### Immersion Experience

My immersion through Compassus Hospice gave me insight into the experiences of family caregivers. During my immersion, I was matched with patients and their caregivers that I would meet with weekly. During this time, caregivers would share their sentiments towards their role in caregiving. Compassus provides talk therapy and bereavement counseling, however, the need for coping skills for the caregivers continued to exist.

### Problem

During my immersion, caregivers struggled with witnessing family members in pain. This not only caused the caregivers further distress, but also hindered their ability to accurately report the pain their family member was experiencing, causing further unnecessary pain and caregiver distress. Current literature describes this as a widespread problem.¹

### History

Hospice has only existed since 1967 with the opening of Dame Cicely Saunders’s St. Christopher’s facility. Previously, death was seen as a failure to the medical community.²

- As a result, hospice practices lag far behind other fields of medicine, and significant gaps in the understanding of the death process and its impact on families exist.²,³
- Research today has identified “caregiver burnout” but has not extensively studied its long-term impacts.

### Caregiver burnout

- Defined by the Cleveland Clinic as “a state of physical, emotional, and mental exhaustion” and is accompanied by attitudes of apathy and negativity.⁴
- Caregiver distress strongly correlated with the nearing of death and expression of pain and distress from family member.⁴,⁶,⁷
- Caregivers currently provide $630 billion of care to family members in the United States.⁵
- Compared to non-caregiving peers, caregivers had a 63% higher mortality rate.⁶

> I don’t know what to expect next and I can’t be afraid in front of [my mother].
> I don’t really do anything besides [take care of my dad] anymore.
> I’m just so tired. All the time. —family caregivers during immersion

### Current understanding and approaches

- Traditional talk therapy is often offered in hospice, but has not been found to improve QOL of caregivers.¹
- Caregiver stress is most strongly linked to distress expressed by the patient.¹,³,⁵,⁸
- Supporting caregivers can reduce distress of patients.⁹
- Effective support related to increasing caregiver efficacy and confidence.¹,⁷

### Conclusion

Due to its previous success for cancer patients and current understanding of support needed for family caregivers, COPE intervention would be an appropriate and effective method used in hospice settings to prevent caregiver burnout.

### COPE Intervention

COPE is psychoeducational intervention based on creativity, optimism, planning, and expert information to train patients and their families to anticipate, cope with, and solve problems.

- Form of CBT therapy, focusing on modifying thought patterns and their resulting behaviors
- COPE found to be highly effective for terminal cancer patients and their families.⁷,⁹
- Problem (internal locus of control) vs. emotional-focused (external locus of control) problem solving.⁷
- Problem-focused linked to higher tolerance to stress.¹,⁷
- Benefits included increased caregiver QOL and reduced burden related to patient symptoms and caregiving tasks.⁷

### Perception of Pain- A Cycle

- Patient is in distress
- Distress increases
- Caregiver is distressed
- Caregiver responds appropriately
- Patient pain appropriately managed
- Caregiver burden reduced
- Patient distress reduced
- Pain goes underreported

### Implementing COPE- Breaking The Cycle