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## AAIM Perspectives

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# Death and Dignity: Exploring Physicians' Responsibilities After a Patient's Death



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Literature focused on care at the end of life is flourishing. The scope of this work has been broad, including how to best communicate bad news<sup>1,2</sup> or discuss patient wishes at the end of life,<sup>3,4</sup> as well as detailing where patients are dying and how it impacts their care<sup>5</sup> and the value of palliative and hospice care during this process.<sup>6-8</sup> As literature on end of life care grows, more attention is also being paid to the importance of caring for bereaved family members,<sup>9,10</sup> highlighting the need to continue to care for those left behind.

In parallel, a newer body of work is emphasizing the importance of studying and avoiding harm associated with failures to maintain the respect and dignity of patients and their families.<sup>11</sup> There is a drive to apply the methods of quality improvement to this realm in a similarly rigorous manner as seen with “never events,” such as wrong-site surgery, falls in the hospital, or pressure ulcers. Several factors make emotional harms difficult to address. They are often only brought to attention after a hospitalization and frequently are directed toward patient relations departments as opposed to the primary providers, thus decreasing visibility. As a consequence there is not necessarily an individual or group who “owns” the harm and can see that it is addressed. Similarly, often

there is not a formal mechanism to share patient feedback or complaints with the providers involved. Furthermore, there is no regulatory oversight focused on emotional harm. A requirement to report harm to governing bodies does not exist as it does for other types of medical errors. Thus, quality improvement initiatives often focus on harm that has mandated reporting infrastructure, such as falls, and fail to focus on emotional harm.<sup>11-13</sup>

This area becomes even more fraught when the harm occurs after a patient has died in the hospital. Who is responsible for ensuring the correct processing of the body of the deceased, from the time of death pronouncement to the morgue, to pathology in the event of an autopsy, to the funeral home? Who is responsible for guiding the family through this process, which might extend days (or weeks, in the case of obtaining autopsy reports) after the inpatient team has stopped caring for the patient? Ideally, at each step along this pathway, members of the health care team clearly communicate with each other and with families. Unfortunately, it is not always the case. Our institution is actively engaged in these areas of quality improvement and has been working to identify and address both failures to maintain respect and dignity as well as failures to provide high-quality end of life care. As a part of this process, several exemplary cases came to light.

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## CASES OF HARM

### Case 1

A woman with metastatic lung cancer is admitted to the inpatient medicine service overnight by a member of the house staff. Her code-status is accurately identified as “do

not resuscitate,” and she dies late in the night of admission, around 3:00 AM, before being seen by an attending or the day team. The house officer calls the family to inform them of the death; when the family asks, “What do we do next?,” the physician states that he believes someone will contact them during the day. When no one calls the family by the following evening, they call the floor to which the patient was admitted. Because the admitting house officer is unavailable and no one else is aware of this patient, the family is referred to the medicine consult resident. The consult resident is also unaware of the appropriate steps that the family needs to take. Over the next several days the consult resident and family work with the admitting department and the morgue to figure out what is needed for the body to be transported to the funeral home.

The solution to this problem ended up being very simple: the family needed to identify and contact a funeral home, which would arrange transport with the hospital morgue and assume responsibility for the process. However, during normal working hours, this next step is usually explained by a nurse or social worker rather than a physician. In this case none of the residents involved understood the process enough to guide the family, leading to an erroneous though perhaps understandable assumption that someone would call the family. There was no system in place to “coach” the family or train the residents, thus the process was unnecessarily prolonged, with a great deal of uncertainty and dissatisfaction.

### Case 2

An orthodox Jewish patient dies early on a Friday morning. The family requests that, per religious tradition, the body be released immediately so as to be buried before sundown. The patient is pronounced dead by the intern, who then fills out a report of death form, which is sent to the admitting office to generate a death certificate. The intern must then go to her continuity clinic, which is off site. When the death certificate is generated the intern is not present to sign it, and the body cannot be released to the funeral home without a signed death certificate. The family is upset that they are unable to observe their intended religious customs after their loved one’s death. The team of physicians caring for the patient did not realize that any physician with knowledge of the manner of death can sign the death certificate, not just the one who pronounced the

patient. This simple administrative oversight caused significant emotional harm to the family.

### Case 3

A generally healthy man is discharged from the hospital to an acute care rehabilitation facility. Several hours after his discharge he goes into respiratory distress and quickly dies at the facility. His family is shocked by his death and requests an autopsy. The physician informs the family that it will likely cost several thousand dollars to have an autopsy performed. The family cannot afford this cost and do not pursue the issue further, left with the mystery of his death. In fact, many academic institutions will perform autopsies at no cost to the family,<sup>14,15</sup> though the family would likely have had to pay for transport of the body back to the hospital. The family later learned the autopsy would have been done for free at the hospital and was distressed.

These cases highlight a critical time in the care of a patient and his or her family: the hours to days after death. And although a plethora of information is available to guide physicians in the time leading up to death,<sup>3,4,16</sup> very little has been published about what a physician should know and do during the immediate post-death period. This time is especially risky, given that at many academic institutions it is largely managed by residents who have limited institutional knowledge and evolving communication skills. The cases demonstrate that the post-death process can go awry—with physicians playing a significant role—resulting in unnecessary emotional harm to the loved ones of the deceased. Additionally, these cases represent only a fraction of such cases uncovered at one institution; the broader extent of the harms caused by physicians in the post-death process is unknown.

### PROPOSED SOLUTIONS

We believe it is crucial to further explore this area and highlight 4 gaps in physician knowledge that contribute to harm to respect and dignity in the postmortem period.

#### Postmortem Processing of the Body

Physicians should have a basic understanding of how a body is processed by their institution. Where is the morgue? Can families go there? Who should families

### PERSPECTIVES VIEWPOINTS

- Difficulty navigating the post-death process is an underrecognized source of emotional harm for families and loved ones.
- Physicians have a responsibility to understand the basic logistics following a patient death, to support families and prevent adverse events in the care of deceased patients.
- Health care systems can mitigate these emotional harms by developing processes that support providers and families throughout the post-death process.

talk to about retrieving belongings such as wedding rings? What are the most important next steps for the family to take after their loved one has passed? Is there someone or some department who is responsible for coaching families through the post-death process? Is there a packet or website that contains this information families need? Although social work, nursing, or other departments may traditionally relay this information, physicians should have a basic understanding of the post-death process, in case they are needed to guide families.

### Necessary Paperwork

Understanding what paperwork must be completed by physicians and the meaning behind it is important. Although post-mortem paperwork may feel like an administrative burden, as case 2 exemplifies it can play a significant role in the family's experience; failure to complete paperwork in a timely and correct fashion can cause significant harm. Because filling out postmortem paperwork likely occurs sporadically for physicians, acquiring expertise in the process may take years of practice. As such, physicians and learners should have training in institutional and state-specific protocols, as well as access to guidance or just-in-time education in the event that a death occurs during their service.

### Autopsy Issues

Physicians involved in care at the time of death should understand the basic process of how autopsies are obtained and reported. What is the time frame during which an autopsy may be requested? How much does it cost? What are the basic steps needed to complete an autopsy (such as removal of organs)? When and how are the results made available? What does it mean if a medical examiner accepts a case? Although it is tempting to say these questions are pathology department specific, frontline clinicians will be asked by families to provide guidance. Lack of or wrong information may lead to unintentional harm to the family.

### Bereavement Services

Finally, to the extent available in a given institution, physicians should be able to refer family members to appropriate bereavement services. Such services have been shown to decrease depression among survivors, though they are offered in a small minority of cases.<sup>17</sup>

In addition to these 4 areas of physician knowledge, several institutional and systemic interventions may be helpful. Online and printed resources outlining the post-death process, necessary paperwork, autopsy issues, and available bereavement services should be available and regularly updated.<sup>18</sup> Training conferences explaining the process and exploring the pitfalls can be useful; cases in

which the post-death process has gone awry are rich fodder for departmental morbidity and mortality discussions. The palliative care service may act as experts on challenging cases. Some institutions have official "coaches" for providers and families about the post-mortem process.<sup>19</sup> Quality improvement systems should capture episodes of postmortem emotional harm and apply the same root-cause analysis approach and system-based solutions as for any other serious harm event.<sup>11</sup>

### CONCLUSIONS

There are many barriers to improving the quality of care given during and after a death. For the individual provider, a death is a relatively rare event, so familiarity with the process may be lacking. The exact role of the frontline clinician after a patient has died is not clearly defined. Often the physician plays only a small part in the process. The necessary tasks are further divided among nurses, social workers, spiritual care professionals, morgue staff, public safety staff, administrators, and others. As a result, generating a shared mental model of the process is difficult, and adverse events become inevitable. We physicians fail our deceased patients if we relinquish our sense of responsibility for them; the care and compassion that we provide patients in life should extend past their death. We must challenge ourselves and analyze our systems of care to approach the post-death process in a safer and more reliable way.

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