ETHICS AT THE HINGE

health-care organizations and family caregivers during discharge planning

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ABSTRACT This essay explores ethical challenges that frequently arise during discharge planning in acute-care and post-acute settings, often involving older adults with continuing care needs, with attention to organizational duties concerning family caregivers. Drawing on bioethics scholarship, empirical data, and their personal experiences and observations, the authors analyze a common set of burdens that a health-care organization will expect to hand off to a family caregiver as part of the discharge process. These burdens are co-produced by a patient's illness, clinical decision-making processes, the limits of public and private health insurers, and collective failures of imagination concerning how the care needs of aging societies can be met more fairly. The essay aims to be of practical use to professionals involved in discharge planning, in health-care ethics, or in executive-level decisions about organizational investments benefiting communities. It includes a set of recommendations premised on caregiver support as an ethical principle for health-care organizations.

ONE THING WE ALL know about hospitals is that most patients want to get out of them, to go home. This real-world observation is reflected in medical anthropologist Sharon Kaufman's (2005) insight that an intensive care unit contains nothing that a typical person "wants" to experience. Kaufman's ethnographical study of treatment decision-making in critical care settings in American

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hospitals explains how this dilemma—I don't want anything here, what I want is to go home—plays out as an informed decision-making problem.

There is another, less well-explored aspect of hospitalization that shadows this problem. As a patient nears the end of a hospitalization, they, or the person accompanying them—often a family member, usually a woman—also has to make decisions about the "discharge plan." How will care at home, or in a residential care setting, be provided, managed, and financed? At the hinge between hospital and home known as the "discharge process," the patient and the caregiver have incomplete knowledge of the options presented to them. They do not yet know what kinds of support they will need and whether the options on offer will meet those needs. Which options will create a new set of burdens for the caregiver, while technically fulfilling the patient's desire to go home, and aligning with "through-put"—the organizational pressure to clear that bed and avoid costly "overstays" (Berlinger 2016; Ludmerer 2015)? Perhaps all of them will create burdens. Perhaps some of these burdens will, as physician and medical ethicist Jason Karlawish (2025) puts it, pit the caregiver's well-being against the well-being of the person she is caring for.

This essay examines ethics at the hinge, and the set of burdens that a hospital will hand off to a family caregiver as part of the discharge process. These burdens are co-produced by a patient's illness, clinical decision-making processes, the limits of acute-care settings, and the limits of public and private health insurers. The context of our analysis is America's aging society, its fragmented approach to delivering and financing health care, and its reluctance to recognize care itself as a human need and social good. Our target readers are professionals involved in discharge planning, in health-care ethics, or in executive-level decisions about organizational investments benefiting communities.

Throughout this essay, we draw on useful conceptual approaches to thinking about moral problems produced by health-care systems, focusing on transitions from hospitals to other settings in the care of persons with aging-associated illnesses. Many of these approaches can be useful for thinking about caregiving for long-term or degenerative illnesses occurring at any point in the lifespan. These approaches include philosopher of health care Alan Cribb's (2011) concept of moral stress as an endemic feature of work in contemporary health-care systems; applications of care ethics theory to the practical problem of caregiver burden and the role of health-care systems in producing or perpetuating this problem; and applications of feminist philosophy concerning the "relational self" to the situation of the family caregiver who is simultaneously in relation to the person she is caring for and to health-care systems (see Campelia 2024; Gary 2023). We also draw on health humanities research on narration and representation, including how care problems and their solutions are framed by health-care organizations and how these cultural narratives shape caregiver burdens as well as patient experiences (Berlinger et al., 2025). Both of us are health-care ethicists and family caregivers, with lived experience of the moral and practical problems we consider and to which we apply our professional skills. The recommendations we offer focus on how health-care systems can use their power to prevent or ease caregiver burdens and provide real support. We also call attention to habits of thought and practice, including aspirational health-care narratives that are problematic or unjust in their presumptions about who will be available to do care work.

Although we consider paid caregivers, such as home-health aides, our primary concern is with unpaid caregivers to older adults. These caregivers are usually (but not always) family members and female, and they are usually referred to among clinicians as "family caregivers" or simply as "the family" or "the daughter."[1] During discharge planning, the caregiver at hand is usually a family member whose role drops out of the organizational picture, becoming invisible in a way that home care organizations and home health aides with billable services do not (see Folbre 2001; Reihard 2015; Waring 1988). We explore how primary caregivers may interact with paid caregivers and include practical information for caregivers as employers. Although we do not explore in detail the care needs of patients who do not have families, we expect that caregiving for such persons by friends and community members will involve similar challenges. Finally, we use the terms *caregiving* and *caregiver* because they are commonly used during discussions of this topic in health-care settings. However, we appreciate critiques of this term by feminist philosophers such as Kate Manne (2017), who explains the justice problem with imagining women as people who "give" care but do not need care, and Mercer Gary (2022), who explains the justice problem when words such as *work* and *labor* are avoided in describing, well, work and labor.

When health-care organizations fail to attend to expectations that family caregivers will provide open-ended work following discharge, they violate basic fairness by treating one set of people as exploitable by others. Caregivers are as deserving of justice as patients or members of the health-care workforce. All need care—both in the sense of care appropriate to their needs, and in the sense of moral consideration, the care we should take concerning our actions.

John Rawls's (1971) influential theory of justice famously permits social and economic inequalities if, and only if, they are "to the greatest benefit of the least advantaged" (16). Caregiving provides benefit to persons in need of care, but in

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[1] Caregiving is highly gendered. According to the Family Caregiver Alliance (2025), "upwards of 75% of all caregivers are female [who] may spend as much as 50% more time providing care than males." The US Bureau of Labor Statistics (2023) reports that 59% of the 37.1 million eldercare providers in the civilian noninstitutional population are women. When men are caregivers, it is usually for their partners; when the role falls to an adult child, the caregiver is almost always a daughter (or daughter-in-law). In our experience, men who perform care labor are perceived as doing something unexpected or special, while women who perform care labor are perceived as meeting their obligations, such that "daughters" may be shorthand for "family caregivers." We value the caregiving labor of men, but we also recognize that caregiving is still likely to be seen as "women's work," and therefore as low-value. This is why we focus on family caregivers as typically female, and on caregiving as gendered even when done by men or nonbinary persons.

our current health-care system, caregiving creates a new class of disadvantaged persons burdened by work and inadequately supported by social systems, such as the assurance of access to affordable respite care. Remedying inequalities is supposed to benefit the worst-off, not create a new class of worst-off. Iris Marion Young's (2011) theory of justice leads us to similar concern. Her five faces of oppression include "exploitation," which redistributes the benefits of work done by one group to another without adequate compensation (see Reiheld 2015). When organizations, through discharge planning and other interactions with family caregivers, treat these persons as mere instruments, this is deeply wrong.

DISCHARGE PLANNING AND MORAL STRESS

Imagine yourself as a family caregiver for an older adult who has been hospitalized. Perhaps this person is your mother. Perhaps this is the first time, or the fifth time. You have spent many hours sitting—hours on end in a folding chair in an emergency room in the middle of the night, followed by days or weeks in a somewhat more comfortable chair, or a recliner if you're lucky, in a critical care unit or a medical ward, maybe both. You know how the parking works, where the vending machines are, whether the hospital cafeteria French fries are good (they are), and how to get through the ID badge system. You are checking work email, checking in with your partner and children, cancelling your own medical appointments, cancelling your vacation. You are going home just to shower and change. Or you are not going home at all, perhaps because you must be on site at your job and cannot work remotely or get time off.

You have discussed your mother's diagnosis and current condition with "the team," whose members keeps changing, though there is one nurse you see every day for a few days at a time before someone replaces her. You may have discussed your mother's diagnosis and condition with your mom, or perhaps she's unable to take in this information. You may have helped your mom to make medical decisions, or may have made these decisions on her behalf, as her surrogate. You may have helped your mom to fill out or update a POLST (physician order for life-sustaining treatment) form, or may have filled it out on her behalf. You are chatting with your mother, reassuring her, fetching her an extra pillow or blanket, requesting that nurses or aides help her when she needs a bedpan, or assistance with a catheter, or to be cleaned after having waited too long. (You have been warned not to help her out of bed and into the bathroom, because she is a fall risk.) You are running back and forth to the nurses' station with questions, advocating for pain relief, calling attention to a newly ordered drug that you know she's had a bad reaction to in the past (isn't this on her chart?), asking why yet another blood draw or scan has been ordered. You are being "trained" for post-discharge caregiving tasks: to administer medications, or flush catheters, or change dressings, or clean wounds. You are trading bedside hospital shifts with another family member, or with no one. You are exhausted.

And now, you've just met a care coordinator, perhaps a social worker, who wants to discuss the "journey home" or the "journey to rehab" or the "journey to hospice," or wherever your mother is going next. Perhaps you've been handed a list of "options" for home health care, or post-acute rehabilitation, or outpatient palliative care. You're told to pick one—now, because "we've got to get mom in" before the end of day, or before the weekend, or the holiday. You have no time to ask your friends, neighbors, or colleagues for feedback on which rehab facilities or home nursing agencies did a good job for them. You don't know how to tell the good ones from the bad ones. Your options are likely to be constrained by finances, unless you are wealthy, yet you are likely to be operating with incomplete knowledge and faulty assumptions about what your mom's insurance covers. What should you do?

This everyday scenario shows how the moral stress created by the conditions of work in health-care systems is also experienced by the unpaid labor in these systems: the family caregivers. Cribb's (2011) concept of moral stress evokes the relentless pressure of the system itself on the workers in the system (see also Buchbinder et al. 2023; Cribb 2024). Cribb asserts that the stressful nature of health-care work should be understood as "moral stress" because it is bounded by sources of moral authority. These sources include codes and standards of conduct, unofficial work rules and practices, and "the assumption that something broadly ethically acceptable or even positively good is going on" in the work of healing and care (Cribb 2011, 122). These are organizations with value-laden words such as *care* and *mission* in their very names.

Working from Cribb's concept, we extend the moral stress of the system to its unpaid workers. In human resources terms, the discharge planning process is the "onboarding" for an employee who did not apply for this job and either has no idea of what happens next or has been through this before and knows that they will be expected to get with the plan, to "make it work." We discuss caregiving as a transformative life experience later in this essay, but first we consider how the tasks demanded of family caregivers during hospitalization and especially during care transitions from hospital to other settings are *work* expectations, enmeshed with social and cultural pressures to perform as "good" family members for the sake of the patient, but also for the system.

DISCHARGE PLANNING AND INFORMED CONSENT

Discharge planning should be recognized as replete with ethical challenges that discharge planners should be prepared to recognize and respond to. Clinical ethics consultation services assist health-care professionals and teams with a range of ethically challenging scenarios. These scenarios often arise from uncertainty or disagreement about how to make decisions concerning medical interventions when a patient lacks decision-making capacity, when their decision-making capacity is unclear, or when a decision involves life-changing consequences.

In the US, good practice concerning potentially life-sustaining interventions reflects both ethical consensus and federal and state law regarding the decision-making rights of patients. In this framework, when patients lack capacity to make the decision at hand and when their advance directives (if any) do not provide guidance concerning this decision, a family caregiver or another family member often serves as the patient's surrogate decision-maker. This dual role of "family"—as patient's agent and as patient's caregiver—can create challenges. For example, it can result in the decision-making authority of patients concerning particular interventions being conflated with the related but distinct question of how care associated with these decisions will be provided, managed, and financed. This second question must be clearly addressed in theory, practice, and policy as part of the clinical ethics consultation, in order to avoid reducing family caregivers to mere instruments of patient preferences and cogs in the system (see Campelia 2024).

Standards for making treatment decisions, which recognize and support the patient as decision-maker and grant authority to family members as surrogates, are insufficient or inappropriate for decisions concerning future care that will be provided, managed, or financed by family caregivers. Reducing discussion of a patient's future care to "what the patient wants" or "concordance with preferences" are insufficient and potentially unjust ways of talking about care that will be provided, managed, or financed by family caregivers. Yet organizational decision-making processes and related guidance for health-care teams typically fail to reflect that family caregivers making decisions with and for patients are also being presented with decisions about their own lives—but without the safeguards of rights and ethics. While a patient or a surrogate has a legal right to refuse a treatment, in the context of discharge refusal is what "difficult" families do—and they are seen as impeding the system.

What would be better? Ongoing research with clinical ethicists, discharge planners, and other health-care professions suggests how ethical guidance for decisions concerning future care should be developed and piloted (Campelia 2024). For example, guidance concerning treatment decisions that will be made during a patient's hospitalization should stipulate that if any treatment option will require the post-discharge involvement of a caregiver, that caregiver must have a voice and a role in making the decision. This is important both in situations in which a patient has decision-making capacity for the decision at hand, and also when a surrogate decision-maker has decision-making authority.

The recommendations at the end of this article offer ways for discharge planners and organizations to recognize the moral stress that caregivers may have been subjected to during the pressure of hospitalization, and how this stress will increase when the patient leaves the hospital and the caregiver must provide, manage, and finance care without the in-patient team to turn to. There is no way to give informed consent to a discharge plan under such pressured—even coercive—conditions, but a caregiver's pushback or rejection of a plan that relies on capacities they may not possess should be recognized as something more than a family member being "difficult." A plan that relies on capacities a caregiver does not sustainably possess is not a good plan: it is bad for the patient, and it is bad for the caregiver.

THE TRIPLE BURDEN

In describing American health care, we have emphasized that the family caregiver may be responsible for providing hands-on care, for managing care provided by others, and for paying for care. This triple burden exists even when a care recipient is publicly insured by virtue of age, disability, or diagnosis. The next sections discuss this triple burden and its ethical implications for organizations.

What Counts as Caregiving?

Family caregiving for people in late life differs from caregiving as a parent. No parent fails to recognize that caring for a baby or a child is caregiving; from the start, it is hands-on work. However, caring for older adults often begins gradually, involving tasks that are shifted to a family member due to an older adult's decreasing mobility. A crisis—a fall, a stroke, a financial mishap due to impaired cognition—may provide the moment of recognition that a family member has become a family caregiver, but sometimes caregivers may have difficulty pinpointing the moment when they took on this role.

A persistent idea is that one must be doing *everything* for another person in order for caregiving to "count." But one goal of this essay is to help readers recognize that *everything counts*: providing hands-on care, driving, grocery shopping, tech support; managing medical appointments, prescriptions, insurance, finances, and taxes; paying for needed care whose cost is beyond the means of the person in need of care—any and all of this counts as caregiving.

The family caregiver's brief may even extend to training health-care personnel. For example, one of the authors cared for her mother after a car accident. The family caregiver had been trained by wound clinic specialists to provide twice-daily wound care for her mother following discharge. Insurance covered one to two home care visits by a nurse per week, but an ever-changing rotation of home care nurses, most of whom had little or no training in wound care, meant that the family caregiver had to demonstrate to each nurse how to provide care according to the wound clinic's instructions. On a day when the caregiver was not available and the nurse dressed the wound incorrectly, these precarious arrangements led to injury. This amount of family caregiving labor is immense, and it is largely built into the system, which presumes the availability of free, ever-present labor as an extension of professional staff.

Administrative Burden

A significant part of care labor on behalf of an older adult entails paperwork. Although this administrative burden has received some attention from researchers (Taylor and Quesnel-Vallée 2017), it is insufficiently captured by metaphors of "navigation" or the goal of "helping family caregivers navigate the system." After all, there are many systems involved in caregiving: medical insurance and arguing with, even begging, insurers for approvals, coverage for prescriptions, applications for services and for residential care, filing taxes, and taking over the monthly bills—not to mention endlessly creating digital IDs and updating client profiles associated with health care, insurance, and finances. None of these are the direct medical caregiving that clinicians and discharge planners sometimes account for, and yet all are inherent to care. The family caregiver is usually alone in these systems, calling yet another customer service number, waiting for callbacks, arguing with chatbots. This labor is Sisyphean, without even the satisfaction of completing a task. Health-care organizations did not create all of these time-sucking, stress-inducing burdens, some of which aim to prevent harms such as financial fraud, but the hinge of discharge planning may be one of the few opportunities for a family caregiver to be alerted to what lies ahead and offered some useful resources.

Financial Toxicity

Our focus concerns caregiving for older adults, corresponding to the Medicare-eligible population. Every family caregiver has experienced that moment of dismay upon learning that Medicare doesn't really pay for care, it pays for specific health-care services. In the cancer care literature, the concept of "financial toxicity" refers to unreimbursed treatment costs that create additional burdens for patients or families (Zafar and Abernathy 2013). Financial toxicity applies in other situations, too, and it has implications for what discharge planners, as a matter of ethics, ought to discuss with patients and caregivers. At a minimum, discharge planners should attempt to disclose and discuss unreimbursed costs associated with treatment options; offer less costly options when available; offer financial assistance when available; and provide contacts within organization and for other organizations that can help post-discharge (when these contacts exist). General references to "programs" that the caregiver must discover on their own are insufficient.

At the hinge of discharge planning, family caregivers may be asked some version of "Can you pay for it?" Without being given any information about actual costs, particularly for home care, this is an unanswerable question. Financial toxicity and care costs should be recognized as foreseeable factors in clinical decision-making. Especially during discharge planning, attention should be given to the potential for these costs to become burdens for caregivers—directly or through unpaid care labor, or both (see Kolluri, Naylor, and Weiner 2023).

THE OTHER SELF IN THE DYAD

When health-care organizations acknowledge the caregiver, they typically do so as part of a two-part unit, or dyad, that includes the patient. Within the organizational narrative of patient-centered care, surrogate decision-makers and other nonclinicians involved in a patient's care are perceived as extensions of the care recipient's agency. Seeing the dyad (if it exists; some patients are alone) acknowledges that autonomy is relational: a person's agency may depend on the willingness of others to support and enact it.

The dyadic relationship between family caregiver and patient has an additional temporary relationship between family caregiver and professional caregivers in the hospital. Sometimes caregivers are recruited onto the medical team, through "training" in direct medical caregiving, as in the wound care example described earlier. This temporary assignment to "the team" renders a caregiver an extension of clinician agency, enabling clinicians, through training and instructions during the discharge planning process, to reach beyond the organization and into the private sphere of the patient's home. But caregivers often have little input into the clinicians' care plan, leaving theme as mere instruments of that plan—assumed to be ever-present and self-sacrificing.

Neither of these familiar ways of seeing caregivers—as part of the dyad or part of the team—acknowledge them as distinct persons. What does their relational autonomy look like? Who supports and enacts their agency? Given the expectations and actual burdens handed to caregivers at the hinge between hospital and home, caregivers need and deserve more from health-care organizations. This starts with better understanding and acknowledgment of what caregivers are experiencing or will soon experience. While not every form of work affects the very self, family caregiving does, both because it is so intimate and because it is bound up with so many expectations.

One feature of caregiving rarely discussed in organizational ethics or medical ethics literature is that caregiving can be what philosopher L. A. Paul (2014) describes as a "transformative experience." Transformative experiences change a person's relationship to their own life profoundly, sometimes breaking the life into what it was before and after the experience. Paul describes parenting as a classic example of a transformative experience. Parents cannot know in advance how becoming a parent will change them: the transformative experience reorganizes their values and concerns. Similarly, becoming a caregiver within a dyad can lead the caregiver to undervalue their own self and agency, as well as shape all levels of life decisions. Everything is "for" the person being cared for, or organized around their needs, and for caregivers to consider their own needs and welfare can feel wrong. Given the intense pressure from the system, from the care recipient, and from other family members (such as the caregiver's siblings) to perform well, caregivers' concerns about their own well-being can become an internalized source of guilt or shame.

At the hinge between hospital and home, when a patient is often eager to "get out of here" and organizations are eager to free up capacity for new patients and their reimbursable services, the caregiver is on the brink of a transformative experience. Because discharge planning has consequences for caregivers as well as patients, we suggest that health-care organizations recognize that caregivers are being asked to assent to a new future for themselves. Caregivers should not be expected to ask for support they have no idea they will need. What do health-care organizations owe to caregivers as follow-up care, and are organizations willing to provide it? If they don't, who will?

WHAT "SELF-CARE" REALLY MEANS

When family caregivers disclose their stress to others or search for wisdom online, they are likely to be told that they need to practice "self-care," or even that they have burned out because they have failed to practice self-care. What does self-care mean when the person who needs it is caring for another person? If care is foundationally a relationship, why is it presented as a DIY project for the caregiver—yet another thing they must do, or fail at, alone? Can we imagine otherwise? Eva Kittay (2002) observes that: "if providing dependency care were not simply assumed to be a familial obligation, but if dependents themselves were able to receive more support, familial caregivers would not be as depleted by caregiving as they currently are and might even be armed with a greater sense of entitlement to good care for themselves" (243).

Research on the experiences of physicians during the COVID-19 pandemic reveals that health-care professionals are fed up with the messages that they receive about self-care, namely, that protecting themselves from the grind of the system is their responsibility (Buchbinder et al. 2023); Cribb 2024). They are weary of being told to breathe, meditate, do yoga. Family caregivers get all of these self-care tips from the system, and more—for example, one caregiver support website suggested bringing the care recipient with them to the caregiver's *own* stress-reducing activities. (Try to picture that for a moment.) Physicians and nurses whose shifts eventually come to an end have far more power to engage in self-care than do family caregivers, who are unpaid and whose ability to take that break, if they can afford it, relies on having back-up care. We are recognizing that burnout among clinicians is a major organizational ethics issue, not resolvable by appeals to self-care. And if physicians and nurses can see through the rhetoric of self-care and the individualization of system-produced moral stress, let's assume that family caregivers can see through such rhetoric as well.

A different kind of self-care is needed by those who are expected to put the needs of another person first and accept depletion, that sense of being sucked dry or cannibalized, as their norm. For caregivers, self-care starts with the insistence that we, too, are worthy (Lorde 1988). We do not exist purely for others to extract value from us; we also deserve a flourishing life. The logic of depletion that positions caregivers as what Kate Manne (2017) calls "human givers" is poisonous.

At the hinge of discharge planning, treating the family caregiver as a person deserving of respect—not merely an instrument of care—should be a focus of discussion for professionals. Clinicians and organizations need to understand that genuine self-care may sometimes require saying "no" to providing yet more labor for another person at a cost to oneself. Self-care is not a solution to a care labor shortage; some other form of support must be provided.

MUTUAL AID: CONNECTING CAREGIVERS WITH SUPPORT

So what should health-care organizations do? They should start by recognizing that the nature of family caregiving makes it very difficult for caregivers to take a break and get some rest, because they need to find and perhaps pay for someone else to take over their duties. Organizations should also recognize that activities for dyads, such as dementia-friendly programs, may not constitute a real break for caregivers themselves, and that bringing the person being cared for to the caregiver's own leisure activities is no break at all. In addition to providing family caregivers with information about support groups, health-care organizations should also provide information about respite care programs. Offering to connect family caregivers with other caregivers, and alerting caregivers to the power of connecting with others like them, can be a crucial source of support.

Mutual aid is how people get through conditions of oppression when the system doesn't aid them. By aiding each other, they create their own informal organization to compensate for bad or inadequate organizations. But for mutual aid to work, caregivers need to be networked. A network can be as simple as a text thread between two neighbors who have recognized what they have in common, or among friends who live in different places but are having similar life-stage experiences of caregiving. Mutual aid for caregivers also tends to work best when caregiving experiences align. Parents with same-age babies or children tend to find each other at the park and other places where parents turn up. It can be harder for caregivers for older adults to find each other. Mutual aid is enriched by mutual understanding. Caregivers with shared experiences of dementia care, or post-stroke care, or frequent hospitalizations for acute episodes of chronic conditions will likely be able to anticipate each other's needs and provide tips for managing bureaucracies. They can also validate that what each is doing matters, is often deeply meaningful, is hard, and will likely go on until the death of the person needing care. Crucially, they can also validate for each other that caregivers, too, are worthy of care.

Caregivers should not be expected to fix broken systems. They do not have to be the primary advocates for care policy: they are already performing the role of advocate for the person they are caring for, while trying to hold a sense of their own self together. However, efforts to improve care systems, including medical decision-making and discharge planning, should strive to include knowledge from caregivers. Standpoint epistemology, a concept from feminist philosophy that recognizes that our knowledge of the world is based on where we stand, reminds us that caregivers are best placed to know how systems are failing them. Who in the health-care system is listening to caregivers? Who will take them seriously as knowers, not merely as sources of good reviews or complaints? Who will bring caregiver knowledge into policy analysis and organizational reform? Who will take on the creation, financing, and maintenance of better systems, including the adequate financing and staffing of home care services? Who will bridge the personal and the political, the private and the public, and acknowledge what is wrong with a health-care system that runs not only on Medicare dollars but on unpaid, unseen, unacknowledged labor?

Homes Are Not Hospitals, Daughters Are Not Nurses

Cultural narratives shape lives, by describing what a society knows through the stories it tells about people like you (Berlinger et al., 2025). In this concluding section, we call attention to several cultural narratives that are about family caregiving or that presume its existence.

In the US, some common cultural narratives about family caregivers and what is expected of them include narratives that that turn on duty, obligation, or shame (your mom did this for you), or the idea that caregiving is intrinsically rewarding; narratives that perpetuate stigma associated with dementia, a condition that creates especially heavy burdens for family caregivers; narratives that perpetuate ageist tropes about caregiving, such as "becoming my mother's parent"—even if that's what it feels like sometimes; and narratives that valorize "aging in place" while obscuring the role family caregivers play in bolstering "independent living" by a person whose health, mobility, or cognitive faculties are declining.

All of these narrative frameworks locate the problem of care with the caregiver and care recipient. They unjustly frame caregiving as an individual or familial responsibility, rather than depicting care work as a crucial feature of aging societies that should be fairly distributed among individuals, families, health-care organizations, and other systems. Some cultural narratives about the future of health care emphasize technological solutions, but they also may double down on injustice, by recasting family caregivers as unpaid hospital staff, responsible for both care and tech support. For example, Mario Aguilar (2024) reports that the "hospital at home" narrative emphasizes how AI-enabled monitoring can enable seriously ill patients to stay at home or return home more quickly, aligning with patient preferences. But what this narrative leaves out—or presumes—is the necessary presence of "the human in the loop": the family caregiver who is the de facto IT manager as well as the hands-on caregiver for a person ill enough to need to be in a hospital. A closely related narrative suggests that home-based AI will eventually put nursing homes out of business. But here again is the presumption that there will be at least one human in the loop to provide the 24/7 care associated with nursing homes. Who is this person likely to be?

Recent work in the philosophy of technology, from scholars such as Shannon Vallor (2011) and Mercer Gary (2022, 2023) analyzes cultural narratives that imagine "carebots" doing work currently done by humans, with attention to what would be lost as human experiences if care work was wholly handed over to technology, as well as the practical limits of this fantasy. When we imagine what AI and other technologies can do for health-care organizations, we should also imagine how these tools could add to the burdens of family caregivers, if they isolate caregivers "at home" and further individualize responsibility for care while seeming to provide "what patients want."

For now, it is crucial for organizations to remember that any form of hospital-level care "at home" will depend on the availability of family caregivers. Omitting them from the story is another way of recruiting them for work without their knowledge or consent, and perpetuating habits of presuming caregiver capacities that simply do not or cannot exist.

RECOMMENDATIONS FOR HEALTH-CARE ORGANIZATIONS

In her autobiographical novel *On the Other Side Is March,* Faroese writer Sólrún Michelsen (2013) depicts a middle-aged woman's gradual immersion into the role of caregiver for her mother, who lives alone and has dementia and other health conditions. This concise work captures life in the remote Faroe Islands and suggests how this small nation's cultural narratives about caregiving, aging in place, and where patients "want" to be align with what care policy is willing to offer. In the novel, the waiting list for a nursing home bed for which the mother qualifies is years longer than her life expectancy could possibly be. The daughter, who must show up more and more often for caregiving duty, notices other dyads: "Now, wherever I go, I meet women, who have old, dependent mothers to care for . . . I see the exhaustion in their eyes. The wrinkles lining the faces. Glimpse the question left unanswered. This see-through army of women" (76). The narrator later suggests that for her, the question is "Who cast me in this role?"

The following recommendations for health-care organizations aim to make the unseen seen, and to genuinely value, respect, acknowledge, and support family caregivers who have been cast in a role that they cannot easily refuse. These recommendations are premised on caregiver support as an ethical principle. Patient-centered care demands caregiver support as a means to achieving good patient outcomes, but caring for caregivers is an ethical principle in its own right.

The ethical goal of integrating caregiver support into organizational behaviors requires attention to the following:

- Prevention of the triple burden when possible, and reducing its weight in other instances.
- Practical guidance for medical decision-making and discharge planning, including encouraging caregivers to speak about their own needs, capacities, and limits, in private if necessary; and ensuring that caregivers have trustworthy websites and helplines, such as the national Family Caregiver Alliance and regional SHIP programs for Medicare Beneficiaries, where they can turn with the questions they will surely have.
- Recognizing the dependence of the system on unpaid care labor and avoiding "problem" framing of patients who have no ready family caregivers.
- Promoting a shared recognition among professionals that family caregiving is hard, and that clinical biases about "good" and "difficult" families can obscure family caregivers' reasons for pushing back on or refusing a discharge plan.
- At the executive level, using health-care organizations' clout as major employers and community presences to assist local efforts to create more and better housing for older adults, including supportive housing with on-site services, congregate housing, senior housing, and other types of housing that support people aging in community, not limited to living independently/aging in place.
- Also at the executive level, advocating for federal and state-level investments in home care and other services that serve patients and relieve caregiver burdens.

When larger health-care organizations such as hospitals implement improvements at the hinge, the improvements will be noticed by other health-care organizations involved in discharge planning and transfers, such as post-acute rehabilitation, home care, and hospice and palliative care. These improvements can be studied, refined, evaluated, and amplified by professional societies in medical social work and other fields involved in care transitions, and by nonprofit organizations focused on improving care transitions and supports for family caregivers.

Changing professional habits and cultures, including concerning how health-care organizations engage with family caregivers, takes vision and persistent work. Health-care organizations that implement these recommendations at the hinge between hospital and home will be better for aging patients and for their caregivers.

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