

**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**Bringing Dying Out of the Hospital's Closet**

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**Abstract**

Why is the transition from “living” to “dying” not socially marked in the same way that death is marked? This question is addressed using classical anthropological theory, which highlights the significance of liminality, the transitional period during a rite of passage. Seriously ill and dying patients are subject to social vulnerabilities as they approach the end of life. Clinicians’ awareness of these factors may improve their patients’ care.

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**Marking the Transitions of Life**

Social norms develop partly to maintain communal cohesion in the face of potential disruption and change. We mark events that signify major life transitions (eg, weddings, funerals)—and even seasonal shifts—because they affect us collectively. We respond by spending time and treasure on gatherings, gifts, cards, and appropriate décor. These trappings are important not because they are functional in themselves, but because their mutually held meanings anchor us as a group of fellow humans. They provide reassurance as we navigate the uncertainties of life.

Rituals and traditions form around individual life changes that are clearly identifiable and have sufficient impact on the community at large. van Gennep famously described rites of passage that facilitate individual movement from one social category to another (eg, single to married).<sup>1,2</sup> These rituals enable the group to formally acknowledge the change and to instantiate individuals in their new social roles.<sup>1,2</sup> A key feature of such movement within the social body is the phenomenon of liminality, a point when the individual has left one category but has not yet crossed the threshold to the new one. In this liminal space, the individual has no clear place in the social system. She is neither one thing nor the other, while combining aspects of both.<sup>3</sup>

Clinicians often observe hospitalized patients whose condition seems to be shifting from “living” to “dying.” For those participating in the patient’s clinical journey, this transition is critically important. But it attracts virtually no social notice in the patient’s larger

world. Why should this be true? Several reasons are possible: (1) seriously ill hospitalized patients are already separated from their communities, their social roles suspended; (2) often the signposts of their current condition are inconsistent (eg, lab values improve despite increasing weakness); and (3) unlike the finality of death, the dying situation is stigmatized and does not abrade the larger social order enough to require a symbol-laden adjustment. I explore each of these facets in turn and discuss why marking the transition from living to dying would serve an instrumental purpose for clinicians even when it seems not to call for a specific response from the community at large.

### **Dying Is a Space of Seclusion**

Turner teaches us that the in-betweenness of liminality is a place of social seclusion.<sup>3</sup> Seriously ill patients occupy such a space. For now, they have no role in the social order, making them “structurally invisible.”<sup>3</sup> They are literally stripped, devoid of the personal effects that signal who they are in the world. For society to notice them under these circumstances would be to violate their dignity. Likewise, their indeterminate status makes persons in transition potentially contaminating to society.<sup>4</sup>

To be in a liminal state renders individuals unclassifiable. When the social body cannot easily categorize its members, it becomes confused. Anomalous persons can pose a threat to the social order.<sup>5</sup> Even in quotidian life, dying is felt to be private, exempt from public intrusion, and somehow untoward. When some public figures’ dying situations have been publicly acknowledged, such as those of John McCain and Barbara Bush, broad-based close scrutiny is rarely welcome.

### **Dying Is Difficult to Identify**

Because US culture prizes rescue and medical advances, identifying the transition between living and dying for patients with serious illness becomes ever more challenging. What patient circumstances would signal to onlookers that the patient has crossed over from living to dying? Prognostic tools are legion but largely unreliable.<sup>6,7</sup> **Medical advances and reimbursement** for them encourage “almost limitless uncertainty”<sup>8</sup> about dying situations that continues to expand.<sup>9</sup> Misidentification occurs as well. It is difficult for clinicians to acknowledge that persons who can look us in the eye could actually be dying. By the same token, many unresponsive patients, made so by their injuries or clinical interventions, can yet be fully restored to sentience if they are given time to heal or their sedation is reversed. Evidence of interactive cognitive activity can be powerful and potentially misleading for both families and clinicians.

### **Dying Is Not a Classification to Be Conferred Quickly, Due to Its Stigma**

To call a patient *dying* demeans the patient who finds herself in a place designed as a bulwark against death. It is to make her “other” than “us,” something that clinicians are usually reluctant to do in the beginning. Furthermore, to do so can erode clinicians’ belief not only in their ability to **rescue persons from imminent death**, but also in the illusion of their own unlimited futures.<sup>10</sup> Outside the hospital, dying is not a status that almost anyone openly embraces. And why should they? In polite society, dying and death are off the table as acceptable conversational topics, much like sex and personal income.<sup>11</sup>

Marking certain life transitions is critical for maintaining the social order. As mentioned above, due to stigma, the suspension of critically ill patients’ social roles, and inconsistent signposts of their current condition, the transition of hospitalized patients

from living to dying does not merit communal attention. The public would be resistant to its proclamation. But for those in the clinical setting who are directly affected by the dying process, noticing and responding to it can have important instrumental uses.

### **Patients' Dual Liminality and Clinician Pain**

As it happens, we can identify 2 distinct areas of liminality that relate to the transition from living to dying and from dying to death in a hospitalized patient. The first occurs when the patient is undergoing active diagnosis and treatment for serious illness, but she is not showing a decisive response. The second occurs later, when the clinicians name the patient's condition as dying.

For clinicians, the first of these liminal spaces is the most difficult. If a seriously ill but rescuable patient does not respond to the application of advanced interventions fairly promptly, clinicians see her as having entered an indeterminate space. While the larger society is oblivious, clinicians must face full on the ambiguity she represents. As the uncertainty persists over time, urgency mounts to resolve it. When liminality and uncertainty seem unending, so does the discomfort they bring.

Clinicians recognize this space as awkward, even if they cannot articulate the source of their discomfort. Often, they ascribe it to patient suffering,<sup>12</sup> regardless of whether the patient is actually in pain, and time's passage exacerbates their unease. They may call the care plan "futile" and doubt the wisdom of resource allocation. Moral distress is common. Once enough time has passed, this "ritual of intensification" reaches a tipping point and clinicians can determine that the patient is dying.<sup>13</sup>

At this point, a significant shift in orientation and in the care plan itself occurs. The team may discuss withdrawal of life support with the family, make a referral to palliative care or hospice, or write a do-not-resuscitate (DNR) order. In the eyes of the clinicians, the patient has completed a transition to the category of "unrescuable." To designate her as dying rescues the clinicians from the pain of liminality by surrounding the patient with a clear category.

Yet, in truth, the patient has entered a new area of liminality. The clinicians are relieved by the opportunity to enact a more appropriate care plan. But the patient's vulnerability as a liminal person persists. She officially embodies death in a place dedicated to its diminution. To be deemed unrescuable—indeed, dying—therefore puts the dying but still-living patient in some peril. Her new category enables her needs specifically as a dying patient to receive attention. But the agendas of others who "need the bed" for higher-status, rescuable patients can create conflict. Outside of hospice or palliative care, hospitalized dying patients may receive inconsistent or unstandardized care for which hospitals are not set up to hold themselves accountable.<sup>8</sup>

### **Bring Dying Out of the Closet**

With an official acknowledgement of dying from the team, the new category becomes discussable among all the participants, with what Glaser and Strauss describe as "open awareness" and McQuellon and Cowan describe as "entering mortal time."<sup>14,15</sup> Dying can come out of the hospital's closet. At no time will the clinicians have another opportunity to optimize the dying process for this patient and this family, to make it as meaningful for them as possible. If such open communication leads to a plan to withdraw life support interventions, clinicians (including social workers and chaplains) can help families honor the life that has been lived and mark the significance of its end.

Openness about the procedure, sharing of pictures and stories, opportunities for prayer, along with a visibly **comfortable patient** are helpful components of this process. It is important for clinicians to prepare families by sharing the unknowable facts, such as how the patient will react to the withdrawal and how much time will pass between the withdrawal and death. Families need assurance that any patient distress will be promptly managed and that the patient will be allowed to take as much time as she needs—death will not be hastened.<sup>16</sup> Discrete “markers” of dying, such as a DNR order in the chart, may be less important than listening to the patient and the family and helping them orchestrate—and make the most of—the critical present in this moment.<sup>10</sup>

But because the hospital is organized around rescue as its most important task, its culture may regard an official designation of dying as an opportunity for closing down or minimizing involvement, perhaps of reassigning staff. Clinicians may see the withdrawal of life support as an opportunity to administer opioids without restraint in order to limit the patient’s—or the family’s or their own—suffering.<sup>17</sup> Patients and families may fear abandonment by their physicians as a result of lack of closure.<sup>18</sup>

What is ethically important here is to notice the possibility for openness and social inclusion as clinicians reinterpret the patient’s condition. Acknowledging this countercultural liminal territory can clear the way to preparation, customization, and reaffirmation of the patient’s importance to those around her. The important ethical considerations in the transitions from living to dying to death include establishing consensus and full communication regarding the transition, enabling the comfortable patient to take her own time, and facilitating best practices concerning the dying process.

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