

Preventing burnout in hospice: Cognitive behavioral therapy (CBT) for family caregivers

Tatum Moleski (Biology), Paul Flaspohler PhD, Katherine Abbott PhD

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 community². The dying were taken care of by their family members or left in almshouses.

- As a result, hospice practices lag far behind other fields of medicine, and significant gaps in the understand of the death process and its impact on families exists^{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 negativity⁴
- Caregiver distress strongly correlated with the nearing of death and expression of pain and distress from family member^{4,8,9}
- Caregivers currently provide \$630 billion of care to family members in the United States⁵
- Compared to non-caregiving peers, caregivers had a 63% higher mortality rate⁶

"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 caregivers¹
- Caregiver stress is most strongly linked to distress expressed by the patient^{1,3,5,8}
- Supporting caregivers can reduce distress of patients⁸
- Effective support related to increasing caregiver efficacy and confidence^{1,7}

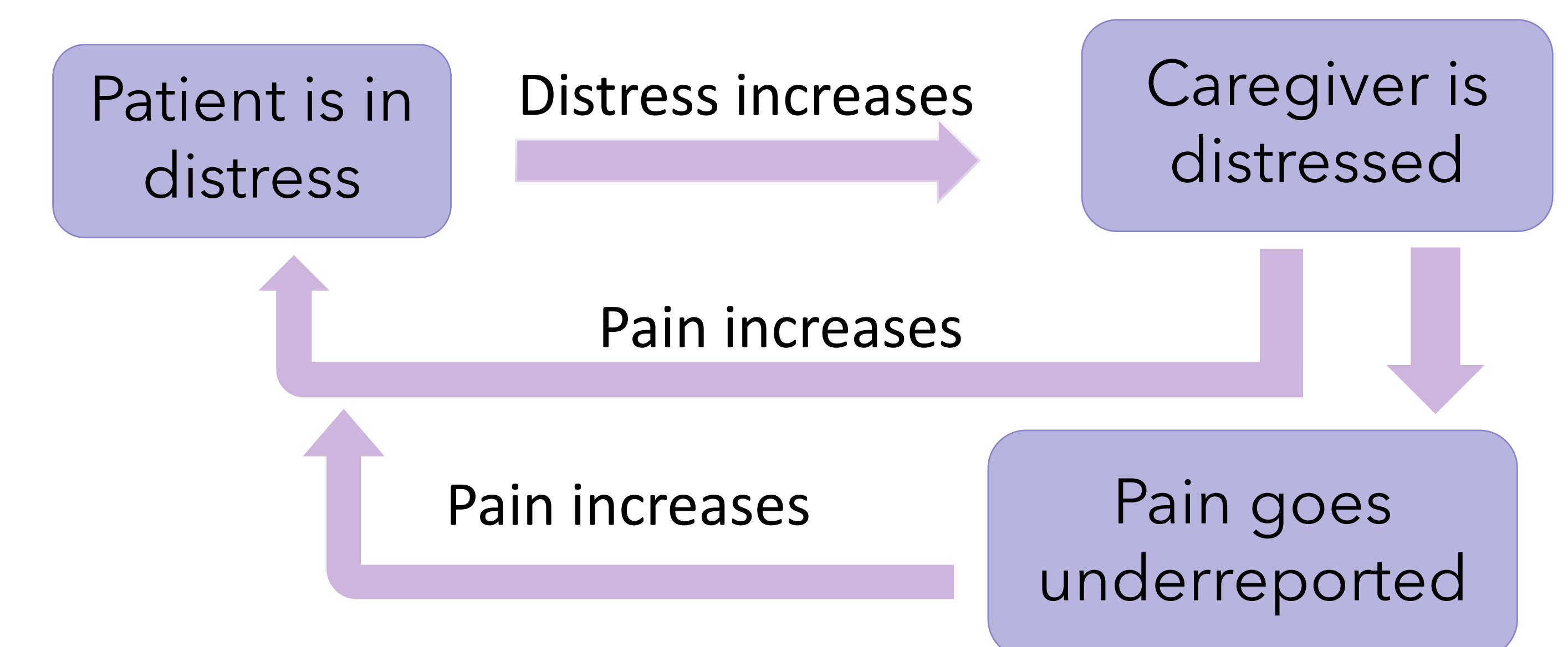
Conclusion

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

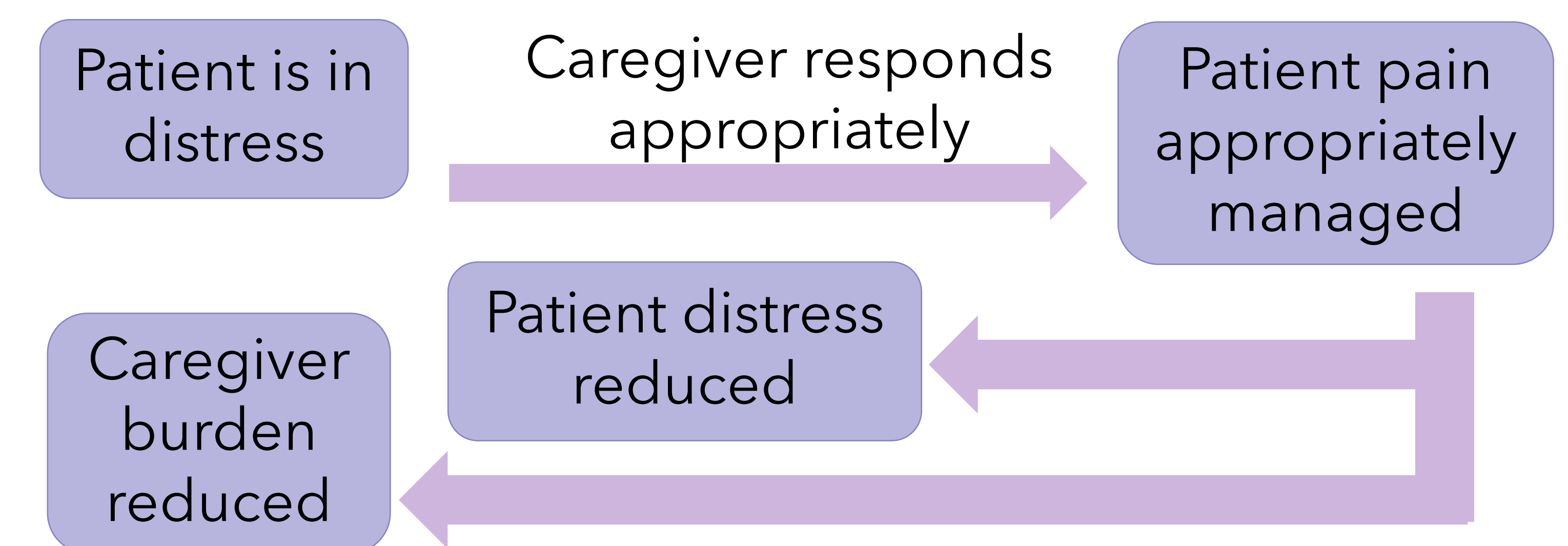
COPE Intervention

- COPE is psychoeducational intervention based on creativity, optimism, planning, and expert information to train patients and their family members 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 solving⁷
 - Problem-focused linked to higher tolerance to stress^{1,7}
 - Benefits included increased caregiver QOL and reduced burden related to patient symptoms and caregiving tasks⁷

Perception of Pain- A Cycle



Implementing COPE- Breaking The Cycle



1. Mcmillan SC, Small BJ. Using the COPE Intervention for Family Caregivers to Improve Symptoms of Hospice Homecare Patients: A Clinical Trial. *Oncology Nursing Forum*. 2007;34(2):313-321. doi:10.1188/07.onf.313-321

2. Pajka SE. Doctors, Death, and Denial: The Origins of Hospice Care in 20th Century America. *MSSA Kaplan Prize For Yale History*. 2017;8. http://elischolar.library.yale.edu/mssa_yale_history/8.

3. Tang ST, Li C-Y, Chen CC-H. Trajectory and determinants of the quality of life of family caregivers of terminally ill cancer patients in Taiwan. *Quality of Life Research*. 2008;17(3):387-395. doi:10.1007/s11136-008-9316-7

4. Caregiving: Recognizing Burnout. Cleveland Clinic. <https://my.clevelandclinic.org/health/diseases/9225-caregiving-recognizing-burnout>. Accessed April 9, 2019.

5. Bastawrous M. Caregiver burden: A critical discussion. *International Journal of Nursing Studies*. 2013;50(3):431-441. doi:10.1016/j.ijnurstu.2012.10.005

6. Schulz R, Beach SR. Caregiving as a Risk Factor for Mortality. *Jama*. 1999;282(23):2215. doi:10.1001/jama.282.23.2215

7. Mcmillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer. *Cancer*. 2006;106(1):214-222. doi:10.1002/cncr.21567

8. Haley WE, Lamonde LA, Han B, Burton AM, Schonwetter R. Predictors of Depression and Life Satisfaction Among Spousal Caregivers in Hospice: Application of a Stress Process Model. *Journal of Palliative Medicine*. 2003;6(2):215-224. doi:10.1089/109662103764978461

9. Andrews SC. Caregiver Burden and Symptom Distress in People With Cancer Receiving Hospice Care. *Oncology Nursing Forum*. 2001;28(9):1469-1474. <https://www.ncbi.nlm.nih.gov/pubmed/11683316>.