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Death and Grieving for Family Caregivers of Loved Ones With Life-Limiting Illnesses in the Era of COVID-19

Considerations for Case Managers

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ABSTRACT

Purpose: Family caregivers of a loved one with a life-limiting or terminal illness are often overwhelmed by, and underprepared for, their responsibilities. They often need help from family members and friends to provide comprehensive care. When death occurs, funerals and other death-related rituals bring family and communities together to honor the life and mourn the death of a loved one and provide needed support to family and caregivers. These collective rituals are often deeply rooted in culturally-bound values and can facilitate grief and help make sense about loss. Rituals act as bridge-building activities that allow people to organize and appraise emotions, information, and actions after a loss. With the emergence of the coronavirus disease-2019 (COVID-19) pandemic and the recommended restrictions to reduce infection and transmission, family members and caregivers are often faced with weighing options for honored rituals to help them grieve. Grieving during the pandemic has become disorganized. The purpose of this article is to provide case managers and other clinical staff with recommendations on guiding caregivers/families through safety precautions when a loved one dies either because of a life-limiting illness or from COVID-19 during the pandemic using guidelines from the Centers for Disease Control and Prevention (CDC). The authors also present information about complicated grief and ways to support coping with death and suggest safe alternatives to traditional death-related rituals and funerals in a COVID-19 era.

Primary Practice Setting(s): Primary practice settings include home health care, hospice, hospital discharge planning, case management, and primary care.

Findings/Conclusions: Precautions necessary in a COVID-19 era may add anxiety and stress to an already difficult situation of caring for loved ones at end-of-life and grieving with their loss. Utilization of CDC guidelines lessens the risk of infection while honoring loved ones' wishes and cultural traditions surrounding death and burial. Recognition of social and spiritual connections that comfort mourners must also be considered.

Implications for Case Management Practice:

1. Safety precautions are necessary for families and informal caregivers when death occurs during the COVID-19 era.
2. We need to understand the various constraints of existing resources associated with the death of a loved one (capacity limitations at funeral home, delayed memorial services) and devise creative alternatives.
3. We must acknowledge the increased potential for delayed/prolonged/complicated grief.
4. Identification of resources to support caregivers/families in coping with grief and loss during the pandemic restrictions is needed—mobilizing support in novel ways.

Key words: *case management, COVID-19, death, family caregiving, grief, palliative care*

Family caregivers (FCGs) provide an estimated $470 billion in direct care to loved ones (Reinhard et al., 2015). By providing direct care, caregivers offset costs from health care systems, making their role critical to managing increasing demands and costs for health care systems. FCGs are, however, often overwhelmed by and underprepared for their role (van Ryn et al., 2011; Walsh et al., 2020), putting both the caregiver

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and their ailing loved one at risk for more health care interventions. Never is this more acutely felt than when FCGs care for loved ones with a life-limiting or terminal illness (Henriksson & Årestedt, 2013; Oechsle et al., 2019). For this reason, the health and well-being of FCGs is vitally important, especially during the current coronavirus disease-2019 (COVID-19) pandemic.

Family caregiving during the COVID-19 pandemic has reduced access to physical and emotional resources and increased social and personal uncertainty, intensifying the stress and isolation already common to FCGs. During the pandemic, when a loved one dies and traditional rituals associated with death are curtailed or postponed, stress can increase, and grieving can be disorganized, delayed, or prolonged. The national conversation surrounding the COVID-19 pandemic currently is focused on the spread of the virus, the increasing death toll, and the urgency for developing a vaccine and a cure. Since the beginning of the pandemic, there has been far less discussion about the implications of COVID-19 on families, especially FCGs, when a loved one dies. Based on ongoing experiences in a study of FCGs with a loved one who has a life-limiting illness, the focus of this article is to provide guidance and recommendations for case managers and clinical staff to consider when communicating with families prior to a loved one's imminent death or in preparation for traditional death-related rituals, and funerals during the COVID-19 pandemic. Suggested guidance and recommendations are further informed by guidelines from the Centers for Disease Control and Prevention (CDC, 2020b) and World Health Organization (WHO, 2020), and from interviews with a hospice case manager, a registered nurse employed in a skilled nursing facility, an administrator in a large Midwestern health system's Office of Decedent Affairs, and a funeral director.

The Study

The authors are conducting a randomized controlled trial to test a technology-enhanced model of care for transitional palliative care among adult FCGs in rural or medically underserved areas. The purpose of the study is to test the efficacy and cost-effectiveness of an intervention to improve FCGs' health and well-being. FCGs are assigned to an attention-control group or an intervention group. The attention-control group receives usual care. Usual care can consist of FCGs and their loved ones receiving consult visits by the palliative care team while hospitalized, usual hospital discharge planning, and primary and specialty care in the community after hospital discharge. FCGs assigned to the control group receive monthly "friendly visitor" telephone calls from a team member. Data are also collected during these calls (Holland et al., 2020).

After their loved one is discharged from the hospital, the intervention group has online video interactions with a palliative care experienced nurse for 8 weeks. These meetings are tailored to each FCG, but involve teaching, guiding, and counseling during hospital-to-home transitions. The intervention is based on evidence of transitional and palliative care principles, which are individualized to improve continuity of care, provide caregiver support, enhance knowledge and skills, and attend to caregivers' health needs (Coleman & Roman, 2015; Coleman et al., 2015; Naylor & Marcille, 2014; Seow & Bainbridge, 2018). The study aims to compare outcomes in:

1. FCG skills (e.g., caregiving preparedness, communication with clinicians, and satisfaction with care),
2. FCG health outcomes (e.g., quality of life, burden, coping skills, and depression), and
3. Cost.

Midway through this study, the COVID-19 pandemic became a reality. Because the intervention is based on virtual visits, the researchers were able to proceed with the study after adjustments to consenting and data collection procedures.

As the virus began to spread, it soon became apparent that the intervention nurses were shifting some focus from general caregiving issues to frequently teaching, guiding, and counseling FCGs on COVID-19 precautions, especially during transitions. Many of the interactions with FCGs included discussions about the impact of restrictions, including the inability or limited ability to visit a loved one in a hospital or facility, loss of social support, their own personal vulnerability to the virus, and additional anxiety about loved ones who were immunocompromised and, therefore, more vulnerable to poor outcomes if they contracted COVID-19. The hospital discharge planning process was fraught with the impacts of pandemic restrictions. FCGs expressed the agonizing choices about discharge disposition, balancing out the heightened risks of virus transmission at skilled nursing centers with the heavy

demands of caring from home toward the end-of-life. Based on concerns voiced from FCGs, the research team needed to quickly acquaint themselves with the CDC and WHO guidelines regarding COVID-19. The CDC and the WHO offer guidelines in clinical management as well as guidance for daily life coping, coping with grief, and funeral guidance related to COVID-19. The guidelines are designed to "provide strategies to protect and support individuals and others when grieving the loss of a loved one, supporting each other, making funeral arrangements, and participating in funeral services and visitations" (CDC, 2020b).

Study team members also heard remarkable stories from FCGs about the impact of limited access to their loved ones, the increase in caregiving burden based on limited contact by extended family, friends, decreased availability of hospice and home health care interdisciplinary agency personnel, and complicated grief due to delayed funerals and memorial services. The organized rituals that aide bereft caregivers were suddenly disorganized. This led us to pursue further information from additional resources to help inform and guide our interventions with FCGs regarding COVID-19 concerns. These concerns included risk of virus exposure to both the FCG and their loved one, dealing with the consequences of a positive COVID-19 diagnosis, and changing federal, state, and facility guidelines surrounding the death of a loved one (including removal of the body and funerals). The researchers contacted resources with a variety of perspectives of this COVID-19 landscape. With our study experiences, CDC and WHO guidelines, and interviews with key informants directly engaged with families during COVID-19, the authors summarized the data and developed information and guidance for case managers.

Clinical Issues

Visitor Restrictions and Social Distancing

Families of dying patients have been thrust into even more uncertainty than usual with COVID-19 restrictions. Initially families thought that receiving a COVID-19 diagnosis for their loved one was a death sentence. Families were experiencing intense anticipatory grief even though many of the COVID-19 patients lived. In some facilities patients who were COVID-19 positive were moved to a different unit or a different facility where they experienced new staff caring for them. The last time family members may have seen their loved one was when they were being put into an ambulance to be moved to another facility. No touching was allowed.

Although visiting restrictions for patients in hospitals or skilled facilities have eased in some areas of the United States, restrictions remain difficult for families and loved ones to endure. This includes limited visitation times, inability to touch or hug the loved one, and requirements to wear personal protective equipment (PPE). Some restrictions in the absolute number of visitors forces families to decide who may visit and who may not. When visiting is allowed, wearing PPE such as masks and gloves means family members are not able to touch their loved one except through a barrier. Both the dying patient and their families experience severe loss at not being able to be together. Loved ones miss the presence of their family members. Even for people with dementia who may not be fully lucid, family members can be a steady presence in the patients' lives. The severe and abrupt change in routine can lead to increased paranoia and behavioral disturbances. Staff often notes an increase or worsening of behaviors associated with anxiety, depression, or delirium.

Visitor Restrictions and Social Distancing Guidance

Case managers can inform FCGs of current visitation rules and provide guidance on alternatives to traditional visiting, such as online or virtual visits, exploring feasibility of visits outside, leaving recorded music, pictures, or video with comforting stories. The case manager may also be a listening presence in helping FCGs process visitation restrictions while encouraging them to advocate on behalf of the patient and their family. Instead of the primary FCG, some families are choosing to designate a friend or family member with lower risk for COVID-related complications and more flexibility in his/her daily schedule in order to assure that visits are consistent and frequent.

Our informants report that when patients die alone, it is heart-breaking for both families and clinical staff. The concern about dying alone has resulted in FCGs and loved ones (when able to weigh in) choosing to discharge to home for end-of-life care in order to ensure family presence at the time of death—often with extraordinary physical care responsibilities for the FCGs.

Prior to and Immediately Following Death

Our informants report that when patients die alone, it is heart-breaking for both families and clinical staff. The concern about dying alone has resulted in FCGs and loved ones (when able to weigh in) choosing to discharge to home for end-of-life care in order to ensure family presence at the time of death—often with extraordinary physical care responsibilities for the FCGs.

After death, funeral home personnel may wish to transport the body as soon as possible. Although universal precautions are practiced routinely by facility and funeral home staff, each may have their own protocols that may include masking and wearing a face shield if the decedent is known COVID-19 positive or suspected to be positive. Because bodies purge liquids when moved, some protocols include putting a bag over the decedent's head to contain contaminants. Whenever possible it is suggested families not be present when the decedent is prepared for transport; additional precautions may be disturbing to staff who have cared for the individual.

Safe Practice Guidance Prior to and Immediately Following Death

Case managers can provide guidance and reinforce safe practices to families and to staff or paid caregivers who have cared for the deceased. They can review CDC guidelines on cleaning and disinfecting the home and any items that will be removed from the home (CDC, 2020a).

Knowing that post-death and funeral practices may vary within and among cultures, case managers can recommend that families consider precautions when engaging in death-related rituals such as preparing (including touching) the body, especially if death occurs in the home. Case managers can also counsel families that traditional rituals immediately following death may be interrupted. Some families may want to pray for several hours over the decedent. They should be encouraged to avoid kissing, washing, or shrouding the body before, during, and after the body has been prepared for burial. Cultural and religious leaders can work with funeral home and cremation services staff to identify how to reduce exposure as much as possible.

Case managers should encourage those at greater risk of severe illness from COVID-19 and members of their household to refrain from in-person funeral planning (CDC, 2020b). Cultures that begin the mourning period by having family members wash the body may be limited to the fewest number of people as possible. PPE should be recommended, and families should safely gather the loved one's belongings while wearing PPE (gloves, mask) and throw the PPE away and wash hands afterward (CDC, 2020b). If removing personal possessions (e.g., wedding rings) from the body, they should clean and disinfect the items and wash their hands right away (CDC, 2020b).

Burial and Memorial Services

COVID-19 resulted in delayed funerals or memorial services, limited attendance requirements, physical distancing, and the use of PPE have impacted families who have lost a loved one. Common forms of sympathy, such as hugging family members, joining together to sing, or sharing a meal following the funeral or memorial service, may put family and attendees at greater risk of transmitting or contracting the virus. To curb these risks at funerals, some states early on in the pandemic mandated that a maximum of 10 people were allowed to be present for a modified funeral or memorial service, masks were required, and physical distancing was strongly recommended throughout the service. Restrictions have since been modified to allow more mourners present (e.g., up to 50% capacity in some houses of worship), but throughout the pandemic the loss of personal and community support through traditional rituals has been especially difficult for grieving families.

Some families have chosen to delay any service until restrictions are lifted or the pandemic wanes. If delayed, community members may not be aware of the death, especially if an obituary on a website or local news source is delayed until closer to the memorial service. Long delays between the death and a service may result in extended family and community members choosing not to attend the service, as some may be hesitant to travel to or attend a service. Delays between death and service may also extend grief by not having a sense of closure that is often associated with a gathering of family and friends.

Burial and Memorial Service Guidance

Case managers can encourage FCGs to begin funeral planning early on and may recommend families have virtual or phone meetings instead of in-person meetings with funeral home staff, cemetery staff, clergy or officiants, and others who plan funeral arrangements (CDC, 2020b). Case managers can remind families there is currently no known risk associated with being in the same room at a funeral service or visitation with the body of a deceased person who had confirmed or suspected COVID-19 after the body has been prepared for viewing (CDC, 2020b); however, that funeral attendees may be asymptomatic and still have the virus, unknowingly putting other attendees at risk. Accordingly, case managers should encourage families to consider modified funeral arrangements, such as:

- Limit attendance at funerals held shortly after the time of death to a small number of immediate family members and friends based on each state's recommendations as well as those of the funeral home and house of worship.
- Suggest a funeral or memorial service in a large, well-ventilated area or outdoors, as circumstances and traditions allow.
- Have additional memorial services when social distancing guidelines are less restrictive.
- Consider hosting a virtual event in which family and friends honor their loved one by reciting a selected poem, spiritual reading, or prayer from within their own households. Some cultures practice a prolonged mourning period with multiple observances. Hosting virtual events now and in-person events later may be in keeping with these practices (CDC, 2020b).
- Propose a hybrid service that includes a small in-person gathering with a virtual option, allowing those not able to travel to participate.

TABLE 1
Adult and Children's Book Recommendations for Grieving

Target Audience	Book Title
Adults	*How to Go on Living* by Therese Rando
Adults	*The Other Side of Sadness* by George Bonanno
Adults	*Healing the Adult Siblings Grieving Heart* by Alan D. Wolfelt
Adults	*The Year of Magical Thinking* by Joan Didion
Adults	*H is for Hawk* by Helen Macdonald
Adults	*Splitting the Difference* by Tre Rodriguez Miller
Adults	*The Iceberg* by Marion Coutts
Adults	*A Grief Observed* by C. S. Lewis
Children[a]	*The Fall of Freddie the Leaf* by Leo Buscaglia
Children[a]	*The Invisible String* by Patrice Karst

Note. From *The 16 Best Books About Dealing With Grief, According to Psychologists,* by D. Pariso, 2019, https://nymag.com/strategist/article/best-books-grief.html
[a]For children, read age-appropriate books with them and talk with them about how they are feeling.

Grief and Loss

The majority, but not all, of the FCGs in the study experienced grief. Processing grief can be a significant challenge to those experiencing loss of a loved one. People often feel isolated and unsupported in their grief, at a time when they need people and support most. During the COVID-19 pandemic, the bereaved are often left to grieve without the support of usual social and cultural rituals, rituals that can facilitate grief and help people begin to make sense about loss (Weick et al., 2005). Rituals can help organize the grieving process. The grief of some caregivers may be compounded due to decreased interactions and support from family and friends. They may experience feelings of guilt if they could not care for their loved one at home, placed the loved one in a facility that did not allow visitation, or were not present at the death of the loved one. Family traditions may not be able to take place. Funerals may not be held the way the deceased loved one or family desired.

Grieving is further encumbered by cascading life stressors derived from policies needed to mitigate the pandemic. Although often heartened by human resilience in response to death and other hardships, for some, the burden of this pandemic will exceed their ability to cope. Guilt, sadness, loss of control, and lack of support may commonly occur especially if extended family and friends were unable to assist with caregiving due to COVID-19 restrictions or fear of contracting the virus. Being able to say goodbye and "I love you" may not have been possible, preventing a sense of closure.

Although books cannot of themselves provide solutions for the grieving process, books can at times help people understand the grieving process. There are no shortcuts in this process, but books can help individuals learn about the stories of those who have struggled before us in meeting these challenges and in validating our feelings (see Table 1 for book suggestions) (Pariso, 2019).

Complicated and Prolonged Grief

Complicated grief is another facet of grieving that is likely to be associated with loss during COVID-19. Complicated grief is identified by clinically significant deviation from the (cultural) norm in either the time

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Complicated grief is identified by clinically significant deviation from the (cultural) norm in either the time course or intensity or the level social, occupational, or other functioning. Although many of the consequences of the COVID-19 crisis are still unknown, a significant number of bereaved people will likely develop complicated grief in its aftermath.

course or intensity or the level social, occupational, or other functioning (Nakajima, 2018). Although many of the consequences of the COVID-19 crisis are still unknown, a significant number of bereaved people will likely develop complicated grief in its aftermath. Although increases in mental health problems following natural disasters and viral outbreaks have been previously documented, there is historically less attention for severe, disabling, and protracted grief responses, like what would be expected during the pandemic (Eisma et al., 2020).

There will likely be an increase in prolonged grief, which is distressing and disabling grief experienced for at least 6 months after a loss. In the development and aftermath of the COVID-19 pandemic, it is anticipated that, worldwide, prolonged grief will become a major public health concern. Recent studies indicate that between 47% and 71% of FCGs report grief while caring for a loved one and 20% experience complicated grief after death (Supiano et al., 2020). Caregivers may experience more prolonged grief if they feel that the dying process was traumatic or unexpected and they may live with regretting care decisions or being unable to say goodbye to their family member (Supiano et al., 2020). These scenarios may be heightened in this time of uncertainty where families may have long periods of time when they are not be able to see or have physical contact with their relative, including at the end-of-life. Families who are able to see a relative who is dying in the hospital may then have to quarantine themselves afterward and not be able to attend the funeral or memorial service.

Guidance Related to Grief and Loss

After the loss of a loved one, many grieving family members may not have the energy after the death to seek help. Case managers can encourage FCGs and other family members to develop support systems to help them cope with the grief associated with the loss of a loved one. They can point to resources that are available, including grief counseling services, support groups, or hotlines (offered over the phone or online), grief-related podcasts or online applications, or face-to-face or virtual support from a mental health care provider (CDC, 2020b). More specifically, case managers can:

- Assist FCGs to identify the people they depend on during difficult times or ask, "Who are your go-to-people?" Then encourage them to connect with these people (family members and/or friends) by phone, Zoom video visits, social media, or in-person visits.
- Suggest family, friends, and loved ones express care in ways that do not involve personal interactions (CDC, 2020b).
- Designate a family member who can help coordinate these activities when the FCG may not have the energy or desire to do so.
- Counsel families to utilize resources provided by mental health professionals.
- Encourage use of postmortem hospice services including bereavement services.
- Consider an immediate announcement of death and another announcement closer to the funeral/memorial in order to begin closure and to gain more social support.
- Encourage the family to take part in an activity that has significance to them and the loved one they lost, such as planting flowers or a tree or preparing a favorite meal, in memory of the loved one (CDC, 2020b).

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Summary

Guidelines related to treatment, management, and mitigation of COVID-19 are evolving, especially regarding end-of-life and funeral planning. Long-term effects on the grief process of FCGs are unknown, but complicated and prolonged grief is likely. Even though most persons have not had COVID-19, society as a whole has experienced a collective grief due to the efforts to contain the spread of the virus, as well as complexities associated with funeral and memorial services. Here, the authors offer experiences and information gleaned from key informants related to helping families of loved ones at end-of-life and planning funerals while navigating the COVID-19 pandemic.

In the development and aftermath of the COVID-19 pandemic, it is anticipated that, worldwide, prolonged grief will become a major public health concern. Recent studies indicate that between 47% and 71% of FCGs report grief while caring for a loved one and 20% experience complicated grief after death.

FCGs are faced with uncertainty and challenges when their loved one has a serious, life-limiting illness during their illness and also in death. They find themselves balancing the benefits and burdens of treatment and how to best care for and support their loved ones and grant their wishes for funerals. In the face of a pandemic, FCGs are now navigating a new landscape with the need to develop new rituals during the grieving process. Websites for CDC and WHO guidelines are provided in Table 2. Also included is a comprehensive community-facing guideline regarding a response to COVID 19 pandemic relevant to many roles (Omaha System Guidelines, 2016).

TABLE 2
Online Case Management Resources and Guidelines for Death and Dying During COVID-19 Pandemic

Source	Resource
CDC	https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/funeral-guidance.html
CDC	https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/disinfecting-your-home.html
CDC	https://www.cdc.gov/coronavirus/2019-ncov/community/tribal/faq-burial-practice.html
CDC	https://www.cdc.gov/prions/cjd/funeral-directors.html
CDC	https://www.cdc.gov/coronavirus/2019-ncov/hcp/disposition-in-home-patients.html
CDC	https://www.cdc.gov/coronavirus/2019-ncov/community/strategy-discontinue-isolation.html
CDC	https://www.cdc.gov/coronavirus/2019-ncov/hcp/disposition-hospitalized-patients.html
Mayo Clinic	https://www.mayoclinic.org/office-decedent-affairs/overview#:~:text=The%20Mayo%20Clinic%20Office%20of%20Decedent%20Affairs%20%28ODA%29,teams%20for%20continuity%20between%20end-of-life%20and%20postmortem%20care.
Mayo Clinic	https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coping-with-coronavirus-grief/art-20486392
NIH	https://www.covid19treatmentguidelines.nih.gov/whats-new/
Washington Post	https://www.washingtonpost.com/lifestyle/wellness/funerals-coronavirus-grieving-mourning-changed/2020/04/23/e86ab616-858c-11ea-ae26-989cfce1c7c7_story.html
WHO	https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/patient-management
WHO	*WHO: Clinical Management of COVID-19: Interim Guidance* (May 27, 2020). Retrieved June 30, 2020, from https://www.who.int/publications/i/item/clinical-management-of-covid-19

Conclusion

Case management of persons with a life-limiting illness and their FCGs is constantly evolving, as knowledge increases and more information is published regarding COVID-19. Regulations regarding end-of-life care, visitation, funerals, and memorial services for loved ones will differ between regions and states based on guidance from local and state health departments. Within the same area, these guidelines may change quickly based on current and projected COVID-19 incidence rates. At any care conference, case managers can ensure FCGs and other family are up-to-date with current policies. If a patient is diagnosed with COVID-19, case managers are in a unique position to help the FCGs understand the risks they face, the potential clinical outcomes for their loved one, and help identify supportive services for both family and the patient.

Potential best practices include:

- Acknowledge the challenges FCGs are facing when caring for their loved ones with serious/life-limiting illnesses during this time of the COVID-19 pandemic. Providing information to assist them in processing and planning the changes to end-of-life care, visitation, and funeral services in advance of death so that they can be prepared.
- Encourage FCG/family to contact the funeral home early on to discuss services and to work with hospice (when appropriate).
- Be aware of differing restrictions in funeral planning by state or locale.
- Identify alternate strategies to connect with families and loved ones for help and support during the grieving process.

By clearly communicating up-to-date information and helping to set family expectations about the death and dying process during the COVID-19 pandemic, case managers can help reduce risks for transmitting the virus within communities while supporting families during these exceptional times.

References

Centers for Disease Control and Prevention. (2020a). *Cleaning your home, everyday steps and extra steps when*

someone is sick. https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/disinfecting-your-home.html
Centers for Disease Control and Prevention. (2020b). *Funeral guidance*. https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/funeral-guidance.html
Coleman, E. A., & Roman, S. P. (2015). Family caregivers' experiences during transitions out of hospital. *Journal for Healthcare Quality*, *37*(1), 12–21. https://doi.org/10.1097/01.JHQ.0000460117.83437.b3
Coleman, E. A., Roman, S. P., Hall, K. A., & Min, S. J. (2015). Enhancing the care transitions intervention protocol to better address the needs of family caregivers. *Journal for Healthcare Quality*, *37*(1), 2–11. https://doi.org/10.1097/01.JHQ.0000460118.60567.fe
Eisma, M. C., Boelen, P. A., & Lenferink, L. I. M. (2020). Prolonged grief disorder following the coronavirus (COVID-19) pandemic. *Psychiatry Research*, *288*, 113031. https://doi.org/10.1016/j.psychres.2020.113031
Henriksson, A., & Årestedt, K. (2013). Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine*, *27*(7), 639–646. https://doi.org/10.1177/0269216313486954
Holland, D. E., Vanderboom, C. E., Mandrekar, J., Borah, B. J., Dose, A. M., Ingram, C. J., & Griffin, J. M. (2020). A technology-enhanced model of care for transitional palliative care versus attention control for adult family caregivers in rural or medically underserved areas: study protocol for a randomized controlled trial. *Trials*, *21*, 895. https://doi.org/10.1186/s13063-020-04806-0
Nakajima, S. (2018). Complicated grief: Recent developments in diagnostic criteria and treatment. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *373*(1754), 20170273. https://doi.org/10.1098/rstb.2017.0273
Naylor, M. D., & Marcille, J. (2014). Managing the transition from the hospital. *Managed Care*, *23*(6), 27–30.
Oechsle, K., Ullrich, A., Marx, G., Benze, G., Heine, J., Dickel, L.-M., Zhang, Y., Wowretzko, F., Wendt, K. N., Nauck, F., Bokemeyer, C., & Bergelt, C. (2019). Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care. *BMC Palliative Care*, *18*(1), 102. https://doi.org/10.1186/s12904-019-0469-7
Omaha System Guidelines. (2016). *Omaha system guidelines*.http://omahasystemguidelines.org/
Pariso, D. (2019). *The 16 best books about dealing with grief, according to psychologists*. https://nymag.com/strategist/article/best-books-grief.html
Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). *Valuing the invaluable 2015 update: Undeniable progress, but big gaps remain*. http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html?cmp=RDRCT-VALUN_JUN23_015
Seow, H., & Bainbridge, D. (2018). A review of the essential components of quality palliative care in the home. *Journal of Palliative Medicine*, *21*(S1), S-37–S-44. https://doi.org/10.1089/jpm.2017.0392
Supiano, K. P., Luptak, M., Andersen, T., Beynon, C., Iacob, E., & Wong, B. (2020). If we knew then what we know now: The preparedness experience of pre-loss and post-loss dementia caregivers. *Death Studies*, 1–12. https://doi.org/10.1080/07481187.2020.1731014
van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., Atienza, A. A., Phelan, S., Finstad, D., & Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology*, *20*(1), 44–52. https://doi.org/10.1002/pon.1703
Walsh, E. P., Flanagan, J. M., & Mathew, P. (2020). The last day narratives: An exploration of the end of life for patients with cancer from a caregivers' perspective. *Journal of Palliative Medicine*, *23*(9), 1172–1176. https://doi.org/10.1089/jpm.2019.0648
Weick, K. E., Sutcliffe, K. M., & Obstfeld, D. (2005). Organizing and the process of sensemaking. *Organization Science*, *16*(4), 409–421. https://doi.org/10.1287/orsc.1050.0133
World Health Organization. *Clinical management of COVID-19*. (2020). https://www.who.int/publications/i/item/clinical-management-of-covid-19

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INSTRUCTIONS

Death and Grieving for Family Caregivers of Loved Ones With Life-Limiting Illnesses in the Era of COVID-19: Considerations for Case Managers

- Read the article. The test for this nursing continuing professional development (NCPD) activity is to be taken online at **www.nursingcenter.com/CE**. Tests can no longer be mailed or faxed.
- You will need to create (its free!) and login to your personal CE Planner account before taking online tests. Your planner will keep track of all your Lippincott Professional Development online NCPD activities for you.
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