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Quality of Life Matters®
Serious illness care news & clinical findings | Issue Q2 2025

OPTIMIZING PALLIATIVE CARE FOR HEART FAILURE PATIENTS: INSIGHTS FROM A VA STUDY

Heart failure (HF) remains a progressive and life-limiting condition with high symptom burden and poor prognosis. Despite clear benefits, palliative care (PC) is often underutilized in this population. A recent study published in the *Journal of Palliative Medicine* explored the factors influencing PC use and its timing among U.S. veterans with HF who died between 2011 and 2020, aiming to uncover opportunities for improvement and earlier PC involvement.

INSIDE THIS ISSUE

Researchers analyzed data from 232,079 veterans hospitalized in the VA system, examining demographics, comorbidities, and timing of PC encounters. Patients were grouped as receiving no PC (56.5%), late PC (within 90 days of death, 22.5%), or early PC (more than 90 days before death, 21.0%).

Findings revealed that while PC use is improving, more than half of patients still died without receiving PC. Those who did receive PC were older and had more comorbidities, such as malignancy, neurologic disorders, and depression, suggesting that PC referrals were often driven by factors other than HF.

Key findings

- **Age and comorbidities:** Older patients and those with multiple comorbid conditions were more likely to receive PC. However, these factors did not notably affect the timing (early vs. late).
- **Missed opportunities:** Nearly half of those receiving PC had late consultations, potentially limiting the benefits of symptom management, reduced hospitalizations, and improved quality of life.
- **Need for collaboration:** The study marked a lack of proactive PC referrals for HF patients, indicating a need for stronger integration between cardiology and palliative medicine practices.

Implications for practice

The findings stress the importance of identifying HF patients who could benefit from earlier PC. Strategies such as embedding PC within cardiology clinics, creating structured referral pathways, and leveraging home-based or telemedicine PC services could enhance care delivery.

This study underscores the urgent need to close the gap in PC access for HF patients. Researchers conclude that by fostering collaboration and leveraging innovative care models, clinicians can ensure timely, patient-centered support that improves outcomes and quality of life.

Source: "Factors Associated with Early Palliative Care Among Patients with Heart Failure." *Journal of Palliative Medicine*, 27(8), 1001–1008. https://doi.org/10.1089/jpm.2023.0539. Meehan, C. P., White, E., Cvitan, A., Jiang, L., Wu, W.-C., Wice, M., Stafford, J., & Rudolph, J. L. (2024).

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BRIDGING COMMUNICATION GAPS IN ADVANCE CARE PLANNING FOR DEMENTIA PATIENTS

A recent study published in *PEC Innovation* examines the significant challenges in advance care planning (ACP) for persons with advanced dementia. Researchers conducted interviews with 17 clinicians and 15 surrogate decision-makers to explore their experiences and needs during ACP discussions.

The findings reveal widespread deficits in understanding dementia's progression and ACP concepts, such as Do Not Hospitalize (DNH) orders, which complicate decision-making processes.

Key findings

Two primary themes emerged from the study:

1. **Deficits in communication:** Surrogates often lacked knowledge about dementia's trajectory, including its terminal nature and associated complications like pneumonia. Many also misunderstood ACP-related terms, such as DNH, creating barriers to informed decisions.
2. **Decision-making conflicts:** Clinicians reported a disconnect between surrogates' understanding of patients' preferences and the ability to act on them. This gap frequently led to unnecessary hospitalizations and life-sustaining treatments that did not align with the patients' goals.

Surrogates echoed these concerns, noting the absence of structured guidance about dementia and ACP. Many relied on self-directed learning or informal conversations, underscoring the need for accessible, evidence-based resources.

Recommendations for improvement

The study suggests several strategies to enhance ACP for patients with advanced dementia:

- **Education:** Providing surrogates with clear, accessible information about dementia's progression and ACP terminology can empower them to make decisions that align with patient goals and values.
- **Standardized discussions:** Clinicians need tools and training to initiate ACP conversations confidently and address specific challenges in dementia care.
- **Resource development:** Creating decision-support materials and practical tools could help bridge knowledge gaps and foster shared decision-making between clinicians and surrogates.

Clinical implications

With dementia prevalence expected to rise sharply—projected to affect 14 million Americans by 2060—addressing these challenges is critical to providing compassionate and effective care, according to the authors, who point out the need for systemic changes in clinical practice. Enhanced training for clinicians, combined with institutional support, could pave the way for more consistent and empathetic ACP discussions.

By proactively addressing communication deficits and developing targeted resources, researchers believe healthcare providers can significantly improve decision-making outcomes by ensuring that decisions align with the values and preferences of patients and their families. They conclude that improved ACP practices will enhance the end-of-life experience and contribute to a more equitable and compassionate healthcare system.

Source: "Perspectives on Advance Care Planning Needs of Persons with Advanced Dementia from Their Surrogates and Clinicians." *PEC Innovation*, 3, 100241. https://doi.org/10.1016/j.pecinn.2023.100241. Golden, S. E., et al. (2023).

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> "Despite the wealth of evidence of the positive impact of patient-centered end-of-life care approaches, the field continues to face barriers to offering maximum benefit to patients, families, and close others... This growing list of challenges must be met with innovative research stemming from multidisciplinary perspectives."
>
> —Emily L. Mroz and Jordan M. Alpert, authors of a *PEC Innovation* special issue introductory editorial
>
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TRANSFORMING SERIOUS ILLNESS CONVERSATIONS: A PATIENT-CENTERED FRAMEWORK

A new study published in *The Journal of Palliative Medicine* introduces a comprehensive framework for improving conversations around serious illness and frailty. The framework aims to equip patients and their decision-makers with detailed medical information before aligning care plans with their values and goals.

The study critiques existing communication models for placing too much focus on values without providing the context of health status and prognosis. This disconnect can lead to premature decisions that may not reflect patients' true preferences when fully informed.

Introducing the PATH Model

The Palliative and Therapeutic Harmonization (PATH) model advocates a structured, transparent approach to decision-making with several key innovations:

- **Comprehensive information first:** Detailed explanations of medical conditions and potential outcomes are shared at the start of the conversation, enabling realistic expectations.
- **Support networks:** Patients are encouraged to include family members or loved ones to assist in processing information and making decisions.
- **Capacity considerations:** When recognizing cognitive impairments like dementia, clinicians are urged to assess decision-making capacity and, if needed, engage substitute decision-makers.
- **Clinician recommendations:** Unlike conventional models, PATH prompts physicians to make specific, evidence-based recommendations tailored to the patient's health context.

Evidence of impact

The PATH approach has shown significant results in clinical settings. For instance, among frail patients initially scheduled for invasive interventions, 75% declined the procedures after undergoing the PATH process. Similarly, during the COVID-19 pandemic, long-term care residents who participated in PATH consultations were far less likely to opt for hospitalization or aggressive treatments than those receiving standard care.

These findings demonstrate that sharing realistic prognostic information aligns care decisions more with patient preferences, such as prioritizing comfort and quality of life over invasive measures.

Practical steps for clinicians

The PATH framework outlines six essential steps for serious illness conversations:

1. **Preparation:** Clinicians review the patient's medical history, prognosis, and treatment options in advance.
2. **Setting the stage:** Introduce the conversation with a clear purpose and invite support persons to join.
3. **Sharing information:** Provide detailed insights into the patient's conditions and prognosis, ensuring the information is shared in a way that is understood.
4. **Framing decisions:** Help patients evaluate options based on realistic expectations of treatment benefits and risks.
5. **Guiding choices:** Offer professional recommendations, balancing evidence with the patient's values and preferences.
6. **Closing the discussion:** Summarize key points, confirm understanding, and document the care plan for future reference.

A cultural shift in end-of-life care

This patient-centered approach challenges traditional paradigms by prioritizing informed decision-making over generalized value discussions. Far from being paternalistic, the authors of the study state, the PATH model respects autonomy by fostering a deeper understanding of health trajectories and treatment implications.

In summary, the authors emphasize the need for healthcare professionals to move beyond surface-level conversations and engage in meaningful, informed dialogues with patients and their families.

Source: "Transforming Communication on Serious Illness and Frailty: A Comprehensive Approach to Empowering Informed Decision-Making." *Journal of Palliative Medicine,* 27(10), 1297–1302. doi:10.1089/jpm.2024.0076. Mallery, L., et al. (2024).

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VA NURSING HOMES SURPASS COMMUNITY NURSING HOMES IN HOSPICE CARE QUALITY

The quality of end-of-life (EOL) care for veterans receiving hospice varies widely between settings. A study published in the *Journal of the American Geriatrics Society* reveals that hospice care provided in Veterans Affairs (VA) Community Living Centers (CLCs) surpasses the care delivered in VA-contracted community nursing homes (CNHs) across several critical domains.

The retrospective study analyzed Bereaved Family Survey (BFS) data from October 2021 to March 2022. Responses from family members of 1,238 veterans who died in either CLCs or CNHs were used to assess care quality. It assessed overall EOL care quality in the last 30 days, focusing on symptom management, communication, emotional support, and access to burial and survivor benefits.

Key findings

1. **Overall ratings:** Families rated the quality of EOL care significantly higher for CLCs than CNHs, with 84.8% of CLC families giving top scores (9-10) compared to 71.2% for CNHs. This 13-percentage point difference emphasizes the consistent superiority of VA-based care, the study authors note.
2. **Domain-specific insights:** CLCs consistently outperformed CNHs in symptom management, communication, and emotional support; e.g., families reported better management of combat-related stress in CLCs (83.6% "always" received help) compared to CNHs (58.0%).
3. **Access to benefits:** CLC families were more informed about burial and survivor benefits, with 85.6% finding the information helpful versus only 48.4% in CNHs.

Challenges in CNHs

Several factors contribute to the disparity in care quality:

- **Care delivery models:** CLC hospice care is directly integrated within the VA system, benefitting from specialized training and consistent oversight. CNH hospice care, in contrast, relies on a combination of CNH staff and external agencies, often leading to fragmented care.
- **Staffing and expertise:** High patient-to-nurse ratios and limited palliative care training for CNH staff are critical barriers. Moreover, CNH personnel may lack the expertise to address veteran-specific conditions like PTSD and moral injury.
- **Coordination issues:** Poor communication and coordination between CNH staff and hospice providers further impact care quality, with lapses in symptom management and emotional support.

Policy implications

The study authors call for targeted interventions to bridge the quality gap such as:

- **Enhanced training programs:** Expanding veteran-focused initiatives, such as the "We Honor Veterans" program, to CNHs could improve staff training in veteran-centric palliative care.
- **Incorporating quality metrics:** VA contracting policies could include BFS scores to incentivize high-quality care in CNHs.
- **Increased oversight:** VA-employed oversight teams could play a more active role in ensuring families receive adequate information about benefits and funeral arrangements.

According to the authors, as the veteran population ages, the demand for high-quality hospice care will only increase. By addressing the deficiencies identified in CNHs, the VA can continue to honor veterans' preferences for dignified, compassionate EOL care.

This study's relevance extends beyond VA settings, stressing the need for better EOL care metrics in non-VA nursing homes, the authors conclude. Enhanced palliative training, stronger hospice-nursing home collaboration, and integration of veteran-centric care models into all health systems could improve care quality nationwide.

Source: "A Comparison of End-of-Life Care Quality for Veterans Receiving Hospice in VA Nursing Homes and Community Nursing Homes." *J Am Geriatr Soc.* 2024;72(1):59–68. DOI:10.1111/jgs.18606. Wachterman MW, Smith D, Carpenter JG, et al.

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IMPROVING END-OF-LIFE CARE FOR NEUROLOGIC PATIENTS

End-of-life (EOL) care for patients with neurologic diseases requires a nuanced approach, yet significant challenges remain. An article in *Seminars in Neurology* highlights the need for neurologists to guide symptom management, advance care planning (ACP), hospice transitions, and caregiver support.

According to the authors, neurologic diseases often follow unpredictable trajectories, complicating prognostication. Conditions like dementia or Parkinson's disease involve gradual declines with intermittent crises, making it difficult to determine the right time for EOL discussions. Many neurologists lack training or confidence in initiating these conversations, hindered by prognostic uncertainty, emotional barriers, and fears of restricting treatment.

Symptom management and prognostic factors at EOL

Neurologists often manage complex EOL symptoms, particularly in hospitalized patients, that require specialized symptom management strategies such as:

- **Dyspnea** is generally treated with opioids, rather than oxygen.
- **Neuropathic and musculoskeletal pain** often require opioids combined with anticonvulsants or corticosteroids.
- **Seizures** are treated with benzodiazepines subcutaneously or sublingually for comfort.
- **Delirium** affects up to 45% of patients in their final week; management includes addressing reversible causes and creating a calm environment.

The authors maintain that though prognostication can be challenging, recognizing EOL in their patients is an important skill for neurologists to hone so that EOL discussions can take place in a timely manner. Some indicators for EOL include:

- Functional decline
- Weight loss/food refusal
- Recurrent infections, UTIs, or aspiration pneumonia
- Dysphagia or dysarthria
- Complex symptom burden and intense pain
- Sleep-wake inversion

Tools like the "Surprise Question" *("Would I be surprised if this patient died within a year?")* and signs of imminent death, such as reduced alertness or changes in respiratory patterns, can also aid in identifying the EOL phase.

ACP and hospice transitions

The authors assert that ACP is vital to aligning patients' care with their values and goals. Neurologists, through long-term relationships with their patients, can help navigate decisions about artificial nutrition or ventilation and encourage allowing natural death over prolonged suffering.

Hospice, focused on comfort rather than curative care, is underused in neurologic diseases due to unfamiliarity with guidelines and restrictive eligibility criteria (e.g., the Medicare hospice benefit requires a prognosis of six months or less, which is difficult to estimate for conditions like ALS or advanced Parkinson's disease).

Supporting caregivers

Caregivers of neurologic patients face significant emotional and psychological burdens, often comparable to those caring for advanced cancer patients. Educating caregivers about the dying process and providing emotional and spiritual support can reduce anxiety and improve bereavement outcomes. Neurologists can play a vital role in addressing caregivers' unmet needs by partnering with hospice and palliative care teams and involving social workers, spiritual care providers, and grief counselors.

As the neurology workforce grows, so does the need for specialized training in palliative care to address the complex needs of patients with neurologic diseases at EOL and their caregivers. The authors conclude that by proactively engaging in advance care planning, improving symptom management, and supporting caregivers, neurologists can help ease EOL transitions and improve the quality of EOL care for this population.

Source: "End-of-Life and Hospice Care in Neurologic Diseases." *Seminars in Neurology*. 2024;44(5):523–533. DOI: 10.1055/s-0044-1787809. Chou CZ, Everett EA, McFarlin J, Ramanathan U.

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PALLIATIVE CARE CONSULTATIONS REDUCE READMISSIONS IN KEY DIAGNOSES

Hospital readmissions pose major challenges to patient outcomes and healthcare costs. A recent retrospective study published in the *American Journal of Hospice & Palliative Medicine* demonstrated the effectiveness of palliative care consultations (PCCs) in reducing 30-day readmission rates for certain life-limiting illnesses.

The study, conducted across a 21-hospital system, analyzed data from 47,846 patients diagnosed with six common conditions listed below. Researchers aimed to determine if palliative consultations could significantly impact readmission rates for these high-risk groups.

Key findings

The analysis revealed notable reductions in readmissions for specific diagnoses, evidencing the role of PCCs in addressing readmissions, especially for heart failure, pneumonia, and sepsis:

- **Heart failure:** Readmissions dropped from 18.8% (no consultation) to 9.8% (with consultation), a highly significant result ($P < .0001$).
- **Pneumonia:** Patients receiving consultations had an 8.3% readmission rate compared to 13.1% for those without ($P < .0003$).
- **Sepsis:** Consulted patients showed a 9.2% readmission rate versus 13.8% without ($P < .0001$).
- **Stroke:** While consultations reduced readmissions (4.3% vs. 8.1%), the results were not statistically significant ($P = .0613$).
- **Acute myocardial infarction:** Consulted patients experienced a lower readmission rate, 4.8% vs. 10.4% ($P = .0993$).
- **Chronic obstructive pulmonary disease:** Readmission rates showed little variation (13.4% vs. 15.4%, $P = .4590$).

Broad benefits of palliative care

Beyond reducing readmission rates, researchers assert that PCCs benefit patients and healthcare systems. Consultations help patients better cope with life-limiting illnesses by managing pain and providing psychosocial and emotional support. This comprehensive care model can improve patient satisfaction and quality of life and foster rapport between patients, caregivers, and providers.

Moreover, hospitals implementing PCCs may experience operational benefits, such as reduced strain on emergency departments and inpatient wards. Lower readmission rates translate into fewer penalties from Medicare's Hospital Readmissions Reduction Program, aligning financial incentives with quality patient care.

Limitations and future direction

The researchers point out that the study's retrospective design limits causation inference. Since the health care system did not release protected health information, the analyzed data did not include patient severity, age, or length of stay. Future research should include this data, as well as explore post-acute outcomes, long-term benefits, and subgroup analyses to better understand the impact of palliative consultations.

Future studies can also be expanded to assess how palliative care could benefit underrepresented populations. Researchers indicate that, with equitable access, palliative medicine can potentially address disparities in underserved regions, particularly where readmissions remain high due to systemic barriers.

Conclusion

The study reveals that PCCs significantly reduce hospital readmissions for specific life-limiting conditions, offering both clinical and financial benefits by improving patient outcomes, alleviating hospital congestion, and reducing costs associated with Medicare penalties for high readmission rates.

Based on their findings, researchers believe that expanding these services could enhance the quality of care and reduce healthcare costs, reinforcing palliative care's essential role in modern medicine.

Source: "Palliative Medicine Consultation Reduces Readmission Significantly in Certain Diagnoses: A Retrospective Analysis." *American Journal of Hospice & Palliative Medicine.* DOI: 10.1177/10499091251313805. Depew, C.N., Wood, M., Walden, J., et al. (2025).

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TELEHEALTH PALLIATIVE CARE MATCHES IN-PERSON EFFECTIVENESS FOR ADVANCED LUNG CANCER PATIENTS

Telehealth has emerged as a viable option for delivering early palliative care, a critical service for patients with advanced non-small cell lung cancer (NSCLC). A recent study, published in *JAMA,* confirms that telehealth palliative care can effectively enhance patients' quality of life, matching in-person care outcomes.

Study overview

The randomized, multisite clinical trial conducted from June 2018 to May 2023 involved 1,250 patients and 548 caregivers across 22 U.S. cancer centers. Participants were diagnosed with advanced NSCLC within 12 weeks and were assigned to either telehealth (via secure video) or in-person palliative care.

The primary goal was to evaluate whether telehealth could deliver equivalent quality-of-life improvements, measured by the Functional Assessment of Cancer Therapy-Lung (FACT-L) questionnaire, with a prespecified equivalence margin of ±4 points.

Key findings

- **Quality of life:** Both telehealth and in-person groups achieved equivalent improvements in quality of life (mean FACT-L scores were 99.7 for telehealth and 97.7 for in-person care; $P = .04$).
- **Caregiver participation:** Caregiver attendance was lower in telehealth visits (36.6%) than in-person visits (49.7%; $P < .001$), likely due to fewer logistical demands for telehealth.
- **Satisfaction with care:** Patient and caregiver satisfaction was similarly high across both methods.
- **Mood and coping:** Anxiety, depression, and coping outcomes were comparable between groups.
- **Efficiency:** Telehealth reduced travel burdens, improving access for patients in remote areas or with mobility challenges.
- **Equity needs:** Strategies need to be developed to ensure equitable telehealth access to overcome limited technology access or language.

> "The findings come at a time when telehealth flexibilities implemented during the pandemic will soon end...[i]ntroduced in May, the Preserving Telehealth, Hospital, and Ambulance Access Act, would as of 2025 extend the flexibilities by two years. The bill has since stalled...
>
> "Some palliative care providers have projected potentially disastrous impacts from the regulatory changes, with mounting concerns as they navigate an uncertain future around telehealth utilization."
>
> —Holly Vossel, senior reporter for *Hospice News* and *Palliative Care News*
>
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These findings reveal telehealth's potential to create a patient-centered model of care that maintains clinical efficacy while expanding access to palliative care by reducing logistical barriers (such as travel time and cost), improving accessibility for patients in remote areas or those with mobility challenges.

Challenges and limitations

The study faced challenges, including lower caregiver engagement during telehealth visits, possibly due to logistical ease reducing shared attendance. Additionally, the COVID-19 pandemic introduced intervention contamination, as some in-person patients were required to shift to telehealth. Researchers also call on the need for future studies to address the equity needs referenced above.

As policymakers consider telehealth's future in post-pandemic healthcare, this study provides robust evidence supporting its equivalence to traditional in-person palliative care. Embracing telehealth can enhance access to vital services for vulnerable populations, ensuring continuity and quality of care for all patients.

Source: "Telehealth vs. In-Person Early Palliative Care for Patients with Advanced Lung Cancer: A Multisite Randomized Clinical Trial." *JAMA,* 332(14), 1153–1164. doi:10.1001/jama.2024.13964. Greer, J.A., et al. (2024).

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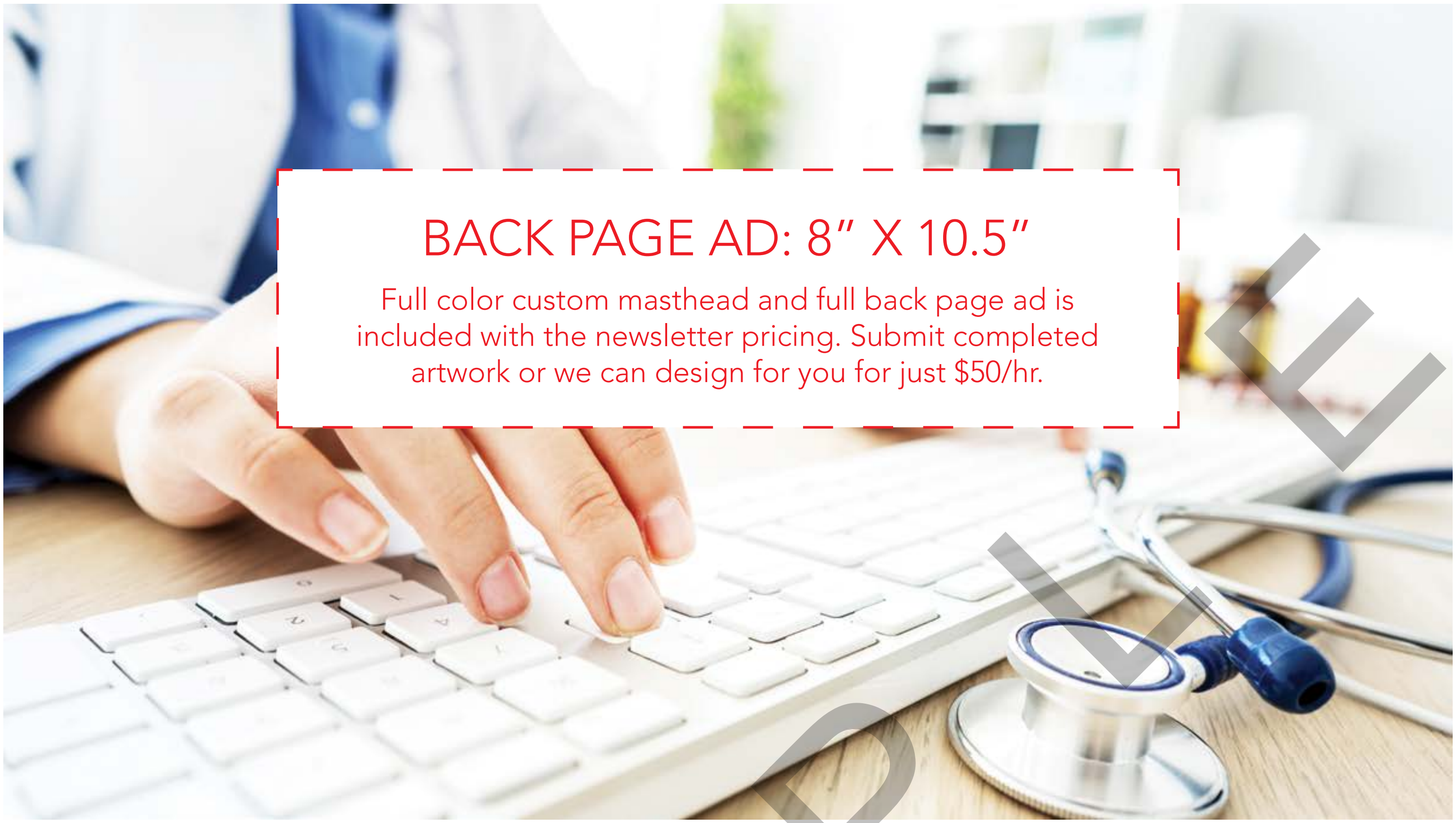

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