

GUIDE TO ORGANIZATIONAL ETHICS IN HOSPICE CARE

2016



National Hospice and Palliative Care
Organization



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EXECUTIVE OVERVIEW

National Hospice and Palliative Care Organization (NHPCO) offers this *Guide to Organizational Ethics in Hospice Care* as a resource to hospice programs and professionals. This document is the third iteration of organizational ethics guidance offered by NHPCO since 2000, updated over time to reflect the current issues in the field (NHPCO, 2001; 2006). Four key concepts of the hospice philosophy of care are presented. Seven organizational values are explained and applied to seven core operational domains of hospice provider organizations, with examples of how the values can be integrated into policies and practices in the domains. The intent is for organizations to use the framework and values in this document to inform development and implementation of organizational policies, procedures, and practices consistent with ethical standards resonant with the hospice philosophy of care.

NHPCO expresses its sincere gratitude to the authors and staff reviewers of this *Guide* for their dedication and time in developing and refining the document.

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SECTION 1: Introduction

When the first US hospices emerged in the 1970s, all-volunteer groups of clinicians and laypersons sought to offer a dying experience that was guided by the values of patients, their families, and the communities in which they lived. In embracing Dame Cicely Saunders' philosophy, early US hospices offered an alternative to the increasingly technocratic approach to dying in a healthcare system that had come to see death as a failure of the system: the opportunity to live one's final days in peaceful resonance with life-long values and beliefs. Over the subsequent four decades, the US hospice landscape has changed dramatically. More than 5,000 provider organizations—over half of which are for-profit entities—now deliver hospice care to over 45 percent of Medicare beneficiaries who die each year in the US (NHPCO, 2014). Nonetheless, the hospice philosophy of care remains largely unchanged from those early days in the 1970s: delivering family-centered care to persons at the end of life that minimizes their suffering, allowing them to live their final days in a manner that is meaningful and consistent with their values.

As hospice care becomes more integrated into the US healthcare system, the complexities and pressures of staying competitive, achieving financial performance targets, and adapting to rapidly changing market and regulatory forces all pose significant challenges to running a hospice organization in a manner that stays true to the hospice philosophy of care and its core values. Recent reports from the Office of the Inspector General and the Medicare Payment Advisory Commission, along with articles in the national news media and clinical literature, have raised concerns about practices in some US hospice organizations that prioritize revenue over patient care. Practices in domains such as marketing, admissions and discharges, and determining appropriate level of care have received intense scrutiny (MedPAC 2009, 2013; DHHS, 2013, 2015; Abt Associates, 2014). Though the prevalence of problematic activities is disputed, hospice utilization data in combination with anecdotal evidence, civil complaints, and whistleblower cases suggest that some organizations are drifting from the core philosophy and values of the hospice movement.

This *Guide* explains and affirms the central role of seven values in directing the practice of hospice organizations across all operational domains. These organizational values are erected from the philosophical foundation of the hospice movement because the motivating principles for the creation and delivery of hospice care have not changed, even if the healthcare market in which that care is delivered has. Too often, ethics are conflated with

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regulatory or legal compliance. In this document, regulatory and legal compliance is assumed, but not addressed in detail. Rather, this *Guide* focuses on operationalizing the concepts and values constitutive of hospice care itself: the defining ideas that make "hospice care," hospice care. In times of financial hardship or personal distress, we should fall back on that which we value most deeply to remind us of who we are and who we want to be. Similarly, in times of robust health, our core values should guide growth and shape our vision for the future. As such, this *Guide* uses the language of "values," rather than "principles," to emphasize one important function of ethics: identifying and integrating the goals, duties, and aspirations that are most important—most "valuable"—to our collective work in giving and receiving care at the end of life.

National Hospice and Palliative Care Organization (NHPCO) is a membership and leadership organization representing US hospice and palliative care programs and professionals. The organization is committed to leading and mobilizing social change for improved care at the end of life. Its vision is a world in which individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

Through its work in supporting providers and professionals, NHPCO serves as an advocate for patients facing the end of life and their families. This *Guide* joins the NHPCO *Standards of Practice* (2010), various position statements, and ongoing educational programming to support an ethical corporate culture among its member organizations and the field as a whole.

SECTION 2: The Hospice Philosophy of Care¹

The shape and content of US hospice care are the product of many (and sometimes conflicting) social, economic, political, and regulatory forces. Understanding those forces and their influence on the current state of hospice care is important; US hospice care was designed to meet a certain need, for a certain population, at a certain time in history (Buck, 2011, 2014). The Medicare Hospice Benefit (MHB)—originally designed in the 1980s—continues to profoundly influence how US hospice care is delivered, and compliance with its associated regulations is an obligation of every US hospice organization that is Medicare certified and serves Medicare patients. It is important to recall, however, that the MHB is not what makes “hospice care,” hospice care. The benefit itself is strongly informed by a pre-existing philosophy of care—a philosophy with its own internal norms and values. Indeed, the very same hallmark philosophical commitments that powerfully shaped the evolution of US hospice care in the 1970s and 1980s, and that drove the creation of the MHB, remain fundamental to understanding the defining nature of hospice care. It is on this foundational framework that the organizational values explained in the remainder of this document rest.

Four cornerstone concepts frame the foundation of the hospice philosophy of care: (1) dying as an experience pregnant with meaning; (2) family-centered care; (3) the nature and relief of suffering; and (4) the integrity of persons as a condition of creating and experiencing meaning in life and exercising moral agency (Kirk, 2014).

¹This section draws heavily, with some passages verbatim, from Kirk, 2014. Kind permission for doing so was granted by Oxford University Press. See Section 2 works cited for full publication information.

Dying as an Experience

Hospice care is focused on the *experience of dying*. There are several important nuances surrounding the way in which the “experience of dying” is conceptualized. The first is that dying is a process, not an event. That is, dying is not something that occurs at the moment one satisfies the clinical criteria for cardiopulmonary or brain death. Rather, dying is the process one goes through in the months and weeks preceding that moment.

Second, dying is not simply a biological event experienced by physiological organisms. Rather, a primary implication of dying as an “experience” is that it is experienced by *persons*, and the process involves all of the different elements of their personhood—their emotional lives, their spiritual lives, their relational lives, their professional

...to consider death as merely a biological process fails to capture the full meaning of the process for all involved.

lives, and many others—and not just their bodies. So, while the death of the body occasions the end of these different pieces of personhood in their current forms (they are, after all, embodied), to consider death as *merely* a biological process fails to capture the full meaning of the process for all involved.

Third, the experience of dying can be meaningful—both for the one dying and for that person’s loved ones. The focus in hospice care on dying in one’s home—rather than the hospital, for example—is rooted in this commitment to the experience

of dying as a valuable one: being surrounded by the conditions in which one has built and discovered meaning throughout life is thought to maximally enable persons to create and find meaning in the last weeks to months of life as well.

In sum, dying is (a) a process that is (b) experienced by persons (not just bodies) that is (c) pregnant with meaningful possibilities. This conceptualization also informs the second cornerstone concept of the hospice philosophy of care: family-centered care.

Family-Centered Care

Supporting a meaningful dying process of persons requires acknowledging and engaging the structures through which persons have found and created meaning throughout their lives. Hospice care incorporates relationships with loved ones in the care of dying persons precisely because relationships constitute some of the very structures through which persons find and create meaning across the lifespan. Indeed, rather than disrupt the relational structures through which we have given and received care across our lives—a disruption that the founders of hospice thought was a significant drawback of hospital-based care—hospice seeks to support patients through those very structures. As in some other specialized models of care such as medical rehabilitation, family-centered care in hospice positions the family as the direct recipient of support and services, with the goal of empowering the family to then care for the ill and dying person through their already-established structures of familial intimacy and support (Bamm & Rosenbaum, 2008).

The impact of intimate relationships is often reciprocal; that is, just as the experiences of dying persons can be significantly impacted by the involvement of their family members as caregivers, so, too, the dying of persons can significantly impact the lives of those who love them. In this way, the hospice model of family-centered care is quite similar to the model used in pediatrics (Mastro, Flynn, & Preuster, 2014). Caring for dying persons in a manner that supports as many elements of their personhood as possible requires supporting and including their loved ones, because relationships with those loved ones constitute a profound and ongoing influence in the identity of dying persons. Therefore, caring for the family is not disconnected from caring for the patient; it is part of the same process.

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The Nature and Relief of Suffering

The third concept, though perhaps for many hospice clinicians the first in order of priority, is that hospice care has one primary goal that informs all of the others: the relief of suffering. Similar to the way in which the “experience of dying” is an expansive and holistic concept, the phenomenon of suffering is equally expansive and holistic. Suffering can occur in relation to any aspect of the personhood of the patient who is dying and, following from the earlier explanation of family-centered care, can also occur via the experience of the patient’s loved ones (Cassell, 2004; Ferrell & Coyle, 2008).

...the relief of a loved one’s suffering may help ameliorate suffering of one’s own.

Saunders developed this idea in her concept of “total pain.” For Saunders, total pain was not simply a bodily phenomenon. Rather, it had the potential to insinuate itself into multiple aspects of personhood, becoming a noxious inhibitor of one’s ability to engage the world in many ways—emotionally, spiritually, psychologically, relationally, and intellectually as well as physically. In short, it could arise from—or find its way into—the totality of one’s existence (Clark, 2000). To *treat* such pain in a biomedical model would require identifying and eliminating its cause. Given that this is often not possible in patients with advanced disease (especially the cancer patients whom Saunders had in mind for hospice), the goal shifted from treating disease to addressing symptoms.

To address total pain effectively means finding ways to support and intervene in patients’ lives that reduce the intensity of suffering and keep it below the level of phenomena experienced by the patient. For Saunders, the kind of care required to address total pain had to engage patients at the level of experiencing persons, not just metabolizing bodies. And it had to do this because it was precisely at the level of experience—where we engage with the world, where we give the things, people, and places we experience meaning, and where we develop feelings about those meanings—that total pain manifests itself during the experience of dying. If (recall from earlier) dying is not simply a biological process in organisms but instead is a meaningful process in persons (hence the difference between dying *per se* and the *experience* of dying), then care of persons who are going through the experience of dying needs to engage them precisely via the openings through which they are experiencing their own dying.

The second and third concepts interact in important ways, insofar as suffering is not always an entirely individual phenomenon. That is, suffering can be experienced individually, but it can also be experienced as a *shared* phenomenon. Similar relational themes emerge in a robust conceptual model of suffering by Cherny, Coyle, and Foley (1994), and again by Cherny (2015), who notes that the suffering of loved ones can exacerbate one’s own suffering and, inversely, the relief of a loved one’s suffering may help ameliorate suffering of one’s own.

Restoring and Supporting Moral Agency

The fourth cornerstone concept of the hospice philosophy of care is delivering care that maximally supports patients such that they can continue to live with the integrity and sense of self required to find and create meaning until the moment of death. This constitutes a robust commitment to *moral agency*: supporting the patient such that she can explore and express who she is, continuing to live in a manner that honors what she finds most valuable and meaningful in life up until the moment of her death.

Saunders believed it was quite possible for medical treatment to impede and violate a patient's sense of self, thereby compromising the patient's moral agency. As such, one of the prime motivations in her development of hospice was to offer patients a care alternative at the end of life that did not require sacrificing the integrity of who they were as persons. Consistent with the hospice concepts of suffering, family-centered care, and dying as a meaningful experience, a core component of the hospice philosophy is to provide care in a way such that support of the patient and family empowers the patient to recover/rebuild/maintain the wholeness and integrity of self through which to find and create meaning across the entire dying experience. Indeed, for Saunders, death was the final act in the life of a person, and the experience of dying is the final opportunity for that person to create and discover meaning. "At no time," wrote Saunders, "in the total care of a cancer patient is the awareness of him as a person of greater importance" (Saunders, 1979, p. 636). As such, preserving and respecting moral agency is an important requisite for actualizing the first piece of hospice philosophy: focusing on the *experience* of dying.

These four cornerstone concepts of the hospice philosophy of care constitute the foundation on which US hospice care was built over 40 years ago. They remain embedded in the structure and processes of care required by federal regulations governing how that care is certified, documented, and reimbursed. They can—and should—also be

reflected in the clinical and nonclinical operations of organizations that deliver hospice care in communities across the United States. The seven values defined in the following section constitute an ethical framework—a framework built on the philosophical foundation explained above—through which hospice organizations can do precisely that.

...the experience of dying is the final opportunity for that person to create and discover meaning.

SECTION 3: Seven Organizational Values for Hospice Providers

The ethics of establishing and operating an organization that delivers hospice care falls into the realm of *organizational ethics*. Organizational ethics differs from *clinical ethics* insofar as the focus is on collective practices, procedures, and policies in all realms of an organization, whereas clinical ethics focuses squarely on the interactions among clinicians, patients, and families. The former, however, has a profound effect on the latter. For example, asserting that hospice liaison nurses have an ethical obligation to be truthful with referring physicians, case managers, and the patients and families referred by such—a common claim in clinical ethics—becomes problematic if those same liaison nurses are paid bonuses calculated by how many referrals are converted to admissions. The latter constitutes an organizational practice that creates an incentive structure that can be in tension with a commitment to truthfulness in clinical practice (Partington & Kirk, 2015). How hospice liaison nurses are paid and otherwise incentivized is a question that falls squarely into the realm of organizational ethics, which explores the values and practices of organizations rather than individuals.

Developing and maintaining organizational practices consistent with the cornerstone concepts of the hospice philosophy of care requires intentionally designed and regularly reviewed policies, procedures, and practices across all areas of organizational activity. Indeed, in what is perhaps her clearest and most direct writing on “the hospice concept,” Dame Cicely Saunders highlights the importance of organizational structure and processes, outlined in 13 “General Principles of Hospice Care”:

1. Management by an experienced clinical team
2. Understanding control of the common symptoms of terminal disease, especially pain in all its aspects
3. Skilled and experienced team nursing
4. A full interdisciplinary staff
5. A home care program
6. Recognition of the patient and family as the unit of care
7. A mixed group of patients
8. Bereavement follow-up
9. Methodical recording and analysis
10. Teaching in all aspects of terminal care
11. Imaginative use of the architecture available
12. An efficient administration
13. The cost of commitment and the search for meaning (Saunders, 1979, pp. 641–651)

The following seven values, distilled from the literatures in organizational and business ethics, quality improvement, and organizational development—and consistent with the basic tenets of a hospice philosophy of care—can be used by hospice organizations to build a strong ethical framework that guides the establishment of goals and practices across the organization, from marketing and business development, to hiring and staffing, to education and resource development, to vendor selection and contract administration, to grant writing and fundraising, and beyond.

Equitable Access

Equitable access requires the use of transparent, appropriate, and uniformly applied criteria when making decisions about who receives care and services. As defined in this guide, the “appropriate criteria” that guide access to hospice care are clinical needs, patients’ and families’ care goals and preferences, and an organization’s ability to give competent care that addresses those needs, goals and preferences. (As a guide in ethics—distinct from compliance—adherence to relevant legal and regulatory requirements including those governing “eligibility” is assumed, but explicit discussion and application of such is outside the scope of this guide). Because hospice care is a community good—a service that supports and facilitates processes and outcomes that contribute to a community’s ability to flourish—in addition to applying appropriate criteria transparently and uniformly, attunement to the values of justice and equality as defined in each community served by an organization is also appropriate.

Whether during the referral and admission process, during the course of care for patients, or when offering bereavement services to loved ones, the value of equitable access supports policies and practices for access to care rooted in the principle of justice as fairness. This principle can govern both the process and outcome of decisions. For example, if decisions to admit patients with certain complex care needs or expensive medications vary significantly depending on which medical director is covering on a particular day, such variation suggests a lack of uniformity in the decision-making *process*: medical personnel are not applying the same criteria in the same way. If the reasons for such decisions are not carefully explained to patients and families referred for care, or to the clinicians who initiated the referrals, such a process also lacks transparency. Similarly, if one hospice care team within an organization is better educated than another regarding when and how to refer a patient with refractory symptom

distress for inpatient-level care, the *outcome* is that patients in that team’s geographic region have better access to inpatient care than patients in another team’s region. Such an outcome also does not meet the minimum standards of equitable access (where like patients would be treated alike), insofar as access to inpatient care is—albeit unintentionally—being determined by factors that lack appropriateness, transparency, and uniformity.

The value of equitable access is easily derived from the four cornerstone hospice concepts. Suffering, for example, is a phenomenon that is possible in the lives of all persons. Suffering does not discriminate on

the basis of race, socioeconomic status, geographic location, language spoken, or ability to pay. If hospice care is intended to address and relieve the suffering of all dying persons in a community interested in receiving care, access to its services cannot be conditioned on any of those elements, either.

If hospice care is intended to address and relieve the suffering of all dying persons in a community interested in receiving care, access to its services cannot be conditioned on any of those elements, either.

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Comfort and Quality of Life

Comfort and quality of life are importantly defined in the context of, and titrated to, the needs and values of individual patients and families. Though frequently discussed as goals of care, there is surprising variance in how comfort and quality of life are defined in healthcare generally and hospice care specifically. Health-related quality of life focuses most directly on functional status and level of symptom distress. As a broader concept, quality of life (QOL) denotes social, spiritual, and relational well being in addition to function and symptom distress. Related to

...organizational practices can significantly facilitate or restrict the ability of patients to have symptom distress adequately managed.

QOL, comfort has multiple definitions in the healthcare literature. The most robust definitions, however, focus on comfort as a phenomenon that goes beyond simply the absence of pain or distress, reaching to a state in which persons can maximize their efforts to pursue the kind of life most resonant with their goals and values.

Timely and effective assessment and intervention for symptom distress—pain, dyspnea, nausea, delirium, anxiety, etc.—are hallmarks of good clinical care in hospice and directly promote patients’ health-related quality of life. And, while efforts to ensure this often focus on education and skills of clinicians hired and retained by organizations,

other “behind the scenes” organizational practices can significantly facilitate or restrict the ability of patients to have symptom distress adequately managed. For example, practices such as:

- having call centers staffed by clinicians experienced and appropriately certified in hospice and palliative care who are trained to assess patients and teach family members over the phone;
- ensuring access to robustly skilled and adequately staffed after-hours and weekend clinicians who make in-home visits; and
- ensuring that pharmacy services deliver medications in an accurate and timely fashion

increase the likelihood that patients’ symptom burdens will be promptly and effectively addressed.

Ensuring effective integration of spiritual care professionals, social workers, volunteers, bereavement professionals, and other supportive care providers into the interdisciplinary care team is essential to promoting broader QOL in end-of-life care. To effectively support patients’ moral agency and open avenues for the pursuit of meaning in the final phase of life, promoting goals of comfort and quality of life requires a highly trained and well-supported interdisciplinary team.

Comfort and quality of life are similarly important values in the lives of hospice employees. Hospice employees—clinician and non-clinician alike—are also moral agents, persons who have rights and obligations in and out of the workplace. A hospice that offers robust bereavement support to families of its patients, but does not offer bereavement time off to its employees, is not honoring these values. Hospice organizations that offer structured and incentivized interventions to identify and address predictors of care fatigue, moral distress, and burnout for clinician employees will simultaneously decrease the risk of these phenomena leading to employee attrition and increase employee quality of life. Employees will be in the best position to enhance the comfort and quality of life for an organization’s patients and families if that organization is actively working to maximize the same in the lives of its employees.

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Teamwork and Collaboration

The interdisciplinary team (IDT), designated by the Medicare Hospice regulations as the interdisciplinary group, continues to be a defining feature of hospice care. Interdisciplinary teams are essential to the hospice philosophy of care insofar as they entail the careful coordination of many disciplines to address the multiple sources of suffering and support the multiple dimensions of personhood. A robust research literature reveals that optimal functioning of teams requires intentionally designed processes and support by the organizations in which they work (Mitchell, Wynia, Golden et al., 2012).

Hiring qualified and high-performing individuals is important, but it is only one part of building effective teams. For example, careful attention to communication processes among team members is essential to collaborative processes that achieve their intended outcomes. Professionals are clear about their roles and corresponding duties and receive guidance on appropriate content, context, medium, and frequency of communication. As in other areas of healthcare, transitions in hospice care—among care settings, among day and evening care shifts, and among different members of care teams (including family members and non-hospice employees)—are predictable loci of gaps in care quality. Continuity of care across these and other transitions can also be dramatically impacted—for better or worse—by practices and events outside of IDTs themselves. For example, a hospice that carefully prepares patients and families for appropriate discharge but abruptly lays off staff without opportunities to transition patients or projects impedes a care team’s ability to deliver care consistent with the hospice philosophy of care, even if intra-IDT processes were carefully designed to do so.

In sum, team composition—hiring appropriately trained clinicians, providing appropriate volunteer services, and optimizing the blend of team members in response to patient and family needs—is necessary, but not sufficient, to ensure effective teamwork. Rather, teams must be actively managed and team processes continuously monitored

and refined. Only with deliberate and effective communication and collaboration within interdisciplinary teams, and only if such teams are carefully managed and supported by colleagues in all operational domains in an organization, can care infused with core hospice values be predictably delivered.

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Excellence

As an ethical value, excellence is defined as robust success in identifying and developing the necessary traits, skills, and knowledge required to fully realize one's purpose in life; doing and being in ways that promote the flourishing of individuals in a manner that simultaneously fosters the flourishing of their communities. In professional ethics, one's "purpose" is significantly shaped by (a) the role and profession into which one enters (e.g., nurse, social worker) and (b) the concrete enterprise in which that role is lived out (e.g., hospice nurse or hospice social worker). Organizational excellence requires that an organization

1. promote and support the individual excellence of its employees and volunteers in a manner that contributes to the collective flourishing of the organization;
2. identify and communicate clear organizational values and a mission consistent with the hospice philosophy of care;
3. develop and implement policies, procedures, and practices that—when engaged by well-supported employees and teams—lead to the organization thriving in a manner guided by its values and mission; and
4. integrate its mission, values, and goals into the community it serves such that the enterprise contributes to the flourishing of the community.

Individuals and organizations may become expert in certain tasks or achieving certain outcomes. However, if those tasks or outcomes do not result in individuals, the organization, and its community flourishing in a manner strongly resonant with its values and mission, such expertise cannot be considered excellence. Indeed, this is one of the defining distinctions between expertise and excellence: Expertise requires mastery of technical skills and operations. Excellence, however, requires a robustly developed integration of individual, organization, and community such that all three excel in pursuing and achieving their mission consistent with their values.

Unlike compliance, which requires that practices conform to a minimum legal or regulatory standard, excellence is not about meeting minimum standards. Rather, as the language of "flourishing" and "thriving" suggests, the pursuit of excellence is a constant striving—individual and collective—toward understanding and achieving the highest possibilities of furthering an organization's mission consistent with its values and the values of its employees

and the community it serves. As such, excellence is aspirational: it requires a clear, well-defined mission, shared and agreed-upon values, and its pursuit is a lifelong activity.

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The NHPCO *Standards of Practice* (2010) suggest metrics to indicate excellence in domains such as clinical care, workforce development, and business operations. These metrics are derived from a shared understanding of the goals, values, and mission of hospice care. Adopting and integrating these standards into the

structure and processes of specific care organizations requires thoughtful, deliberate attention to the place of such organizations in their local communities, the unique needs and capabilities of patients and families served by the organizations, and the skills and capacities of employees at such organizations.

Finally, excellence as an organizational value is concerned with *process* as well as *outcome*. That is, *how* tasks are completed and practices are engaged is just as important as *which* and *that* tasks are completed and practices engaged. Therefore, monitoring and promoting excellence within organizations requires process goals and measures as well as outcomes goals and measures. For example, an organization that pays its employees accurately in over 90 percent of its payroll disbursements can be said to have developed a certain amount of expertise in the realm of payroll accuracy. If such payments are frequently delayed, however, or if queries from employees about paid time off or mileage reimbursement are rarely addressed, it is difficult to claim that payroll practices are achieving excellence. The outcome may be achieved, but the process of achieving the outcome falls short of excellent.

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Stewardship

Stewardship is the prudent use of an organization's resources to maximize its ability to achieve its mission in a manner consistent with its core values. Hospice organizations are entrusted with resources—human, clinical, financial, operational—that come from stakeholders—patients, families, employees, volunteers, payers, donors and funders, investors, communities. Accepting such resources incurs obligations to those stakeholders that the resources be used to further the organization's stated mission. Together with integrity and transparency, stewardship highlights that hospice care organizations—public or private, nonprofit or for-profit—have ethical responsibilities defined, in part, by their relationships to persons and entities outside of the organizations themselves. And, it requires recognition that those relationships unfold in the contexts of (a) the communities in which care is given and received and (b) the larger community of hospice providers across the nation.

Importantly, stewardship is not a single-minded focus on efficiency or cost-effectiveness—though both can, at times, be inferred from stewardship. Indeed, efficiency and cost-effectiveness are values subordinate to stewardship insofar as attention to both is required to ensure that organizations maintain the financial health necessary to continue delivering services to the community consistent with the hospice philosophy of care. As subordinate values, efficiency and cost-effectiveness are never ends in themselves; their value is conditioned on the organization robustly fulfilling its mission of caring for dying patients and their families. There is nothing inconsistent between fulfilling that mission and offering financial stakeholders a return on their investment. Stewardship is grossly distorted, however, when financial performance goals supersede in priority the provision of care that is appropriately responsive to the needs of patients and families and consistent the hospice philosophy of care.

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Transparency

Transparency maximizes the accessibility, quality, accuracy, and timeliness of information relevant to the structure, processes, and practices of an organization. It is a phenomenon of both *intention* and *perception*: those who have

Transparency promotes accountability by acknowledging that many different parties... have a legitimate stake in understanding not only what is happening in a hospice organization, but why it is happening and who is making which kinds of decisions.

(or should have) such information act with the intention of maximizing its accessibility, quality, accuracy, and timeliness, and stakeholders who receive the information perceive it to be available to them with a measure of accessibility, quality, accuracy, and timeliness appropriate to their roles (Schnackenberg & Tomlinson, 2014). Similar to the related values of stewardship and integrity, transparency promotes accountability by acknowledging that many different parties—employees, investors, patients, families, volunteers, community members, referring healthcare providers—have a legitimate stake in understanding not only *what* is happening in a hospice organization, but *why* it is happening and *who* is making which kinds of decisions.

Transparency engages and respects the moral agency of those in an organization who make significant executive and operational decisions by highlighting the obligation and responsibility that accompanies the authority to make such decisions. Transparency acknowledges and respects the moral agency of those carrying out, and affected by, the decisions of others by highlighting their right to accessible, high-quality, accurate, and timely information that explains what is occurring, and why it is occurring in this way and at this time. As a value focused on process as well as outcome, it opens opportunity

within organizations to engage mutually respected methods of operating an organization even when there is substantial disagreement about the results produced by those methods (Daniels, 2000).

ADDITIONAL READING:

Bennis, W., Goleman, D. & O'Toole, J. (2008). *Transparency: Creating a culture of candor*. San Francisco, CA: Jossey-Bass.

Turilli, M. & Floridi, L. (2009). *The ethics of information transparency*. *Ethics and Information Technology*, 11(2), 105-112. doi:10.1007/s10676-009-9187-9

Integrity

Organizational integrity requires three kinds of phenomena. First, it requires the establishment of organizational values that combine well together to support a coherent and internally consistent mission. That is, the entire set of values that guide an organization need to fit together—to integrate—in a manner that supports a clear, coherent vision and mission for the organization. Honoring one of an organization's integral values cannot require an employee or department to violate another of an organization's integral values. Second, organizational integrity requires design and engagement of organizational practices that strongly promote the values of the organization. An organization that states one of its values is transparency, but does not engage in business practices consistent with that value—for example, does not keep employees regularly updated on its financial status or sends invoices to patients for costs and services that were not clearly explained at the start of service—is not practicing with integrity. Finally, organizational integrity requires that organizations support and promote the ability of its teams and employees to practice with integrity—individually and collectively. For example, an organization that supports its clinicians in keeping up to date with clinical developments by incentivizing discipline-specific speciality certification ongoing continuing education enables them to honor their professional obligation to practice in a manner that

maximizes benefit and minimizes harm to patients and families. Supporting practice consistent with professional values as articulated by, for example, the Hospice and Palliative Nurses Association, creates resonance between professional and organizational values, thereby promoting integrity.

Organizational integrity requires that organizations support and promote the ability of its teams and employees to practice with integrity—individually and collectively.

ADDITIONAL READING:

Iltis, A. S. (2001). Organizational ethics and institutional integrity. *HEC Forum*, 13(4), 317-328. doi:10.1023/A:1014762830800

Paine, L. S. (1994). Managing for organizational integrity. *Harvard Business Review*, 72(2), 106-117. Retrieved August 24, 2015 from <https://hbr.org/1994/03/managing-for-organizational-integrity>.

Solomon, R. C. (1993). *Ethics and excellence: Cooperation and integrity in business*. New York, NY: Oxford University Press.

SECTION 4: Essential Domains of Organizational Operations

Hospice organizations come in all shapes and sizes, but there are certain sets of activities common to all. We use these essential areas of organizational activities to systematically explicate how organizational values might be operationalized within a hospice provider. These categories are not unique to hospice and may indeed be found in many US healthcare organizations. Activities include not only the actions of the hospice and its staff or volunteers, but also the development and implementation of organizational policies to guide those activities in accordance with the values and relevant regulatory requirements, as well as the allocation of financial and staff resources to enable activities. Though a given hospice organization may use different words to describe the activity or the staff/volunteers who engage in the activity, the following seven domains capture many core operational activities in US hospice organizations: admissions, clinical services, discharge, governance, human resource management, marketing and community outreach, and fundraising.

Admissions include the activities surrounding the process of people being evaluated for and beginning to receive hospice services. This includes both the explanation of services to patient and family, process of consent, and initial and comprehensive assessments in accordance with the Medicare Conditions of Participation. It also includes connecting patients and families with resources (such as social services) to assist in understanding options and making decisions about services to select upon admission to hospice.

Clinical services include all care-related services provided to hospice patients, their families and loved ones, such as nursing and medical care, hospice aide services, social work and counseling, care coordination, or bereavement counseling. It also includes the location of care, whether home-based, facility-based, or inpatient hospice care. Together with human resource management, clinical services captures the education, competency, and expertise of the staff who provide those services, such as nurses, social workers, chaplains, hospice aides, bereavement counselors, physical therapy/occupational therapy/speech and language therapy, allied therapists (music, art, complementary, etc.), volunteers, physicians, and others affiliated with the hospice.

Discharge means practices and procedures which address the various ways that patients leave care, whether through death or through live discharge initiated by the hospice or patient/family (referred to as revocation). Mortuary and funeral arrangements and partnerships also fall within this category of activities. The hospice continues to be involved in the care of patients through these transitional stages. (Note: bereavement counseling and support are included in "clinical services.")

Governance addresses the structure, composition, and processes that shape the organization from the top down, such as the development and enactment of mission, values, vision, and strategic plan, as well as the activities of the leadership of an organization, its board and executive team, who provide the administrative backbone and oversight for the organization.

Human resources management encompasses activities surrounding recruitment, selection, hiring, management, and termination of employees and volunteers. These activities also include opportunities for training and orientation, engagement and support, and advancement and professional development for staff and volunteers.

Marketing and community outreach comprises activities that build awareness of a particular hospice organization but also of the field and services of hospice generally. These activities may include not only typical marketing activities such as cultivating relationships with individual physicians or facilities, but also externally oriented educational efforts such as providing grand rounds seminars at local hospital systems and informing the public about advance planning for the end of life. Marketing and outreach activities can occur on local, regional, and national levels.

Fundraising is an activity often undertaken by departments called Development or Philanthropy and consists of generating revenue outside of reimbursement or payment for clinical services. Examples include soliciting donations via direct mail or social media; holding a gala or golf event to raise funds through donations, ticket sales, or silent auctions; submitting applications to foundations or government agencies for project-specific funding; or cultivating individuals to make significant donations or legacy gifts.

SECTION 5: Integrating Organizational Values into Operational Domains of Hospice Care

Each organizational value is further refined in this section with explanations of activities and processes through which the value is expressed and exemplified. The explanations and examples are aspirational—that is, they represent an ideal state of affairs and set of actions. Hospices are encouraged to meet these ideals wherever possible. Likewise, examples are not intended as a comprehensive or exhaustive list of applications of the value to the organizational activity.

Equitable Access

Admissions: Admission decisions use transparent, appropriate, and uniformly applied criteria; criteria are based on clinical need, patients' and families' care goals and preferences, and an organization's ability to give competent care that addresses those needs, goals, and preferences. The organization works to lower or dismantle barriers to communities or groups that typically experience barriers to care or are underrepresented in the service population. Bases for admissions decisions are clearly communicated to patients and families and do not differ based on payer (e.g., private insurance vs. Medicare).

Examples:

- Provide access to all eligible community members through responsible budgeting, fundraising, and financial planning, with the governing body holding managers and administrators accountable for measurable access goals across a diverse spectrum of socioeconomic, diagnostic, demographic, and residential categories.
- Admit a patient who has exhausted all possible sources of funding for care.
- Provide admission services on evenings, weekends, and holidays.
- Accept otherwise eligible patients whose care needs are acute or require high-cost palliative treatments.
- Not recommended: Restrict recruitment and admissions according to selected patient profiles (non-cancer, long-stay, low acuity, insured, etc.) for purpose of maximizing revenue.
- Not recommended: Delay a patient's admission until the patient completes a course of expensive palliative treatment.

Clinical services: Appropriate clinical services are delivered promptly to enrolled patients any time of day or night, every day of the year. Bereavement resources and support are available to the community as well as to families of patients. Organization demonstrates fairness in allocation of resources across patients.

Examples:

- Maintain adequate staffing to provide timely clinical support outside of regular business hours; monitor and adjust response times regularly.
- Ensure IDT visit frequency matches the needs and preferences of patients and family members as reflected in individualized plans of care, rather than being determined by rigid formulas uninformed by case-specific variables.
- Ensure availability of and facilitate access to all four levels of care (routine home care, continuous care, general inpatient care, respite care) for all enrolled patients—regardless of place or type of residence within service area—corresponding to clinical need and eligibility.
- Not recommended: Limit number of GIP beds available to patients with no or lower pay source to keep beds available for patients with higher reimbursement rates.

Discharge: Patients have the right to revoke their hospice services at any time and for any reason and should be treated with respect. Hospice-initiated discharge follows regulatory requirements and is implemented according to consistently applied organizational policy concerning demonstrable clinical criteria, policies on safety of hospice staff and volunteers, and alignment of patient preferences with goals of hospice care. Discharges are not initiated for administrative or financial reasons. For patients discharged due to death, care continues to be provided to families throughout transitions, including assistance with funeral plans, acute bereavement, and other support services as needed.

Examples:

- Honor expressed patient wishes for revocation and provide guidance to the patient and family; establish plans for continuity of care.
- Discuss and document mortuary and funeral plans and preferences with all patients willing to do so. Offer information and choices for mortuary providers without prejudice or conflict of interest.
- Offer timely notification to patients and families at risk for discharge for cause, following regulatory guidance for the development of a well-constructed plan to remediate conditions leading to discharge and offer assistance in engaging other care options appropriate for the patient.
- Not recommended: Discontinue care due to a perceived threat or danger without exhausting efforts to address the obstacle to safe caregiving.
- Not recommended: Discontinue care because one of the patient's family members is a drug abuser.

Governance and administration: Governing boards reflect the demographics of the service community and include representatives of key stakeholders; recruitment of board members and administrators is open to all qualified candidates and selection is subject to defensible criteria and consistent process. Organization demonstrates fairness in allocation of resources across services or programs.

Examples:

- Conduct regular reviews of board membership to ensure broad representation of populations, stakeholders, skills, and expertise.
- Establish process for standardized and accountable method of recruiting and vetting prospective board members and administrators according to industry best practices.
- Develop and regularly review departmental/service line budgets and funding to ensure appropriate resources and address gaps.
- Not recommended: Appoint board members solely on basis of personal recommendation or amount of financial contributions to the organization either via donation or business relationship.
- Not recommended: Allocate budgets or staffing of departments/service lines solely on basis of revenue generated by the department/service line.

Human resources management: Recruitment is open to all qualified internal and external candidates, and hiring practices are nondiscriminatory. Opportunities for advancement are open and transparent. Volunteer recruitment is open and nondiscriminatory, with efforts made to reflect demographics of community served. Diversity of cultural background, training, appearance, and orientation is also crucial in both internal (staff, volunteers, managers, administrators) and external (vendors, partners, referral sources, community groups) stakeholders. Organization demonstrates fairness in allocation of resources across departments or employees.

Examples:

- Openly post all staff openings and opportunities.
- Regularly evaluate staff and volunteer demographics against service area demographics and address gaps.
- Provide regular cultural competency training for staff and volunteers.
- Allow no tolerance for expressions or actions reflecting bias or prejudice against any class or category of persons.
- Not recommended: Fill open positions with predetermined internal or external candidates.
- Not recommended: Establish partnerships or vendor relationships according to favorable or unfavorable bias.

Marketing and community outreach: Marketing and outreach activities increase public awareness of and education about the existence and purpose of hospice in order to improve access to care. Marketing messages and materials reflect diversity and open access to patients from all backgrounds and traditions.

Examples:

- Focus outreach efforts on communities historically underserved by hospice or underserved in the hospice's service area.
- Partner with community groups to educate members about hospice care.
- Provide marketing and educational materials in multiple languages as reflected in service area demographics.

Fundraising: Funds raised facilitate the provision of equitable access to services for all people regardless of ability to pay. Fundraising provides resources to support outreach to underserved and minority populations.

Examples:

- Initiate development campaigns to support “charity care” for uninsured patients, as allowed by law and applicable regulation.
- Dedicate a significant portion of funding distributions from foundations run in association with for-profit hospice organization to supporting and increasing hospice care access for patients and families in need.

Fundraising provides resources to support outreach to underserved and minority populations.

Comfort and Quality of Life

Admissions: The essential purpose of hospice care in promoting comfort and supporting quality of life throughout the end of life in accordance with patient/family preferences is unequivocally communicated during admissions process.

Examples:

- Explore patient and family understanding of terminal diagnosis, prognosis, and goals for care; ensure patient goals align with hospice goals.
- Provide specific examples of how hospice care differs from acute care or nursing facility care; ensure understanding by asking patient/family to restate in their own words their understanding of hospice care. Provide clear, simple written materials for later reference.
- Not recommended: Avoid or distort purpose of hospice by agreeing to use terms like "enhanced home care," "pain management" or other descriptors which mask the non-curative, end-of-life nature of care.

Clinical services: Plan of care and delivery of services are all focused on ensuring comfort and quality of life for the patient and family, as the patient and family define it. Clinicians respect and safeguard the dignity and safety of the patient/family/bereaved. Comfort and safety of hospice personnel are considered in allocating staff and providing services.

Examples:

- Clarify patient's definitions of "comfort and quality of life" to ensure mutual understanding and congruence with plan of care.
- Offer reasonable security to personnel working outside of regular business hours at hospice facilities or administrative offices or serving patients in high crime areas.
- Offer reasonable accommodations to patients whose cultural norms require caregivers of a certain gender or religious affiliation.
- Incorporate assessment of comfort and quality of life—including, but not limited to, symptom distress—into all visits by all care disciplines.

Incorporate assessment of comfort and quality of life... into all visits by all care disciplines.

Discharge: Throughout the dying process, patient's comfort is maintained; family members are informed of stages in process and supportive measures; social and spiritual support are made available to patient and family. Upon death, arrangements for transfer to mortuary or other after-death services provider are made with respect and discretion.

Examples:

- Ensure that the family has as long as needed to be with the body when patient dies in a facility.
- Respectfully pack and provide patient's belongings to the family.
- Assist patients moving out of the service area in finding a new hospice care provider; take care to initiate real-time IDT-to-IDT communication about the patient's needs and services as provided thus far.
- Give patients being discharged for cause and their families ample opportunity to rectify the conditions leading to the discharge and support in doing so."

Governance and administration: The essential purpose of hospice care (as defined above) is central to governance, administration, and resource allocation decision making.

Examples:

- Develop and implement evidence-based metrics to assess whether care provided to patients is adequately providing comfort as reported by patient and/or family.
- Not recommended: Assess and document patient and family comfort and quality of life only via clinician-reported process measures.

Human resources management: Attention to the comfort and quality of life of staff, volunteers, and managers/administrators is embedded in hiring and management practices, as well as in employee benefits and assistance programs.

Examples:

- Offer reasonable protections, accommodations, and support to staff members whose identities (racial, ethnic, religious, gender, sexual preference, etc.) are subject to bigoted or offensive remarks or behavior by patients or families.
- Establish and promote wellness and self-care programs for staff and volunteers.
- Address workplace quality of life in annual evaluation discussions.
- Survey staff and volunteers annually on job satisfaction and/or engagement and address concerns or gaps.
- Ensure support is available for staff and volunteers experiencing personal challenges that impact their work.

Marketing and community outreach: Marketing messages emphasize the essential goals of hospice. Outreach activities support and uphold the essential goals of hospice.

Examples:

- Emphasize comfort and care in marketing content, appropriately and explicitly messaging the palliative, noncurative focus of hospice services.
- Prioritize maintaining the comfort and dignity of patients/families in the practice behavior of liaisons; avoid behavior that is intrusive to privacy or uses coercive sales techniques such as appeal to fear of symptom distress, etc.

Fundraising: Fundraising supports provision of comfort- and quality-of-life—oriented care to all patient populations, especially the un- or underinsured and underserved.

Examples:

- Solicit patient/family images or narratives for use in fundraising—if at all—with careful attention to protecting the vulnerability of sick and bereaved persons, including any and all HIPAA protections, privileging the care and comfort of such persons over their potential value to an organization's fundraising efforts.
- Develop and enforce clear guidelines addressing if, when, how, and by whom patients and families currently under care can be approached as potential donors. Guidelines explicitly privilege comfort and quality of life for patient and family care recipients, separating the roles of clinical caregivers from the roles of fundraisers.

Teamwork and Collaboration

Admissions: Admission to hospice requires collaboration with external referral sources, the patient’s attending physician (if any), patients and families, other clinical team members to effect a smooth respectful, and minimally disruptive transition to hospice care with patient and family needs and preferences paramount.

Examples:

- Establish systems to ensure clear and consistent communication of needs and goals among referring physician/facility, attending physician (if any), patient and family, hospice admissions team.
- Prioritize ensuring patient and family comfort with transition to hospice care over logistical or administrative convenience to referring providers or hospice.

...ensure clear and consistent communication of needs and goals...

Clinical services: Members of interdisciplinary teams contribute individual, particular perspectives and skills in the holistic and integrated care of patients and families. Teams, as distinct from groups, blend these perspectives and skills to create outcomes and benefits that exceed the sum of the parts. Clinical services are comprehensive and integrated, as achieved by the collaboration of interdisciplinary hospice providers addressing the different types of needs of patients and their loved ones.

Examples:

- Managers pay close attention to interpersonal and interdisciplinary functioning of team and address dysfunctions quickly and directly.
- Provide teams with education in team dynamics and communication.
- Ensure cross-disciplinary awareness so team members understand the unique expertise each provides to patients/families.

Discharge: Patient deaths are promptly reported to the interdisciplinary team (including assigned volunteers), administration, and others such as external partners, as appropriate. Patient- and hospice-initiated live discharges are discussed by the interdisciplinary team; a plan is prepared and communicated to patient and family. Hospice staff works with external partners and facility staff as appropriate to ensure prompt communication and completion of plans.

Examples:

- All members of interdisciplinary team contribute to discharge planning for patients being discharged from hospice care prior to death.
- Provide care team members regular and appropriate opportunities to acknowledge and process thoughts and feelings about patients who have died. Incentivize exercise of those opportunities.
- Provide timely and compassionate notification of patient deaths to non-hospice clinicians—community physicians, privately hired aides, care facility staff; when appropriate, offer bereavement support.

Governance and administration: The essence of teamwork extends to governance and administration in which organizational goals and activities rely on the contributions and talents of the team rather than any one individual. Interdisciplinary stakeholders are incorporated into governance structures.

Examples:

- Infuse interdisciplinary team structure and functioning principles into conduct of management and board of directors: roles and expectations for executive team members are clear and specific; executive and board retreats include training on collaboration and group process; performance evaluation criteria for senior executives include concrete measures for mentoring, supporting, and evaluating subordinate teams.
- Ensure clinical disciplines engaged in hospice care are represented on the board of directors.
- While observing protections of patient and employee confidentiality and all HIPAA considerations, arrange opportunities for board members and administrators to observe delivery of clinical care through “ride-alongs” and attendance at interdisciplinary team meetings; incentivize clinical managers to observe delivery of nonclinical services through shadowing of business operations and executive team members.

Human resources management: Recruitment and hiring decisions take into account the needs and characteristics of the “team” that the candidate will be joining, whether clinical or administrative. Management practices foster individual growth and development but also work to form and support teams with common goals and integrated interactions. Decisions and actions regarding terminations take into account the impact on the team.

Examples:

- Structure employee and volunteer relations in order to foster an interdisciplinary team environment.
- Incorporate measures of collaboration, team building, and communication into concrete performance goals and assessment of all employees.
- Assess hiring and firing decisions according to impact on team and team members as well as individual characteristics and performance.
- When team members resign or are terminated, ensure support to remaining members and team activities/goals to minimize disruption and disintegration.

Marketing and community outreach: Marketing efforts are integrated with clinical goals and values. Liaisons effectively represent and model the commitment to teamwork in their interactions with referral sources and clinical partners, enhancing their understanding of hospice philosophy and goals, supporting their efforts toward improved quality of care, and building relationships of mutual value. Community outreach activities entail collaborations with community partners to contribute to collective efforts to improve access, understanding, and quality of care for terminally ill patients and families within and beyond the organization’s immediate service area.

Examples:

- Participate in a voluntary coalition to promote the importance of end-of-life care planning with other healthcare providers in the community.
- Invite clinical liaisons to IDT meetings quarterly to observe postadmission care coordination and services; invite IDT members to shadow clinical liaisons annually to observe the ways liaisons navigate the hybrid roles of organizational representative, educator, and clinician.

- Seek out opportunities to offer education on hospice to clinical staff or patient groups at referring facilities, such as hospitals or nursing homes.
- Review marketing materials and “scripts” regularly to ensure coherence with actual available services, practices, and capacity.
- Offer access to bereavement support and counseling services to staff and volunteers at referring facilities, local police departments, or school systems.

Fundraising: Fundraising and development activities support demonstration or pilot programs to improve teamwork and collaboration. Design of grant-funded projects includes collaboration with external partners and stakeholders.

Examples:

- Seek funding to pilot a care coordination program with external partners such as a shared end-of-life decision-making protocol about cardiac devices with cardiologists, a readmissions reduction plan for hospital partners, palliative care services with local home health agencies.
- Integrate perspectives of multiple care disciplines and administrative staff when identifying funding needs and setting fundraising priorities.
- Establish clear and transparent policy/guidelines regarding the collaboration of clinical staff and development/fundraising staff.

Excellence

Admissions: Staff conducting admissions process, including interdisciplinary assessment, are trained adequately and competencies are assessed routinely. All members of the interdisciplinary team assess the patient within timelines required by regulation and the organization’s policies, with visits according to the plan of care.

Examples:

- Offer periodic refresher education (in addition to orientation training) for admissions staff, specific to assessment of physical/medical status and decision-making capacity.
- Ensure admissions manager periodically attends admissions interviews to observe and offer constructive critique of process.
- Seek feedback from patients/families on their experience in admissions process; address concerns or gaps.
- Integrate admission nurses into IDT operations, incentivizing regular and direct communication between admission staff and care staff (if separately specialized) to promote mutual understanding of opportunities and challenges in maintaining continuity in care through intake process into care continuum.

Clinical services: Clinical staff are licensed, trained, and have obtained or are working toward certification or advanced skills in hospice-specific practices. Competence and skills are routinely assessed, including ability to engage patients and families in manner that facilitates plan of care. Organization implements quality standards and measures, monitors progress, and adjusts services to address gaps or deficiencies.

Examples:

- Provide substantive continuing education opportunities for staff to enhance skills and certifications, or offer financial support (including paid time) for registration or tuition to attend external educational programs.
- Ensure services and interventions align with evidence-based best practice guidelines and culturally appropriate norms.
- Use electronic health records (EHRs) and other technological platforms to improve care quality, monitor quality and compliance, and facilitate timely interventions.
- During provision of care, monitor patient outcomes (e.g., relief of pain, symptoms, and psychosocial-spiritual distress), and adjust care to address deficiencies for individual patients or over time for patient populations.
- Survey families following patient death or discharge to evaluate experience of care; report and adjust care to address deficiencies.
- Ensure performance evaluations of clinical staff include assessment of technical competence and feedback from patients/families on interpersonal skills.

Discharge: Care for patients and families during the active dying process is provided according to highest standards of clinically effective and culturally sensitive care. If indicated, continuous care or inpatient care is provided to manage severe symptoms. The hospice team communicates with the designated postmortem care provider, including follow-up to ensure timely transfer of the body. Patient- or hospice-initiated live discharge is handled with professionalism and attention to continuity of care.

Examples:

- Keep family members informed of a patient's condition and progress through the active dying process and coach them in providing comfort to patient and each other.
- Ensure the team nurse visits the patient and family at least once during the active dying process to confirm that comfort and other needs are met. Offer support from other members of the team and provide as requested.
- Give family members the time they request to be with the patient's body prior to transfer by postmortem care providers.
- Intentionally design and regularly assess communication processes with post mortem care providers—e.g., funeral homes, veterans services, religious body care providers, relevant government and public health officials.

Governance and administration: Administrators identify and involve a variety of stakeholders, including a patient or family member and IDT clinicians, in determining and updating mission, vision, and values. Governing body(ies) are established and maintained (with checks and balances) incorporating varied stakeholders. Policies and procedures adhere to business and nonprofit best practices. Board members and executive leadership are provided training and opportunities to enhance skills.

Examples:

- Routinely assess managers' and executives' performance against clearly communicated goals and consistent standards resonant with the hospice philosophy of care; support professional development and improvement efforts.
- Routinely monitor the organization's programs and services against mission and organizational goals.
- Use external benchmarking to compare quality indicators with other hospice and palliative care organizations; address gaps and deficiencies.
- Engage external consultants to evaluate governing board's performance and suggest improvements in composition or practice.
- Not recommended: Infrequent self-assessment of performance by the governing body; infrequent or informal assessment of administrator.

Human resources management: Managers and employees identify individual, measurable performance goals based on best practice standards, professional expectations, and industry standards. Regular performance evaluations against goals are conducted with the aim of striving toward excellence. Excellence is expected and enabled in all staff, managers, and volunteers, not just clinicians.

Examples:

- Provide access to, and incentivize, ongoing discipline-specific professional education to ensure all staff members are equipped with up-to-date evidence-based skills appropriate to their role and responsibilities.
- Train volunteers in skills appropriate to their role to ensure safety and uphold excellence of care; regularly assess competencies in same.
- Educate, support, and evaluate managers in effective personnel and administrative management techniques.
- Not recommended: Require employees or volunteers to work with patients and families before being oriented or trained in their job responsibilities.

Excellence is expected and enabled in all staff, managers, and volunteers, not just clinicians.

Marketing and community outreach: Organization uses quantitative and qualitative data to assess community (provider and patient/family) needs, develop hospice services to meet them, and tailor marketing messages to communicate offerings. Marketing techniques are based on industry best practice standards and monitored for effectiveness against measurable criteria. Community outreach programs are evaluated against identified goals whether raising general public awareness of end-of-life care or measurable increases in referrals or admissions.

Examples:

- Obtain and analyze data on patient populations, case mixes, admitting diagnoses, and provider types among referral sources and partners and evaluate services to meet demonstrated needs.
- Establish and maintain marketing performance measures that speak to meeting patient and community needs along with financial goals.
- Not recommended: Manipulate, exaggerate, or invent measures of quality or effectiveness in order to increase market share or obtain business.

Fundraising: Funds are raised according to established industry best practices; development staff members are offered opportunities to improve skills.

Examples:

- Incentivize employees engaged in development and fundraising to learn and implement best practices as defined by professional fundraising associations and peer-reviewed literature.
- Monitor and assess fundraising practices via organizational quality, performance evaluation, and compliance programs.
- Align fundraising practices with the Association of Fundraising Professionals *Code of Ethical Principles and Standards* (2015).
- Integrate fundraising best practices with the mission and vision of hospice organization through the collaboration of board of directors, program executives, and fundraising employees.

Stewardship

Admissions: Admissions criteria, decisions, and procedures are designed to maximize the organization's ability to achieve its mission. Criteria balance goals of (a) opening access to each patient and family who can benefit from services with (b) distributing high-quality care resources to the greatest number of patients and families in the service community. Intake processes are intentionally designed to balance goals of maximizing the quality of each admission with timely admission of all patients in need of services.

Examples:

- Ensure each patient and family receives appropriate assessment, explanation, and shared decision-making opportunities via standardization of admission visit procedures, while also preserving the flexibility to address unique patient and family circumstances.
- Consider admission of patients with unique, clinically complex, or especially costly treatment needs in light of the organization's ability to provide care, the needs of each patient and family, and the effect on other patients and families already on/in need of service. When possible, ensure admission criteria related to specific treatments are standardized and uniformly applied across programs.

Clinical services: To steward clinical resources guided by the organization’s mission, patient and family needs are matched with services that are most effective in addressing patient/family values and preferences at highest quality and optimized efficiency. The organization contributes to the training of new generation(s) of clinicians and enhancing the awareness of hospice and palliative care in the healthcare community at large. To the extent made possible by the organization’s resources, the organization supports research relevant to hospice care.

Examples:

- Regularly review use of resources against industry benchmarks and specific organizational goals; evaluate and refresh processes regularly to meet evolving needs of community and patient population.
- Organizational mission informs selection of and contract administration with vendors providing clinical services and durable medical equipment. Assess vendor-provided services for quality and efficiency at established intervals. Pay special attention to regulatory requirements regarding contracting for core services.
- Partner with local medical, nursing, or social work schools, CNA training programs, and health chaplaincy organizations to expose clinicians-in-training to careers and best practices in hospice care.
- Offer grand rounds at local hospitals on palliative techniques, psychosocial-spiritual care, or bereavement.
- Partner with research-oriented initiatives to test emerging palliative practices or enhance understanding of care at the end of life.

Discharge: Clinical factors are the foremost criteria in making live discharge decisions; safety of clinical personnel, resource allocation, and other factors are considered in open, transparent discussions with relevant stakeholders. Live discharges are reviewed at regular intervals to ensure use of organizational resources is optimized to serve patient, family, and community needs consistent with the organizational mission.

Examples:

- Engage in quality measurement and improvement that includes monthly review of live discharges attentive to patterns and predictors. Update upstream practices and procedures to reduce likelihood of live discharge.
- Partner with referral hospitals and care facilities to explore and minimize preventable discharges.
- Implement organizational policy guiding interdisciplinary team member participation in patient funeral and memorial services, attentive to balancing the needs of bereaved families and providing care to patients still on service.
- Not recommended: Initiate live discharge based primarily on financial (cost of care, cap calculations, reimbursement rate) or length-of-stay considerations.

Ensure use of organizational resources is optimized to serve patient, family, and community needs consistent with the organizational mission.

Governance and administration: Administrators and board members engage in responsible budgeting and financial planning to ensure adequate financial and human resources to operate consistent with the organization's mission.

Examples:

- Ensure adequate fund reserve to continue operations through periods of unexpected decreased census or financial crisis.
- Maintain lean and efficient administrative operations; undertake growth with prudence to ensure sustainability.
- Not recommended: Cut employee salaries or professional development funds while maintaining or growing executive reimbursement and perks.

Human resources management: Staffing models are integrated with organizational mission and values to align distribution of employees and expertise with the service needs of patients, families, referral sources, and community. Employees are respected and supported by managers by recognizing successes, rewarding commitment, constructively correcting deficiencies, and supporting quality of life to minimize attrition and maximize professional development and service quality.

Examples:

- Balance hiring and compensation of sales/marketing staff with investment in clinical staff to ensure quality of care.
- Ensure scheduling of clinical and service staff during evening and weekend hours sufficient to meet the needs of patients, families, and stakeholders; avoid overstaffing during regular business hours and understaffing during "off" hours.
- Provide personal and professional growth and self-care opportunities for employees and volunteers through in-service training, educational benefits, regularly scheduled process groups, and incentivized professional development opportunities.
- Not recommended: Institute incentive-based compensation for marketing staff that results in disproportionately high earning potential not available to clinical staff.

Marketing and community outreach: Marketing budgets and advertising channels are resourced proportionately to mission-focused outcomes and other organizational budget lines. Efforts are targeted to underserved populations with care needs in the service community. Brand awareness strategies are sensitively integrated throughout clinical and nonclinical operations to maximize cost effectiveness.

Examples:

- Direct media campaigns toward currently underserved populations via strategically chosen community-based newspapers and websites. Establish realistic and appropriate qualitative as well as quantitative measures to determine the effect of community outreach and education programs.
- Not recommended: Purchase expensive sponsorship of charity events attended primarily by community members already served by hospice care.

Fundraising: Development and fundraising strategies are designed to meet immediate needs as well as to ensure the future viability of the organization. Donors and foundations are recognized and honored for their contributions and relationships maintained professionally.

Examples:

- Include a mix of immediate and longer term needs in devising fundraising strategies and targets; include planned giving, endowments, and other long-term programs alongside campaigns to meet current needs.
- Establish a “futures” committee of board members, staff, volunteers, and other stakeholders to identify emerging needs or evolving trends in the service community.
- Regularly celebrate contributions of all kinds, not just monetary.

Transparency

Admissions: Admissions staff accurately and completely explain services offered, the palliative rather than curative nature of hospice care, cost, staff availability, and goals of hospice care. The description of hospice care includes the availability of services after hours and during the weekend through on-call services. Services that may be needed but are used less frequently (e.g., inpatient, continuous care, CPR) are discussed with patients and families at time of admission.

Examples:

- Review limitations of service prior to admission.
- Review the services provided and any associated costs to the patient upon admission.
- Explain that all care related to the terminal prognosis must be approved by the hospice provider or the patient could be liable for the cost.
- Assess patient and family understanding of information regarding care and services, as well as business and financial relationships.
- Acknowledge financial relationships with other providers during the intake and consent process.
- Not recommended: Rely on printed admissions packet material to explain and disclose services and costs without explanation by the staff.

Clinical services: Patient plan of care, including all medications, procedures, equipment, and services provided and not provided, is reviewed regularly with patient and family throughout period of care. Information about metrics of care and service quality is shared with prospective and current patients and families, community members, and service partners.

Examples:

- Develop and communicate a plan of care that specifies the number of visits from hospice team members, and other services according to patient/family needs, circumstances, and available resources.
- Discuss medications and treatments with the patient and family and carefully review discontinuation recommendations based on the physician’s assessment of efficacy and ongoing need.
- Post quality assessment metrics, outcomes, and any plans of correction on organization website. Make the same available to referral sources and stakeholders.

Discharge: Reasons for any hospice-initiated discharge (e.g., patient no longer meets clinical criteria for hospice care) are disclosed to the patient/family. Discern and address reasons for patient-initiated revocations. Rates of live discharge and revocation are accurately recorded and documented. Availability and type of bereavement services offered by hospice and community organizations are clearly communicated.

Examples:

- Review—at admission—possible reasons for discharge prior to death.
- Address patient and family complaints promptly and with respect.
- Not recommended: Discharge patients due to burdensome costs of care, length of stay, or reimbursement rate while claiming discharge is due to unsafe environment in patient's home.

Governance and administration: Information regarding mission, values, policies, and processes is systematically and intentionally shared with all stakeholders—employees, volunteers, patients, families, community members, and partners. Transparency is operationalized, including the weighing and prioritizing of competing interests such as obligations to patients/families, obligations to communities, and obligations to investors/funders. Outcomes and quality metrics and methodology used to identify outcomes and metrics (e.g., numerators, denominators, included versus excluded patients/services, etc.) are clearly and regularly reported.

Examples:

- Post mission and values on website and in a prominent place in the office; make essential policies and procedures available for review by any employee, volunteer, board member, or stakeholder.
- Leaders make regular reports to staff concerning: progress toward organizational goals; definitions and outcomes of quality metrics; significant changes in policy or organizational direction; growth or reductions in business lines, staff, or resources; participation in research or program/service evaluation.
- Maintain regular channels of communication such as newsletters, social media postings, and annual reports to external stakeholders and community.
- Appropriate governance bodies regularly review business and financial relationships of the organization, and document these relationships in a clear and timely manner.

Outcomes and quality metrics and methodology used to identify outcomes and metrics are clearly and regularly reported.

Human resources management: Open positions with accurate job descriptions and candidate requirements are publically posted. Accurate information about current hiring processes, performance review processes, and promotion/raise policies are shared with potential candidates and current employees. Reasons for termination are documented and communicated clearly and respectfully to the person being terminated.

Examples:

- Provide employees and volunteers with a copy of the organization’s statements of mission, vision, values and ethical principles, and provide guidance on what type of behavior is expected in their respective positions.
- Offer prompt and frequent informal feedback, especially regarding areas of needed improvement, so staff members can self-correct and continuously improve.
- Establish and enforce regular performance review process, even when organizational resources do not allow salary adjustments.
- Establish clear, specific, and measurable goals and expectations for employee performance; offer opportunities and clear guidance for correction in addressing deficiencies.
- Not recommended: Predetermine hires into available positions without open, competitive process to identify best candidates available.
- Not recommended: Terminate an employee on the basis of subjective criteria without prior discussion of deficiencies and opportunities to correct.

Marketing and community outreach: Marketing messages and outreach information are accurate and complete regarding services offered and not offered, costs, and criteria for admission and discharge.

Examples:

- Communicate regularly with referring physicians through visits, mailings, newsletters, managed care networks, websites, and e-mail.
- Communicate with the media to clarify principles of quality end-of-life care, as well as clinical and financial aspects of hospice and palliative care, including those pertaining to the physician–patient relationship.
- If the organization is engaged in clinical research, ensure accurate communication of research goals, enrollment criteria, and patient protections.
- Not recommended: Fabricate testimonials or patient stories to manipulate public perceptions.
- Not recommended: Conceal organization’s participation in research projects.

Fundraising: Fundraising processes, policies, funding sources, and allocation of funds are reported as required by law and industry best practices. Requests from donors to remain anonymous are honored unless prohibited by law. Reports to donors and foundations are complete, accurate, truthful, and timely.

Examples:

- Establish a formal mechanism to account for and report on donor-restricted funds or restricted grants (e.g., money donated to purchase a specific item was used for that purpose).
- Annually report donors and donations in a manner that respects donor’s preferences for privacy (e.g., list amounts separate from names; report total amount donated without itemizing, etc.).

Integrity

Admissions: Criteria for, and process of, admission integrates the seven organizational values as explained in section 3 and illustrated in section 5. Incentives for staff responsible for admission process align with publicly stated program admission criteria consistent with relevant regulatory requirements. Admission staff members are supported in role requirements appropriate to their scope of practice and consistent with professional codes of ethics.

Clinical services: Structure and processes of care integrate the seven organizational values as explained in section 3 and illustrated in section 5. Care services are designed and delivered to carefully balance organizational mission and values, best practice standards in relevant care disciplines, and the hospice philosophy of care.

Discharge: Structure and processes for live and death discharges integrate the seven organizational values as explained in section 3 and illustrated in section 5. Support for patients and family members throughout the discharge process is designed and delivered to carefully balance organizational mission and values, best practice standards in relevant care disciplines, and the hospice philosophy of care.

Governance and administration: Governance structure and practices integrate the seven organizational values as explained in section 3 and illustrated in section 5. Lines of reporting and accountability are clearly demarcated in a well-defined and accessible organizational structure. Relationships between organizational goals, values, processes, and the hospice philosophy of care are regularly reviewed, with modifications made to structure and operations to maximize coherence and minimize dissonance.

Human resources management: Human resources practices integrate the seven organizational values as explained in section 3 and illustrated in section 5. Recruitment, selection, hiring, management, development, and termination of employees and volunteers proceed consistent with deliberately designed procedures, outcomes of which are regularly reviewed for alignment with organizational mission, values, and the hospice philosophy of care.

Marketing and community outreach: Marketing and outreach practices integrate the seven organizational values as explained in section 3 and illustrated in section 5. Internal and external messaging explains and promotes practices and services that exemplify organizational mission and values consistent with the hospice philosophy of care.

...messaging explains and promotes practices and services that exemplify organizational mission and values consistent with the hospice philosophy of care.

Fundraising: Fundraising practices integrate the seven organizational values as explained in section 3 and illustrated in section 5. Identification, solicitation, and relationship management with donors is guided by explicit and regularly assessed procedures consistent with these values. Priorities for allocation of development funds clearly align with the hospice philosophy of care.

CONCLUSION

The *Guide to Organizational Ethics in Hospice Care* provides a conceptual framework for ethical behaviors and practices of hospice organizations. It outlines the philosophy of hospice care (as derived from the teachings of Dame Cicely Saunders) as an anchor for current practices: delivering family-centered care to persons at the end of life that minimizes their suffering, allowing them to live their final days in a manner that is meaningful, comfortable, and consistent with their values. The seven organizational values for hospice providers (equitable access, comfort and quality of life, teamwork and collaboration, excellence, stewardship, transparency, and integrity) are defined and then explicated within the context of seven essential domains of hospice organization operations (admissions, clinical services, discharge, governance, human resources management, marketing and community outreach, and fundraising).

This *Guide* serves as the beginning of an ongoing conversation among stakeholders. Hospice provider organizations can use section 3 to inspire and guide their own discussions about what values do or should drive their practices and mission. Section 5 provides examples that hospice stakeholders can use when conducting a company-wide “ethical audit” of their existing practices or when developing new policies and practices.

Our hope is that hospice organizations adapt and use this *Guide* to systematically assess and improve organizational structure and processes to foster an ethical climate in which employees can thrive, patients and families can receive high-quality care, and communities can fully integrate the hospice philosophy of care into flourishing societies.

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