

Comment

The process of dying: whose business is it anyway? Reflecting on ‘Stealing on insensibly: end-of-life politics in the United States’

MARY RUGGIE*

Adjunct Professor of Public Policy, Harvard University, Cambridge, USA

A successful passage to life during childbirth is more certain now than in the not too distant past, a fact that overrides criticisms of medicalization. In contrast, passage to death is no longer a relatively simple event but one fraught with complications and complexities. For decades the main obstacle to a peaceful transition at the end-of-life was the aggressive use of medical technology. Medical culture is slowly shedding prioritization of life above all other considerations and yielding to patient and family preferences for end-of-life care. However, as Lawrence D. Brown elaborates in his insightful 2012 article, politics and its ensuing proliferation of policies, while claiming to protect patients and uphold the public interest, insert instead unintended and unfortunate consequences into the process of dying.

As a political scientist, Brown sees the stage beset by competition and conflict among actors with diverse perspectives and goals. He divides the warring factions into three policy spheres: advance directives (ADs) embody the politics of the personal, hospice and palliation are mired in the politics of payment, and physician-assisted suicide is immersed in the politics of principle. Despite the hostilities, Brown envisions patients and their loved ones emerging as victors through an incremental process of ‘stealing on insensibly’. I agree fully with Brown’s assessment of the muddying role of politics and policy in end-of-life care as well as his conclusion that patients are poised for triumph. But as a sociologist I see an additional set of dynamics shaping the emergent ‘authority’ of end-of-life patients. Brown notes but dismisses this dynamic, perhaps because he locates its source in a statement by the American Medical Association: “end-of-life decisions are best viewed as exercises in negotiation and consensus building” (2012: 472). Brown is dissatisfied with the inconclusiveness of these dynamics; all they achieve is a re-staging for more

*Correspondence to: Mary Ruggie, Adjunct Professor of Public Policy, John F. Kennedy School of Government, Harvard University, Cambridge, MA, 02138, USA. Email: Mary_Ruggie@hks.harvard.edu

‘conversations’. I suggest that conversations incrementally and sensibly construct the bridges and pathways that enable patients to emerge victorious.

I also suggest that the battles among Brown’s three spheres of politics and policy contain another overarching contest: between the domains of law and medicine. Policymakers have not interfered in conventional medical decision-making to the same extent as in the medical decisions surrounding end-of-life. Physicians have adamantly asserted their dominance in the former, but have refrained from leading change in the latter. As a result, end-of-life discussions have become ensnared in complex and formalistic statutes, precluding the kind of conversations necessary for negotiation and consensus building. Were ADs, hospice and palliation and physician-assisted suicide placed more squarely in the field of health care, patients could take advantage of three initiatives that would enable them to articulate their ‘wishes, values, interests and relationships, ... without [the intrusion] of special laws, special burdens of proof, or unique requirements for documentation’ (Shepherd, 2014, 1696) – patient-centered care, shared decision-making and integrative health care. I briefly discuss how these inter-related initiatives are being implemented in and transforming health care and then apply them to the case of end-of-life care.

Initiatives in health care

As the term ‘patient-centered care’ has been coopted to justify the positions of politicized actors of all persuasions, it is best to define it using the words of pre-eminent medical institutions. The authors of a 2001 Institute of Medicine (IOM) report elaborated the concept as a set of practices that are “respectful of and responsive to patient preferences, needs, and values ...” (IOM, 2001: 6). They also recommended that medical students and clinicians receive training in patient-centered communication techniques, which emphasize listening to patients and their families and presenting information in terms that are understandable and meaningful. As a bonus, health care workers come to better understand their own values, beliefs, preferences and biases. Relevant in its own right, patient-centered care also ‘ensur[es] that patient values guide all clinical decisions’ (IOM, 2001: 6). This phrase links patient-centered care with shared decision-making. Since physicians are accustomed to more paternalistic approaches, the IOM sponsors workshops, publishes discussion papers and offers tools to facilitate education in and implementation of shared decision-making. Patient-centered care and shared decision-making are important for all patients, but they are especially critical for underserved and vulnerable populations, as the IOM emphasizes in its many reports.

Although patient-centered care and shared decision-making were first developed to enhance physician–patient relations and shape the clinical encounter, they have since been applied in yet another health care initiative. Interactions in a doctor’s office are now understood less as discrete events and more as components of

an episode of care, in which treatment is preceded and followed by several encounters involving a variety of health care providers. For decades managed care organizations have worked to integrate the fragmented US health care system, combining primary, specialist and hospital services under common delivery and/or payment frameworks. The majority of privately insured and Medicaid patients are now enrolled in some sort of managed care. Newer models of integrative care coordinate the roles of primary and specialist physicians with those of ancillary health and social care workers. Depending on patients' needs, integrative health care teams may consist of physical therapists, nutritionists, social workers and psychologists, among others. These providers collaborate amongst themselves and with patients and families to manage diseases, keep patients out of hospitals or in hospitals for as short a time as possible, and maintain health.

However much one may deride patient-centered care and shared decision-making within integrative health care teams as empty buzzwords that derail the business of health care, these initiatives are here, and they are probably here to stay. Experiments in new delivery systems supported by new methods of financing have been unfolding across the United States for several years (McCarthy *et al.*, 2009). They are now supported by provisions in the Affordable Care Act (ACA) for Accountable Care Organizations and bundled payments. The ACA also proposed federal funding for yet another initiative, intended as a venue for those who have been excluded from the benefits of primary care, mainly Medicaid and Medicare recipients and the under-insured or uninsured. Patient-Centered Medical Homes are community-based delivery systems, staffed by a range of health care providers who are reimbursed through bundled payments or salaries. The ACA built on a model for medical homes advanced by the American Academy of Pediatrics in 1967. This professional organization, in collaboration with others, elaborated the concept over time 'to include these operational characteristics: accessible, comprehensive, family-centered, coordinated, compassionate, and culturally effective care' (Patient Centered Primary Care Collaborative, 2007).

Clearly, leaders in health care are beginning to understand patients as whole persons who exist in a context of place, time, social relations, values and emotions. We can anticipate that as more people gain coverage through the ACA and enroll with a primary care provider, the benefits of new initiatives in health care will encompass vulnerable populations and their diverse health and social care needs and preferences.

Embedding end-of-life care in health care

End-of-life care has largely been removed from these developments and ruled instead by statutory law. This venue has not offered a comfortable fit for adjudicating diverse rights, liberties, obligations, values, interests and goals. That the laws governing end-of-life issues vary across states in the United States and across countries weakens judicial legitimacy. That said, the three initiatives presented

above, and many others, are being implemented in certain fields of health care that are more likely to entail end-of-life issues. Cancer care is one (IOM, 2011). The discussion below offers a typical, albeit ideal, sketch of how end-of-life care can be integrated with health care.

When a diagnosis of cancer is first made, physicians present patients with information about their choices. Whether from the first phase of decision-making about treatment or shortly thereafter, physicians encourage patients to enlist the assistance of family or significant others. Once treatment begins, patients and their loved ones become part of a team of primary, secondary and complementary providers whose roles are coordinated according to best practice models. If and when a terminal phase of cancer arises, the transition between treatment and non-treatment should represent the same flow of patient-centered, consultation-based planning among all relevant actors. Decisions evolve along with changing contexts. Various institutions have prepared sample scenarios and scripts that identify barriers to and facilitators for effective communication, as well as roadmaps suggesting decision trees and alternative routes to achieving patient-centered, shared decision-making (IOM, 2014: 3–38).

At various times, documents may need to be signed. However, preference is growing for the use of tools that are less formal and legalistic than ADs. Whether or not cancer patients have ADs, their value may diminish over the course of treatment. The decisions people made when in sound mind may not foresee the clinical circumstances that arise when they are dying. Moreover, physicians must often guess about the timing of death and the quality of life preceding it under different conditions. Assumptions in the law about rational actors confronting clear options in a process governed by universal, ethical principles are far from the reality of end-of-life health care. As Brown notes, even the American Bar Association has roundly questioned the utility of ADs (2012: 471). Brown and many in the legal profession favor instead some sort of durable power of attorney. In terms of the initiatives in health care presented above, the purpose of this assignation is achieved through the processes of patient-centered teamwork and shared decision-making, but without the requisite attention to written statements and signatures.

Two additional innovations in the United States are noteworthy. A handful of states have enacted the Uniform Health Care Decisions Act, which allows patients to give oral or written instructions, the latter with or without signatures (Uniform Laws Commission). In addition, a majority of states employ the National Physician Orders for Life-Sustaining Treatment Paradigm. Following its guidelines, physicians engage in conversations with patients and loved ones and prepare a simple, two-page document that expresses patients' wishes for care. This document becomes part of a patient's medical record and empowers providers in different treatment settings to implement wishes according to a patient's current condition (for more, see POLST).

In a recent report on *Dying in America*, the IOM hints at the possibility of understanding two additional features of end-of-life care that Brown addresses –

palliation and physician-assisted suicide – within a health care framework. Palliative care, which offers pain relief and comfort to patients, is becoming mainstream in health care as well as end-of-life care; best practice models, especially in cancer care (IOM, 2014: 2–11), guide its use. Nevertheless, debate continues about specific substances, dosages and duration of use. Such concerns merge with questions about what to do when patients wish to choose when, where and how to die. Brown discusses the vicissitudes of physician-assisted suicide in state policies. Only two additional states have enacted legislation since his publication, bringing the total to five. Four European countries and now Canada also have death with dignity laws. We can assume that the slow pace of change will continue as long as this issue remains embroiled in the ‘politics of principles’ grounding the rights and obligations of patients, those whose assistance is required to help them fulfill their wishes, and those who are witness to the process. Better, perhaps, is to understand the power of words and to acknowledge that the patient, the physician and any other ‘stakeholders’ would not be pitted against each other were physician-assisted suicide re-interpreted as aid in dying and aid in dying re-interpreted as another form of palliative care – specifically, patient-centered palliative care. Those who seek aid in dying wish to avoid the pain of prolonged suffering. In a patient-centered framework, pain may or may not be limited to physical experience. For some, suffering includes emotional and psychological experiences and may extend beyond the self to include social relations. What palliative care means to a dying patient is impossible to determine formulaically.

Integrating patient-centered palliative and end-of-life care into normal health care procedures requires a strong partnership between patients, families, physicians and medical institutions. The IOM envisions the eventual integration of end-of-life planning in regular health care, noting that ‘The Conversation’ (Brown, 2012: 481) is not a one-time activity but a life-cycle process (IOM, 2014: 3–1). Everyday conversations with loved ones as well as with medical professionals may not specifically include the topic of end-of-life; nevertheless, these conversations express the values and beliefs that inform a person’s end-of-life preferences. We cannot remove politics and policy, laws and legislation, rules and regulations from end-of-life care; indeed, protections are critical for everyone involved. However, we can reduce the detrimental impact of rigid rule-orientation on the process of dying.

References

- Brown, L. D. (2012), ‘Stealing on insensibly: end of life politics in the United States’, *Health Economics, Policy and Law*, 7: 467–483.
- Institute of Medicine (IOM). (2001), *Crossing the Quality Chasm: A New Health System for the 21st Century*, Washington, DC: The National Academies Press. <http://www.nap.edu/catalog/10027.html>.

- Institute of Medicine (IOM). (2011), *Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary*, Washington, DC: The National Academies Press. http://www.nap.edu/catalog.php?record_id=13155.
- Institute of Medicine (IOM). (2014), *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, Washington, DC: The National Academies Press. http://www.nap.edu/catalog.php?record_id=18748.
- McCarthy, D. M., K. Mueller and J. Wrenn (2009), 'Geisinger Health System: Achieving the Potential of System Integration Through Innovation, Leadership, Measurement, and Incentives', http://www.commonwealthfund.org/~media/files/publications/case%20study/2009/jun/mccarthy_geisinger_case_study_624_update.pdf [10 February 2015].
- Patient Centered Primary Care Collaborative. (2007), 'Joint Principles of the Patient Centered Medical Home', http://www.aafp.org/dam/AAFP/documents/practice_management/pcmh/initiatives/PCMHJoint.pdf.
- POLST. www.polst.org [10 February 2015].
- Shepherd, L. L. (2014), 'The end of end-of-life law', June <http://ssrn.com/abstract=2457152>.
- Uniform Laws Commission. 'The Uniform Health Care Decisions Act, 1993', <http://www.uniformlaws.org/Act.aspx?title=Health-Care%20Decisions%20Act> [10 February 2015].