

CLINICAL CORRESPONDENCE

Caring for loved ones with cancer during the COVID-19 pandemic: A double hit risk for social isolation and need for action

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"I'm having a lot of trouble with the family for Mr. S. Any advice would be appreciated!" This was the urgent page I received from a medical intern asking for help with communication for a distraught caregiver. The caregiver's husband had been re-admitted for treatment complications related to his bone marrow transplant. The wife, his primary caregiver, played a critical role as his advocate, always by his side, and helping him manage his symptoms and stress following treatment. On this day, admission into the hospital felt more fraught with distress than prior hospitalizations. The COVID-19 pandemic led the hospital to impose a no-visitors policy in an effort to curb the potential spread of the virus. The medical teams communicated their support to families through telephone and video conferencing. As I talked to the caregiver about how hard it was to be apart from her husband, I gently asked, "Who is supporting you through this?" And she broke down, crying out "I have no one. I am alone in this!". Her anguish was compounded by her fear that he might die in the hospital alone. The patient had told his wife that his biggest fear was dying without her present and she felt helpless in preventing this.

The current COVID-19 pandemic and the related containment measures—namely quarantine, social distancing and self-isolation—can have detrimental effects on one's mental health and well-being.¹ Social distancing has become a part of our everyday lexicon in the era of the COVID-19 pandemic and heightens the risk for individuals to experience social isolation, and potentially, loneliness. Under normal circumstances, cancer patients rely heavily on family caregivers (ie, family or friends; hereafter referred to as "caregivers") for care and support. Even before the current pandemic, the standard precautions to mitigate the risk of infection for cancer patients also affect the caregivers who often socially isolate from extended family and avoid public gatherings. Unfortunately, the added effects of the current

pandemic further isolate cancer caregivers not just from important social connections such as close family and friends but also their loved one with cancer. Thus, while the COVID-19 pandemic may "doubly hit" cancer patients in terms of their risk of infection, we must not forget that caregivers in parallel may also be "doubly hit" **in their risk for social isolation.**

As our society faces the devastating illness of COVID-19 and the shared experience of isolation, the inherent resilience of cancer caregivers may offer some valuable lessons in coping during COVID-19. Finding positive meaning as a caregiver engenders resilience and has the potential to increase over the course of illness trajectory. At Dana-Farber Cancer Institute, patients have demonstrated increased resilience during treatments—such as bone marrow transplant—which have forced them to face isolation and adhere to a routine.² Caregivers have the potential to emerge from their caregiving experience with similar lessons of resilience. Within the caregiving relationship, for example, adjusting to changing roles and having social support outside of that patient-caregiver relationship can increase resilience which, not surprisingly, is inversely related to caregiving burden.³ Encouraging reflection of shared experiences within patients and their caregivers may also promote resilience and growth. In a review of 24 studies on mitigating the loneliness associated with quarantine, a sense of mutual altruism was found to potentially increase resilience.⁴ Coming together for a shared mission can alleviate suffering during isolation—a skill at which many caregivers are likely already adept. Reminders about the shared mission of protecting the patient—irrespective of contact precautions interfering with their ability to be physically present—can foster resilience and serve as a reminder that isolation is temporary.

Despite the potential “double hit” of isolation for caregivers during COVID-19, this pandemic has also revealed positive avenues for caregiver support. As the telehealth model of care evolves and becomes more commonplace, special attention should be made toward investment in initiatives for supporting caregivers. Nurses and other front-line healthcare workers—practicing appropriate social distancing during clinical encounters—may be in a unique position to facilitate caregivers’ engagement in novel support methods such as online platforms.⁵ While meta-analyses of the current research on web-based support groups for caregivers can increase social support and self-efficacy,⁶ many of the efforts across other countries to combat loneliness involve contact through the telephone.⁷ These often leverage volunteer and befriending services to break down barriers in engaging with technology to mitigate isolation. This mirrors other effective interventions that target loneliness through increasing social networks for older adults. At Dana Farber, we have established a One-to-One Program to connect caregivers with one another, a program specifically for parents, in addition to offering general support for caregivers. Similar work with Caregiving-Initiated Mentoring has the potential to reduce isolation by connecting caregivers with other family caregivers.⁸ As healthcare delivery has demonstrated unprecedented flexibility in its delivery during this pandemic, future models should strive to increase social connection for caregivers who care for individuals with serious illness. We all need to be innovative in how we maintain connection to our social network and cancer caregivers may need an additional layer of support by frontline healthcare workers, such as assistance with computer access, check-in phone calls, and provision of available virtual support services.

In addition to leveraging technology through research and local healthcare partners, important advocacy at state and national levels can also help to address caregiver burden and isolation. Recent reviews of caregiver support call for rapid implementation of legislation supporting caregivers.⁸ While policy initiatives such as the Caregiver Advise, Record, Enable (CARE) Act, the National Family Caregiver Support Program, and The Lifespan Respite Care Act continue to take shape on a national scale, there is COVID-19-specific legislation in the Family First Coronavirus Response Act in addition to the Family Medical Leave Act already in place. As researchers, we must consider what measures can be taken to enhance policy initiatives to increase social connectedness for caregivers. Furthermore, bridging policy and research is critical in supporting caregivers, and the National Institutes of Health have established calls for applications to address caregivers’ loneliness prior to COVID,⁹ underscoring the issues discussed herein.

Finally, we can take steps as individuals to ensure potential isolation experienced by caregivers is not forgotten. While quarantining is still prominent nationwide, we should strive to remember and reach out to our caregiving friends with a simple phone call, check-in or meal delivery. As reviewed in the research findings above, this connection has real impact. The American Association of Retired Persons (AARP) recommends pulling together a team, creating a plan to stay connected, and maintaining personal safety and self-care. We have offered some solutions to how you can help caregivers stay

Key Points

- With social distancing and visitors limited in healthcare, caregivers of cancer patients are at increased risk for isolation.
- Caregivers may have learned particular lessons that can foster resilience from isolation.
- Telehealth and phone check-ins offer opportunities to support caregivers.
- Policy initiatives have the potential to continue support for caregivers post-COVID.
- Supporting caregivers is a community effort, and its importance should not be forgotten post-COVID.

connected with others. Similarly, we must not forget about the exciting momentum in the larger research and policy communities to mitigate caregivers’ risk for isolation and expand innovative support for caregivers during these trying times. As their loved ones rely on them during this time, caregivers of cancer patients need support of their extended network of family, friends and volunteers as they manage social isolation. Caregivers may also benefit from the support of the broader community of psycho-oncology researchers, clinicians, patient-family advisory councils and policies to formulate ways to mitigate social isolation and loneliness. During this critical time and following the pandemic, we all need to come together so caregivers are not left feeling alone.

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DATA AVAILABILITY STATEMENT

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