



**Weill Cornell Medicine**

# Home Hospice Care: A Journey from Understanding Hospice Discharge to Developing Caregiver Interventions.

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# Financial Disclosures

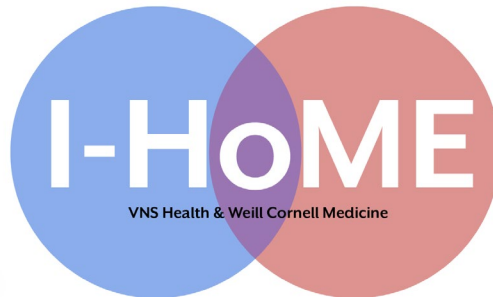
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My research has been focused on improving end-of-life care in the home hospice setting.



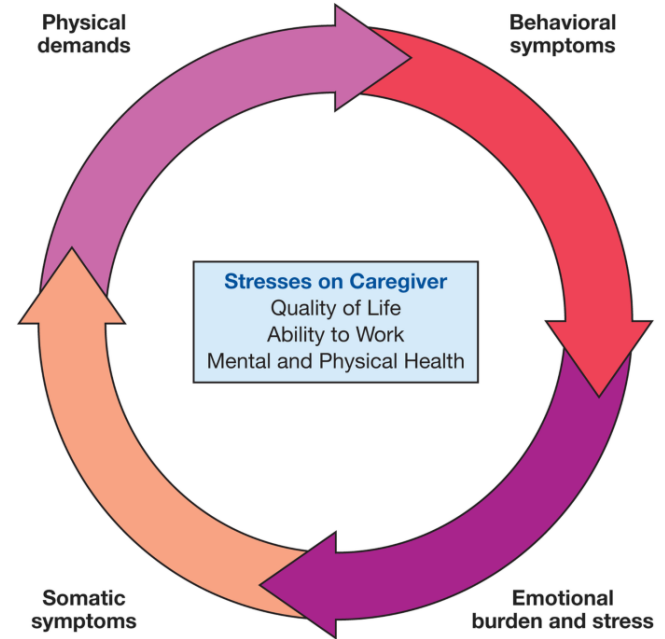
Symptom Burden

Caregiver Burden



# Family caregivers dedicate significant time to caring for patients at the end of life.

- 2.3 million people care for people 65 years or older in their final year of life
- 40-65 hours of care per week
- 90% are unpaid
- Underappreciated and overburdened



\*Ornstein, Katherine A., et al. A national profile of end-of-life caregiving in the United States. Health Affairs 36.7 (2017): 1184-1192

\*Luth EA, Pristavec T. Do Caregiver Experiences Shape End-of-Life Care Perceptions? Burden, Benefits, and Care Quality Assessment. J Pain Symptom Manage. 2020 Jan;59(1):77-85

\*Image: Shapiro, E., et al. Analysis of the caregiver burden associated with Sanfilippo syndrome type B: panel recommendations based on qualitative and quantitative data. Orphanet J Rare Dis. 2019;14:168

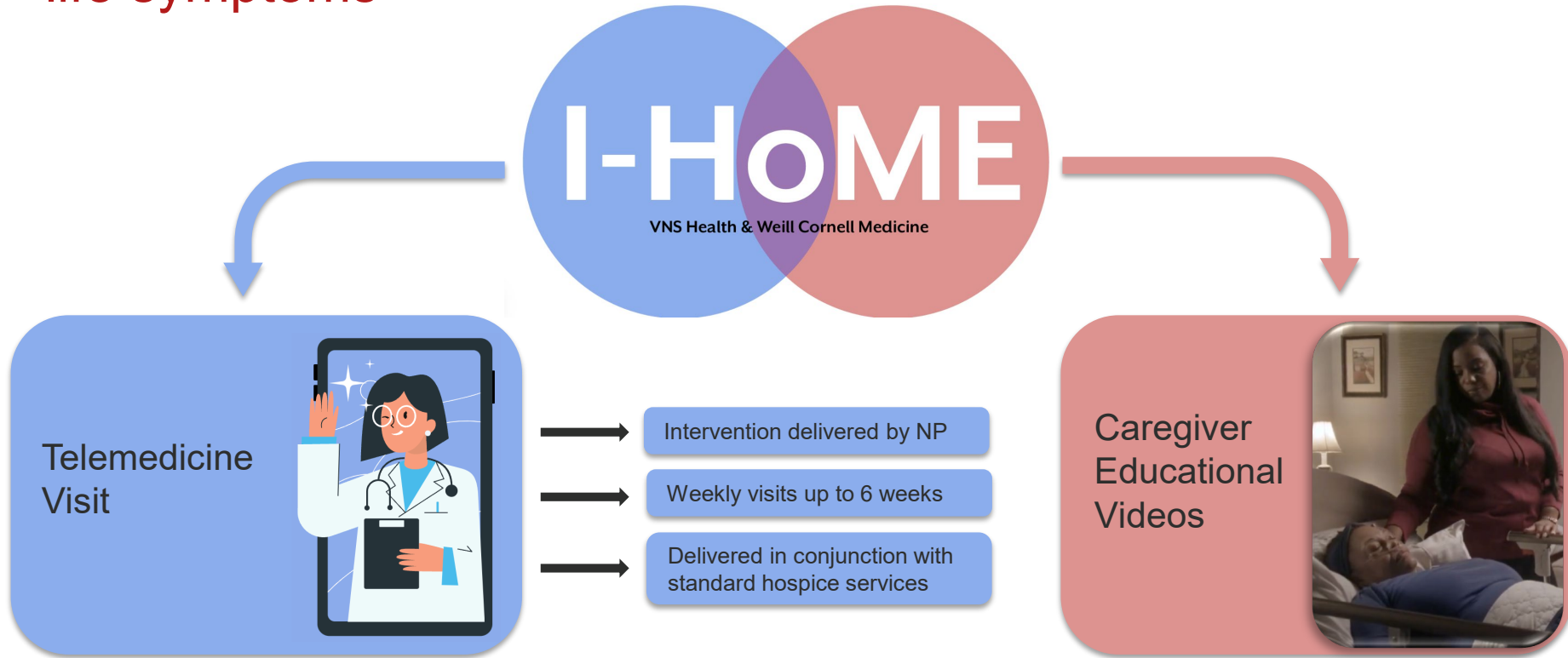
# Family caregivers are more burdened and stressed in home hospice care.

## Data from our pilot study of 80 hospice caregivers

- Provided, on average, 12.6 hours of care per day
- Reported caregiver responsibilities
  - 81% provided personal care to the patient
  - 90% managed symptoms
  - 86% administered medications
  - 92% communicated with hospice staff
- 38% moderate to severe anxiety, 24% moderate to severe depression



# I-HoME – Improving Home hospice Management of End-of-life symptoms



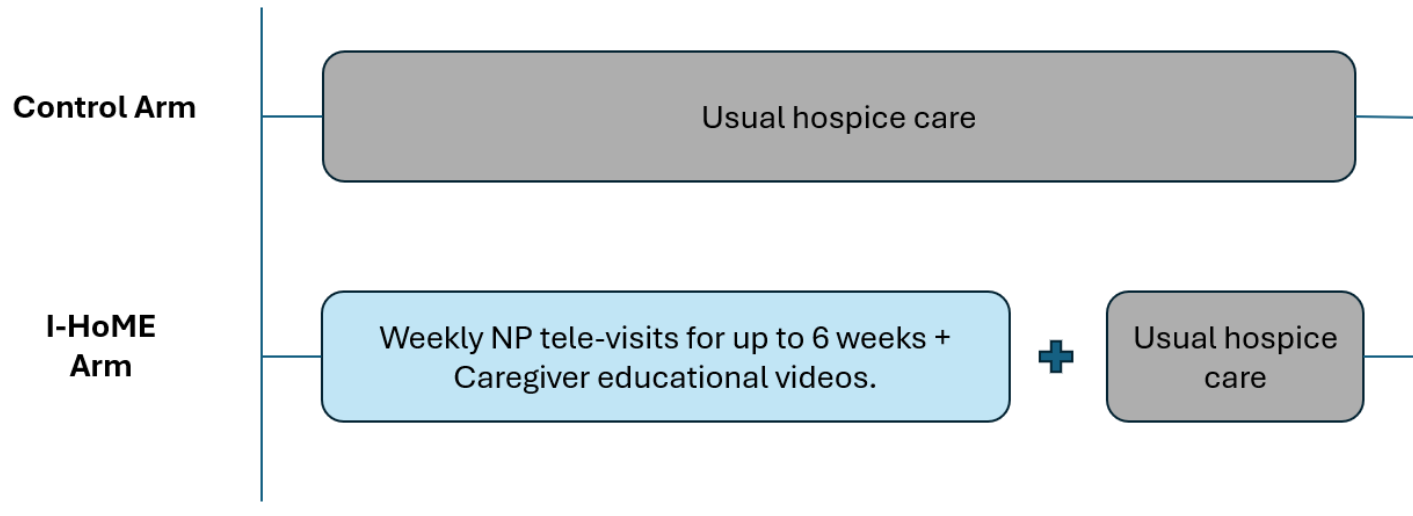
An example of a caregiver videos we developed.



# This was a pilot RCT trial.

**Baseline assessments**  
ESAS, ZBI-12, GAD-7, PHQ-9.

**Weekly assessments for up to 6 weeks**  
ESAS, ZBI-12, GAD-7, PHQ-9.



## We found moderate feasibility with the intervention.

- 121 out of 145 potential tele-visits (83%) were completed
- Minimal caregiver dropout (6%)
- 60 videos were recommended – only 23 videos were watched (38%)
- Overall, 96% caregivers found the delivery of the intervention to be feasible

## We found high acceptability with the intervention.

- 96% reported being either satisfied or very satisfied with the tele-visit session
- 74% of caregivers found the videos helpful
- 83% of caregivers agreed or strongly agreed that the intervention enhanced their knowledge of EoL symptoms.
- 83% agreed or strongly agreed that it prepared them to better manage the care recipient's symptoms



# Lessons learned: What are the challenges when designing and implementing interventions in the hospice setting?

Family caregivers are busy

Difficult to recruit hospice patients

Attrition due to patient death

\*Cruz-Oliver DM, et al. Recruitment, Retention and Intervention Delivery Experiences With Hospice Family Caregivers. *American Journal of Hospice and Palliative Medicine*. 2023;40(4):409-415

\*Oliver DP, et al. Challenges in Implementing Hospice Clinical Trials: Preserving Scientific Integrity While Facing Change. *J Pain Symptom Manage*. 2020 Feb;59(2):365-371

# Our work has emphasized the important role that hospice caregivers play in EoL care and symptom management.

- Studying interventions that can support caregivers during this intense caregiving experience.
- Significant caregiver mental health symptoms – anxiety and depression
  - Exploring testing single-session interventions to support caregiver mental health
- Exploring opportunities to use technology to support symptom management in patients
  - Use of wireless sensors to detect and predict respiratory distress

# Thank you

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