patient is going to just be so upset with you. The more you do it and the more experience you see, or you see your preceptor say death and dying to patients, you realize that it's not really as harmful as I think we make it out to be."

"As you become more senior and you're more in charge, and you understand the patient's illness better and you've seen more of it, you're more comfortable making that prediction in your own mind and therefore, having that discussion directly with the patient as opposed to sort of more hand waving when you're less likely to want to use that word."

Notably, the fact that trainees focused on neuropalliative care specifically at end-of-life identifies an unperceived educational

need amongst trainees. Trainees did not exhibit awareness that neuropalliative care can be offered throughout the illness trajectory and not solely at end-of-life.

### *Emotional Toll*

Facing neuropalliative situations in daily clinical practice had a high emotional toll and was identified as a source of distress for trainees. There were multiple contributors to this distress. From a procedural point of view, trainees were distressed by the possibility of upsetting patients and families, saying the wrong thing during a family conference, or taking away hope.

" . . . you never want to completely take away hope for the patient and the family. You want them to always hope that there is going to be some sort of, not necessarily a good outcome but an outcome that keeps them at peace and gives them some comfort at the end-of-life."

" . . . you almost feel like you're hitting them over the head with it . . . you want to still be supportive but you don't want to give them false hope."

Trainees were concerned about their ability to control their own emotional responses when breaking bad news during a family conference.

"How to prepare for the emotional content? I don't, I just squish it down and then when it wells up and I can't control it, it's too late. You just go in with a barrier up as much as you can in that regard because you don't want to make your patients cry and console you."

This was even more pronounced if the trainee had an established and longer-term relationship with a patient and family or when patients are younger.

" . . . where you've been following them for quite some time with advanced neurological disease, the emotional piece kind of comes through in bits and pieces . . . that can certainly impact how I feel throughout the day and how I interact with the patient. You can imagine being in their scenario and being in their shoes and having lost function or having not been able to do what you previously could do is really emotionally taxing."

"the younger the patients are, and the more people are depending on them the harder it is for me."

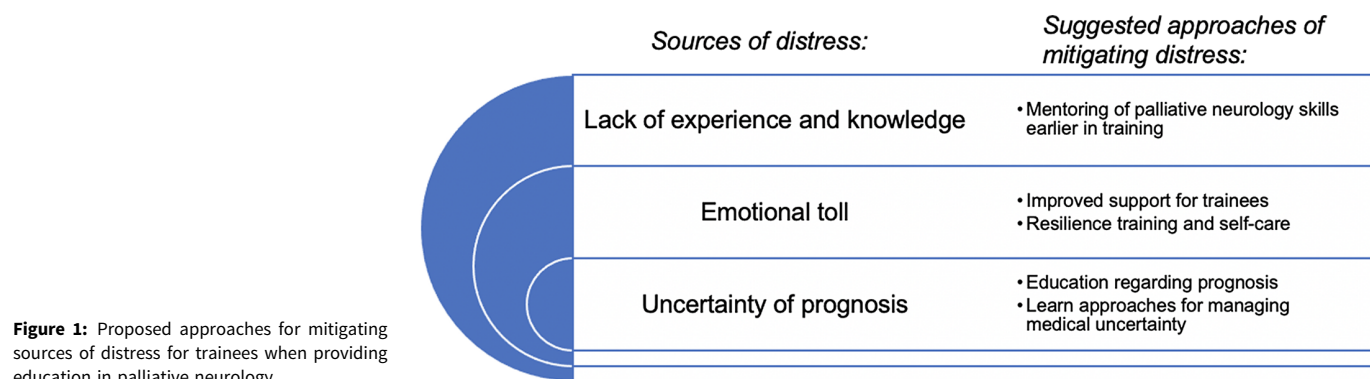
A high emotional toll occurred simultaneously with and was exacerbated by a perceived lack of experience or knowledge on the part of the trainee and in situations in which there was prognostic uncertainty.

### *Prognostic Uncertainty*

Uncertainty was identified as a barrier to the provision of neuropalliative care in the larger study.<sup>5</sup> When considering trainees more specifically, prognostic uncertainty was also an important source of distress. Trainees, however, expressed concern not only with the overall variability and uncertainty of disease progression commonly seen in advanced neurological conditions but also with their own lack of experience and knowledge specifically with respect to illness trajectories in neurology as a whole.

"It's very difficult because families want absolutes, and we cannot give them that. I think that's a very big barrier because families feel, and we feel uncomfortable having those discussions because there is so much uncertainty."

"I still felt very uncomfortable coming back and having those conversations because I really didn't have any specific training for this sort of uncertainty . . . You don't learn how to have that type of conversation."



**Figure 1:** Proposed approaches for mitigating sources of distress for trainees when providing education in palliative neurology.

### Other

In addition to the aforementioned themes, trainees identified discomfort with administering medications commonly used in palliative medicine.

“If we control their pain too adequately, their consciousness level is impaired and that’s not something I like.”

“I’m pushing medication in a very short period of time, and in this half-second decision, to push more and more of this and just hoping I don’t kill her right now.”

“I think there needs to be a lot of comfort level around what you’re giving.”

Furthermore, trainees felt uncomfortable in approaching spiritual and cultural aspects of care, especially when different from their own.

“The spiritual and religious aspect is always awkward when brought up. I think that’s something that we think of probably the least.”

“I’m not particularly comfortable talking about going to heaven. I’m not a religious person.”

“Maybe religion is something that we would avoid but not necessarily avoid with purpose. It’s just that it is not something that’s common in my life, and so it’s not something that I would commonly ask.”

### Discussion

This exploratory study reveals key sources of distress trainees experience when providing neuropalliative care. The results stem from a *post hoc* qualitative analysis of focus groups that answered questions related to challenges faced in neuropalliative care in general. Three core areas of distress faced by trainees in neuropalliative care are as follows: 1) a *lack of experience and knowledge*, 2) the *emotional toll* of learning the practice of palliative neurology, and 3) navigating *prognostic uncertainty*. From an educational point of view, these three themes may be considered perceived learning needs since they were identified by trainees as gaps in their expertise. Additionally, the fact that trainees only discussed neuropalliative care in the context of end-of-life care, rather than throughout the illness trajectory, is an important unperceived learning need amongst trainees. The results highlight the need for neurology curricula to include strategies for approaching prognostic discussions in the face of uncertainty as well as incorporating teaching strategies for improving trainee comfort and confidence with communication in neuropalliative care (Figure 1).

Our results suggest that sources of distress stem from a lack of confidence in communicating effectively with neuropalliative

patients and their families in complex situations. Neuropalliative care depends on dyadic care, which relies heavily on emotional components established by relational-communication skills. The physician must establish trust to carry out effective conversations related to death while considering a patient’s beliefs, preferences, and values when it comes to medical decision making, and for advanced care planning and substitute decision making.<sup>2</sup> Therefore, distress among trainees around communication issues paired with the vital role communication plays in this process indicates the necessity for enhanced communicative training.

Effective communication skills are essential for managing prognostic uncertainty, existential distress, and relationship-based components of palliative care. Neurology training programs should consider incorporating and standardizing communicative-relational methods into training. These skills are not core areas of training in most medical disciplines but are fundamental to the practice of neuropalliative care.<sup>4</sup> Short, yet intensive, courses have shown to significantly improve end-of-life communication skills in trainees.<sup>13–15</sup> Indeed, residents who received interventional training in these studies to improve their communication skills reported substantial increases of confidence ratings in delivery of bad news and felt more comfortable with information sharing and reacting to emotional cues from patients and families. Moreover, one study demonstrates the feasibility of incorporating communication training into pre-existing curricula for end-of-life care using several short training sessions over lunch breaks and before rounds.<sup>15</sup> In fact, residents reported increased self-efficacy in communicating challenging news following these training sessions. Alternatively, less rigorous and more practical interventions have been reported to increase trainee confidence in end-of-life care. For example, reference cards that focus on symptom management and knowledge have been shown to be effective educational tools.<sup>16,17</sup> One study reported improved knowledge and comfort in providing pediatric palliative care compared to those who did not have reference cards.<sup>17</sup> Other studies have suggested that clinicians should strive to include trainees and medical students as often as possible when having challenging discussions to gain observational experience in communication.<sup>18</sup> Comfort and practice are essential for instilling confidence and self-efficacy in communication skills for trainees who encounter palliative care scenarios and may serve to address feelings of lack of experience and guidance when approaching neuropalliative care.

A structured approach aimed at building competency over time in palliative neurology training may also be successful in improving neuropalliative and end-of-life care education.

System-level solutions include increased palliative education earlier, at the undergraduate level, as medical students may benefit from exposure to palliative care during neurology clerkship and experiences in hospice settings. Early exposure to palliative care practice may lead to increased confidence for trainees when faced with neuropalliative situations during their formal training. In Canada, only 29.7% of Canadian undergraduate medical students reported completing a clinical rotation in palliative care.<sup>19</sup> Furthermore, 28.2% of neurology trainees completed a palliative rotation during neurology residency. This lack of formal training may play a role in the distress trainees experience when encountering neuropalliative care situations in the neurological sciences due to lack of experience and exposure. Our results highlight that resident trainees will stand to benefit from formal palliative care training, as neuropalliative care situations are common.

Discomfort in reaching out for support was also reported as a significant source of distress. Physicians, and healthcare providers alike, should be more aware of specific challenges trainees face and be proactive in ensuring that they feel comfortable and supported. Role modeling by supervisors with opportunities to explicitly discuss complex scenarios is one way to address this issue.<sup>20</sup> The facilitation of supportive debriefing after providing emotionally distressing care is also effective in palliative education.<sup>21</sup>

There are unique challenges in neuropalliative care. Specifically, challenges regarding uncertainty in prognosis and illness trajectory, inconsistency in attitudes among healthcare providers, and existential distress are key barriers to the provision of neuropalliative care.<sup>5</sup> The emotional toll of learning and practicing palliative care is not unique to neurology and is well documented in various medical disciplines engaging in palliative care. For example, internal medicine residents value opportunities to learn from dying patients but often lack confidence, resulting in emotional distress and wariness in approaching families for withdrawal of care discussions.<sup>21,22</sup> Furthermore, residents have reported that the main difficulties encountered during palliative training are the ability to provide adequate explanations, understand the patients' needs, and have sufficient theoretical knowledge.<sup>23</sup> The results of the present study highlight that trainees experience an added dimension of distress such that their perceived lack of skill is due to their level of training and experience.

This study was completed at a single academic center, limiting the generalizability of the results. Participants took part voluntarily, which may have led to a self-selection bias. Participants may have had a pre-existing clinical relationship with the primary investigator which could have resulted in responses that were not reflective of the participants' thoughts and feelings. Additionally, there is a possibility that participants may have also chosen responses to questions that they believed were socially desirable, as trainees may have felt uncomfortable discussing specific difficulties for fear of judgment from peers. Further, we are unable to comment on whether these results are different between neurology and palliative medicine trainees as the interview sessions consisted of trainees from both fields and the results from these interviews are anonymized. Lastly, this study had a small sample size. However, the consistent results in the sample of participants suggest that a large participant group may yield similar results.

## Conclusions

In conclusion, this study highlights sources of distress that trainees face when providing neuropalliative care. These results suggest that there should be greater emphasis on teaching communication skills

specifically to help residents better support patients and families facing complex neurological illness throughout the illness trajectory. Developing and practicing effective communication skills early in training may allow for increased opportunity to practice learned skills that ultimately increase confidence in the delivery of care thereby alleviating sources of distress for trainees, and allowing for more bandwidth to focus on providing high-quality care to this patient population. Future research should focus on developing, implementing, and evaluating effective communication-based training to enhance trainee competency in neuropalliative care and to address the emotional toll experienced by trainees.

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**Statement of Authorship.** KK, MC, and TG analyzed and interpreted the data. TG conceived and designed the study and MC and TG collected the data. KK and TG wrote the manuscript. All authors participated in the preparation of the final manuscript.

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