

Book Review of Hadley Vlahos. 2023. *The In-Between; Unforgettable Encounters During Life's Final Moments*. Ballantine Books: New York

By

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Introduction

All of us will die. Some of us will elect hospice care beforehand. **The In-Between** by Hadley Vlahos can help all of us better understand death, dying and hospice. Vlahos is a registered nurse with six years of experience working in hospice and palliative care.

Because **The In-Between** is partly a memoir, readers will learn many things about Hadley's life including about her supportive mother, her verbally abusive father, her strict religious upbringing, her eating disorder, her years as a teenage mother and her eventual completion of a nursing degree. But the reason her book has become a *New York Times* bestseller is that her stories of eleven hospice patients and her mother-in-law's final years before succumbing to brain cancer are compelling.

Although this is not a book that refers explicitly to research, many of the topics she discusses in these cases are supported by many studies. Interested readers can go beyond this book to learn about hospice care in America today. We count ourselves among those readers.

Hospice is a type of medical care for people near the end of life. Its focus is to enhance quality of life by providing patients with physical- and psychological-symptom management and support for family caregivers (Ernecoff & Price 2023).

When life expectancy increased in the US in the 20th century, several things happened: the small hospices that often depended on volunteers were no longer able to meet the demand for their services; Congress noted that hospice provided a low-cost option for Medicare benefits; in 1982, Medicare policy expanded to include hospice care (Ernecoff & Price 2023).

The hospice movement changed end-of-life care for many. In 2003, 0.2% of patients died in a hospice facility; in 2017, it was 8.3%, with significant interstate differences (Cross, et al. 2021). Among Medicare recipients, hospice use increased from 22% in 2000 to 52% in 2019 (Teno et al. 2022). Today there are more than 5000 hospices serving almost 2 million people per year (Ernecoff & Price 2023). Hospice is recommended when curative treatments are no longer beneficial and healthcare providers don't expect the patient to improve. In these cases, providers allow patients to enter hospice care. Medicare, Medicaid and most private insurers cover most hospice care costs when the person has a life expectancy of six months or less if their illness was to run its natural course (the Cleveland Clinic, 2023).

Across all diagnoses, the mean length of stay in hospice in 2021 was 92 days with the median stay 17 days (NHPCO 2023). The length of stay in hospice and use of palliative care has great variability by diagnosis and age. For example, patients with neurological disorders like Alzheimer's tend to have an average stay of 155 days while cancer patients average 51 days in hospice (NHPCO 2023). One study of those with advanced lung cancer found that these patients typically lack access to adequate palliative care and support. They continue to receive aggressive care including prolonged hospitalization and invasive procedures towards the end of life (Brown, et al. 2022). A good friend of Emily's, at age 82, was diagnosed with advanced lung cancer. For the next four months, she spent her days alternating between receiving chemotherapy and then recovering from its side effects in the hospital. When she finally entered hospice care, she died two days after coming home.

Insights into End-of-Life Experiences That Readers May Find Consoling and/or Useful

Many of us find it difficult to think about dying before we, or someone we love, receive a terminal diagnosis or are faced with death itself. Roger never really thought seriously about death until his wife Bev died suddenly and unexpectedly three years ago of a heart attack. Bev and he had lived for 55 years together and, if he ever thought about either of them dying, he probably supposed they'd both go at the same time, maybe in a plane crash on a holiday trip . . . or that he'd be the one to go first, maybe playing tennis or golf. After all, isn't that what husbands are supposed to do? He probably avoided thinking about death partly out of fear, but it wasn't a fear of sudden death for himself. A drawn-out period of dying was just too scary to contemplate.

Sudden deaths are relatively uncommon in the United States, however, accounting for perhaps 15% of deaths among working age adults (Keen, et al. 2021). So, most of us will not be fortunate enough, by Roger's lights, to die quickly. Many of us, or our loved ones, will be eligible for hospice sometime—and Vlahos's book will be consoling and/or interesting for us.

But what are some of the consolations? One is that hospice care does bring physical and, in most cases, psychological comfort. Hospice enables the dying person to remain at home (Gaille, 2020). Research suggests that 80% of Americans say they wish to die at home, but only 25% do so; by contrast, 75% of hospice patients do so (LMHPCO 2023). Ten of the twelve patients Vlahos writes about died in their own homes and all ten expressed gratitude for her services there.

One of Vlahos' patients, Mr. Carl, initially resisted hospice care and was rude when he first met Vlahos. "No" was his response to the news that he had a hospice nurse. But Mr. Carl eventually looked forward to Vlahos' visits, not just for the medications that helped control the symptoms of his congestive heart failure, but also for Vlahos' efforts to create common ground by asking him to tutor her about sports (so that she could talk more knowledgably with her boyfriend) and other news of the world. The friendship they developed made Mr. Carl's life (and dying) less traumatic. Moreover, after Mr. Carl died, Mr. Carl's wife tried to ease Vlahos' own grief by saying, "We both love you so much. God put you in our lives. We both know this." Thus, the psychological benefits of hospice seem to extend to loved ones as well as clients, at least by Vlahos' lights.

Research supports Vlahos' implication that hospice patients and their caregivers experience comfort. Kumar

et al. (2017), for instance, matched a sample of families of cancer patients who had died while in hospice with families of such patients who had not used hospice. They found that those who used hospice were more likely than others to report that "just the right amount" of pain medication had been used, that patient's end-of-life wishes had been followed, and that they had received "excellent" quality end-of-life care.

Hospices also generally support families of dying clients with bereavement services before and after death (Meier 2011). Roger experienced no pre-death supports because of Bev's sudden death. But he has grateful friends who have been enabled by hospice to attend the death of loved ones in their own homes and hold their hands as they died.

Roger did join a grief support group provided by his local hospice facility and reaped immediate benefits, not the least of which was his discovery that the feeling of "insanity" brought about by Bev's death was "normal"—virtually everyone in his group had felt this way too. Roger is now a group facilitator for another grief group organized by the hospice facility. This hospice organization has over 200 volunteers as well as over 700 employees, suggesting that the original dependence of hospices on volunteers (mentioned above), and not just professionals like Vlahos, lives on.¹

Vlahos presents evidence that people, at the end of life, often have other comforting experiences, not particularly related to hospice. Most of the twelve patients Vlahos discusses experienced "visitations" of deceased family members or friends in the days before their deaths. And all of these visits were accompanied by a "sense of calm and peace" (p. 250). For "Glenda" the visitor was her deceased sister whom she knew Vlahos couldn't see, even though the sister was, in Glenda's view, standing right next to Vlahos. Glenda apologized by saying, "You think I'm crazy, huh?" Vlahos assured her that she didn't, but the reader might guess Glenda was hallucinating.

But if her sister's visitation was a hallucination, it was clearly not what we usually think of as one. It wasn't at all frightening for Glenda, and it lasted for quite a while. Glenda woke up from sleep and was happy to find her sister was still with her. She evidently took pleasure in her sister's company. One of Vlahos' other clients, Ms. Sue, even seemed delighted by the prospect of her imminent death because her deceased husband was, in her view, "here to get me." And she was finally going "to be with him again" (p.67).

¹Thanks to Robin Blanchette, Volunteer Supervisor, and Deanna Upchurch, Senior Director at HopeHealth for their help.

What Vlahos calls “visitations” are more frequently called “deathbed visions” (DBVs) in the research literature. DBVs may be seen by as many as 60% of hospice patients (Rabitti et al., 2024). The research generally suggests that DBVs have positive effects on the dying person, “not the least of which is lessening the fear of death” (Claxton-Oldfield 2022). Distinguishing between DBVs and frightening hallucinations is important not only for families of the dying, but also for health professionals who might be tempted to respond with medications that diminish DBVs’ comforting effects (Devery et al. 2015).

Vlahos also writes about clients who apparently have some control over their time of death. Her mother-in-law, Babette, for instance, was surrounded by most of her immediate family as she was dying, but seems to have hung on until her son, Eric, is contacted and phones her to say, on speakerphone, “Mom, I love you . . . just as Babette took her final breath” (p. 190).

In Roger’s case, it seemed as though Bev chose to die just after sending him off, with their dog, to mail a letter. The facilitator of his hospice support group claimed that she’d heard so many stories about dying people sending a loved one away, to protect them from the pain of watching them die, that she thought it was no accident. There doesn’t seem to be any scientific evidence that people can control the timing of their deaths, but anecdotal evidence continues to accumulate (Glicksman 2022).

There does seem to be scientific evidence, however, that some of us will experience a “surge” of energy just before we die. Normally, when a dying person experiences something positive, such as the physical and psychological benefits of hospice, the loving caregivers experience parallel benefits. This is not always the case with the energy surges that often occur a few hours before death (Juliao et al. 2023). Shortly before he died, Vlahos’ octogenarian and non-ambulatory client, Mr. Carl, for instance, started walking around his home, apparently playing hide-and-seek with his daughter, Anna, who had drowned as a two-year-old. This, according to Vlahos, caused Mary distress. Mr. Carl, on the other hand, seemed calm and playful, enjoying what Juliao et al.(2023) call a brief “honeymoon period” of physical energy and alertness. Researchers believe that the distress that family members and health providers experience during these surges might be reduced if they were aware of the likelihood of their occurrence.

Hospice as a Business

Vlahos briefly mentions that “hospice and nursing home care are a business” (p. 112), but she does not elaborate. She does not describe what hospice enrollment covers nor how often the care is adequate. Patients who enroll in hospice are restricted in the care they receive as the Medicare Hospice Benefit’s payment arrangement limits expensive palliative treatments and prohibits life-prolonging treatments like dialysis, even when delivered with palliative intent (Ernecoff & Price 2023).

In the U.S., Medicare pays for most hospice care with hospices getting a *per diem* rate for the care of each patient; the hospice is then responsible for covering all costs related to the terminal condition from that per diem rate (Ernecoff & Price 2023). This means that the hospice is not reimbursed based on how many services it provides (Kofman 2022).

Although the hospice movement began with a vision that patients could die with dignity at home, now “it’s a twenty-two-billion-dollar industry plagued by exploitation” (Kofman 2022) with for-profit organizations dominating this sector (Odejide & Aldridge 2023). Companies in the hospice business can get the biggest returns in the American health care sector for the least amount of effort.

In her discussion of her cases, Vlahos shows that she is committed to each of her eleven patients. She goes above and beyond the minimum care required. For example, as one of her patients was homeless Vlahos made many visits to his “home” under a bridge. We don’t know if she is a typical hospice nurse as Medicare requires only that a registered nurse make an on-site visit to the patient’s home once every 14 days – and even this requirement is frequently unmet (OIG 2019). With these minimal requirements and the ability to outsource the bulk of the labor to unpaid family members and low paid staff and volunteers, organizations can make a great deal of profit. Exposé’s have documented how some organizations engage a great deal of fraud, including bribing physicians to bring them new patients and recruiting patients who are not dying (Kofman 2022).

One of the most important aspects of a hospice organization is its profit or nonprofit status. Vlahos does not tell us if the one that employed her was a nonprofit. Typically, for-profit organizations provide fewer nursing visits and use less skilled staff. A recent report from MedPAC, the independent agency advising Congress on Medicare spending, “found that in 2020, for-profits received 20.5 percent more from Medicare

than they spent providing services. The margin for nonprofits, whose daily per-patient expenditures are higher, averaged 5.8 percent” (Span 2023). Studies of family experiences with hospice conclude that quality of care varies in all types of hospices. However, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey data from 653,208 caregiver respondents found poorer care experiences reported for the for-profit ones (Price et al. 2023).

The upshot of our look at the research is that, if one is looking into hospice for oneself or a loved one, it makes sense to investigate reports about the quality of care they offer. Even those most critical of the for-profit sector confess, however, that most of its players “do a decent job” and that most family caregivers still give “hospice care high approval ratings” (Span 2023). But a little care in choosing any specific one makes sense.

Stresses on Caregivers and Hospice Workers

Vlahos tells us that “Caretaking is hard, emotional, exhausting work that can go on for an extended period of time . . . Even with Medicare covering the cost of a hospice nurse like me, the caregiver is still in charge of the day-to-day care of the patient which can be a lot” (2023, p. 112). Her descriptions of the stresses on spouses, children and other caretakers of hospice patients and the ways that hospice staff can help are useful. The twelve dying patients in her case studies all had at least one supportive friend or family member including some care givers who were employed. Studies find that family caregivers find the situation emotionally difficult even when they are satisfied with the care others provide. Those who combine work and end-of-life care experience more of a burden. When obligations increase over the course of the illness trajectory, family caregivers were more likely to experience burnout and needed to take sick leave (Bijnsdorp et al. 2022).

Caring for dying people is not easy. Vlahos describes one patient who upon meeting her said, “I don’t understand what the point of you is” (p. 42). As she became more confident in her role, Vlahos learned to reframe her work to think of doing “nothing” as doing something by “being there, offering comfort and solidarity” (p. 54). Her work as a hospice nurse was not to cure people or bring them into the ER if there were major problems, but to offer comfort care, pain relief and help in ways she could - even if it meant just watering someone’s plants and making sandwiches (p. 65). Studies of hospice employees echo Vlahos’s feelings as they report feeling valued and supported in their

professional role by patients and their family members (Lehto et al. 2020).

Hospice staff experience the suffering of their patients and family members and can have risks to their mental and physical health (Yu et al. 2023). Vlahos describes her grief when her patients die, sometimes sobbing with family members (p. 39). Studies of nurses describe how they are emotionally and physically affected when they first experience a patient’s death (Keskin, Kızıltepe & Koc 2024).

In addition to managing the grief associated with the death of patients, hospice workers report many challenges, among them the burden of heavy caseloads, changeable assignments and schedules, travel-related and weather problems, administrative demands, balancing work and family/personal life and taking ‘work’ home (Lehto, et al. 2020). Working in hospice can result in compassion fatigue - the emotional and physical exhaustion caused by the long-term demands of caregiving in their role (Keidel 2002).

Although compassion for patients is critical, hospice workers must also prioritize their own needs. Studies have found that self-compassion is positively related to the psychological, social, and spiritual well-being of hospice professionals (Garcia et al, 2021). Vlahos gives an example in her description of the strong guilt feelings she had for leaving a home after the death of her hospice patient, Reggie, only to find out the next day that Reggie’s wife had committed suicide soon after the death (p. 158). Dealing with her sense of guilt and self-blame took quite a while and therapy before she forgave herself.

Vlahos notes the high turnover among hospice workers, many of whom experience burnout. She describes a change that helped her continue in job – feeling empathy rather than sympathy. With sympathy she had put herself in her patients’ shoes, felt their pain and their loss and was deeply affected (p. 237). She notes that “Empathy allows me to be present and compassionate without taking a situation as my own, and it has allowed me to continue being a good nurse without burning out or engaging in the dark humor that so many in my profession do, for their own sanity.” (Vlahos 2023:238).

CONCLUSION

We have obviously been inspired to investigate some of the research associated with hospice care by Vlahos’ book. We hope we haven’t given the impression that **The In-Between** is as dry as our review may sound. On

the contrary, it is an easy read for both social scientists and a more general audience interested in the topic. More specifically, this book could be used, in our view, in courses on the sociology of aging and or death and dying.

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