The Hospital at Home (HaH) movement in the US is accelerating. Established in 1994 at Johns Hopkins University, this care model became an important strategy during the COVID-19 pandemic. Unfortunately, HaH does not offer sufficient consideration of the role of and effects on family caregivers, including family members, neighbors, and friends who provide paid or unpaid care to people in their homes. Caregivers are essential partners in policies to spread the model, but the burdens of caregiving may overwhelm the caregiver and undermine the success of HaH in improving outcomes and lowering costs.

Hospitalization is not without hazards, placing older adults with multiple, progressive health conditions at greater risk for adverse outcomes. The HaH model enables acutely ill but stable patients to be cared for in their own homes instead of being admitted to a hospital.

Emergence of Hospitalization at Home During COVID-19

When COVID-19 overwhelmed hospitals in 2020 and triggered the declaration of a public health emergency, officials from the Centers for Medicare & Medicaid Services (CMS) recognized the potential value of the HaH model and created a waiver allowing Medicare-certified hospitals to treat patients with inpatient-level care in their homes. Guided by the Johns Hopkins model, CMS criteria define which conditions are eligible (eg, congestive heart failure); whether the home environment is safe for home management (eg, air conditioning for someone with respiratory conditions); and how, when, and by whom care processes such as telemetry monitoring should be delivered, such as daily visits by nurses and physicians.

The Acute Hospital Care at Home (AHCaH) initiative, launched in November 2020, provides payment for Medicare fee-for-service and nonmanaged Medicaid beneficiaries with a range of medical conditions who come to the emergency department or are briefly hospitalized and are offered and accept care at home. The Medicare payment is comparable to that paid if a person had been hospitalized. As of June 28, 2022, 107 health systems and 242 hospitals in 36 states had applied for and been approved for this waiver.

The Hospital Inpatient Services Modernization Act (S.3792/H.R.7053), introduced in Congress in March 2022, would extend the AHCaH for 2 years after the public health emergency ends. The proposed act requires an evaluation of the waivers on Medicare beneficiary access, quality of care, safety, equity, and outcomes (health, utilization, and cost).

Concerns about the proposed legislation include the view that 2 years of experience with the AHCaH may be insufficient for a meaningful evaluation. An analysis of 186 hospitals that had implemented AHCaH identified some lessons learned from the CMS trial, but the sample size was too small to determine outcomes. However, over the past 4 decades, the HaH concept has been implemented in other countries, such as Australia, where 6% of “hospital bed days” are provided in the home. An analysis of 10 systematic reviews and meta-analyses assessed HaH studies mostly conducted outside the US; this analysis found that compared with inpatient care for comparable patients, HaH was associated with similar or improved clinical outcomes, reduced costs, and enhanced patient satisfaction with care.

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With more than 60 heterogeneous programs with diverse patient groups included in these reviews, few studies have examined the effects of HaH on family caregivers. Among these studies, little information was provided on who the family caregivers were or how they were engaged and supported. When included, assessment of effects was limited to caregiver stress or strain.

Although little is known about family caregivers’ experiences under the AHCAH, the overall effects of caregiving on family members have been extensively studied. The experience can be meaningful and satisfying, but too often family caregivers are not given the support they need to avoid the potentially debilitating physical, mental, social, and economic consequences of providing complex care to loved ones at home. The burdens of caregiving fall disproportionately on women and caregivers in racial and ethnic minoritized groups with constrained financial resources who often cannot afford to take time off from work and have other family responsibilities.

The AHCAH initiative does not require the care-at-home option to be discussed with family caregivers. Currently, most US HaH programs stipulate they do not rely on the involvement of family caregivers. However, even when these caregivers are not required to give medications, provide wound care, or prepare special diets, they are critical to the success of HaH. They provide vital observations, communication, and support; indeed, they may provide medical and nursing tasks when nurses and other professionals are not present. The evolving and concerning shortage of home care workers is likely to increase expectations of complex care by family caregivers.

New research is needed to understand the effects of HaH on family caregivers. Because of major differences in the organization of health and social services and payment for these services in most other countries, rigorous evaluations of the effects of HaH programs on family caregivers in the US are essential. Investment in a research agenda that addresses the effects of HaH on family caregivers should be prioritized by the National Institutes of Health, foundations, academic research centers, and advocacy groups.

The proposed Hospital Inpatient Services Modernization Act should be amended to reflect that family caregivers are critical to the success of HaH and must be involved in decision-making, not just at the point of program enrollment but throughout the acute episode of illness. The CMS should require as a condition of participation that HaH programs consult with family caregivers. In addition to seeking informed consent from patients, clinicians should request family caregivers’ assent while clearly delineating all expectations of them. If family caregivers are expected to help with the actual care, instructions and supports to assure they are prepared to deliver quality care are essential. A growing trove of written instructions and videos is available for clinicians and caregivers to access. Meals and access to home health aides should be provided to meet the needs of both the patients and family caregivers. Additionally, the proposed legislation include an evaluation of the effects of the HaH program on family caregivers, especially related to equity.

Finally, equitable, high-quality outcomes for patients and their family caregivers under HaH programs will only be achieved if acute care services are integrated into an ecosystem of seamless, longitudinal care supported by value-based payment models. Segmenting HaH from primary, palliative, behavioral and post-acute health care will increase care fragmentation and the navigational burden on caregivers. Programs and payment models for HaH will need to address access barriers for people in impoverished communities and rural settings. Evaluation of the quality of HaH programs should include metrics specific to family caregivers, and the performance on these measures should be linked to reimbursement. This agenda requires that clinicians, administrators, policy makers, and payers commit to family-centered care and embrace family caregivers as true partners in HaH care.
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