

Tension around autonomy increases family conflict at end of life

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Jacquelyn Benson, assistant professor of human development and family science, says communication, support and self-care are critical in reducing stress related to caregiving at end of life. Credit: University of Missouri

Conflict within families can be stressful and confusing, and it can lead to feelings of sadness. It also is incredibly common and in many cases, a necessary part of family dynamics. New research from the University of Missouri highlights how caregivers can better manage family conflict as



they deal with the approaching death of a loved one.

Jacquelyn Benson, assistant professor of human development and family science, found that autonomy is a central tension in caregiving at the end of life. She suggests that several strategies, including communication, formal support and emotional self-care, can be used by caregivers to address family conflict.

"Conflict is stressful, we all know that," Benson said. "However, it also is necessary and can lead to positive change. I hope these findings will inspire alternative ways to think about family conflict when it comes to end-of-life decision-making."

Benson and her team analyzed data originally provided by caregiving participants of a clinical trial. They specifically looked at interviews from caregivers who were actively caring for a loved one in <u>hospice care</u> to study how the caregivers discussed conflict as it related to caregiving.

The central theme that emerged from the data was that of autonomy. Throughout the data, Benson found that struggles over who had control was a common feature in most of the conflicts and tensions the caregivers discussed.

One caregiver described this tension in simple terms, saying that her father's insistence on remaining independent was "a burden." When her father's struggle to remain autonomous lessened, her caregiving burden eased. In another example, a caregiver caring for her spouse felt her husband's brothers did not appreciate the severity of his health condition and the level of caregiving that he required, which led to tension when caregiving decisions were made.

"Our findings highlight how family conflict is experienced and managed by caregivers," Benson said. "Avoiding conflict altogether is not the



answer because it's an unrealistic goal. Instead, caregivers should have conversations with hospice staff about ways they can improve their caregiving experience by communicating their needs and concerns with the person they are caring for and other family members."

For example, although hospice staff and nurses might not witness overt conflict related to <u>caregiving</u>, they might witness caregiver reactions that are symptomatic of <u>family</u> conflict. Those observations can lead to conversations that will minimize psychological distress and minimize <u>conflict</u>.

"Accounts of <u>family conflict</u> in <u>home care</u>: the central role of autonomy for informal caregiver resilience," was published in the *Journal of Family Nursing*. Other authors on the study were Debra Parker Oliver, and Karla Washington from MU and George Demiris from the University of Pennsylvania. This research was supported in part by the National Institute of Nursing.

More information: Jacquelyn J. Benson et al. Accounts of Family Conflict in Home Hospice Care: The Central Role of Autonomy for Informal Caregiver Resilience, *Journal of Family Nursing* (2019). DOI: 10.1177/1074840719828091

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