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From the Editor



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Geriatric nursing: Helping to solve the challenges to complex caregiving at home



In April of 2019, AARP released their report Home Alone Revisited: Family Caregivers Providing Complex Care.¹ The project, which was funded by the [John A. Hartford Foundation](#) and the [AARP Foundation](#), provides some interesting new perspectives about caregiving today that I believe are important for us to keep in mind. With the aging of the population the implications of these findings are going to be critical. Moreover, I am not convinced that babyboomers and their children are going to be willing to accept the burden of caregiving, the stress of caregiving and the expectation we have of caregivers. We need to begin to think about how we can help caregivers and optimize the care older adults will receive in the future.

I continually remind my husband how lucky he is to have married a geriatric nurse practitioner who understands aging and loves to provide the direct hands on care needed after all types of procedures or interventions. Not all family members are inclined to be caregivers and to provide either the very difficult hands on care that we go to nursing school to learn or even the psychological support needed to optimize recovery. A review of the findings from this new report can help guide our focus on next steps to help future caregivers for the babyboomers and beyond.

Major findings from home alone revisited

There were five major findings from Home Alone Revisited. The first finding was the fact that today's caregivers provide intense and complex care including direct hands on care such as wound care and tube feedings as well as managing pain and making decisions about pain medication. The second was that today's caregivers are diverse with regard to their experiences as well as age and cultural background. The third finding was that caregivers who are socially isolated or have no choice about caregiving are more at risk for experiencing difficulties with complex care. The fourth finding was the caregivers performing medical/nursing tasks experience both positive and negative impacts related to

providing those activities. These individuals worry about making mistakes, they worry about finances and/or they worry that the care will get even more complex. Conversely, there were also positive benefits noted such as recognizing that the care they provided was allowing their family member to stay at home and that they were getting time with and interacting with this individual in ways they never did before. The final major finding was that many family caregivers reported insufficient education and guidance from health care providers in terms of the tasks they were required to perform.

Based on these findings, the study team provided recommendations. The recommendations included increasing awareness of caregiving today, updating assessment tools for family caregivers to evaluate their ability to perform complex care tasks, encouraging health care providers to anticipate the stress and anxiety associated with complex caregiving, providing better private sector support for caregiving (employers and industry), and increasing community based involvement in developing programs and services for caregivers. These are not easy solutions and they require significant infrastructure and resources. We can all advocate and work towards these from a policy perspective as well as within our own institutions and settings.

Reflect on your own caregiving experiences or care receiving experiences

My guess is there is not a nurse out there among us who has not been a caregiver for a family member at some point in time. Reflect on how difficult it was when you alone are the decision maker for how to dress that wound, how much morphine to give, how to best manage the delirium your mother, father, or uncle is experiencing post surgery, or how to motivate your care recipient to get out of bed and ambulate to the bathroom. Remember this when you are working with family caregivers and share with them the things you may have learned or simply empathize and inform them there will be

some hard and uncomfortable decisions. There is no perfect solution to many of the care approaches we use and they should know that it is okay to try some things and if they do not work to reach out and get guidance on other options.

The question for caregivers is who to reach out to? While it is worth getting guidance from the experience of health care providers with expertise in the area of concern (e.g., pain management, wound care, and tube feeding), more practical information and guidance may come from patients and caregivers who have experience with the same clinical problem. For example, I have found repeatedly that the esophageal cancer patients online support group has better recommendations and solutions for the many lingering problems post treatment and esophagectomy than the surgeons, oncologists, radiologists and nurses that work in this area.

Flip this now to your memory of being a care recipient. Who did you trust to understand your pain, help manage a dressing change (to an area of course that you could not reach yourself!), or serve as your care partner and motivator? This may have been a spouse, a child, a friend or a hired nursing assistant or companion. It was likely their confidence and caring that served as a source of comfort and the belief that they would do their best to help you.

Our responsibility to caregivers today

For those of you working in acute and subacute care please think about teaching caregivers the skills related to procedures you know will need to be done for patients following discharge throughout the patient's admission. Do not wait till the day of discharge! Instead of you doing the wound care, giving medications that need to be crushed and put in pudding, flushing a tube, or inserting a Foley catheter have the family member/caregiver practice this under your supervision. Acknowledge that the caregiver may not feel comfortable doing the procedure and explore with him or her if there are

other options (e.g., hiring someone to do it; community resources). If there are no other options exploring the individual's feelings (e.g., fear and disgust) may help manage the discomfort. In addition, practicing the procedure will help increase confidence and will allow for an easier transition once at home. Provide positive reinforcement for all attempts, eliminate uncomfortable feelings associated with the procedure such as the fear that they will hurt the individual or do something wrong. In addition, think about the psychological stress and challenge of also being the cheerleader for the patient. Provide caregivers with the techniques needed to motivate older adults to engage in his or her personal care and physical activity to assure optimal recovery and maintain function over time (see www.functionfocusedcare.org). Lastly, remind caregivers to take care of themselves. Give them permission and help them establish a plan to get away from the demands of caregiving, to engage in regular physical activity and other activities they enjoy, and to not feel guilty when doing so. I have long believed we have very high expectations for family caregivers and it seems these just keep increasing. We need to lead the way in nursing to help address the "home alone" crisis caregivers are feeling and optimize the care that older adults receive in the community.

Reference

1. Reinhard SC, Young HM, Levine C, Kelly K, Choula RB, Accius J. (2019). Home alone revisited: family caregivers providing complex care. Available at: <https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html>. Last accessed July, 2019.

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