Older Adults, Caregiving, and Late-Life Mental Health Issues

By Nancy P. Kropf

A trio of late-life mental health scenarios demonstrate that families must seek to understand and cope with their older relatives' mood and behavior changes.

Older adults become caregivers in later life for a variety of reasons, giving rise to role transitions and altered family relationships. This article offers three late-life mental health scenarios that require spouses or partners, adult children, and-or others in close relationships with an older adult to deal with changes in mood and behavior. Two of these conditions, geriatric depression (experienced along with physical health conditions) and complicated grief, typically arise during later life. The third condition, severe mental illness, emerges earlier in the life course, but includes age-related changes, in both the care provider and care recipient, which impact the caregiving relationship.

For each condition, a brief summary of the nature of the mental health condition is described, as well as its impact on caregiving and support relationships.

Specific changes, such as role transitions and added care-provision responsibilities, are highlighted and illustrated in an accompanying case example (see the Author's Note on page 28).

Geriatric Depression

Physical and health changes that occur in later life can be accompanied by comorbid psychosocial conditions. In particular, patients who have had heart attacks and strokes have high incidences of anxiety and depression, post-event (Simning, Seplaki, and Conwell, 2018). This is notable, as these two health conditions are leading chronic conditions in adults older than age 65 (Federal Interagency Forum on Aging-Related Statistics, 2016).

In particular, a stroke often results in physical changes that require rehabilitation to restore functioning. In a meta-analysis on research about depression and stroke, Ayerbe et al. (2013) reported that 55 percent of post-stroke patients experienced depression during recovery. A predictor of depression is disability status, especially paresis (muscular weakness) and incontinence, and resulting functional limitations (Ayis et al., 2016).

→**ABSTRACT** During later life, older adults may be caregiving for people with late-onset mental health issues. The situation can alter family relationships and cause role transitions. This article offers three late-life mental health scenarios that require spouses or partners, adult children, and-or others to deal with an older adult family member's mood and behavior changes. Through case examples, the author explores geriatric depression, complicated grief, and provision of extended care for persons with severe mental illness, and highlights support for older care providers. | **key words**: *care provision, aging and mental health, complicated grief, geriatric depression, aging and severe mental illness*

For care providers, this experience can result in multiple care-related outcomes. One is assuming new tasks that were previously performed by the patient—such as an older woman becoming the primary driver after her husband's stroke. Another is when providers must undertake care-related tasks such as assisting the patient with activities of daily living. Due to the rate of depression among stroke survivors, caregivers also may deal with clinical symptoms that can compromise patients' abilities to regain degrees of functioning. As a result, caregivers need to adjust to physical, emotional, and social changes after such an acute physical event. If the patient does not regain previous levels of functioning, numerous transitions may result that impact relationship dynamics.

Case example No. 1

The following case example involves an older couple after the husband sustains a serious stroke. This scenario highlights how the wife must take on new roles in caring for the husband, as well as manage the household—and changes in the family system.

Arthur and Melinda Pembroke are an African American couple in their late sixties. Arthur worked in the post office for forty years and retired about four years ago. Two years ago, Arthur suffered a significant stroke, and spent time in a long-term-care rehabilitation facility prior to returning home.

Arthur has experienced substantial changes in his physical and social condition. A proud man, he had handled many household responsibilities such as driving, paying the bills, and taking care of the lawn. In his retirement, he had started doing most of the cooking, as he always enjoyed being in the kitchen. His three adult children and their families often would come over for barbecues, which he enjoyed very much.

Post-stroke, Arthur had difficulty with ambulation and experienced muscle weakness. He was unable to drive, had to use a walker, and also was incontinent. A slight woman, Melinda had a difficult time assisting Arthur, who was tall and overweight. Also, she was unprepared to take over the many household tasks, especially driving, as she had never been comfortable in this role. Arthur's jovial personality changed, and he became sullen, withdrawn, and disengaged.

Because of these multiple changes, the couple became reclusive. For the most part, they stopped leaving their home and declined offers to socialize—even from their children, who invited them to their homes. Their house, always a source of pride, fell into disrepair. Although their adult children offered help, Melinda was unwilling to accept aid and Arthur was adamant that he did not want "strangers" in his house (e.g., home health aides, a homemaker service). Because of the couple's physical status, combined with a deteriorating physical environment, family members became concerned about Arthur's and Melinda's overall health.

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This case example illustrates the intersection between physical and mental health functioning. Although Melinda is determined to provide care for her husband, the associated tasks appear to be beyond her capacity, and Arthur's decreased functional ability changed his personality, which compromised his convalescence and recovery. Although the family is willing to help, the couple becomes more isolated and is reluctant to receive aid and support.

Currently, the Pembrokes have not made use of services that could provide support and relief. An initial concern for professionals in aging services who would serve these clients is how to ensure the family accesses available services, as Melinda and Arthur have become isolated and estranged from their social network. Because Arthur does not want "strangers" in his house, one possibility is support offered through their faith community. Examples of programs that are provided through places of worship include respite and friendly visiting. Likewise, Arthur may be open to exploring an adult day or senior center where he could participate in activities and make social connections. This option would offer respite for Melinda, as well as allow Arthur to establish relationships with other individuals who are in similar life circumstances, and who can help with adaptation and acceptance.

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Likewise, others in the Pembroke family would benefit from resources. Melinda and her adult children have limited understanding of the consequences of a stroke and the ways to provide care for Arthur. Additionally, they could use support to help them meet Arthur's physical challenges and also to know how to process the emotional aspects of care provision. (The National Stroke Association, along with other healthcare organizations, offers several resources [tinyurl.com/yc86ydzp]). While Arthur would benefit from programs to help him adapt to his post-stroke functional abilities, the family also can use support and resources to adjust to his physical and emotional changes.

Complicated Grief

Besides the occurrence of changes in physical and functional status, losses happen in later life. Loss is a normal part of the life course and, in later life, older adults experience the death of significant individuals in their lives. Many older adults are able to cope with these losses, however, others may experience complicated grief, which is a prolonged and acute experience that extends for a significant amount of time (Ghesquiere, 2014). Complicated grief involves intense sorrow and emotional pain regarding the death, and preoccupation with the deceased or the circumstances of the death. One estimate is that 4.7 percent of the older population suffers from complicated grief; risk factors for complicated grief include losing a spouse or a child, having a cognitive impairment, and possessing a low level of education (Newson et al., 2011).

Most often, those who have experienced a loss do not receive therapeutic interventions for their grief (Benkel, Wijk, and Molander, 2009). Instead of abating, their grieving may worsen over time. One person reported her family's impatience with her after a person extremely important to her died. They said, "You should be feeling better now . . . . You should be moving on. You need to get out. You need to do this, you need to do that" (Ghesquiere, 2014).

As caregivers and other support professionals are involved with older adults' grieving experiences, they may adhere to a different trajectory around mourning. Thus, they may be less able—or willing—to engage with bereaved individuals over an extended period of time (Logan, Thornton, and Breen, 2018). Consequently, family and friends experience a double loss—of the individual who died, and also of their former relationship with the grieving person in their care, who now may be disengaged or isolated.

Case example No. 2

The following case concerns an older widow, Alma, who experienced the death of her youngest son, Joseph.

After the death of her husband (seven years prior to her son's death), Alma had moved into the household of her oldest daughter Frances, age 62. Although she grieved for her husband, Alma's large family was instrumental in keeping her active and engaged. After the untimely and sudden death of her son, however, Alma's health started to decline as she become more withdrawn and inactive.

Joseph, age 46, had worked as a long distance trucker. He had never married, and remained close to his mother, who was age 82 when he died. Although he lived across town and was on the road a great deal, he and his mother spoke several times a week and he would take her out to dinner when he was not working.

Joseph was found dead in his rig at a truck stop, and his autopsy revealed an undiagnosed cardiac condition. While it was a shock to the entire family, Alma was devastated. When Joseph died, her behavior was radically different than it had been when her husband had died. Over time, she became more isolated from her children and grandchildren. After coming home from work, Frances frequently would find her mother on her bed, tearful and disengaged. Though Alma was devout, she stopped attending mass at the local parish church, as she said, "God should have taken me—not Joseph." She discontinued activities such as taking daily walks, listening to music, and connecting with her grandchildren. Her physical appearance changed—she looked frail and unsteady.

Apart from Joseph's death, the family experienced other losses. Besides Joseph's sudden passing, they no longer had their mother and grandmother as part of their family life. Important rituals such as Sunday night family dinners ceased. The entire family, and especially Frances, felt helpless to assist their mother, who seemed to be unable to get past her loss, instead becoming increasingly frail and disengaged.

In this case example, the loss of an important role for Alma—her close relationship with Joseph—had a deleterious impact on her health and social functioning. Alma's remaining adult children, having sustained the loss of a sibling, felt helpless as they experienced an additional loss of the "mother that they knew." Seeing Frances as Alma's main source of support, the siblings looked to her to help their mother cope with the loss of Joseph. Previously a close-knit family, Joseph's death started to strain existing familial relationships.

This example demonstrates several complex dimensions of care provision. Although there was no physical caregiving element in Alma and Joseph's relationship, clearly there was a strong emotional bond. Joseph was a source of connection and companionship when Alma became a widow. In contrast, daughter Frances, the primary source of Alma's care, is herself entering later life. Along with dealing with the loss of her younger brother, she now has an increased responsibility for her mother, who is emotionally devastated by Joseph's death.

At this point, Alma clearly should have treatment and support for her grief. There are effective intervention models for complicated grief (see Nam, 2017; Shear et al., 2014), however, older adults may resist seeking professional help. Often, declining health is noted in primary healthcare practices, and these health professionals should screen for depression and assist with treatment referrals. Frances would benefit from support from other care providers who are dealing with these issues. Involvement in a family support group could help Frances and her siblings work through their grieving over the loss of their brother, and bolster their efforts to care for Alma.

Severe Mental Illness

Caring for someone with severe mental illness (SMI) is a complicated situation. SMI is defined as mental illness that results in a "serious functional impairment that substantially interferes with one or more major life activities" (National Survey on Drug Use and Health, 2012). Examples of psychiatric conditions that are classified as severe mental illnesses include bipolar disorder, schizophrenia, major recurrent depressive disorder, and personality disorders. Many people with SMI exhibit erratic and unpredictable behavior, hallucinations, and poor judgment, which can leave their families especially unprepared for this caregiving role (Jönsson et al., 2011).

As individuals with SMI age, care providers frequently are family members, such as older parents and siblings. Estimates suggest that about 85 percent of aging adults with SMI are living in community-based settings, with about

50 percent living with family (Cohen and Ibrahim, 2012). This caregiving role may be even more difficult for families if relationships within the family group have been severed, as behaviors associated with SMI can create strain. Unfortunately, many communities lack comprehensive services and supports for people with SMI; this leaves caregivers with insufficient resources to meet the multiple and complex needs of this population (Band-Winterstein, Smeloy, and Avieli, 2014; Cummings and Kropf, 2009). Community supports that provide assistance to older family caregivers include employment and activity programs for the person with SMI, respite and residential options, and community health programs that focus on the critical needs experienced by later-life caregivers.

Because of their own aging process, older parents who remain as caregivers to an adult son or daughter aging with SMI face challenges in their role. As the course of the mental illness changes, care provision needs also evolve, requiring new skills plus an understanding of the particular care that is needed (Möller-Leimkühler and Wiesheu, 2012), which can include management of "negative psychiatric symptoms" such as lethargy, depression, withdrawal, and cognitive slowing—symptoms that often are more difficult for older parents to handle (Cummings and Kropf, 2011). Due to the simultaneous aging process of both care receiver and caregiver, older care providers may have less capacity for assuming more demanding caregiving tasks, while their adult child with SMI requires additional assistance (Cummings and MacNeil, 2008).

Case example No. 3

The following case scenario exemplifies the care transitions that can occur in this caregiving situation (Greene and Kropf, 2014).

Phillip Bowman, age 40, was diagnosed with schizophrenia in his early twenties. He lives at home with his 75-year-old parents, William and Claudia. Although he has had numerous psychiatric hospitalizations, Phillip has been at home for the past two years. Currently, he has a flat affect, hallucinations involving religious and sexual themes, and mild paranoid ideation.

Due to Phillip's illness, William retired early to be a full-time caregiver, providing the majority of care because Claudia has her own health problems. The cumulative stress of caregiving has isolated them from their friends, community, and their other son's family. William is very concerned about potential danger for Claudia, as she has osteoporosis and is quite frail. A few years ago, Phillip pushed Claudia down, resulting in a fall that broke her arm. Phillip's parents live in fear of his having another psychotic episode, in which he could exhibit violent behavior.

Phillip's parents live in fear of his having another psychotic, possibly violent, episode.

Despite the challenges, the family is very religious and the parents view Phillip's care as their responsibility. But there are few psychiatric resources in the community—especially for individuals who are in mid-life. Added to the ongoing stress of his care, William and Claudia worry about Phillip's future when they can no longer care for him.

In this caregiving situation, older parents have been in a care provision role for their adult son. However, the intersection of Phillip's, William's, and Claudia's aging processes creates new risks around the caregiving role, and the lack of in-community services for people aging with SMI causes a gap in support at a time when this family needs additional resources and support.

This case also exemplifies the need for future planning, as Phillip may outlive his parents. Another article in this issue of *Generations* (see VanderVeen's article on page 104) explores the issue of financial and estate planning, which is critical in situations such as this one. The Bowmans—

and other families in similar situations—should seek assistance from attorneys who have knowledge and expertise in this area; these professionals can help families to make financial decisions that can safeguard their adult children's futures. They also can identify any appropriate resources for other needs families may have in later life.

Conclusion

In a typical caregiving pattern, an older adult is the care recipient. The three scenarios in this article offer examples of situations in which older adults are the caregivers. When late-life physical health challenges arise for these caregivers, such as the occurrence of a stroke, geriatric depression can be a comorbid condition that can complicate their ability to provide care. In addition, complicated grief or bereavement can compromise an older adult's functioning and create strain within the caregiving relationship. The final situation presented, of an older adult child aging with a severe mental illness, juxtaposes the aging process of the care recipient with the older parents' diminished ability to sustain their caregiving role. Taken collectively, these three scenarios offer a range of caregiving situations that confront practitioners who are dealing with issues specific to aging families.

As these cases show, the mental health issues of late life affect family relationships and dynamics. Even under the best of circumstances, caregivers experience stress, struggles, and transitions (Feinberg and Levine, 2016). As a result, the family system may benefit from becoming the focus of treatment and interventions. As treatment plans are made, practitioners and service providers who are helping the caregiver may also need to assess the care provider's ability to assume new care responsibilities, provide links to appropriate services, and-or connect to others who can be a source of mutual aid and support. As they age, older adults may assume either role—of care recipient or care provider—and appropriate and relevant practice, policy, and research must take this into account.

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Author's Note

The case examples used in this article are blended, though realistic stories created to illustrate the narrative; they are not associated with real-life individuals.

References

Ayerbe, L., et al. 2013. "The Natural History of Depression Up to 15 Years After Stroke: The South London Stroke Register." *Stroke* 44(4): 1105–10.

Ayis, S. A., et al. 2016. "The Natural History of Depression and Trajectories of Symptoms Long Term After Stroke: The Prospective South London Stroke Register." *Journal of Affective Disorders* 194(April): 65–71.

Band-Winterstein, T., Smeloy, Y., and Avieli, H. 2014. "Shared Reality of the Abusive and the Vulnerable: The Experience of Aging for Parents Living with Abusive Adult Children Coping with Mental Disorder." *International Psychogeriatrics* 26(11): 1917–27.

Benkel, I., Wijk, H., and Molander, U. 2009. "Family and Friends Provide Most Social Support for the Bereaved." *Palliative Medicine* 23(2): 141–9.

Cohen, C. I., and Ibrahim, F. 2012. "Serving Elders in the Public Sector." In H. L. McQuiston et al., eds., *Handbook of Community Psychiatry*. New York: Springer.

Cummings, S. M., and Kropf, N. P. 2009. "Formal and Informal Support for Older Adults with Severe Mental Illness." *Aging & Mental Health* 13(4): 619–27.

Cummings, S. M., and Kropf, N. P. 2011. "Aging with a Severe Mental Illness: Challenges and Treatments." *Journal of Gerontological Social Work* 54(2): 175–88.

Cummings, S. M., and MacNeil, G. 2008. "Caregivers of Older Clients with Severe Mental Illness: Perceptions of Burdens and Rewards." *Families in Society* 89(1): 51–9.

Federal Interagency Forum on Aging-Related Statistics. 2016. *Older Americans 2016: Key Indicators of Well-Being.* Washington, DC: Federal Interagency Forum on Aging-Related Statistics, U.S. Government Printing Office.

Feinberg, L. F., and Levine, C. 2016. "Family Caregiving: Looking to the Future." *Generations* 39(4): 11–20.

Ghesquiere, A. 2014. " 'I Was Just Trying to Stick It Out Until I Realized that I Couldn't': A Phenomenological Investigation of Support-seeking Among Older Adults with Complicated Grief." *OMEGA—Journal of Death and Dying* 68(1): 1–22.

Greene, R. R., and Kropf, N. P. 2014. *Caregiving and Care Sharing: A Life Course Perspective.* Washington, DC: NASW Press.

Jönsson, P. D., et al. 2011. "Experience of Living with a Family Member with Bipolar Disorder." *International Journal of Mental Health Nursing* 20(1): 29–37.

Logan, E. L., Thornton, J. A., and Breen, L. J. 2018. "What Determines Supportive Behaviors Following Bereavement? A Systematic Review and Call to Action." *Death Studies* 42(2): 104–14.

Möller-Leimkühler, A. M., and Wiesheu, A. 2012. "Caregiver Burden in Chronic Mental Illness: The Role of Patient and Caregiver Characteristics." *European Archives of Psychiatry and Clinical Neuroscience* 262(2): 157–66.

Nam, I. 2017. "Restoration-focused Coping Reduces Complicated Grief Among Older Adults: A Randomized Controlled Study." *The European Journal Of Psychiatry* 31(3): 93–8.

National Survey on Drug Use and Health. 2012. *Physical Health Conditions Among Adults with Mental Illness.* Washington, DC: U.S. Department of Health & Human Services, Substance Abuse and Mental Health Services Administration.

Newson, R. S., et al. 2011. "The Prevalence and Characteristics of Complicated Grief in Older Adults." *Journal of Affective Disorders* 132(1): 231–8.

Shear, M. K., et al. 2014. "Treatment of Complicated Grief in Elderly Persons: A Randomized Clinical Trial." *JAMA Psychiatry* 71(11): 1287–95.

Simning, A., Seplaki, C. L., and Conwell, Y. 2018. "The Association of a Heart Attack or Stroke with Depressive Symptoms Stratified by the Presence of a Close Social Contact: Findings from the National Health and Aging Trends Study Cohort." *International Journal of Geriatric Psychiatry* 33(1): 96–103.