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Engaging Requests for Nondisclosure During Admission to Home Hospice Care

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It is not uncommon for hospice admission nurses to receive requests from loved ones to withhold information from patients about their diagnosis or prognosis. Such requests may occur in the context of similar requests having previously been honored by other, nonhospice care teams. This article explores the ethical questions raised by such requests and the motivations behind them. Following, it offers ways to engage requests for nondisclosure that honor ethical obligations to patients and families in a manner consistent with the hospice philosophy of care. The principles of truthfulness, sensitivity, and beneficence are introduced, and a framework using those principles to respond to requests for nondisclosure is proposed.

KEY WORDS

beneficence, clinical sensitivity, disclosure, ethics, hospice and palliative care nursing, hospice care, hospices, patient admission, truthfulness

Although disclosure of diagnosis and prognosis to patients in the United States has become increasingly commonplace,[1] it is not unusual to have patients who have not been informed of their diagnosis or prognosis referred to hospice care programs. In such circumstances, hospice admission nurses may be asked to withhold information about diagnosis and prognosis from patients. When such requests for nondisclosure originate from patients' loved ones, the primary motivation—expressed or implied—is often a noble one: to prevent harm. Family members may fear that the patient will "lose hope" or be consumed with fear or anxiety or that their dying process may be otherwise accelerated via distress associated with knowledge that they are terminally ill.[2]

Requests for nondisclosure may have been honored by other clinicians prior to hospice admission for any number of reasons: the often rushed nature of hospital discharge, multiple clinical services caring for a patient—each of which thought the other discussed prognosis with the patient—or reluctance on the part of prior clinicians to have what is perceived as a "difficult conversation" arising out of a lack of training or experience or the belief that such disclosure is the job of the hospice care team and not the referring clinician.[3]

Whether for these or other reasons, admission nurses can find themselves encountering a request for nondisclosure in the context of the same request having been previously honored by a patient's prior care teams. This was the situation in the admission of Ms L., whose case is an aggregation of phenomena well known to many of our colleagues in hospice care. Using the case of Ms L. as an example, this article explores the ethical questions raised by such requests and the motivations behind them. Following, it offers ways to engage requests for nondisclosure that honor ethical obligations to patients and families in a manner consistent with the hospice philosophy of care. The principles of truthfulness, sensitivity, and beneficence are introduced, and a framework using those principles to respond to requests for nondisclosure is proposed.

THE CASE OF MS L.

> Ms L. was an 83-year-old woman originally from Portugal hospitalized with pneumonia. She was alert and oriented on admission to, and discharge from, the hospital. During her hospitalization, she was diagnosed with lung cancer with metastasis to the brain and spine. Her primary caregiver was her daughter, who requested that staff not inform her mother of the lung cancer diagnosis. The hospital staff honored this request. Given the advanced stage of the cancer and Ms L.'s fragility, the care team did not recommend aggressive treatment, and her daughter agreed with this recommendation.
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> After inpatient treatment, which focused on resolving the pneumonia, Ms L. was discharged home with a plan to begin hospice care. During the hospice admission visit, Ms L.'s daughter asked that hospice staff not use the words "hospice" or "cancer." She was adamant that no one tell her mother about her diagnosis or prognosis. The daughter had told Ms L. that she would be getting home care to "build her strength" following the hospitalization. Ms L. lived with her husband who, because of his Parkinson

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> disease and dementia, was not involved in her care. Her only daughter was to be her primary caregiver if Ms L. was admitted to hospice care.

In cases similar to Ms L., how should admission nurses engage a family member's request for nondisclosure? What values, norms, and concepts should inform nurses' thinking and actions?

In our experience, the most helpful sources of guidance in such situations are ethical principles firmly grounded in the hospice philosophy of care. A brief explanation of that philosophy of care follows.

THE HOSPICE PHILOSOPHY OF CARE

Four cornerstone concepts constitute the foundation of the hospice philosophy of care: (*a*) dying as an experience pregnant with meaning, (*b*) family-centered care, (*c*) the nature and relief of suffering, and (*d*) the integrity of persons as a condition of creating and experiencing meaning in life and exercising moral agency.[4]

In the hospice philosophy, death is not viewed as merely an event in which an organism ceases to sustain its vital metabolic functions. Rather, death is part of a larger experiential process—dying. And, dying, as a process that unfolds simultaneously with living, is experienced by persons, not organisms. Because dying and living are coconstituent of one another and because both are experienced by persons who give and receive hospice care, the process of dying is pregnant with possibilities for meaning. A central aim of the hospice philosophy of care is to support and facilitate the creation of such meaning by patients and their families.[4,5]

Hospice care is person- and family-centered care,[6] meaning that much of what "care" means in this paradigm is the education and support of dying persons' loved ones. Hospice care professionals engage a patient's loved ones to create a primary circle of care, and much of the direct care given to patients is then delivered not by care professionals, but by loved ones supported by the hospice care team. One of Dame Cicely Saunders'[5] motivating insights in building a hospice philosophy was that end-of-life care should be structured and delivered in a manner shaped primarily by the unique needs, values, and preferences of each dying person. As such, she sought to reorient care to follow the pulses and rhythms of the patient's life, rather than the institutional pulses and rhythms of an acute care hospital. Engaging a patient's loved ones as primary caregivers—presuming this is the preference of the patient—allows the patient to receive care and create meaning via the core relationships she has already established and engaged to navigate the joys, challenges, and mundanities of life.

The primary way in which hospice care seeks to maximize the quality of life for dying persons is to minimize the intensity and frequency with which the quality of one's life is compromised by the experience of suffering.[6] While suffering can be caused by the experience of pain and symptom distress, it is not equivalent to such. Rather, the hospice philosophy of care conceptualizes suffering as any experience that is perceived by persons as a potential threat to their unique identity as persons. This is often explained using language developed by Cassell,[7] who described suffering as an interruption of personal integrity—an unwelcome change in the way the different aspects of a person's life fit together such that she can no longer live that life in a manner consistent with the values and goals that help shape who she is. In attempting to reduce the extent to which phenomena accompanying a final illness cause suffering, hospice care professionals offer interdisciplinary care and support to ameliorate suffering arising from multiple domains of a patient's life.

The way in which hospice care seeks to reduce suffering is to restore in persons a sense of wholeness—to help them and their families reintegrate the pieces of their lives such that the creation of meaning can resume. Such restoration constitutes the rebuilding of persons' moral agency—their "ability to identify and embrace guiding values in life and to execute decisions, participate in actions, and develop character traits that reflect and express those values."[8] Hospice care helps persons integrate their experiences at the end of life into their experiences across the lifespan, facilitating through such integration the creation and discovery of meaning. In so doing, they engage and support persons' moral agency.

Because hospice care has such a rich history and philosophy of care and because that philosophy helps to define just what it is that hospice clinicians do for patients and families—and why they do it—any ethical principles used to guide care decisions should strongly resonate with the core tenets of the hospice philosophy of care. In the following section, we explain how 3 principles consistent with that philosophy—truthfulness, beneficence, and sensitivity—support certain ways of engaging Ms L. and her daughter in the admission process and responding to the request for nondisclosure.

ENGAGING REQUESTS FOR NONDISCLOSURE: TRUTHFULNESS, BENEFICENCE, AND SENSITIVITY

At their most useful, ethical principles can be touchstones used to help hospice care clinicians navigate relationships with dying persons and their families and guide a process of shared decision making. Identifying which principles are most relevant to a particular care encounter and discerning the best way to incorporate those principles into care processes require hospice clinicians to carefully integrate the values and preferences of patients and families into the larger hospice philosophy of care. When considering how to engage the request made by Ms L.'s daughter, we propose the use of 3 carefully constructed ethical principles: truthfulness, beneficence, and sensitivity.

Truthfulness

A significant component of truthfulness in health care is "truth-telling": disclosing accurate and complete information to persons for the purpose of making decisions about giving and receiving care. Truth-telling clearly supports not honoring Ms L.'s daughter's request and disclosing to Ms L. her cancer diagnosis and prognosis. However, it offers little in the way of guidance regarding *how* to engage the daughter's request in a manner that builds and maintains a therapeutic relationship with her or *how* to tell Ms L. the truth in a way that integrates the larger goals and concepts of hospice care. It is for this reason that we encourage the admission nurse to consider *truthfulness*—rather than only truth-telling—as a guiding principle in this case.

Building and implementing a hospice plan of care is a collaborative enterprise—with hospice clinicians, dying persons, and their loved ones all contributors to the process. Eliciting and integrating the contributions of all parties—requisite to using family-centered care to engage moral agency—begin in the first care encounter. In the case of Ms L., this is the admission visit. In our experience, the admission visit should not be considered something that happens "before care begins." The first contact with a hospice team member—whether a liaison in the hospital, a referral nurse on the phone, or the admission nurse in the home—is an integral part of hospice care itself.

In an admission visit, the patient, her, loved ones, and hospice clinicians work together to interpret the meaning of clinical developments in the patient's life up until the visit, build a shared understanding of what hospice care could look like for this particular patient and family, and discern together if and how enrolling in hospice care is resonant with the goals and values of the patient. This collaborative process builds a collective perception of the prospective truth of hospice care for each patient and family. Truth, in other words, is not something possessed by clinicians or family members and disclosed to patients. Rather, the truth of patients' situations is discerned through a shared process of inquiry, discovery, and meaning making.[2,9,10] Multiple perspectives, histories, spheres of expertise, and value systems combine to develop a plan of care driven by the goal of allowing patients to live their lives authentically as persons, especially during the experience of a serious or final illness.

As an ethical principle, "truthfulness" asserts the value of all of these perspectives. This is done by promoting patterns of engagement that create a supportive environment in which all parties can explore, share, and integrate their points of view. The goal is to achieve the fullest understanding of a patient's situation and possibilities, and engagement of loved ones and caregivers is often a requisite component of doing so.

Looking to truthfulness as a guide and keeping in mind the hospice commitment to family-centered care, one way to respond to a request for nondisclosure like that made by Ms L.'s daughter is to engage the requester with a primary goal of understanding—understanding what is motivating the request, understanding her perception of her mother's diagnosis and prognosis, and understanding her goals in requesting hospice care and how her request for nondisclosure is connected to those goals. Empathic response to the perspective of a family caregiver is an implicit recognition of the evolving, collective aspect of the "truth of the situation." Not simply a conveyance of objective facts from health care provider to patient and family, truth is a living dynamic entity and is formed out of the life narrative of the patient and family. The truth—the meaning of the illness experience, the associated giving and receiving of care, and how these meanings are integrated into the larger meanings in the lives of patient and loved ones—can be discovered and cocreated via conversations between the patient, family, and the health care team.[10] In this way, truthfulness can be seen as a process that takes place over the course of multiple conversations and encounters, rather than a 1-time event focused on disclosure. The process should begin, however, during the admission visit.

After gaining an initial understanding of a loved one's request for nondisclosure, an admission nurse is in a more informed position from which to explain why the patient needs to be an important participant in the next piece of the visit's discussion and how withholding information about her diagnosis and prognosis before understanding what role the patient herself wishes to play in care and decision making inhibits the process from moving forward. There simply cannot be a shared understanding of the truth of the situation, and a good decision about whether to begin hospice care, without the patient's perspective and participation in the discussion. And, her perspective will be quite limited if there are facts about her clinical situation known to others but not to her—facts that, if known to her, may powerfully change what she chooses to do in the remaining weeks of her life. So, while truth may be shared and dynamic, as it operates at the level of meaning, it does not negate the existence of facts. The patient's diagnosis is a fact that needs to be a part of the shared truth that forms the basis of the admission decision.

Beneficence

The emotional and psychological impact of a hospice admission visit can often be quite powerful. Family members may be facing the truth of the prognosis for the first time, and the symbolic meaning of the start of hospice care may release previously sublimated emotions. Family caregivers may also feel betrayed by a health care system they think has failed them.[11] When facing a request for nondisclosure, taking time to listen and understand the perspective of the family member helps to establish connection and trust.[2] Establishing a shared commitment to doing what is best for the patient—*beneficence* in health care ethics parlance[12]—and acknowledging that requests for nondisclosure frequently arise from such a commitment on the part of loved ones can be an effective way to engage family members as partners in caregiving. Indeed part of the strategy of joining with families in a shared definition of beneficence is to verbally recognize that a request for nondisclosure often is motivated by kindness and love.[13]

Beginning with the goal of understanding the request also creates an opportunity to explore feelings of anticipatory grief that may influence desires for nondisclosure. Family members may believe that nondisclosure will protect patients, not realizing that such requests are often driven by unacknowledged fears and anxieties in the requester. Beneficence incurs an obligation for health care teams to provide beneficial care to not only patients, but also loved ones. Uncovering fear, anxiety, and anticipatory grief in a caregiver is an important opportunity to incorporate addressing such into a plan of care if the patient is admitted.

> In her conversation with Ms L.'s daughter, the admission nurse discovered important parts of the family narrative. Ms L. had been caring for her husband for several years, with occasional help from her daughter, an only child. Facing the realization that her mother's prognosis was limited, Ms L.'s daughter was overwhelmed with the emotional impact of losing her family as she knew it. Her relationship with her father was always difficult, and she had developed a very close bond with her mother, especially in recent years.
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> By offering an initial response of caring enquiry with a goal of understanding the request, the admission nurse created a safe environment in which an invitation to connect via a shared commitment to doing what was best for Ms L. was offered to the daughter. By accepting that invitation and opening up to the admission nurse, Ms L.'s daughter began to recognize that her request for nondisclosure was in part motivated by her need to protect herself from the reality of her mother's illness and approaching death.

After establishing a relationship based on a shared value—doing what is best for the patient—and demonstrating genuine interest in, and respect for, the requester's perspective, the admission nurse can begin to explain that a full understanding of the patient's values and preferences is necessary to proceed with the admission process. If it seems appropriate, she can explain that research conducted with cancer patients—precisely those like Ms L.—shows that disclosing diagnosis and prognosis to patients usually helps, rather than harms, their ability to cope with illness and that such patients report wanting to know such information to help them plan for the future.[14,15] In other words, a shared commitment to beneficence is an opportunity to gain agreement from the requester that figuring out the kind of care that is most beneficial to the patient requires the patient, herself, to be an informed participant in care discussions and that such participation requires disclosure.

It can be reassuring to reluctant family members to let them know what you are going to say to the patient. Family caregivers can also be asked their understanding of what the patient already knows and how she has handled health care decision making in the past.[2,13] The use of such communication skills makes it possible to reinforce the moral agency of the patient without taking away hope and also opens the door to conceptualizing a new definition of hope.[16]

If resistance to disclosure continues, admission nurses can explain that there are legal and regulatory requirements that also guide the admission process. For example, federal regulations governing the process of electing hospice care for Medicare beneficiaries—who constitute more than 80% of hospice care recipients in the United States[17]—require that patients have "a full understanding of the palliative rather than curative nature of hospice care, as it relates to the individual's terminal illness."[18] While these regulations do permit "authorized representatives" to elect hospice care on behalf of patients, such election is permitted only when patients are "physically or mentally incapacitated."[18] In such conditions—which were not present in the case of Ms L.—regulations defer to state law on the question of who can sign the election.[19] In most states, however, if a patient has decision-making capacity—and there was no indication that Ms L. did not—the patient is required to participate in such discussions and express her consent for care to commence.

We emphasize who participates in ongoing discussions—rather than who signs admission forms—because signatures on such forms do not constitute "consent" or "election." Rather, it is through ongoing discussions in which patients display an understanding of the care they are choosing in a manner that is informed, well deliberated, and uncoerced that legal consent and election take place. Signatures—while important—are merely signs; they certify that such discussions took place. So, in the case of Ms L., a consent or election signature by her daughter would have been inappropriate if Ms L. had capacity. And, signatures from Ms L.—or any other patient—without corresponding, well-documented discussions about the nature of the care to which she was consenting and why do not satisfy the minimum criteria for consent or election.

As such, if an admission is to proceed, the patient's diagnosis and prognosis must be explained to her if she has decision-making capacity, as they constitute necessary information for her to (*a*) understand why she qualifies for hospice care and (*b*) deliberate whether she wants to forego curative interventions that will no longer be reimbursed if she elects hospice care. Disclosing the existence and importance of such requirements is supported by truthfulness—relevant state laws and regulatory requirements are facts that need to be understood by everyone in the interest of a shared understanding of the situation. Guidance regarding *how* to bring a patient like Ms L. into the admission discussion, and *how* to integrate information about her diagnosis and prognosis into that discussion, may be strengthened by looking to a third ethical principle: *sensitivity*.

Sensitivity

Clinical sensitivity is careful attunement to (*a*) the impact of the illness experience and (*b*) the effects of clinical interventions and relational encounters initiated by care team members on the overall well-being and quality of life of patients and their families.[20] It requires paying careful attention to the meaning of what is being experienced by patients and families and acknowledging the vulnerabilities and power imbalances inherent in caring for persons during a final illness. Sensitivity resonates strongly with the hospice philosophy of care:

> Cecily Saunders summarizes an approach to sensitive communication when she says, "the real question is not 'what do you tell your patients?' but rather 'what do you let your patients tell you?'" (from page 59 of reference 21 in Kirk et al[8]) Learning about significant areas in patients' lives—such as family, work or school, goals, and dreams—is a way for them to become known; it shows respect for what they have done and who they are. By allowing the uniqueness of each person to reveal itself, communication barriers can be broken down.[8]

Clinical sensitivity provides a backdrop for obtaining informed consent—including the process of consenting to admission to hospice care. In cases like that of Ms L., sensitivity provides important guidance in *how* to partner with the patient and her daughter to engage the admission process. While admission nurses should be sensitive to a loved one's request for nondisclosure and the perception that disclosure may harm patients, they should also help requesters understand the importance of being sensitive to the risks of nondisclosure: patient isolation, conversations not taking place, unfulfilled wishes, and uninformed choices.[21] As Siminoff[22] notes, "The main characteristic of informed consent is communication, and the quality of the communication will be determined by the quality or 'trueness' of the consent."[22(p52)] If patients are not given information, they tend to create "facts" for themselves, sometimes leading to a false set of assumptions on which they then base their health care decisions.

> After discussing the hospice philosophy of care and explaining the regulatory requirements for informed consent and election of the hospice benefit to Ms L.'s daughter, the admission nurse spoke with the daughter and patient together. She began by asking Ms L. what she understood about her own condition. In listening to Ms L.'s response, the admission nurse and the daughter discovered that Ms L. had some awareness that she was very ill and that this illness was "different" from other times she had been sick. Ms L. also explained that in the weeks prior to her hospitalization she had set up an account with funds to assist her daughter in paying for privately hired caregivers to assist in care for Ms L.'s husband. Ms L. wanted to wait until "the time was right" to let her daughter know about her concerns for her daughter and her desire to assist after her death.

If the admission nurse had not sensitively insisted on bringing Ms L. into the admission conversation, Ms L.'s daughter might have lost the opportunity to know about this gift of love and caring from her mother. Ms L. would have also not obtained the peace of mind and sense of legacy from knowing that her daughter would have extra support when she was no longer there to provide it.

Even when sensitivity is used as a guiding principle, not all family caregivers will agree to a conversation like the one that happened with Ms L. and her daughter. Importantly, admission nurses do not need the permission of loved ones to speak with a patient and disclose her diagnosis and prognosis as part of the admission process, presuming they are doing so in an informed, sensitive manner and the patient wishes to receive such information. However, doing so over the objection of loved ones risks alienating them from the care team—a result that may hinder the effectiveness of hospice care if those loved ones, like Ms L.'s daughter, are also the patient's primary caregivers. If a patient like Ms L. does not wish to know more, the nurse can be sensitive to that and explain as much as she is required to explain to facilitate informed consent, using her best efforts to limit the disclosure of clinical information not necessary for consent and election consistent with the patient's wishes. *How* to do so is, in our experience, more art than science.

If a patient like Ms L. does not wish to receive enough information to meet the minimum requirements of consent and election, that is her choice. But, she then needs to understand that the hospice program will not be able to admit her for care. That would be an acceptable outcome—an

TABLE Engaging Requests for Nondisclosure

- Engage in conversation with the caregiver to elicit the reason(s) for her request
- Use supportive listening to uncover feelings that may be causing the caregiver to favor nondisclosure
- Acknowledge the request may be motivated by kindness and love
- Demonstrate that you both have the goal of providing best care for the patient
- Provide teaching on the hospice philosophy of care and legal or regulatory requirements relevant to the request
- Discuss how nondisclosure may be more harmful than helpful
- Share the words you will use to speak to the patient
- Offer the opportunity for the patient to have the caregiver present during the discussion, if desired by the patient
- Present information needed to ensure free and informed consent and election of hospice benefit by the patient
- Let the patient determine which additional clinical information she wishes to know, and when

outcome that arose from a process guided by truthfulness, beneficence, and sensitivity (Table).

> Upon learning of Ms L.'s understanding of her situation, the admission nurse proceeded to explain the nature of hospice care and asked Ms L. if she would like to understand how and why such care might be appropriate for her. Ms L. did, indeed, wish to participate fully in the admission process. The nurse explained why Ms L.'s hospital team had recommended hospice care and explored with her the benefits and drawbacks of electing hospice care, pursuing curative treatments, or initiating other home care options. While not focused on diagnosis and prognosis, the discussion included very clear information about Ms L.'s cancer and her physician's perception that the cancer was likely a "final illness." After spending a few minutes discussing the decision with her daughter, Ms L. agreed to begin hospice care. The nurse carefully documented her conversation with Ms L. and her daughter, obtained Ms L.'s signature on consent and election forms, and called her manager to schedule a first visit from Ms L.'s hospice nurse and social worker.

CONCLUSION

We have explained how truthfulness requires that a patient like Ms L. has the requisite information to understand her situation so that she can engage the remaining weeks of her life in a way that creates meaning consistent with her values. Drawing on truthfulness and the foundational commitment to family-centered care, we also explained how engaging a nondisclosure request carefully and adopting a posture guided by goals to understand and acknowledge the requestor's values and point of view, required an important process of collaboration and partnership. Such a process is likely to lead to a robust and shared understanding of the truth of the situation, one that integrates the perspectives of the patient, loved ones, and admission nurse.

The principle of beneficence was introduced, guiding a process in which a shared goal of doing what is best for Ms L. was agreed to by the admissions nurse and Ms L.'s daughter. Establishing this shared goal can help a family member understand why diagnosis and prognosis need to be disclosed to the patient and can help the admission nurse consider ways to disclose this information such that the perceived risk of harm—to the patient and her loved ones—is minimized. We demonstrated how proceeding in such a manner increased the likelihood of engaging and supporting the patient's agency, another foundational commitment in the hospice philosophy of care.

Finally, we integrated the principle of sensitivity, a strong reminder that a hospice clinician's actions should always be seen as a form of response—response to the needs and values of patients and their loved ones. And, while this notion of response does not always take the form of simply saying "yes" to a request like that made by Ms L.'s daughter, it also rarely takes the form of simply saying "no." Rather, adopting a posture of inquiry, understanding, and collaboration will frequently uncover points of connection via shared values and goals. And, a full, therapeutic response is not complete without engaging patients like Ms L. in an open, unrestricted discussion in which the nurse ascertains what the patient understands about her current situation, what she understands about hospice care, and whether she wishes to learn more information about both if such is needed to make a decision about admission.

Integrating the principles of truthfulness, beneficence, and sensitivity—principles we have developed in a manner consistent with the core concepts of hospice philosophy—gives the reader a framework of concepts and principles through which to navigate a way forward in cases similar to that of Ms L. and her daughter. In so doing, we have demonstrated that engaging a process guided by such principles is ethically sound, whether or not it results in a patient being admitted to hospice care on the day of her first admission visit. In the case of Ms L., it did result in such an admission. In other cases, diligently proceeding in a manner guided by ethical principles resonant with patient values and the hospice philosophy of care may result in a delayed or refused admission. This, too, may be an acceptable outcome of an ethically sound process.

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