Q&A Summary
Advance Your Skills in Supporting the Family Caregiver
September 14, 2021

Presenter: Kathryn Sexson, PhD, APRN, FNP-BC, Betty Irene Moore School of Nursing at UC Davis, Sacramento, CA

Available On Demand:
optumhealtheducation.com/family-caregiver-2021

1. Is there a way to assess a caregiver's ability to complete a task? Is there recommended literature that address this?
    a. Interesting question. I have not seen this in the literature. In general, the recommendations to assess someone's ability center around requesting a return demonstration after teaching or asking them to communicate what they thought they understood from the explanation. I try to remember what may seem like an easy task to one person may be tremendously difficult for another and for a variety of reasons.

2. Where could I recommend caregivers seek help if a family member is at risk, such as with dementia or psychosis, but refuses care? Does the care recipient need a competency evaluation? What if the recipient refuses the evaluation?
    a. Excellent question. The Alzheimer's Resource Center can be an invaluable resource for navigating this complex situation.
    b. If the family member is at risk for harm, Adult Protective Services would be appropriate.
    c. If you are pursuing guardianship, then an Elder Law Professional would be an appropriate interprofessional team member to involve in the process.

3. How do you help caregivers, when their efforts are no longer safe or sufficient, to accept alternate care environments?
    a. Clearly understanding their motivation for providing care is extremely helpful. I find that most frequently when people are emotionally reticent it may be a promise made to never "put" the care recipient somewhere. It can be helpful to ask, in this case, if that promise would hold given the impact it is having. Was the intent of the promise to be sure they were well cared for and not "put someplace and forgotten"? Giving people permission to maintain the intent of the promise can open the door for them to be the daughter, son, spouse, etc. It is helpful to remind people that an alternate site simply changes the venue, but the level of involvement is something that can be negotiated if they still wish to provide some care or ensure the quality of care provided.

    b. Sometimes the barrier is financial. Without long-term care insurance (and in some cases even with insurance) costs for assisted living and nursing home facilities may not be covered. Costs can range from $3500 to more than $10,000 depending on the level of care. A care coordinator well versed in this arena can be exceedingly helpful in navigating possible sources of assistance.

4. What are you best recommendations for Alzheimer's parents?
    a. If for caregivers, the SAVVY Caregiver is a great program. The Family Caregiver Alliance also has some excellent resources. AARP’s Caregiving Resources also has great information. Please feel free to reach out as it sounds as though you may have some specific questions.

5. Are there specific resources per state?
    a. Yes, and even per region within a state. Your state Division of Senior Services can be a great starting point as can your local Area on Aging organization. The social worker and/or care coordinator at the hospital in your area may also be a resource for directing you to state and local resource agencies.

6. Are there methods to address gender differences in caregiving, and how to effectively help different genders cope and thrive in their new roles?
    a. This is an area where the research has been either equivocal or inconsistent. There are many factors to be considered including patient-related factors, sociodemographic components, impact of kinship, cultural norms, and others. As of 2017, 40% of caregivers were male; challenging our previously held belief that males made up a small portion of the caregiving population. I have found that using the Caregiver Preparedness Scale is an excellent way to open the conversation to discover the caregiver’s areas of strength and areas where there is opportunity for learning/supporting. I approach this as: “It sounds like you might benefit from learning more about x” or “it sounds like providing intimate personal care for your parent is an uncomfortable space for you. Would you like to explore some options or resources for help in this area?” Keep your eyes open in the literature. Currently, funding for caregiver research abounds and we are seeing a burgeoning body of evidence developing around best practices.

7. Is there enough research about the relationships between health literacy and caregiver burden among caregivers diagnosed with chronic illnesses?
    a. There is a significant amount of research around burden and literacy from a readability and numeracy lens, but not from the perspective of the 6 domains of health literacy, which are a more comprehensive approach to the concept of health literacy.

8. What should a provider or a care coordinator do if a caregiver is starting to struggle caring for a family member who is depending on them? How do you start a conversation with the caregiver about how to transfer care to someone else or somewhere else (i.e., a skilled nursing facility, live-in facility, hospice) without hurting the caregiver?
    a. Begin by recognizing the love and/or dedication that has gone into providing care thus far. Acknowledge that you are noticing they appear exhausted or that their health has begun to fail or that they are struggling to meet the increasing demands. I talk with them about the fact that we never ask anyone outside the family caregiver to provide 24/7/365 care. Acknowledging that this may no longer be possible doesn't mean that they cannot continue to be involved, and it may simply mean a different venue. For caregivers who are worried about the transition, I often encourage them to look for a facility where they can stay with the care recipient for the first few days/weeks. I find the internal struggle often happens when the care recipient is unaware of the toll it is taking, or the caregiver doesn't want the care recipient to feel unloved or that they are a burden. Sometimes, having access to a temporary respite facility can be enough to either recharge or recognize someone else may be able to help. Together, you provide more comprehensive care around the clock. I avoid making statements that might inadvertently communicate that they are not providing quality care because they are really doing the very best they can given the situation.

If you have questions regarding this document or the content herein, please contact: moreinfo@optumhealtheducation.com.