

Hospice Death Vigils: The Final Seven Days

The State of the Science and Practice

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Objectives

1. Identify common challenges for hospice staff and family during the final 7 days of a patients life.
2. Discuss ways to improve the death vigil experience
3. Create a list of action items to take home to discuss with the hospice team

Challenges for Hospice Staff During Vigils

Patient challenges: Physical challenges

When a patient is struggling to breathe and you're trying to keep them comfortable, some of the gasping and some of the noises that the patients make, it's uncomfortable for the family. (P2026)

Caregiver challenges: Medications, exhaustion, visitors, psychosocial distress, family stress

The every hour medication, the changing of diapers, management of symptoms, turning, lifting. They're not medical people, and it's pretty big, it's a lot to ask of a family member because they're not medical and they don't understand.... You can just call them back after you've left the house. "Hey, are y'all okay?" Unless it's in the middle of the night, I usually try to follow up to see how they're doing after a medication change, and that seems to help their anxiety.

Challenges for Hospice Staff During Vigils

Personal struggles

You lose out on sleep. You lose out on family time. You lose out on so much of your personals because of this job, but it's caring for others and really supporting others and being there for them as they go through difficult situations. Because I understand the physiological things; I understand the emotional. But challenging is, for me, the work hours. ... I wish sometimes I could be available 24 hours a day, because I know they're going to die. (P2017)

The Voices of Hospice Staff

- ▶ *I would say giving the medications is probably the biggest thing because they're in those final hours, and you're giving the morphine and Ativan, the comfort medications, and atropine. A lot of people have a misconception that morphine kills people. . . . They struggle with giving those medications. . . . They don't give the medication because they're afraid that if they give that dose of morphine, then [the patient is] going to die faster. (P2024)*
- ▶ *... patients can have that gurgling sound, and it's not distressful to the patient at all. It's not harmful or distressing, but it's very distressing to the family. Oftentimes, when I talk to families months after the patient passes, that's something that they remember forever, that sticks out in their mind forever. (P2018)*

Challenges for Hospice Caregivers

Community Resources

- ▶ *I was part of an Alzheimer's Association caregiver group, and I found several online sources for support groups and webinars. I treated it like my job. I did something like that every day to take care of me. To help me understand what was coming next. (P1049)*

Hospice Agency characteristics (Staff, consistency in care, education)

The hospice gives you this booklet. . . . I remember one of the most wonderful things with the booklet is it talks about how it's not unusual for your loved one to get a burst of energy and almost feel like themselves It goes on to say that's kind of the energy coming to help them to pass to the next stage. I thought that was a beautiful thing to read. (P1033)

Challenges for Hospice Caregivers

- ▶ Symptoms
 - ▶ Pain
 - ▶ Abnormal Breathing
 - ▶ Restlessness/Delirium

Voices of Hospice Family Members



And Another



Challenges for Hospice Caregivers

- ▶ **Social Support**
- ▶ **Flexibility of employment**
 - ▶ *I was real fortunate because this work from home stuff, I had that 10 years ago. I was really fortunate because the job that I do—I'm a number cruncher basically. Everything I do is like computers and spreadsheets so even then it didn't really matter if I was at work. I had a very understanding boss who just let me come in for meetings and stuff while this was going on. (P1002)*
- ▶ **Family with medical training**
 - ▶ *My nephew was a nurse. He gave her the medicine. They didn't stay the 24 hours. They just came, and then they would leave and tell us what to do. (P1007)*
- ▶ **Financial Resources**

Challenges for Hospice Caregivers

Medication administration

Administering morphine and lorazepam, I was comfortable doing it for the most part, but then on the other side of it, it is your loved one, and giving them medication can be emotionally stressful. I think especially because you're giving them something really strong. (P1008)

Physical Demands

What made it most difficult was, again, probably the diapering and just lifting him. In the very beginning, he did get up a couple of times to go to the bathroom or he wanted to sit in the chair. Physically moving him was probably the hardest. (P1116)

Fatigue/Lack of Sleep

I was only sleeping maybe an hour at a time and sometimes less. It was just me, so it was extremely hard, I have PTSD from it. (P1014)

Recommendations for change

- ▶ Emotional/physical toll on staff- Burnout
- ▶ Need for 24-hour patient care
- ▶ Caregiver fatigue