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# The Significance of Palliative Care Education and Areas for Improvement

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# The significance of palliative care education and areas for improvement

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## Defining palliative care and its outcomes

Palliative care is a specialty of medicine that focuses on optimizing quality of life and relieving suffering for patients with serious illnesses. Palliative care may be provided for patients with illnesses such as advanced cancer, heart failure, HIV/AIDS, liver failure, cerebrovascular accidents, chronic illnesses, and life-limiting diagnoses- but this is not a comprehensive list by any means. Palliative care aims to help patients understand their prognosis, address their needs, and meet their goals of care (Ramanayake et al., 2016). Misconceptions about the difference between palliative care and hospice care can make it difficult for patients and their families to understand what care they are receiving; palliative care focuses on enhancing quality of life regardless of the goals of treatment (whether they involve curative measures or not), and includes hospice, but is not limited to it. On the other hand, a patient is only eligible for hospice if they have a life expectancy of less than six months and have decided to decline curative treatment, focusing instead on solely improving their quality of life and controlling symptoms in their remaining time. While some may misconceive that hospice is akin to ‘giving up’ and palliative ‘speeds up death’, both avenues of care are provided in the best interest of the patient. Palliative care is not incorporated into treatment when a physician has ‘given up’, instead, a consult is placed when the physician feels that a patient would benefit from that care. It should be noted that palliative care is not an alternative to failed life-prolonging care.

Palliative care can be administered in a variety of settings, including hospitals, outpatient offices, community programs, home health organizations, and hospice programs; the interprofessional palliative team is comprised of many healthcare workers, such as physicians, physician assistants, nurse practitioners, social workers, pharmacists, and chaplains. Primary care physicians, hospitalists, and emergency medicine physicians can arrange the first interventions for palliative care, then the care team coordinates interprofessionally after that as necessary.

The provider is typically responsible for four main components when providing palliative care to a patient, including physical and medical treatment, psychological care, social care, and spiritual care. Physical and medical treatment aim to relieve pain and symptoms, which vary depending on the diagnosis, but commonly include pain, dyspnea (shortness of breath), nausea, vomiting, fatigue, anxiety, depression, poor nutrition, constipation, diarrhea, bed sores, and chronic edema. Treatments for this can be pharmaceutical, utilizing non-steroidal anti-inflammatory drugs (NSAIDs), opiates, antidepressants, antiepileptics, and steroids, or non-pharmaceutical, such as acupuncture, massages, heat and ice, injections, meditation, and other therapies. Healthcare professionals also provide psychological support, because some patients need intervention in addition to what their family and friends can yield. The provider is present at the bedside, communicating effectively, compassionately reassuring them, giving hope when possible, and actively listening to their concerns, frustrations, hopes, and needs. The social component of palliative care isn’t always necessary, but involves receiving support regarding employment issues and assistance in securing financial guidance. Spiritual care may be deemed necessary because serious diagnoses can cause patients to re-examine their religious beliefs, and the care team can connect them with spiritual resources or the chaplain to get proper support (Teoli et al., 2023).

In addition, healthcare professionals must effectively communicate with their patients receiving palliative care. Medical education often uses the “SPIKE” mnemonic as a communicative aid: set up, perception, invitation, knowledge, emotions, and strategize. Providers are instructed to set up a meeting time with the patient and prepare accordingly, then gain perception about the patient's understanding of their illness and prognosis. In this stage, they may ask the patient questions like '*How are you feeling? What are your concerns right now?'* to better understand their perspective. With invitation, the provider gains an understanding of how much information the patient wants, and who is appropriate to receive that information. They should share their medical knowledge with the patient effectively by avoiding the use of too many complex scientific terms, and present the information at a pace that is easy to understand. Providers should address emotions and uncertainties as they arise, explaining the implications of the patient's diagnosis in a compassionate way while clarifying and validating their feelings. Lastly, this mnemonic instructs providers to summarize and strategize what they have shared in the meeting while assessing knowledge gaps, sharing a timeline of interventions moving forward, and implementing a plan for communication and follow-up (Teoli et al., 2023).

The provision of palliative care in medicine has been linked to a multitude of positive outcomes, including improved quality of life, improved symptom control, lower cost of care, and in some cases, better survival rates. Palliative care aims to reach a high level of goal-concordant care, the alignment of healthcare to patient preferences and values. It also improves the utilization of intensive care unit (ICU) resources while decreasing emergency department visits, subsequently reducing hospital readmissions for these patients, which, in turn, also decreases overall healthcare costs. In addition to improved patient outcomes, the provision of palliative care is linked to better caregiver outcomes, including reduced dysfunctional grief and stress.

## Current gaps in palliative care

While palliative care provides significant benefits to those who receive it, unfortunately, barriers to access and gaps in provision of palliative care make it inaccessible to many in the

American healthcare system. Almost one-third of large United States (US) hospitals don't house any palliative care services at all, and on average, patients receive a consultation just 38 days before their death (Hawley, 2017). One study of 55,656 admissions to two acute care hospitals in the Bronx in 2013 found that 37% of patients with palliative care needs had no evidence of being provided with such services. This demonstrates a large unmet need for palliative care to eligible patients in the inpatient setting, and the large aging population in the US presents a growing demand that cannot be met by current resources. This research established criteria for palliative care need as one of the following circumstances: inpatient death or use of cardiopulmonary resuscitation (CPR), nursing home residency presenting with at least two comorbidities, ICU length of stay over 10 days, use of mechanical ventilation or vasopressors if length of hospital stay exceeds 10 days, stage IV cancer, use of mechanical ventilation for over 15 days, a hospital stay over 30 days long, intracranial hemorrhage requiring mechanical ventilation, multiple ICU admissions during one visit, and three or more organs in failure simultaneously (Chuang et al., 2017).

Improper communication about palliative care involving both medical colleagues and patients results in another barrier to care. Due to the fear of upsetting patients and the misled idea of not wanting to 'abandon' their patients, healthcare professionals may be reluctant to place palliative referrals, viewing them as admission to their own failure as a provider; there is an underlying misunderstanding that initiating conversations about this care is concurrent with stopping aggressive treatment for the patient. Additionally, some family members may avoid the conversations associated with this care because they believe that discussion relevant to death will bring 'bad karma' to the patient (Hawley, 2017).

A mail survey was performed on practicing cardiologists across the US, where participating physicians were presented with hypothetical patient scenarios and asked to answer questions about their recommendations concerning palliative care for the corresponding patient. One patient scenario involved a 75 year-old male with class IV congestive heart failure, nonsustained ventricular tachycardia, and other distressing symptoms; the other scenario involved an 85 year-old male with class IV congestive heart failure presenting with orthopnea (shortness of breath while supine). The American College of Cardiology (ACC) and American Heart Association (AHA) guidelines recommend that a palliative care referral be placed when a patient exhibits signs and symptoms of heart failure, despite any current treatment, and said referral should include discussions about prognosis, advanced directive, care coordination, and symptom control. In both instances, the patients' severity of symptoms and additional complicating conditions made them appropriate candidates for those discussions of care. Results of the survey were analyzed and it was established that over half of the participating physicians did not adhere to recommended guidelines about their inclinations to discuss palliative care with their patients (Matlock et al., 2010). Although this study is only one example, it illustrates the lack of proper utilization of palliative care resources evident in the modern healthcare setting.

Additionally, the workforce shortage of palliative care physicians contributes to the gap in care. *The American Journal of Medicine* conducted a workforce survey of palliative physicians, and projected a shortage of 18,000 physicians over approximately the next decade, based on targeted appropriate patient ratios and needs. Their data estimates about a 1% growth in these specialized physicians, which is not enough to meet the number of patients eligible for palliative care, speculated to increase by 20%. The shortage of physicians exacerbates the ability to provide patient-centered care to the seriously ill (Kamal et al., 2017).

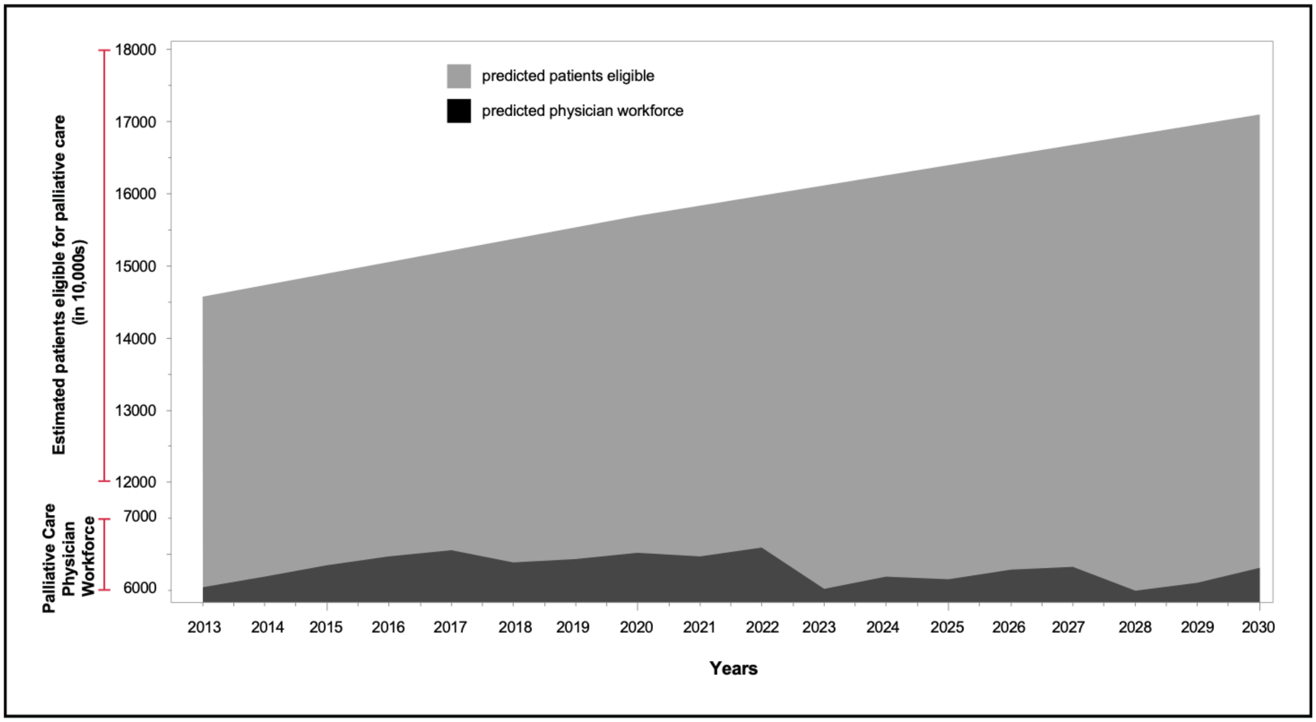

***Figure 1:*** *This graph illustrates the stark contrast between the number of patients predicted to be eligible for palliative care through 2030 and the physician workforce available to provide such services.*

The evidence discussed above demonstrates a gap in the provision of palliative care, much of which stems from inadequate education on such care for healthcare professionals.

## Current structure of palliative care education

Despite the importance of providing patients with palliative care, the current education system in the medical model is not designed to support such needs. Some researchers speculate that it's underdeveloped because the importance of such education is misunderstood. The Liaison Committee on Medical Education (LCME), which is responsible for accreditation of medical school education, enforces the inclusion of end of life (EOL) care into education, but not palliative care, and a medical rotation is not required in this area. The weakness of these accreditation requirements doesn’t properly prepare physicians for their interactions with the seriously ill and dying patients, and the lack of palliative care content on standardized exams supports the notion that such knowledge is unnecessary. Literature surveyed across different medical schools in the US portrays a fragmented, non-standardized curriculum in which schools vary in their instruction methods, content, target audience, and time commitment, using isolated rotations in palliative medicine or optional modules, and lacking consistency on what structure of education is provided to students. The lack of proper education is likely due to the already strained curriculum, insufficient time to incorporate more learning, and the shortage of medical school faculty and preceptors with the appropriate qualifications to teach such content (Head et al., 2016).

A literature search for articles including topics such as “palliative”, “medical school”, “end-of-life”, “training”, and “education”conducted by the *Journal of Cancer Education* revealed that physicians across many specialties don’t feel prepared for chronic care, and resident physicians reported feelings of distress and unpreparedness in that area as well. Many medical students finish their education without any exposure to dying patients or death; in the instance where palliative care training is mandatory, it’s restricted to classroom time, and clinical rotations involving palliative care are elective, reducing students’ exposure to those patients in-person (Chiu et al., 2014).

Overall, the three main areas of concern in the palliative education for providers are (1) trainee emotional distress regarding death and dying, (2) the lack of uniformity in didactic (classroom) training for hospice and palliative medicine, and (3) inadequate exposure to chronically ill and dying patients during clinical rotations (Chiu et al., 2014). Kayla Sheehan, a fourth-year medical student, is also able to identify gaps in the current education model, and notes that students are often only exposed to these patients through a hospice rotation or other “end of life training”, which is not equivalent to learning about palliative care medicine. She has observed many students experience significant anxiety when caring for patients who are eligible for palliative care, because they are not properly trained to address them. The implementation of palliative care into education is important in providing better quality of care and strengthening the healthcare system for the future (Sheehan, 2020).

For context, in regards to local medical schools, the College of Human Medicine at Michigan State University has a two week rotation in palliative care and pain management as part of their middle clinical experience (MSU, n.d.). The University of Michigan’s medical school may offer an elective rotation in palliative medicine, but it is not one of the core requirements (UMich, n.d.). The Wayne State University School of Medicine does not offer a clerkship clinical rotation in palliative medicine (WSU, n.d.).

## The Importance of palliative care education for providers

James Cook University completed a systematic review of 39 research studies regarding palliative care education from 1969-2019, evaluating a total of 5879 participants, which were primarily healthcare professionals. These studies examined PCE programs and identified the following key themes in their content (a) introduction to death, palliative care, and hospice, (b) symptom management and medical care, (c) communication, (d) cultural beliefs of death and palliative care, (e) ethics, law and organ donation, (f) grief and bereavement, (g) care for the family, (h) care for the dying, (i) advanced planning and directives, (j) spiritual beliefs, (k) community resources, and (l) impact of death on healthcare professionals and volunteers. This demonstrates the comprehensive nature of the palliative care education content, which students would not receive in the absence of such training in their curriculum. 31 programs were evaluated on effectiveness based on specific criteria related to participants, including attitude, knowledge, and confidence in palliative care, how comfortable they were in discussing end of life care and pain management, how familiar they were with hospice and advanced care plans, and their ability to cope with death among the patient population; 30 of these programs indicated significant improvements in these areas. Three studies evaluated the curriculum, and most participants reported being satisfied with the content. The other studies evaluated the overall learning outcomes, demonstrating that participants learned to cope with death and dying in a more positive, productive way; satisfactory rates of participants in those studies were 88-100%. The two most significant themes in the education programs reviewed were symptom management and communication. Participants were educated in both physical and psychological symptom management, and learned how to properly communicate in their deliverance of palliative care, which involves building a relationship with the patient, talking to the family, and dealing with emotions. The review also found the prevalence of eLearning in delivering palliative care education, which opens possibilities for accessibility (Li et al., 2021).

The Kirkpatrick model, which consists of four levels of program evaluation (reaction, learning, behavior, and results, numbered 1-4 respectively), is important in assessing education. *Reaction* indicates whether the participant finds the training useful and relevant; *learning* measures the participant's progress in knowledge, skills, attitude, and confidence relevant to the program; *behavior* gauges the participant's change in behavior as a result of the program; and *results* measures whether the outcomes resulted from the program specifically. These studies show positive evaluations at levels one and two of the Kirkpatrick model, reaction and learning, which is encouraging, but still leaves room for improvement in the remaining two levels (Li et al., 2021).

One survey from the University of Pittsburgh School of Medicine reported that students who had encountered experiences with death were statistically more likely to have a positive attitude about theirs, or another physician's, ability to care for dying patients; these students were also less likely to have inappropriate emotional reactions to a patient's death. This evidence demonstrates that exposing medical students to the experiences of death, and realities of dying patients, can lead to improved outcomes (Chiu et al., 2014).

A more extensive study was completed at the University of Adelaide School of Medicine in Australia, and provides an example of a successful implementation of palliative care education. They require students to attend palliative care lectures during every year of their education, and some students complete an additional clinical elective rotation in their final years, where they are responsible for palliative patients under the supervision of another physician; 14 graduates who had completed the rotation were interviewed on the basis of the value of skills learned during that time. During the interviews, graduates recounted their experiences with palliative care and how their education impacted their work, and researchers identified two main themes from their responses, collectively: (1) *from apprehension, to gaining a sense of control* and (2) *gaining perspective on the practice of medicine.* Doctors noted the transition from being 'sheltered' from dying patients to directly caring for them, particularly during intern year when they are the main line of communication between the clinical team, the patient, and the family. They felt they had gained confidence in their communication skills during end-of-life care, and, although still difficult and emotional, could better initiate discussions about goals and comfort.

Participant eight remarked,

> I became comfortable with the idea of no longer actively treating a disease, no longer trying to stop its progression, but just trying to manage somebody's comfort levels, and I think it is so much more patient-centered, in a way, in that you are actually giving people what they really want. They are less concerned about their blood pressure and their white cell count and all those other measures of health and well-being, and what they are really concerned with is subjectively how they feel. I really liked that we could actually focus on what they wanted, and do our best to give it. (Crawford, et al., 2015)

Students felt better emotionally prepared to care for dying patients after graduation, specifically because they had previously experienced it in their palliative rotation. One key aspect they appreciated was the focus on debriefing among the clinical team, supporting one another, and having discussions about personal emotions and reactions as they arose. Students were able to learn self-awareness and coping strategies through these methods. Additionally, participants learned how to better accept death as an inevitable process and not always a negative outcome, since some patients have needs more important than solely focusing on a cure, a realization that is difficult to come by in the modern world of medicine. The development of this perspective is evident in participant nine's interview,

> I do think that there is a lot of focus, while you are studying medicine, to make people better, and I especially notice this with children; everyone wants to fix them, and sometimes that's not the best thing to do. I think it would be worthwhile, at Uni [University] and in our training, if there was a bigger focus on accepting things, but that's the way it is, and you don't have to change the end outcome to be doing a good job. If you can just help the patient and family to be comfortable and achieve the best that they

> can between now and then, that would still be successful. Even if the patient passes away, that wouldn't be a failure as long as you've made that last period of time in their life comfortable or valuable for them. (Crawford, et al., 2015)

In gaining perspectives on the practice of medicine, as a result of their education, participants identified that they could incorporate aspects of palliative care into other areas of medicine and their lives, becoming advocates for such care, and strengthening their sense of purpose in medicine. They found the palliative rotation to be particularly helpful later on in intense clinical work, such as in a hospital setting with high-acuity interventions, and can recognize the need for palliative care intervention in those circumstances. Participants also noted the education's impact on their personal sense of purpose, strengthening their passion for patient care and quality of life, as they learned that medicine goes further than just science, and that prioritizing patient goals is vitally important, too. In general, medical students have limited exposure to death and dying, and are consequently unaware of the relevance of palliative care in their practice; this only worsens the understanding and utilization of the field. The study of the University of Adelaide graduates who completed the palliative care rotation demonstrates the potential for enhanced competencies, and the ability of physicians properly trained in this area to foster a patient-centered, ethically conscientious, and fulfilling field of medicine (Crawford, et al., 2015).

## Recommendations and resources for improvement

Palliative care education has great potential for advancement, the most evident of which is in the primary curriculum for medical students. Researchers from Springer science, after conducting a careful review of the current palliative care education model, made a series of recommended interventions for improving the curriculum. They establish that palliative care training should be systematically integrated into existing programs by introducing it early on in the course of medical school, and that defining chronic illness, palliative care, and hospice accurately during these times is crucial; it is important that students are properly able to distinguish between these areas. They recommend the standardization of education to specify a defined number of hours dedicated to palliative care and use uniform methods of evaluation to meet competencies. Students may also benefit from participation in small groups and interprofessional work, both in the classroom and in clinical settings, to explore their fears about end-of-life care and mortality (Chiu et al., 2014).

Innovative education efforts in palliative care can take a variety of formats. One cohort of 352 students completed online case-study based modules and participated in small group learning for 12-48 hours total, resulting in positive evaluations at the Kirkpatrick levels one and two. Another class of 133 students engaged in small group discussions, reporting greater knowledge in assisting patients with advanced care planning; a similarly structured group of 134 students participated in small group seminars and completed a clinical exam in advanced pain management skills. Both of those groups demonstrated positive results at Kirkpatrick levels two and three. Additional methods of innovative education can include lectures, case studies, group learning, bedside teaching opportunities with a preceptor (in a clinical setting), and online modules (Head et al., 2016). However, curriculum reform is difficult to implement with the time-constrained structure of medical school education; other options may include online education and opportunities for knowledge advancement, recognized by certifications and badges.

Ariadne Labs, a prominent public health department at Brigham Health and Harvard's School of Public Health, has a Serious Illness Care program that includes communication tools for patients, family members, and health professionals, clinical training, and support for leaders in an effort to make systemic changes. The program aims to implement better, earlier conversations between providers and patients to improve care. They have successfully trained over 28,000 health professionals across 32 healthcare systems, reaching an estimated 378,000 patients. The program's structure is primarily the *Serious Illness Conversation Guide*, which contains instructional techniques in communicating with patients using "person-centered language", and is applicable to diverse populations and contexts. Through this resource, clinicians can learn to discuss their patients' goals and values, properly set up the conversation, assess the patients' understanding of their prognosis and their preferences, effectively explain the prognosis, explore the patient's hope in the context of their situation, and appropriately end the conversation. The guide has shown positive results regarding patient, clinician, and system outcomes. Patients reported that having additional conversations about values, goals, and prognosis earlier in the course of their illness- about 2.5 months earlier than without this intervention- helped reduce symptoms of anxiety and depression. With enhanced planning, implemented using those conversation techniques, patients had better communication with their families, and felt closer to their providers. 90% of clinicians who utilized the Serious Illness Conversation guide found it effective in practice, and 70% of those felt more satisfied in their role as provider after learning the content. Additionally, evidence from the Brigham and Women's hospital showed reduced medical expenses in the last six months of life associated with having conversations as guided in the Ariadne Labs program (Ariadne Labs, 2021). The guide is accessible to physicians, nurses, social workers, chaplains, and other health professionals as a means of advancing their knowledge and improving practice.

Another resource available to aid clinicians in providing palliative care is VitalTalk, a non-profit organization that focuses on helping professionals advance their communication skills. VitalTalk offers courses that aim to better equip providers for serious, difficult conversations and discussions of goals of care, and has educated over 36,000 professionals. They offer four main courses: ‘Navigating Serious Conversations’ is a self-paced, online three-module course for quick learning; ‘Delivering Serious News’ is another self-paced, online option that includes videos with six hours of communication improvement exercises; ‘Mastering Tough Conversations’ consists of two, virtual four hour sessions involving role play and feedback with simulated patients; ‘Building Connection’ is a modular online course that teaches skills in promoting racial equity in difficult conversations. Some courses also qualify as continuing medical education (CME), ongoing education for physicians and advanced practice providers that aims to help maintain competencies and gain new knowledge, required at a specified level of credits or hours per licensure cycle. This aspect can incentivize the education for healthcare professionals. In addition to in-depth courses, they offer free, one-page PDF quick guides that offer concise insight into a variety of topics and conversations. Quick guides of particular relevance are *Serious News*, *Discussing Prognosis*, *Transition/Goals of Care*, *Responding to Emotion: Respecting*, *PAUSE Talking Map*, and *Talking About Dying*, in addition to other helpful information offered. These guides provide quick education when more in-depth learning is not accessible or not financially feasible. Training provided by VitalTalk is linked to positive outcomes, leading to earlier and more comprehensive conversations about serious illness. These communication interventions are associated with higher goal-concordant care, better rated patient-care experiences, higher patient-evaluated quality of life, longer survival, less depressive and anxious symptoms, and lower healthcare costs (VitalTalk, n.d.). Providers trained in this area advocate for the importance of these conversations.

An additional way to expand competency in the provision of palliative care is by obtaining certifications, which indicates further mastery of such knowledge. The Hospice and Palliative Credentialing Center (HPCC) offers certificates to healthcare workers with extensive experience in the field upon completion of an exam. This education is aimed at nurses and social workers, who play a vital role in the care of patients. Certified individuals earn a digital badge, which can be shared on a resume, LinkedIn, and other platforms to demonstrate skills and credentials (HPCC, 2024). Certification offers intrinsic rewards, fostering greater confidence in caring for patients with serious illnesses, and also may be incentivized by the potential for job growth and opportunities.

Graduate certificates for palliative care can be obtained through universities and other educational institutions. Grand Valley State University, for instance, offers a Palliative and Hospice Care Graduate Certificate, administered as an online, 15 week-12 credit course. The course involves education on chronic and terminal illnesses from both palliative and hospice perspectives, information on complex pain and symptom management, and a course on death, grief, and loss (GVSU, n.d.). Earning a graduate certificate allows participants to deepen their expertise and gain potential for career advancement, in a more time-savvy and affordable manner than obtaining an additional master's degree, in addition to the benefits for patient care.

Grand Valley State University also offers the Palliative and Hospice Care II Graduate digital badge. This recognizes a participant's completion of a course that teaches symptom management and skills for considering physical, psychologic, sociological, and spiritual factors while practicing palliative care. Obtaining a badge is a way to enhance previous education, highlight knowledge and skills to employers, and efficiently complete specialization in palliative care. Most importantly, it provides professionals with a deeper understanding of perspectives and meaningful methods to deliver palliative care (GVSU, n.d.). The digital badge offers another opportunity to incentivize healthcare professionals to further their expertise in palliative care, and expand the current structure of education.

## Conclusion

Palliative care is vital in prioritizing quality of life for patients with serious illnesses. However, physician shortages, improper utilization, and the fragmented, non-standardized medical curriculum amplify the gaps in care and demonstrate significant room for improvement. Refining the structure and administration of palliative care education is an important step in closing this gap. The innovation of palliative care education in medical schools and post-graduate is necessary to meet the present and future health care demands of society and further improve patient outcomes.

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