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“It’s not a one-person show” E-learning course in neuropalliative care: A qualitative analysis of participants’ educational gains and self-reported outcomes

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Abstract

Objectives. Patients with progressive neurologic illness still lack access to quality palliative care services. Barriers to the comprehensive provision of neuropalliative care include gaps in palliative care education. To address this barrier, a novel international model of neuropalliative care education e-learning program was launched in 2022.

Methods. This is a qualitative study on the self-reported learning outcomes and educational gains of participants of a neuropalliative care e-learning course.

Results. Thematic analysis shows changes in the participants’ perceptions of neuropalliative care and several specific educational gains. After attending the course, participants recognized neuropalliative care as a multiprofessional and interdisciplinary effort requiring more than medical knowledge and disease-specific treatment skills. They gained understanding of the complexity of prognosis in neurological diseases, as well as ethical concepts as the basis to approach difficult decisions. Valuing the needs of patients and caregivers, as well as honest and open communication were recognized as key components of the caring process. In particular, providing emotional support and building relationships to enhance the spiritual component of care were avidly discussed as essential nonmedical treatment options.

Significance of results. E-learning courses are helping to close the gaps in healthcare professionals’ knowledge and skills about neuropalliative care.

Introduction

Neurological diseases, due to their prolonged course, progressive disability, and difficult-to-predict prognosis, contribute to multidimensional suffering for patients and their families. Evidence suggests that patients with neurological diseases experience better quality of life and improved symptom control when referred to palliative care (Oliver *et al.* 2016). Neuropalliative care emphasizes quality of life over burdensome and futile treatments, helps coordinate care across healthcare settings, improves patient and family satisfaction, and reduces healthcare costs.

According to the World Health Organization, approximately 60 million individuals need palliative care annually with less than 15% having access to it (WHO 2020). Over 78% of those needing palliative care reside in low-to-middle-income countries that have inequitable access to palliative care. Further, as palliative care has historically been focused on cancer diagnosis, the majority of patients with progressive neurologic illness lack the same access to quality palliative care services.

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India currently has 2,500 neurologists, 1,800 neurosurgeons, and 200 palliative care physicians for a population of 1.38 billion. Approximately 55 million people become impoverished in a single year because of high healthcare costs and out-of-pocket spending (Dhamija et al. 2021). In Puducherry, a district of South India, patient costs for palliative care services through a hospice ranged from ₹200 to ₹11,000, depending on the nature of the services. Fees were high when services were provided by qualified nurses and varied considerably when physicians made home visits. In addition, organizations charge a monthly fee (Sharma et al. 2023).

The establishment of the International Neuropalliative Care Society (INPCS) brought new hope for increased access to neuropalliative care (The Lancet Neurology 2021), however, barriers still prevail (Kluger et al. 2023). Major barriers to the comprehensive provision of neuropalliative care include gaps in palliative care education, difficulty in integrating palliative care skills into routine neurological care, and lack of specialist palliative care services (Kluger et al. 2023). While there is no uniformly agreed upon optimal international model of palliative care for patients with neurological disease (Grossman et al. 2023), skill sets for neuropalliative care clinicians have been identified. These include effective communication skills, the ability to navigate complex person-centered decision-making, and the management of end-of-life symptoms and options (Grossman et al. 2023).

As one of the international and collaborative efforts of the INPCS, a novel international model of neuropalliative care education e-learning program was launched in 2022. This program, consisting of hybrid asynchronous modules and classroom lectures, was targeted at both neurologists interested in palliative care as well as palliative care professionals interested in the palliation of patients with neurologic conditions. The e-learning program was divided into two 6-month courses. Completion of both courses was required to receive a certificate. The course content was divided into 3 streams: neurology basics, palliative care basics, and neuropalliative care essentials. The structure of the curriculum, educators' experience of designing the course, and experiences are described by Bu et al. (Bu et al. 2024). This paper describes the participants' self-reported learning outcomes and educational gains.

Methods

This is a qualitative study based on the self-reported results of the course participants. The year-long e-learning course began in July 2022 and consisted of 12 modules, with 1 new module being covered every 4 weeks. Course participants came from a variety of professional backgrounds, among them 39 clinicians (neurologists, neurosurgeons, palliative care providers, geriatricians, psychiatrists, internists, intensivists, pediatricians) and 1 advanced practice provider (Bu et al. 2024). Upon completion of the course, all participants were asked to provide feedback on their learning experience as part of the course evaluation. Participation was voluntary. Course evaluation included an opportunity for participants to self-reflect on their learning process and to understand their self-perceived educational gains. The ability to self-reflect is 1 of the 4 core competencies in palliative care all healthcare providers are expected to command (Paal et al. 2019).

Because the course was built on several cases and contained significant theoretical input, the evaluation questions focused mainly on perception and knowledge, rather than skills development. Participants were asked to reflect on the following questions: (1)

How has your perception of neuropalliative care changed or developed after completing this course? (2) Please describe 1 or 2 key ethical considerations in neuropalliative care. How has this course equipped you to address these? (3) How has this course helped you to understand the emotional and spiritual needs of neurologic patients and their caregivers? (4) Reflect on any personal experiences or insights you have gained during the course and how these might influence your approach to neuropalliative care.

Reflective questionnaires included how participants plan to change their practice and those who gave an agreement were interviewed 1 year after completion of the course. These results will be discussed separately.

Data collection and analysis

"The qualitative analysis process is cyclic and lacks a finite interpretation, requiring researchers to repeatedly revisit the data and coding process" (Vaismoradi et al. 2013). To capture the essence of the participants' experiences, thoughts, and feelings, the interview transcripts were organized using Excel. Two researchers (SB, PP) began the thematic analysis by familiarizing themselves with the transcripts. They independently created and labeled codes to describe the content of the identified meaning units. Patterns between codes were then identified, and codes were grouped to form themes. The preliminary themes were transferred to Miro Board, where the researchers discussed the meaning and contribution of each theme to the overall understanding of the data. Final themes were labeled to capture significant aspects of the participants' presentations (Vaisamoradi et al., 2013). While this method might initially seem rudimentary, thematic analysis is essential for detecting new patterns and generating hypotheses and theories (Holloway I, 2003).

Results

Participants characteristics

Forty participants originally registered for the course, which was the maximum number prescribed by the supervisory authority. Twenty-four (60%) finished both 6-week sections, Part 1 and Part 2, while three completed only Part 1. Of these 27 participants, 6 (22%) had a neurology background and 2 (7%) were psychiatrists. The others were involved in palliative care. Two (7%) participants had training in nursing; the others (93%) were physicians.

Data analysis

Two themes with subsequent subthemes resulted from the thematic analysis: (1) change in participants' perceptions of neuropalliative care and (2) participants' self-reported educational gains.

Theme 1: Change in participants' perceptions of neuropalliative care. A total of 3 subthemes, summarized in Figure 1, were identified that described participants' perceptions of neuropalliative care: Palliative care is indispensable in neurology; Neuropalliative care is not passive; Neuropalliative care requires trained staff.

Palliative care is indispensable in neurology. After finishing the e-learning program, participants stated that they felt motivated to learn and implement their newly gained neuropalliative care knowledge and skills. In terms of personal perceptions, participants stated that neurology felt less intimidating.



Figure 1. Change in participants' perceptions of neuropalliative care.

"After completing the course, I'm less intimidated by neurology. I feel more confident when speaking to patients and families, because at least I feel I know what I'm talking about!" (ID006)

"I understood that palliative care is indispensable in neurology and should be made an integral part of the treatment plan. Palliative care is to neurology what salt is to food." (ID002)

Participants also felt they had become a member of the neuropalliative care community. For many, the perception and management of the care of neurological patients changed. They felt more confident advocating for neuropalliative care and addressing patients' complex needs and caring for neurological patients and their caregivers.

"The perception and thinking about the care of neurological patients has changed after this course. The approach towards the management of such patients has been swung away in different ways. The way of breaking bad news, the need for long-term care, the emotional and spiritual aspects have changed my role and practiced method." (ID011)

The gain in knowledge was related to new concepts, such as covert consciousness and the disability paradox, as well as understanding the complexity of ethical decision-making, neurological disease trajectory, or palliative sedation. Participants reported that their symptom assessment and management skills had improved, as had their communication and advance care planning skills.

Neuropalliative care is not passive. Participants described neuropalliative care as an interdisciplinary field that requires a team approach.

"I realize more that neuropalliative care is interdisciplinary. It is not a one-person show that I have been doing." (ID005)

They identified that collaboration with neurologists is necessary for good symptom-specific treatment. Furthermore, there was an evolution in perspective that neuropalliative care is not passive and that it can extend care beyond diagnosis.

"I used to think neuropalliation is all about being passive, meaning not doing much to patients with terminal neurological illness allowing them to pass away when the time comes. But after the course, I understand that neuropalliation is more of active palliative medicine, where an active effort is taken to curtail the symptom burden in patients and thereby improve the quality of life of patients as well as their families and caregivers." (ID010)

"The treatment in neurology is not just limited to the diagnosis and telling the patients that they have to now live with it, but we can extend the care beyond the diagnosis, and help in an empathetic way them right from giving proper information." (ID013)

Participants shared that neuropalliative care is more than symptom control, although its primary goal is to reduce symptom burden and improve the quality of life for patients and caregivers. Participants were aware that many conditions would benefit from neuropalliative care, but currently, the field of neuropalliative care faces unique challenges due to disease trajectories, limited knowledge, and insufficient research. In palliative care, referrals of non-oncology patients were noted to be rare if not non-existent, yet, palliative care is indispensable in neurology.

Neuropalliative care requires trained staff. Participants emphasized the disconnect between the importance of neuropalliative care and the current training of medical professionals. While they acknowledged its value as a component of palliative care, they highlighted the need for both palliative care physicians to have training in neurology and neurologists to have training in neuropalliative care. In their opinion, this is the basis to meet the complex needs of people with neurological conditions, including the unique needs of the pediatric population, and understand the differences of palliative care in neurological settings.

"First and foremost: neuropalliative care has to be delivered by a trained person. Physicians with insight to neuropalliative care are great assets in delivering palliative care." (ID028)

Theme 2: Participants' self-reported educational gains. A total of 7 sub-themes describing participants' educational success, summarized in Figure 2, were identified: (1) *Prognosis is difficult in neuropalliative care;* (2) *Treat the whole person, not just the disease;* (3) *Distinguish best interest decision making from substituted judgment;* (4) *Improving quality of dying is as important as improving quality of life;* (5) *Valuing the needs of patients and caregivers makes all the difference in care;* (6) *Communication and nonmedical treatment are influential;* (7) *Relationships are an essential component of spiritual care.*

(1) *Prognosis is difficult in neuropalliative care.* Knowledge about disease trajectories enables better prognostication and patient care. The course underscored the unique challenges faced by neurological patients due to the combined burden of symptoms and the unpredictable course of their diseases. This unpredictability creates significant difficulties for everyone involved, including the patient, their family, and the entire care team.

"Another ethical issue arises when a patient is in a condition where we cannot really prognosticate and it leads to the question of "how long the patient (and the family) has to suffer?" These two aspects are commonly faced by me in my practice, which I find difficult to deal with." (ID013)



Figure 2. Participants' self-reported educational gains.

Surrogate decision-makers need good prognostication, information, and sufficient funds to manage the care. Screening tools and assessments are helpful in managing unmet needs of neurological patients and their care has to be adjusted according to disease trajectories.

(2) *Treat the whole person, not just the disease.* The study revealed that participants gained valuable insights into ethical decision-making for patient care. This includes balancing beneficence and nonmaleficence, effective communication with families and respecting patient autonomy, preferences, and values. Participants further recognized the importance of explaining these concepts to families. They also identified ethical decision-making, prognostication, and consideration of treatment goals (benefits and burdens) as crucial foundations for equitable care and social justice.

"I as a physician would always be in a zeal to treat the disease but the neuropalliative course has taught me to treat the person as a whole and not the disease by addressing the emotional and spiritual gaps in a patient's life." (ID010)

Withholding or withdrawing life-sustaining treatment is considered one of the most difficult decisions for the treating physician. Participants reflected on this and gained knowledge on how to approach this topic.

"This is the decision to stop or not start treatments that are considered to be life-sustaining. This can be a difficult decision, and it is important to consider all of the factors involved, including the patient's wishes, the prognosis, and the potential benefits and burdens of treatment. This course has equipped me to address this ethical consideration." (ID025)

(3) *Distinguish best-interest decision-making from substituted judgment.* Participants gained experience in techniques to elicit values, engage in shared decision-making, and facilitate advance care planning discussions. They learned to be aware of the importance of surrogate decision-makers and the importance of early communication to explore values and preferences.

"It is important to differentiate 'best-interests' decision making from substituted judgment. Sometimes what is best for the patient is not what he would have wanted. For example, my locked-in patient whose family said he would have wanted to live on at all costs, just to be there for his family as he is their 'rock'. Knowing the difference helps me to reconcile within myself and be supportive to the patient and family regarding their healthcare decisions." (ID005)

A value-based approach helps to define realistic goals and avoid potential conflicts between disease-modifying treatments and palliative care goals of improving quality of life and holistic approach. Above all, advance care planning requires open and compassionate communication.

(4) *Improving the quality of dying is as important as improving the quality of life.* The course highlighted the multifaceted nature of neuropalliative care, particularly its emotional, contextual, and cultural features. Participants learned that quality of life and death can only be defined based on individual values. Additionally, the ethical challenges surrounding autonomy in patients with cognitive decline became apparent. Life-sustaining treatments presented a complex dilemma, forcing consideration of existential suffering, the appropriateness of prolonging life, and the ethical implications of withholding or withdrawing care.

"All the while I thought that palliation is all about improving somebody's quality of life. But through this course, I have understood that there is an equally important aspect called quality of death." (ID010)

(5) *Valuing the needs of patients and caregivers makes all the difference in care.* Participants realized that neurological patients experience the disease as intrinsic, as the symptoms affect identity and personality. Neurological patients' complex needs, due to physical and cognitive limitations, necessitate a holistic approach to symptom control beyond just the disease itself. Understanding the patient as a person is equally crucial to managing their demoralization.

"We have learnt that, in regard to spiritual well-being, neurology patients experience their disease as something intrinsic to their person, which clearly differs from patients with cancer who see 'the cancer' as something outside of themselves." (ID001)

Participants acknowledged the high caregiver burden due to the uncertainty of the disease course. Caregiver fatigue and the need for respite care should be addressed, as well as encouraging self-care activities to caregivers.

(6) *Communication and nonmedical treatment are influential.* Communication is one of the key skills to assess and understand the needs necessary for neuropalliative care. Participants stated that the course improved their communication skills and that these are essential for building trust and providing support. Truthfulness and veracity in communication are especially valuable. The course fostered a shift in participants' communication style. They moved away from imposing their views on relatives and embraced a more collaborative approach. This involved actively engaging with patients and families by asking relevant questions.

"Recognizing the impact of communication on patient-centered care, I now appreciate the need for empathetic and compassionate communication skills in delivering neuropalliative care." (ID009)

(7) *Relationships are an essential component of spiritual care.* Participants realized that spiritual care is often neglected in the care of patients and caregivers because emotional and spiritual needs are often not recognized due to lack of time, personal and cultural factors, and lack of training.

"The engagement of family caregivers in spiritual care appears underutilized. Relationships formed an integral part of spirituality as they were a spiritual need, caused spiritual distress when broken, and where the way spiritual care was given." (ID011)

However, this course focused on the emotional burden and guilt of caregivers, the depth of emotional needs, the connection between faith and hope, and the interplay of neurology and psychology. Participants indicated that they learned how to incorporate spiritual care into neuropalliative care, for example, by exploring distress in order to help patients to find spiritual fulfillment, or how to address emotional and spiritual gaps.

"One of the major ways in which spiritual care can be provided to a person is by 'getting to know the person'. Hence I began to connect with people by asking them relevant questions. Ask them about themselves. Ask them about the story of their life. Ask them about their childhood. I make sure that I am connected with them by being interested in their 'stories'." (ID017)

The course taught participants that patients and caregivers are under tremendous emotional, spiritual, and physical distresses, which are linked to uncertain prognosis, disease trajectory, and inconsistency with care.

Spirituality includes values, meaning, and purpose in life, as well as connections. Emotional and spiritual suffering aggravates physical suffering, and therefore, spiritual care is essential. Spiritual caregiving respects individual personhood and emotional and spiritual support is only possible with an understanding of patients' and caregivers' lives. Spiritual practices are comforting and relevant in terminal disease.

"Emotional and spiritual aspects make a major part of the reasons for which we suffer. The neurologically impaired and their caregivers are no exception to this. This course through the excellent video sessions have helped me to

really learn to appreciate the fact that even those who are otherwise incapacitated will also have lots of emotional and spiritual aspects attached to their sufferings which should be addressed." (ID012)

Discussion

The lack of structured and broadly accessible educational programs is a key barrier to implementing palliative care into broader neurology services, although there are several initiatives on local and national levels (Kluger et al. 2022), (Gleicher et al. 2022), (Sharma et al. 2023). Still, creating a palliative care course is often a voluntary effort by "champions" of palliative care, struggling between clinical duties, patient care, and teaching at the university (Toussaint et al. 2023). All palliative care-related topics, including death and dying, require specific and well-planned teaching strategies, including sufficient bedside training and practical, self-reflective, and communication tasks (Toussaint et al. 2023).

The demand for palliative care for people with neurological disease and their caregivers is rising globally. Palliative care development, particularly education and training of health care workers, is central to improving access to palliative care and palliative care standards. The Action Plan from the UK (Cicely Saunders International 2021), as well as the Mapping of Palliative Care Services in Indian province (Sharma et al. 2023), clearly demonstrate that in countries with long tradition in palliative care and advanced services as well as in regions where access to palliative care is scarce, the educational challenge of adding (1) palliative care philosophy, (2) understanding the complex symptom assessment and management competencies, (3) designing care plans based on patients and families wishes integrating multi-professional and interdisciplinary approaches, and (4) the ability to listen and self-reflect (Paal et al. 2019) in healthcare providers form the skill set across the healthcare sector and services still remain limited.

The e-learning program evaluated in this study used a phenomenological approach to teach different aspects of neuropalliative care. The teachers' evaluation, which was conducted as a part of the course of the evaluation has been described elsewhere and indicated that this program is consistent with the mission of the INPCS and contributes to building an international neuropalliative care community (Bu et al. 2024).

Qualitative analysis of participants' self-reported outcomes and educational gains following participation in the 12-week e-learning course suggests changes in participants' perceptions of neuropalliative care and includes a long list of participants' self-reported educational gains. According to the participants, neuropalliative care is not a one-man show, but a multiprofessional and interdisciplinary effort that requires much more than medical knowledge and disease-specific treatment skills. The participants' evaluation indicates that the e-learning program boosted understanding of the complexity of prognosis in neurological diseases, which affects treatment, and needs to be thoroughly discussed with people involved in the care process. Among their educational gains by attending the course, participants listed several ethical concepts, such as patient autonomy or social justice. They learned ways to approach difficult decisions, such as withdrawing or withholding life-sustaining treatments based on ethical deliberation. Valuing the needs of patients and caregivers, as well as honest and open communication were recognized as key components of the caring process. In particular, providing emotional support, and building relationships to enhance the spiritual component of care were avidly discussed as essential nonmedical treatment options. Course participants indicated that their perceptions of neuropalliative care

have changed which impacts their personal practice in terms of collaborating with other disciplines or responding to the needs of people with neurological conditions and their caregivers. The most important message for implementing neuropalliative care is that it requires trained staff.

The course was based on case studies to demonstrate the complexity of managing various neurological conditions and the associated challenges of patient autonomy, and ethical and medical decision-making. The goal was to help palliative care physicians overcome their neurophobia (Chhetri 2017).

To achieve learning goals, it is important to set learning goals. Faculty evaluation indicated that pre-course screening should have been more focused in this regard (Bu *et al.* 2024).

As the demand for neuropalliative care is rising, the implementation into neurology services is lagging behind. Poorly organized and uncoordinated educational activities are a key barrier to palliative care access for neurological patients and their caregivers. Despite all the challenges, our study shows that e-learning courses are helping to close the gaps in healthcare professionals' knowledge and skills.

Limitations

The chosen evaluation strategy, which was intended to provide room for self-reflection, might be influenced by response shift or justification bias. Motivated participants who have invested considerable resources in completing a course might tend to overestimate their learning outcomes, leading to "effort justification bias," which has been described before (Paal *et al.* 2020). To determine the long-term impact of this e-learning course on participants, further evaluation steps are planned.

Ethical approval. Participant feedback was collected anonymously and voluntarily as part of the e-learning program curriculum evaluation. Written consent to collate and use the data for research purposes was obtained from all participants. Participants could refuse to respond without consequence. Ethics waiver was obtained from the Karunashraya ethics committee, Bengaluru, India as well as Paracelsus Medical University, Salzburg, Austria.

Competing interests. All author declare that they have no competing interests.

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