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Study suggests self-determination as key to avoid caregiver burden

by Nanyang Technological University



A Singapore study of family caregivers of the terminally ill suggests that self-determination is the key factor that can protect them from caregiver burden—a negative state impacting a carer's wellbeing.

The study, conducted by a team of Nanyang Technological University, Singapore (NTU Singapore) psychologists through interviews with 20 [family caregivers](#), revealed that they tend to be motivated and satisfied in their caregiving when they have built up self-determination. This is defined by the researchers as becoming competent in caregiving related tasks, gaining a strong

sense of kinship with both the patient and other [family members](#), and taking control and ownership of their caregiving responsibilities.

The study examines internal psychological processes that motivate family caregivers to support their loved ones who are at the end of their lives. It also provides recommendations for therapists and those in the palliative service on ways to enhance family caregivers' sense of self-determination, instead of the usual focus on a pragmatic approach.

Previous studies in other countries have suggested that pragmatic interventions focused on external circumstances, such as access to resources and availability of social support, are key to a caregiver's wellbeing.

However, NTU's study focused on the beliefs, values and goals of caregiving that motivate the Singaporean caregiver, and found that each of these was viewed as equally important factors in sustaining the family member's caregiving.

Principal investigator of the study Associate Professor Andy Ho from the Psychology program at the NTU School of Social Sciences, said, "Policymakers and healthcare professionals often focus on the hardware for family caregivers, such as healthcare subsidies and proper lift-and-carry techniques. While it is undoubtedly beneficial to relieve family caregivers of those tangible stressors, our findings serve as a reminder that the 'heartware' is equally important too. The internal beliefs, values and goals of family caregivers are ultimately what give them the strength to sustain themselves positively and embrace the caregiving journey when the going gets tough."

Therapists and those in the palliative care service can use insights from the study to develop programs aimed at boosting self-determination of family caregivers of the terminally ill.

Findings from the study, which was published recently in the journal *BMC Palliative Care*, may also be relevant to other Asian societies, said Assoc Prof Ho.

Internal motivations give family caregivers strength

Working closely with collaborators from the HCA Hospice Care, Tan Tock Seng Hospital, Dover Park Hospice, Methodist Welfare Services and the Singapore Cancer Society, the NTU-led research team conducted detailed interviews with 20 family caregivers of older palliative care patients aged over 50 and with a prognosis of less than 12 months.

The Singaporean patients and family caregivers were drawn from various socioeconomic backgrounds and ethnicity, and all interview participants were over 21 years old and identified by the patient as their primary carer.

The psychologists analyzed the transcripts of the interviews and revealed six consistent themes that could either nurture or diminish a caregiver's wellbeing. Among them was the concept of

honoring fidelity, where caregivers were motivated to commit to caregiving to avoid regret, and the notion of preserving gratitude—where caregivers were driven to show appreciation to their family member for how they had treated them in the past, say the authors.

However, most important to nurturing a caregiver's wellbeing in the end-of-life caregiving role is fulfilling and enhancing one's sense of self-determination.

The authors believe that it would be more useful for healthcare professionals and policymakers to support family caregivers by adopting a self-empowerment approach—in particular, one that pays attention to the Asian value of honoring filial piety. For example, programs should be designed to help caregivers feel connected and supported by the family, and to emphasize filial piety through love and compassion, instead of obligation and duties.

Such programs can take the form of peer support or goal setting to develop a caregiver's self-efficacy, or through mindfulness practice and the arts, which can give participants a sense of control.

New self-help book to support family caregivers and patients

Informed by the research findings and their earlier works, Assoc Prof Ho and his team published in November 2020, a self-help book called "A Family Dignity Intervention Journey: Our Lasting Legacy" to help family caregivers and family members strengthen bonds.

Family caregivers and the family members they are caring for can increase the bond of relatedness between each other through family projects that encourage the recall of shared memories and by expressing appreciation.

Through a series of introspective activities, the book guides patients and family caregivers towards intentionally revisiting important memories in their lives, to express appreciation, find reconciliation, pass on wisdom, and build a legacy document.

"When the typically pragmatic Asian ways of showing affection such as bringing home an income or cooking a meal are no longer attainable amid a serious illness, we must turn to other meaningful forms of communication," said co-author of the study Geraldine Tan-Ho, a research associate at the NTU School of Social Sciences. "Our Lasting Legacy' aims to facilitate this process of deeper emotional connections between individuals and their families, and to find hope, meaning and dignity through shared memories."

Published in both English and Mandarin, the book was funded by Singapore's Ministry of Education and will be distributed to more than 60 palliative care units and hospice care institutions.

Dr. Chong Poh Heng, medical director of HCA Hospice Care, Singapore's largest home hospice care provider and among the first institution to receive the book said, "The self-help book is a concrete

tool that patients and caregivers can use to continue conversations started by hospice care teams. It adds another element to the family-centered intervention that delivers many benefits proven in our collaborative study to enhance dignity in the dying."

Ms Evelyn Leong, chief executive of the Singapore Hospice Council, said, "Some people are uncomfortable in verbalizing their feelings and thoughts. With the guided questions in this self-help book, it will help readers reflect on their life experiences and express their innermost thoughts through writing and drawing."

Following publication of the self-help book, the research team hopes to develop an interactive online version, and to train more palliative care workers in family dignity intervention to better support the psycho-socio-spiritual needs of patients and their [family](#) caregivers facing life's end.
