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Neuropalliative Care in the Emergency Department: Three Roles, One Goal

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Abstract

Over the last decade, there has been an increased focus on incorporating palliative care principles into the practice of neurocritical care and emergency medicine (EM). In this article, we describe three different roles that EM clinicians can fill as they initiate the provision of primary neuropalliative care to neurocritically ill patients: the stage setter, the spokesperson, and the screener. As the stage setter, EM clinicians start to build trust with the family by “breaking bad news”; encouraging them to consider the patient’s values, preferences, functional baseline, and directives; and providing support to the family during this emotional time as they hand them over to the admitting team who will continue this conversation. As the spokesperson, EM clinicians are involved in early treatment decisions, including whether the patient is admitted to the acute care service or the intensive care unit or transferred to a tertiary care facility, with the goal of preventing both the overuse and underuse of life-sustaining treatment. Lastly, as the screener, EM clinicians have a role to ensure that patients with chronic neurological diseases and patients with a medical history that puts them at high-risk of developing a neurological emergency have goals-of-care conversations and have acceptable control of their daily symptom burden. Further investigation is needed before interventions targeting the practice of neuropalliative care in the emergency department can be developed.

Keywords

Palliative care; Emergency medicine; Neurological disorders; Brain injury

Introduction

Most patients admitted to the neurological intensive care unit (neuro-ICU) start this journey in the emergency department (ED). This is where patient-centered care starts, meaning that the patient’s values and preferences guide treatment decisions. Recently published

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Author Contributions

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Conflicts of interest

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guidelines for palliative care in the ED state that all seriously ill patients should receive primary palliative care concurrently with their life-sustaining treatment (LST) [1]. The practice of palliative care in the ED may decrease patients' symptom burden, improve access to needed services, reduce hospital length of stay, enhance care at the end of life, decrease the number of undesired ICU admissions, and orchestrate psychosocial support for the family [2, 3]. Goals-of-care conversations (GOCC), which explore a patient's quality of life, views, and priorities within the context of medical treatment, may increase the likelihood that a patient's end-of-life care preferences are known and followed [4].

Most of the work involving palliative care in the ED involves older adults with preexisting life-limiting conditions, such as incurable cancer [5]. Less is known about the impact of early palliative care for patients with severe acute brain injury (SABI), including stroke, traumatic brain injury (TBI), and hypoxic-ischemic encephalopathy after cardiac arrest. Patients with SABI face a sudden threat to their life and personhood [6] and a high degree of prognostic uncertainty in terms of morbidity and mortality, especially in the hyperacute setting [7-9]. Many of these patients, or more accurately their family members, in the ED are immediately confronted with choices regarding intubation, cardiopulmonary resuscitation (CPR), endovascular thrombectomy, decompressive hemicraniectomy, or invasive intracranial pressure monitoring. These are complex medical decisions that must be made in a short amount of time and often involve additional intricacies, such as transfers to larger academic centers or admissions to a neuro-ICU.

For the last decade, there has been an increased focus on the integration of palliative care into the practice of neurology [10, 11]. The "neuropalliative care approach," recognizes the unique palliative care needs of patients with neurologic disease and their families. This multidisciplinary, multidimensional approach to symptom relief, psychosocial support, and end-of-life care can be applied to patients with neurological illness presenting to the ED (Table 1). We describe three different roles that emergency medicine (EM) clinicians are uniquely poised to fill in order to provide comprehensive primary neuropalliative care to patients that starts in the ED: the stage setter, the spokesperson, and the screener (Table 2). This review serves two purposes: (1) to describe roles for EM clinicians and (2) to provide context for neuro-ICU clinicians about what neuropalliative care their patients may receive prior to arriving to the neuro-ICU and how the practice of neuropalliative care beginning in the ED ultimately benefits their patients.

The Stage Setter

The role of the stage setter is to prepare the family for what is ahead by having an initial GOCC. When a patient presents with SABI, EM clinicians are typically the first to talk with and "break bad news" to the patient's family members. In this role, EM clinicians take on a large responsibility as they start establishing trust and expectations with the family. Fortunately, there are established frameworks for breaking bad news, such as the SPIKES protocol [12], the ABCDE mnemonic [13], and the use of a "headline" [14], which can help guide the stage setter. Regardless of the model that is used, the general message to the family is that their loved one suffered a brain injury and their hospitalization will likely be long, with an expected level of recovery that is uncertain. Messaging also aims to orient

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the families to the unique aspects of neurocritical illness, such as prognostic uncertainty, unpredictable nature of an ICU course, involvement of multiple health care teams, and roles of supportive care resources (e.g., palliative care, social work, and spiritual care). The language used by EM clinicians to convey the patient's condition to the family can be passed along to the neuro-ICU clinicians so that they may be able to use the same phrasing or course correct as needed. Use of consistent language may enhance the family's understanding of the patient's condition and also demonstrates seamless care transitions from the ED to the ICU.

"Setting the stage" also includes encouraging family members to begin formulating the patient's values and preferences and how their past experiences may relate to their current situation without discussing the patient's prognosis. In older adults, collecting information regarding their baseline physical and cognitive function, as well as perceived quality of life, is especially important. Older adult ICU survivors experience a significant decline in their functional status over the year following their admission, especially if they already had an impaired functional baseline [15]. Although sharing a prognosis is ideally avoided in the ED, experts suggest that if clinicians discuss prognosis with a patient's family members, it is important to acknowledge the uncertainty associated with SABI [16]. Guidelines recently published by the Neurocritical Care Society regarding neuroprognostication for patients in a coma following cardiac arrest [7] or critically ill from an intracerebral hemorrhage (ICH) [8] or moderate and severe TBI [9] recommend not beginning to assess prognostic factors for at least 72 h after the injury. All three guidelines endorse the use of all indicated medical and surgical interventions within this time frame, unless the patient is imminently dying from their injury or they have clear documentation stating they do not want to receive any life-prolonging interventions [7-9].

Therefore, we recommend that the focus of this initial GOCC not be on making any large immediate decisions regarding withholding/withdrawal of life-sustaining treatment (WWLST), including CPR, unless clear and well-established goals to focus on comfort-directed care already exist. Given this recommendation, we also advise against hospital policies that require EM clinicians to establish code status prior to admitting the patient, as the prognostic uncertainty of neurological emergencies often makes this consistent practice inappropriate. When having GOCC, EM clinicians tend to be more focused on asking for preferences regarding specific procedures, such as intubation and CPR, potentially misleading patients/surrogates rather than first eliciting a patient's values and then developing a treatment plan that best aligns with the patient's preferences [17]. The perceived length of time required to explore a patient's values was reported as a potential barrier to a preference-based GOCC in the ED [18]. We do not expect that the entire conversation can be completed in the ED and are instead advocating that EM clinicians simply start the preferences-based conversation with the patient's family members in order to encourage them to think about the patient's qualities and prepare them for their continued conversations with the neuro-ICU, neurology, and neurosurgical teams. By initiating the GOCC, EM clinicians will allow neuro-ICU clinicians to demonstrate the understanding of patients' baseline function, perceived quality of life, and values and goals for medical care elicited by EM clinicians. By seamlessly continuing the GOCC, family members will feel heard and understood from the first day of their neuro-ICU stay.

As the stage setter, the EM clinicians can provide emotional support to the surrogates. Family members face several unique psychosocial challenges, such as coming to terms with the significant prognostic uncertainty; unaddressed physical needs, such as housing and food; and a lack of consistent compassion, communication, and messaging from their health care team [19]. Social workers and spiritual care providers can supply the families with their invaluable resources and insights. Providing initial support will help establish a strong relationship between the clinicians and the surrogates. It is critical that any psychosocial needs of the family that are identified in the ED be passed on to the neuro-ICU team to address these needs up front in the neuro-ICU.

Finally, although the stage setter has the opportunity to develop trust between the health care team and the family, it is also important to note there is a risk of creating irreversible distrust. This can occur by providing misinformation regarding the patient's prognosis, being overly adamant about obtaining a patient's code status, offering or withholding treatment options that would be better introduced by other clinicians (such as the placement of an external ventricular drain or the initiation of hemodialysis), or insisting on continuing the GOCC with family members who are highly distressed after the "breaking bad news" portion of the conversation. It is important for the EM clinicians to be candid about any tension that may have arisen between the EM team and the family so that the neuro-ICU team knows what to specifically address in an attempt to rebuild any lost trust. Therefore, the role of stage setter is a large responsibility that would demand specific training in primary palliative care and communication skills in every EM residency.

The Spokesperson

As the patient's spokesperson, EM clinicians are responsible for advocating guideline- and goal-concordant care while preventing underuse or overuse of LST. Overly pessimistic neuroprognostication may result in LST not being offered or declined by the patient or family members and may lead to potential underuse of LST [20]. Conversely, for patients for whom LST, within the context of an uncertain prognosis, is clearly not within their GOC based on previously stated or documented directives, admission to the neuro-ICU or transfer to a tertiary care center may be inappropriate (i.e., potential overuse) [20]. To succeed in this role, EM clinicians must be aware of the factors and biases that affect the decision to pursue the initiation of LST, continuation of LST, or WWLST [20].

As stated previously, current neuroprognostication guidelines for patients with SABI recommend that all interventions be pursued in the acute phase of injury, unless the treatments are inconsistent with the patient's previously stated goals [7-9]. However, the decision to WWLST in the ED has been justified for a variety of medical reasons, such as a lack of improvement following initial treatment, a belief that the patient's injury is irreversible, or an expected level of recovery that is not consistent with the patient's minimally acceptable quality of life [21, 22]. The use of a medical justification for the WWLST of patients with SABI would ideally be avoided in the ED, as there is too much prognostic uncertainty in the hyperacute setting. Instead, we recommend that in the role of spokesperson, the EM clinicians advocate for guideline-concordant care, after gathering relevant information from the family, and make a recommendation regarding the use of

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further LST within the context of the patient's stated goals in conjunction with the neuro-ICU, neurosurgical, and neurology clinicians. In fact, if a medical justification is being used for the decision to WWLST in the ED, it is appropriate for EM clinicians to advocate for a multidisciplinary team huddle prior to speaking to the patient's family about a treatment plan.

One approach to offering this initial treatment plan and preventing the underuse of LST when the patient's prognosis or values are uncertain is to introduce the concept of a time-limited trial (TLT) of LST [23, 24]. Although initiating a TLT is traditionally considered the ICU clinicians' responsibility, introducing the concept of a TLT in the ED is an important tool for the spokesperson to combat their own bias, and that of their consultants, to be influenced by a premature neuroprognostication. By introducing a TLT in the ED, EM clinicians can help set the expectations with the family and allow them to formulate their GOC while the TLT is occurring. EM clinicians can take the following precautions when introducing the concept of a TLT: clearly communicate prognostic uncertainty to the family and that a range of outcomes are possible, which the intensivists will further clarify, and defer to the ICU team regarding the discussion of indicators of clinical improvement and deterioration and regarding the time frame for rediscussing GOC after arrival to the ICU. Furthermore, given the complexity of these treatment decisions, any initiation of a TLT is best with a team approach consisting of bidirectional communication among the multidisciplinary team of EM, neuro-ICU, neurology, and neurosurgery clinicians. As they will be the team providing the continued care, it is best if the neuro-ICU team is present for the conversation introducing the concept of a TLT to the family so that there is continuity for the plan to be in place. A high-level of collaboration might not be available for every patient in the ED. However, we propose it as a goal when considering a TLT. Introducing a TLT may also be appropriate for some patients whose overall goal is comfort-focused but who have a potentially reversible condition. For example, it may be appropriate to temporarily reverse a patient's DNI code status and intubate them for endovascular thrombectomy if there is a chance to decrease or eliminate the degree of disability the patient will experience [25]. Others have suggested that in cases in which the patient's values and preferences are unclear, the provision of potentially unwanted aggressive care may be ethically justified in some emergency or ICU settings, as long as it is provided with a clear offer of a TLT and continued, skillful conversation [26]. For example, if a patient with a TBI is unable to participate in a GOCC due to their injuries and no family members are identified, it is likely appropriate to proceed with a decompressive hemicraniectomy to prevent herniation until a GOCC can occur. As illustrated by the examples in this paragraph, TLTs introduced in the ED acknowledge prognostic uncertainty and the fluidity of a patient's GOC in the hyperacute setting and allow for both aspects to evolve as a patient's clinical picture becomes clearer. This is an ongoing area of research [23].

In the opposite aspect of the spokesperson role, EM clinicians can also prevent the overuse of LST by advocating for the avoidance of procedures, treatments, admissions, and transfers for patients in whom pursuing LST would not be within their GOC, even if prognostic uncertainty exists. Patients with SABI are often transferred to larger academic centers for further evaluation or definitive treatment of their condition. However, a transfer to another care facility may not be within a patient's GOC and could potentially be separating

a critically ill patient from their family members. Therefore, initiating such a transfer will ideally include a GOCC in order to determine that the procedure that the patient is potentially being transferred for or the transfer itself is within the patient's stated GOC. A retrospective study of patients who died within 72 h of transfer to a large tertiary care center found that only 10% of patients had a documented GOCC prior to being transferred [27]. When having this conversation, it is important to note that not all patients who are transferred for higher levels of care receive an intervention and that not all patients benefit from being transferred [28]. Informing the patient and/or their family members that, in some cases, the transfer is just for further evaluation and for help formulating a prognosis is also important, as families may not want a transfer for those reasons and may not require further clarity on the patient's prognosis to make treatment decisions. As with any LST, a transfer to a tertiary care center provides the patient with a chance for improvement that they may otherwise not get and may still end with a comfort-focused pathway if the desired outcome is not achieved [29]. Presenting the transfer to the decision maker in a comprehensive manner, including the downstream effects of the transfer, has the potential to prevent transfers that are not consistent with patient preferences and could save the family significant emotional and economic distress, in addition to ensuring that the patient is receiving goal-concordant care. One recommendation would be for accepting neuro-ICU clinicians to ask the referring EM clinician if a preliminary GOCC has occurred and if they believe the transfer is concordant with their treatment preferences.

The Screener

Whereas the stage setter and spokesperson roles are more applicable to patients presenting to the ED acutely with a life-threatening neurological illness, the screener is suggested as a role for EM clinicians to assess the neuropalliative care needs of all patients presenting to the ED. As much of this review has focused on patients with SABI, we will discuss the screener role as it pertains to stable patients who are at risk of presenting to the ED in extremis in the future. In this distinctive role, EM clinicians are the assessors of gaps in the neuropalliative care needs of patients with neurodegenerative diseases and patients with medical histories, such as prior strokes or epilepsy, that put them at risk of acute neurological decompensation in the future. For the first part of this role, EM clinicians can screen patients for ongoing neuropalliative care needs in relation to gaps in addressing their GOC, pain, nutritional, and functional status during brief conversations initiated through the use of serious illness conversation triggers. Subsequently, they can make immediate medication adjustments or a referral to their outpatient clinician, as appropriate. For the second part of the role, the intention is to elicit the values, preferences, and treatment goals of patients who have survived severe neurological emergencies to share their insights regarding their future care if their condition were to recur or a new emergency were to develop. It may be important to have this conversation documented before the patient is in a situation in which they are incapacitated, but knowledge of that information is paramount. In general, the screener plays a supportive role to the patient's primary care physician or to the patient's primary neurologist by ensuring that any gaps in the patient's neuropalliative care have been addressed. Ideally, EM clinicians are building off prior conversations and management that the patient has had with their primary clinicians. However, as patients

with chronic serious neurologic illness frequently present to the ED for management of their chronic conditions, the need for this role is likely increasing.

Patients with neurodegenerative disorders are at risk of being functionally dependent as their disease progresses but have low rates of documented GOCC [30]. Additionally, one retrospective study of health system administrative data found that nearly two thirds of patients with a neurodegenerative disease had at least one ED visit in the last year of their life [31]. Patients with chronic neurological conditions presenting to the ED for pain, nutritional problems, or gait instability are often better treated on an outpatient basis [32], assuming that the patient has the ability to follow up with a clinician. There is a potential need and opportunity for EM clinicians to address gaps in patients' GOCC and symptom management related to their neurodegenerative disease as they near the end of life. In the screener role, EM clinicians will identify serious illness conversation triggers in order to initiate a discussion that reveals the patient's neuropalliative care needs. Although these triggers will need to be defined for the practice of neuropalliative care in the ED, several have been suggested for the general practice of neuropalliative care [33]. Events such as numerous hospitalizations; new weight loss and comorbidities; and changes in cognitive, mobility, and functional status have been proposed as potential triggers [34]. Research is needed in order to establish serious illness conversation triggers specific to patients at risk of and with neurological emergencies as well as steps to meet the identified needs.

An additional opportunity for the screener exists with patients who have a medical history of stroke or other conditions that put them at risk of presenting to the ED with a neurologic emergency requiring neuro-ICU admission in the future. Each year, approximately 185,000 patients experience recurrent strokes [35]. When patients present with a recurrent stroke, they may be too incapacitated to express their treatment preferences. These patients may also have invaluable insights regarding their future care based on prior hospitalizations. Despite the importance of GOCC with this patient group, less than half of stroke survivors presenting to the stroke clinic had completed advance directives and even less had EMS documentation of these directives in one single-center study [36]. Although three quarters of the patients had some form of GOCC, more than half preferred to have additional dialogue [36]. Therefore, for this group of patients, we propose the use of a serious illness conversation trigger based on their medical history, such as stroke, seizures, progressive neurologic disease, or frequent falls. For instance, upon admitting or discharging a patient with frequent presentations for seizures, the EM clinician can ask the patient about their preferences and values that may be applicable to a decision to intubate the patient if any of their future presentations warranted such an intervention. Successful screeners have the potential to provide patients with the end-of-life care that they prefer by ensuring that their values and preferences are clearly documented in the chart before the patient presents for a life-threatening condition. Therefore, the neuro-ICU clinicians could use this information in the future to develop a patient-centered, goal-concordant treatment plan for the patient. More research is needed to determine whether fulfillment of this role is feasible for EM clinicians given the time constraints often present in the ED.

Conclusions

Expanding the practice of neuropalliative care into the ED may be one of the next steps to ensuring the consistent delivery of high-quality, patient-centered care to patients with neurological emergencies, and more research and educational efforts are required. Its successful integration may ease the transition for patients to the neuro-ICU. In an effort to encourage EM clinicians to practice primary neuropalliative care, we have described three succinct roles: the stage setter, the spokesperson, and the screener. By combining the aspects of these three distinct roles, EM clinicians can help establish trust between the family members of patients and their care team, advocate against the underuse of LST in situations of inappropriately premature neuroprognostication and against the overuse of LST in situations in which the patient has clear directives contrary to the use of LST, and address the gaps in the management of patients with neuropalliative care needs who present to the ED. As communication between EM clinicians and the inpatient teams is paramount to each role, systems, such as sections in the written documentation or verbal handoff that are dedicated to the discussion of GOCC, need to be established for these three proposed frameworks to be successful. The practice of neuropalliative care in the ED requires further investigation before targeted interventions, perhaps incorporating the three roles outlined here, can be developed.

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Table 1

Four general principles of providing neuropalliative care in the emergency department

-
- Recognize the limitations of neuroprognostication in the hyperacute setting
 - Understand the importance of aiming to provide goal-concordant care
 - Avoid creating distrust with families by providing inaccurate diagnostic or prognostic information
 - Strive for effective communication between EM and neuro-ICU clinicians regarding patients' GOC
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EM, emergency medicine; GOC, goals-of-care; neuro-ICU, neurological intensive care unit

Table 2
Summary of the three roles for emergency medicine clinicians to address when practicing neuropalliative care in the emergency department

	Stage setter	Spokesperson	Screener
Key elements	<ul style="list-style-type: none"> “Break bad news” Encourage formulation of patient values, preferences, functional baseline, documentation Provide family support 	<ul style="list-style-type: none"> Prevent overuse and underuse of life-sustaining treatment Initiate time-limited trial Goals-of-care conversation prior to hospital transfer 	<ul style="list-style-type: none"> Ensure high-risk patients have documented goals-of-care Evaluate daily symptom burden
Potential pitfalls	<ul style="list-style-type: none"> Creating mistrust Making do-not-resuscitate or treatment deescalation decisions Providing a detailed, premature neuroprognosis 	<ul style="list-style-type: none"> Providing goal-discordant care Inappropriately withholding care Conflict with other clinical teams 	<ul style="list-style-type: none"> Altering preexisting treatment plans Clinician biases limiting participation in this role
Skills required	<ul style="list-style-type: none"> Providing an appropriate “headline” Preferences-based goals-of-care conversation style 	<ul style="list-style-type: none"> Synthesize a treatment plan based on the patient’s goals-of-care 	<ul style="list-style-type: none"> Identify serious illness conversation triggers