Hospice's Hidden Workforce: Financial, Ethical, and Regulatory Challenges Facing Informal Caregivers

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Often considered ideal, dying at home offers familiarity, comfort, autonomy, and the opportunity to remain surrounded by loved ones. Hospice care was developed to prioritize symptom management, quality of life, and dignity rather than curative treatment. Yet nurses understand a reality often overlooked - hospice does not replace caregiving. Instead, hospice relies heavily on family members assuming responsibility for the majority of care. In this article, informal caregivers, refers to individuals who provide ongoing care and support outside of a paid healthcare role, which most commonly includes family members but can also may involve friends, neighbors, or other trusted persons. These caregivers often have limited preparation and no financial compensation. As healthcare continues to shift from hospitals to homes, informal caregivers have become an essential, yet largely invisible component of the healthcare system (World Health Organization [WHO], 2020).

Nationally, informal caregivers provided an estimated 49.5 billion hours of care in 2024, representing more than $1 trillion in economic value (AARP, 2026). A national report highlighted significant economic burden, noting that one family spent approximately $65,000 to support a loved one's wish to die at home (Campbell, 2026). Additionally, many caregivers experience lost income, reduced work hours, and long-term financial hardship, further increasing the true cost of home-based end-of-life care. Significant emotional and personal sacrifices frequently compound these heavy financial burdens (Campbell, 2026).

Why This Matters for Ohio

The implications of family caregiving are particularly significant in Ohio. The state's population is aging rapidly, increasing the demand for hospice, palliative care, and long-term services (National Academy for State Health Policy [NASHP], 2023). Approximately 24% of Ohio adults, roughly 2.2 million people, currently provide unpaid care for a loved one (AARP, 2025). Concurrently, Ohio faces healthcare workforce shortages and rising rates of chronic illness, with more than 236,000 Ohioans living with Alzheimer's disease (Alzheimer's Association, 2025). For Ohio nurses, informal caregiving is not simply a hospice issue. It is a workforce issue, a public health issue, and a healthcare sustainability issue. As demand for home-based care grows, the ability of informal caregivers to safely support patients at home will become increasingly critical to Ohio's healthcare infrastructure.

Ethical Considerations

One of the most common ethical dilemmas in hospice care involves balancing patient autonomy with caregiver well-being. While respecting patient autonomy is a foundational ethical principle of nursing practice (American Nurses Association [ANA], 2025) many patients express a strong desire to remain at home throughout the end-of-life journey. Honoring that preference, however, can place substantial physical, emotional, and financial demands on informal caregivers. Nurses regularly encounter situations in which a patient's wishes exceed a caregiver's ability to safely provide care. Ethical decision-making requires balancing respect for patient preferences with realistic assessments of caregiver capacity and available support systems.

The ethical principles of beneficence and nonmaleficence also extend beyond the patient to include informal caregivers. These individuals frequently experience anxiety, depression, sleep disruption, social isolation, physical strain, and financial hardship (Adelman et al., 2014). Nurses have an ethical responsibility to recognize caregiver burden, provide education, facilitate support services, and advocate for interventions that protect caregiver well-being (ANA, 2025).

Patient Safety and Professional Accountability

As healthcare shifts increasingly into the home, informal caregivers routinely perform complex clinical tasks such as medication administration, symptom monitoring, transfers, and management of medical equipment. Although caregivers are not licensed healthcare professionals, nurses frequently teach and support them in performing complex care activities. This reality creates important patient safety considerations. Consequently, nurses must assess caregiver understanding, competency, and ability to safely carry out instructions. Effective education should include clear explanations, hands-on demonstration, teach-back methods, and ongoing support. Quality palliative care guidelines identify caregiver assessment, preparedness, and support as core components of care delivery (National Coalition for Hospice and Palliative Care, 2018). Thorough documentation is equally important. Clinical records should clearly reflect the education provided, the caregiver's understanding of

instructions, any identified concerns, and subsequent referrals to supportive services. Detailed documentation not only supports continuity of care and demonstrates professional accountability, but also helps safeguard patients, caregivers, and nurses alike (ANA, 2021).

Regulatory Considerations

The growing reliance on informal caregivers also raises broader regulatory questions regarding caregiver training, patient safety, and healthcare workforce capacity. While caregivers are not licensed healthcare professionals, they frequently perform responsibilities that directly influence patient outcomes. Consequently, Ohio nurses have an important role in advocating for policies that fund caregiver education, expand respite services, ensure safe transitions of care, and facilitate access to community resources. These actions align with the Ohio Board of Nursing's (OBN) mandate that nurses promote patient safety, provide comprehensive education, and advocate for safe care environments across healthcare settings (OBN, 2023). Ultimately, safeguarding patients in the home requires strengthening the informal caregivers who make home-based care possible.

What Nurses Can Do Today

While policy reform is essential, nurses need not wait for legislative action to make a difference. First, nurses should recognize that the caregiver is often a second patient. Because caregiver burden is often hidden, comprehensive clinical assessments should routinely evaluate caregiver readiness, confidence, emotional well-being, and available support systems. Second, nurses should promote safe care through education and early referral. Engaging hospice and palliative care services early creates opportunities for caregiver training, realistic goal setting, and proactive support before crises emerge (National Hospice and Palliative Care Organization, 2024). Connecting families with resources, such as the Ohio Department of Aging, local area Agencies on Aging, hospice organizations, and respite services can significantly ease the caregiver burden. Finally, nurses should advocate beyond the bedside. Supporting policies that expand respite care, caregiver education programs, paid leave, and aging-in-place initiatives can strengthen both patient outcomes and caregiver resilience. As Ohio's population ages and healthcare workforce shortages persist, caregiver support policies must be viewed as investments in both public health and healthcare workforce sustainability.

Conclusion

Informal caregivers are not peripheral participants in hospice care; they represent an indispensable component of the broader healthcare workforce. As Ohio's population ages and demand for home-based care increases, the sustainability of hospice care will depend not only on traditional healthcare, but also on the informal caregivers who provide countless hours of unpaid care each day. Making this hidden workforce visible, and advocating for the support it deserves, is both a professional responsibility and an ethical imperative for nursing. ■

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