

health care prices, if they are to actively support particular cost-saving proposals, they will have to be shown that those approaches would actually reduce what they pay for care. And if the public's view is going to converge with that of many experts, they will have to be convinced that overuse of services plays a greater role in high health care costs than they currently believe.

Disclosure forms provided by the authors are available at NEJM.org.

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This article was published on May 29, 2019, at NEJM.org.

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DOI: 10.1056/NEJMp1905710

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Serious-Illness Care 2.0 — Meeting the Needs of Patients with Heart Failure

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Heart failure is the most common cause of hospitalizations among elderly Americans, and despite much medical and scientific progress, it remains a source of substantial suffering, expense, and caregiver burden. Palliative care can improve quality of life, symptoms, and functioning for people with serious illnesses, and a recent observational study in patients with heart failure showed that enrollment in home hospice was associated with fewer emergency department (ED) visits and intensive care unit stays, shorter stays in the hospital, and longer survival.¹ Yet palliative care and hospice care remain grossly underused for heart failure, owing to both general and disease-specific barriers (see box). In the next phase of serious-illness care, innovations in care delivery can help providers integrate approaches to improving functioning and quality of life into the care of people with heart failure.

For example, advance care planning enables patients to influence the kind of care they will receive if and when they are un-

able to make their own decisions. Clinical staff can be trained and empowered to integrate advance care planning conversations into their workflows. Planning documents could be designed specifically to address common heart-failure scenarios, including options for managing permanent pacemakers and implantable cardioverter-defibrillators (ICDs). Patients may decide at some point not to receive further ICD shocks, for example, but to continue benefiting from antitachycardia pacing to terminate ventricular arrhythmias. Many patients with heart failure are at risk for progressive cognitive decline and could be supported in making decisions about future use of inotropes or mechanical circulatory support, including ventricular assist devices or extracorporeal membrane oxygenation. Even traditional do-not-resuscitate or do-not-intubate orders might not be specific enough for patients with heart failure, since treatment for ventricular tachyarrhythmias differs greatly from treatment for pulseless electrical activity or asystole.

Because of the difficulty involved in predicting future circumstances, however, patients often cannot make specific decisions regarding future care, especially when they're relatively healthy. This limitation highlights a role for value-based advance care planning that doesn't focus on specific treatments, instead preparing patients and their surrogates using education and exploration of values and goals.²

Another innovation entails concurrent delivery of cardiac and palliative care. A major barrier to adoption of palliative care is the misconception that palliative care is incongruent with conventional care. Concurrent care can be provided in any care setting, including hospitals, outpatient clinics, and nursing homes, and can be used to support home-based care when travel becomes burdensome and 911 calls and ED visits become the defaults for symptom crises. Reliable, continuous home-based support involving telemedicine, collection of patient-reported outcomes using new devices such as wearables, and cardiac or palli-

ative care services could improve care quality when delivered in close partnership with cardiologists. Concurrent care models require implementation of routine, validated screening tests to assess symptom-related distress, functional dependency, cognitive impairment, and family caregiver burden in order to identify remediable issues and permit adoption of palliative care supports as appropriate.

Management of late-stage heart failure is also ripe for innovation. The natural history of heart failure is punctuated by decompensations necessitating hospitalization, often caused by decreasing gut absorption of oral diuretics used to treat volume overload and dyspnea. Research is needed to determine the efficacy and feasibility of subcutaneous administration or inhalation of diuretics at home when oral options fail. Supervised exercise has been shown to improve outcomes, and its effect on patient-centered outcomes could be further investigated. Interventions aimed at alleviating other common symptoms including fatigue, pain, depression, and spiritual distress warrant rigorous study, as do strategies for integrating such interventions into conventional care and for developing efficient, flexible, team-based approaches to assure responsive, high-quality care.

Several policy and systems-level changes would facilitate the delivery of palliative care for patients with heart failure. First, palliative care could be provided on the basis of need. Given the difficulty involved in assessing prognosis for patients with heart failure, we recommend using functional status, changes in utilization of health care services, family caregiver burden, and symptom burden to determine eligibility.

General and Heart-Failure–Specific Barriers to Improved Palliative Care for Patients with Heart Failure.

General Barriers

Misperception among clinicians that palliative care is appropriate only at the end of life and that patients will react negatively and lose hope if palliative care is introduced. Workforce shortages throughout palliative care disciplines, including among physicians, nurses, social workers, and chaplains, especially in home and outpatient settings. Inadequate training, supervision, and support of family caregivers, who provide most of the day-to-day care and care coordination for patients with serious illness. Lack of reimbursement for personal care and home medical services beyond time-limited episodes and for team-based care. Insufficient organizational capacity, in part because of fee-for-service payments and lack of regulatory requirements, oversight, and accreditation standards. Inadequate evidence base and limited funding for research regarding pain and symptom management, communication skills, care coordination, and optimal care models.

Heart-Failure–Specific Barriers

False expectations among patients and clinicians given frequent exacerbations followed by partial recovery, resulting in avoidance of discussions about likely future outcomes. Prognostic uncertainty, which can distract clinicians from patient and family need as the indication for concurrent palliative care. Lack of training for cardiologists in the core principles and practices of palliative care (pain and symptom management; communication about future goals and priorities for care; and assessment and support of family caregivers). Poorly coordinated care for patients with heart failure and coexisting conditions. Assumptions by some clinicians that patients' sole priority is life prolongation, to the exclusion of attention to quality of life. Inadequate support for managing recurrent exacerbations of dyspnea and other heart-failure symptoms in community settings.

People with at least one serious illness and functional impairment who have had one or more hospitalizations or skilled nursing facility stays in the past year have a 47% risk of hospitalization and a 28% risk of death in the subsequent year.³ Anyone with heart failure who meets these criteria could be evaluated for palliative care needs.

Second, reimbursement for hospice care could be more flexible, and payments could be increased. Patients with heart failure who have reduced ejection fraction, for instance, derive hemodynamic and symptomatic benefit from ambulatory inotropic therapy (e.g., milrinone or dobutamine). Because of their cost, however, inotropes are rarely covered by hospice agencies. We propose that additional payment models be explored to support care for patients with complex medical needs.

Third, care coordination for patients with coexisting condi-

tions could be improved. People with heart failure usually have multiple coexisting conditions and often experience fragmented care, polypharmacy, and frequent transitions between health care settings, particularly as their disease burden increases. Randomized trials of care coordination led by a palliative care clinician have yielded promising results among patients with heart failure,⁴ and additional approaches could be tested.

Fourth, education in palliative care could be mandated for cardiologists. Though there is a shortage of palliative care providers, medical and cardiology teams that manage care for patients with heart failure are theoretically well suited to deliver palliative care. Cardiologists often have a poor understanding of palliative concepts, however, and receive little training in pain and symptom management, communication skills for advance care planning,

and assessment and support of family caregivers.⁵

Finally, to assess the effectiveness of palliative care provided to patients with heart failure and to devise strategies for improvement, quality-assessment metrics could be developed. For hospice, such metrics could include rate of referral to hospice, timing of referral, hospice length of stay, and rate of hospital readmission. Additional metrics could include frequency of staff training, assessment and management of heart-failure symptoms, and demonstrated competency in concurrent heart-failure and palliative care.

We believe that there is a pressing need to integrate palliative care into conventional care for people with heart failure. Clinicians, researchers, and policymakers can set agendas to match available health care services to the needs of patients and their families.

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DOI: 10.1056/NEJMp1900584

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Crossroads

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His fingers trace the threads of the coarse hospital blanket, etching an answer his voice can't find. I grasp his hand, the parchment-thin skin atrophied by prednisone, stretched tightly over deep purple hematomas. "This is the crossroads," he announces hoarsely.

I look at him and nod as we reflect on what the turning point means for each of us. Much of my time with Paul has been spent maintaining the enormity of his medical problems in a fragile equilibrium, a tenuous balance that has allowed him to keep bowling and playing with his grandchildren. During that time, we resisted becoming mired in medical talk any more than necessary. We often spoke of our own lives, but mostly shared fond memories of his former doctor, Jamie, who had been one of my partners. We talked about that embarrassing laugh, and whether Jamie or I had more gray hair. Their mutual love of baseball. Jamie's accessibility at

all hours. His children beaming from desktop photographs. It felt as if the three of us were crowding together in the exam room, the atmosphere more Guys' Night Out than office visit.

The first to die of the patients I'd inherited from Jamie was Christopher. Barely a week after I assumed his care, we huddled in front of the computer so I could point out to him the faint silhouette lurking in the shadows of his chest x-ray. There was so much medicine to cover at each visit: the chemotherapy bothered his eyes, his bowels barely moved once he'd started an opioid regimen. But we would also laugh, smile, and occasionally grow quiet, remembering Jamie. With Christopher, too, my partner's presence lurked in the room — in his beloved spirometry machine, his patient handouts in the drawer, the familiar cadence of his visit notes. Christopher's decline was predictably swift, his last days spent hallucinating and delirious as the

cancer hijacked his thin frame. With his death, I lamented my lost connection to Christopher, a product of that privileged intimacy born of flimsy johnnies under harsh fluorescent lights. It was the kind of relationship that drew most of us to medicine to begin with, and to primary care in particular. But with Christopher, a piece of Jamie slipped away, too, and one death became two.

My memories of Jamie are filled with lessons. As students, my classmates and I seldom ventured onto the wards without the reference book he'd authored in our pockets. I was lucky enough to have him as an attending early in my residency. He paged me his first day on service to suggest that there might not be anything "unknown" about the man I had hastily diagnosed with "fever of unknown origin." In my cursory exam, had I noted the man's tender sternoclavicular joint? We returned to the patient's room so he could show me the septic joint I had overlooked.