

Grief in dementia care

Family caregivers of people with dementia may experience grief in advance of the death of their care recipients, which is termed anticipatory grief. It involves stages of coping from mourning to psychosocial reorganization incurred by the anticipation of the loss of a loved one in the near future¹. For dementia caregivers, in particular, this sense of loss can entail the losses of companionship, personal freedom, control, well-being, and personhood for the care recipient. The grieving process is often characterized by anticipation and ambiguity about the future as well as a wide range of negative emotions, such as anger, frustration and guilt².

Studies from the western countries estimated that around 47% to 71% of the caregivers experience anticipatory grief^{3,4}, and close to 10% may be at risk of severe grief reactions needing professional help⁵.

Anticipatory grief of family caregivers may be attributable to the behavioral problems of the care recipients. A study⁶ involving eighty dementia caregivers revealed that anticipatory grief of spouse caregivers was more affected by disruptive behavioral problems, whereas adult children caregivers reacted more to depression-related behavior problems. Higher levels of anticipatory grief is positively associated with a number of negative outcomes, including depression and poor emotional health, burden, less satisfaction with care, and poorer problem solving abilities in dementia caregivers^{2,7}. Furthermore, longitudinal data suggested that dementia caregivers with greater anticipatory grief tended to suffer from greater grief reactions following the death of their care recipients^{8,9}. The above research findings carry important implications on how healthcare professionals ought to take anticipatory grief into consideration when delivering services or interventions for dementia caregivers.

Despite numerous research findings on the issue, research on anticipatory grief in Chinese dementia caregivers is scarce. One qualitative study on twenty Chinese family members of terminally ill patients found that anticipatory grief was one of the most common experience reported by these family members¹⁰. Similar to their counterparts in western countries, Chinese family members also expressed feelings of anger, unease, sadness, and helplessness. This suggests that anticipatory grief is highly relevant in the Chinese culture.

In Hong Kong, support services provided for dementia caregivers focus more on reducing caregiver stress, burden, and depression. Caregiver training is designed to address care task-oriented skills, such as education on disease process, behavior management, increasing competency, stress management, and utilization of community services. More studies are

needed to understand the grieving process within the Chinese dementia caregiving context so that a more holistic service mode can be developed.

With the Knowledge Transfer Project Fund of the Chinese University of Hong Kong, the Jockey Club Centre for Positive Ageing collaborates with the Department of Medicine & Therapeutics and the Department of Social Work, CUHK to implement a study on anticipatory grief in dementia care. The study will examine the grief pattern the family caregivers of people with dementia, and how grief affects dementia care in local context. The study also intends to develop self-help strategies for the caregivers to handle their grief in dementia care for a smoother caring journey.



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