


The Forgotten and Misdiagnosed Care Transition: Live Discharge From Hospice Care

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Abstract

Every aspect of the United States healthcare industry presents transitions in care—hospitalizations, rehabilitation, long-term care placement—each requiring careful attention. With a goal of maintaining safety during a known point of vulnerability for patients, discharge planning is required in hospitals, skilled nursing facilities, and home health agencies under Medicare guidelines. Yet, no required discharge planning or clear guidelines are available for a discharge from hospice; it is a forgotten care transition in our healthcare system. Of the 1.6 million Medicare recipients hospices serve each year, hospices discharge 17.4% alive. Under Medicare regulations, if clinicians cannot document acceptable patient decline, then patients are decertified from hospice categorized as “no longer terminally ill”, otherwise known as a live discharge. These patients are often referred to as “not dying fast enough,” or “failure to die on time,” as ultimately, they are still dying, and they are still terminally ill, just not within the prescribed 6-month framework. This paper outlines what is known about the occurrences and experiences of live discharge from hospice care and provides suggestions for improving both practice and policy.

Keywords

transitions of care, hospice, end of life, palliative care

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Every aspect of the United States healthcare industry presents transitions in care—hospitalizations, rehabilitation, long-term care placement—each requiring careful attention. With a goal of maintaining safety during a known point of vulnerability for patients, discharge planning is required in hospitals, skilled nursing facilities, and home health agencies under Medicare guidelines. Yet, no required discharge planning or clear guidelines are available for a discharge from hospice; it is a forgotten care transition in the U.S. healthcare system. While Medicare is a uniquely American entity that informs medical practice, the impact of care transitions and supporting both the patient and their caregivers is a universal health concern. The medical community is making strides in increasing access to hospice as nearly 52% of all Medicare decedents received hospice in 2019, up from 48.2% in 2015 (National Hospice and Palliative Care Organization [NHPCO], 2021). However, of the 1.6 million Medicare recipients hospices serve each year, hospices discharge 17.4% alive (NHPCO, 2021). This paper outlines what is known about the occurrences and experiences of live discharge from hospice provides suggestions for improving both practice and policy.

Defining Live Discharge From Hospice Care

The U.S. healthcare community works tirelessly to combat the stigma that hospice care is only for final days and weeks, with 50% of hospice patients dying within 18 days or less (NHPCO, 2021). Yet there is a tension between eligibility for enrollment—patients believed to have a 6 month or less prognosis—and the need to recertify patients to remain on services. To remain on hospice, an individual must demonstrate ongoing, steady decline at recertification intervals of every 90 days for the first 6 months, then every 60 days thereafter until death or discharge. Persons with more chronic illnesses, such as Alzheimer’s Disease and Related Dementias (ADRD), stroke (CVA), lung and heart diseases (i.e.,

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COPD, CHF), have a trajectory that is less predictable in decline, unlike cancer. Hospice lengths of stay for these diagnoses is longer (82–106 days on average) compared to patients with cancer or kidney disease (35–45 days) (NHPCO, 2021). Yet, all patients are held to the same standard of progressive and demonstrable decline, regardless of diagnosis. With a focus on quality of life and patient-centered care, hospice makes sick patients feel better, often resulting in temporary improvements of their condition and longer survival, though they remain terminal (Luth et al., 2021). Under Medicare regulations, if clinicians cannot document acceptable patient decline, then patients are decertified from hospice, otherwise known as a live discharge.

While NHPCO (2021) separates live discharges into two categories, patient- and hospice-initiated, these are very different phenomena, particularly in regards to choice. Patient-initiated discharges include transfers to a different hospice provider or revoking hospice to pursue other treatments or services, like hospitalization or curative treatments. An individual, or their healthcare proxy, can choose to leave hospice at any time. Hospice-initiated discharges include when a patient moves out of service area, when hospices discharge for cause (i.e., safety), and those that occur when a patient is decertified—categorized as “no longer terminally ill” (NHPCO, 2021). While this is true for some patients whose clinical status changes, most patients are discharged with the same terminal diagnosis that qualified them for hospice in the first place. 6.5% of all hospice discharges (death or otherwise), are due to decertification, the largest category of live discharges, tied with revocations (NHPCO, 2021). These patients are often referred to as “not dying fast enough,” or “failure to die on time,” as ultimately, they are still dying, and they are still terminally ill, just not within the prescribed 6-month framework.

Live Discharge as a Misdiagnosed Care Transition

Under the Hospice Medicare Benefit, a patient receives medical, psychosocial, and spiritual care in their homes, minimizing the need for office visits or further testing, while the cost of medications to manage pain and symptoms related to the patient’s diagnosis and needed medical supplies or equipment are all provided where the patient calls home. Unlike other models of care, hospice care services are available around the clock (NHPCO, 2021) and services are provided regardless of ability to pay. When a patient is no longer enrolled to receive hospice services due to decertification, home visits from the hospice team and supportive resources stop, the provided equipment is removed from the home, and the cost of supplies and medications, and support from the interdisciplinary team are no longer covered.

All care transitions, or the movement patients make between practitioners and settings as their condition and

needs change, are ripe with challenges. While patient-initiated discharges from hospice to acute care, and often back again, are identified as a burdensome health-care transition (Teno et al., 2018), discharge from decertification is missing in most discussions of care transitions. Even the Centers for Medicare & Medicaid Services (2018), discussed live discharges as care transitions, did not explicitly differentiate by type. In fact, hospice teams often present the discharge in a positive way, using the term “graduation” as part of their discharge practices (Wladkowski & Wallace, 2019). Reality, however, is vastly different from the visions of celebrations that arise from the term graduation (Hunt & Harrison, 2021). Instead, individuals who stabilize in condition are kicked off hospice care, losing access to resources (Wladkowski, 2016), with caregivers assuming or resuming additional responsibilities, and both patients and caregivers left experiencing grief and abandonment (Wladkowski, 2017). Misdiagnosing a live discharge from hospice as a celebratory graduation, or through using language “no longer terminally ill” when a diagnosis has not changed, denies opportunity for assessment and intervention to prepare patients and caregivers for a quality transition between services.

Improving Hospice Discharge Practices

Understanding the complexities of live discharge as a care transition is important to properly prepare patients and caregivers. Focusing on the discharge process is one approach for improvement. Currently, there is no consistency across how hospices approach a live discharge (Wladkowski & Wallace, 2019). There is also no incentive for an agency to implement a discharge practice, since hospice is reimbursed on a prospective, flat-rate basis, and no reimbursable discharge protocol currently exists. While adding a reimbursable discharge protocol is one potential policy change, another approach is to allow patients with a consistent terminal diagnosis who are not pursuing curative treatment to remain on services until death regardless of evidence of decline (if they so choose). This would eliminate the need for a live discharge as failure to decline in condition while on hospice is often a temporary state. One-third of discharged patients dies within 6 months of hospice disenrollment, often without hospice readmission, suggesting benefit from continued hospice services (LeSage et al., 2015). Minimally, for patients with chronic illnesses (i.e., ADRD, CHF, COPD, CVA), policy requirements for recertification, and therefore, maintaining eligibility, must be re-evaluated to better reflect their disease process.

In lieu of potential policy changes, a model for consistent or equitable discharge practices is needed. Hospice social workers report that patients with greater resources and those in urban areas with access to home-based palliative care programs do better following a

transition from hospice than others (Wladkowski & Wallace, 2019). This is particularly noteworthy as individuals receiving home hospice care are more than 7 times as likely to be discharged alive than those receiving hospice in other settings such as nursing homes and hospice inpatient facilities (Luth et al., 2020). Perhaps delaying a discharge for an extended period of evaluation would allow hospices to verify whether a patient's stabilization is temporary. Not only would this minimize the frequency of discharges and discontinuity of care, but it would also allow hospice organizations to better prepare patients and caregivers in the event a discharge is still warranted.

Historically marginalized racial/ethnic populations in the United States are less likely to enroll onto hospice services (Hughes & Vernon, 2019), yet when they do enroll, they are more likely to be discharged alive (Russell et al., 2017). Commonly reported challenges to hospice care which may contribute to disparities in live discharges for racial/ethnic individuals include cultural incongruities, less knowledge about hospice services, and lower completion and/or discussion of directives and end-of-life wishes (Russell et al., 2020). Additionally, live discharges are more common among patients who live in lower-income neighborhoods and neighborhoods with a lower proportion of college-educated residents (Russell et al., 2020), highlighting more areas of inequity in our healthcare system. These disparities in live discharge call for needed support of an inclusive culture and increasing community-based outreach and partnerships. Further investigation into accessibility of community resources is imperative, as the hospice model of care cannot be replicated following a hospice discharge (Wladkowski & Wallace, 2020). With more people dying at home than in the hospital (Cross & Warraich, 2019), policies and practices for promoting access and maintaining services to all individuals with serious and/or life limiting illness must be a priority. Additionally, research examining potential disparities in outcomes post-hospice discharge is needed, along with considerations of potential interventions.

Finally, the U.S. healthcare community needs a consistent framework to talk about live discharges from hospice. Live discharge must be treated as any care transition in our health system would be, with consistent language, equitable community resources, and adequate time for hospice clinicians and their patients/caregivers to prepare for the live discharge. As hospice enrollment continues to increase, total individuals discharged alive will also grow and the need for specialized support is critical. Primary and specialty care providers should recognize when their patients have experienced a live discharge from hospice to assist with discontinuity of care, while hospice providers must work to establish a "warm handoff" in their discharge plan. Recognizing changes in condition that requalify patients for hospice can also assist in reestablishing necessary supports before death,

which then follow families through bereavement. Acknowledging live discharges as a care transition, rather than being forgotten or misdiagnosed, will go a long way in identifying those affected and incorporating proper assessment and intervention to support ongoing continuity in their care.

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