

FACULTY GUIDE

Supplemental Module 4

Taking Care of Those Caring for Persons with Dementia

May 2017

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Slide 1:

- Taking Care of Those Caring for Persons Living with Dementia: This module is intended to raise provider awareness of issues around taking care of the caregivers of persons living with dementia. It is part of a module series that was developed under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. This work was funded by the U.S. Department of Health and Human Services, Office of Women's Health.

Slide 2:

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Slide 3:

- Primary care providers and other members of the health care team need to be concerned about the health and well-being of caregivers for persons living with dementia for a variety of reasons. The risk factors for caregiver burden include female sex, low educational attainment, living with the care recipient, a high number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver. Caregivers may neglect their own health in their commitment to caregiving, and this may have deleterious effects on their ability to sustain caregiving. They are at high risk for stress-related disease. They may be at risk for frailty, as evidenced by caregivers of persons living with dementia experiencing accelerated cognitive decline themselves compared to non-dementia caregivers. Caregivers are the backbone of care provision. If the caregiver becomes ill, the person living with dementia may have no safety net and may become at risk for residential care placement.

Slide 4:

- Caring for persons living with dementia can be hazardous to the health of the caregiver. Approximately 38% of dementia caregivers indicated that the physical impact of caregiving was high or very high. About three quarters of dementia caregivers report that they were either somewhat or very concerned about maintaining their own health since becoming a caregiver. They are more likely than non-caregivers to report that their health is fair or poor. Sleep disturbances can occur frequently in caregivers of persons living with dementia.

Slide 5:

- The chronic stress of caregiving has been shown to be associated with physiological changes that result in an increased risk of the caregiver developing chronic health conditions. Caregivers of spouses living with dementia are more likely than married non-caregivers to have elevated biomarkers of cardiovascular risk and impaired kidney function risk. They are also more likely to have physiological changes that reflect declining physical health. These changes include high

levels of stress hormones, reduced immune function, slow wound healing, increased incidence of hypertension, coronary heart disease, and impaired endothelial function.

Slide 6:

- Caregiving for persons living with dementia comes at a cost. The physical and emotional impacts of dementia caregiving is estimated to have resulted in over \$10 billion in healthcare costs in the United States in 2015. Dementia caregivers had more hospitalizations and emergency department visits if they were caring for persons who were depressed, had low functional status, and had behavioral disturbances.

Slide 7:

- Health care providers may have varying relationships with their caregiving patients. In some cases, they may care for both the caregiver and the person living with dementia, or they may care for either the caregiver or the person living with dementia. Whatever the caregiving arrangement, all of these scenarios call for proactive health care for the caregiver. This module provides suggestions about what to ask a caregiver who is a patient in your practice, whether or not the person living with dementia is. In the case that the caregiver has a different primary care provider, it is still in the interest of the person living with dementia that you observe the caregiver and encourage them to take good care of their personal health and monitor and address their stress levels.

Slide 8:

- When primary care providers care for both the person living with dementia and the caregiver they need to be extremely vigilant for indications of stress in the caregiving relationship. Stress has multiple sources and may be a factor in all of your patients but you should raise the subject of stress more frequently with people who are caregivers. Caregivers may be so overwhelmed that they automatically deny they are having problems. Therefore, you may ask about stress on a regular basis to give them more time and opportunity to reflect on the topic. Caregivers need to be strongly encouraged to talk about their caregiving experience. By acknowledging the stress of caregiving and asking about it, you send a message that their health is important. Also, encourage caregivers who are not your patients to speak with their providers about maintaining their health and managing their stress. You should be prepared to refer all caregivers to local support groups, home and community-based services including meals or transportation, self-help books, or trusted information on the internet.

Slide 9:

- When the caregiver is the patient, primary care providers should inquire about medical problems that the caregiver is experiencing. For example, ask specific questions about how well the caregiver is sleeping; or if they are having any eating issues, such as unexpected weight gain or loss. In addition, how they are managing agitated behaviors exhibited by the persons living with dementia? Do they have any fears about controlling their own anger or that of the persons living with dementia? Finally, review the medications the caregivers are taking to ensure they are comfortable with their own medication regimen.

Slide 10:

- There are many ways that primary care providers can address the stress that caregiving may place on caregivers' psychological health and social lives. Providers can talk with caregivers about the quality of their relationships with the person living with dementia and explore any feelings of guilt they may have about not doing enough. Providers can also discuss issues related to family dynamics, particularly the relationship between the caregiver and other family members, both local and distant. It may be useful to address issues such as powers of attorney regarding legal and medical matters and ensure that the caregiver has an emergency preparedness plan. Providers can also explore the caregivers' feelings of competence and need for assistance or training. Regularly reviewing how the caregiver addresses behavioral and psychological symptoms may help to reassure caregivers that their feelings of grief are normal, though an intervention may be necessary if feelings impair day-to-day functioning.

Slide 11:

- At each visit, providers should ask caregivers about their unmet needs related to caregiving, including how they manage with daily activities, if they get time off from caregiving, or if they need information. It is important to ask about informal support from family members and professional support from a variety of service agencies in the community. Be prepared to prompt them for their replies on this issue because caregivers may underreport the need for additional support. In conducting this review, providers can use the care plan to identify needed assistance.

Slide 12:

- Many caregivers have existing physical and/or mental health issues when they take on the caregiving role. A concern exists that caregivers may ignore their own health while caring for persons living with dementia and may not report new health problems that may arise. As a result, you should closely monitor the caregiver's health status and regularly inquire about how they are managing their personal health.

Slide 13:

- Although caregiving can be very rewarding, at times it is stressful. Inquire about feelings of sadness, anxiety, depression and stress. Several screening tools can help you assess the caregiver health. A basic screening test for overall caregiver stress is the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Risk Appraisal. An easy-to-use screening tool for depression is the Patient Health Questionnaire (PHQ-9), described on the next slide. While the Generalized Anxiety Disorder 7-item (GAD-7) scale helps screen for anxiety. In addition, you should pay particular attention to other signs of stress, especially weight change and sleep problems.

Slide 14:

- The PHQ-9 (Patient Health Questionnaire) is a frequently used tool to screen for symptoms of depression. If the first two questions elicit a positive response, then the full nine questions are

asked. The tool is available in the public domain and more information about its use can be found in an article by Kroenke et al, listed in the references.

Slide 15:

- The PHQ-9 is a screening, not a diagnostic tool. Providers can use it to uncover potential areas that deserve more examination. To interpret the PHQ-9, the scores derived from the responses are added together to determine a general level of severity. If there are at least five checkmarks in the two furthest right-hand columns, of which at least one corresponds to the first two questions, you should explore the possibility of a major depressive disorder. If there are two to four checks in the right-hand columns, with at least one from questions 1 or 2, then you might consider that a less serious depressive disorder may be present. The results of the screening should prompt you to make further assessments and referrals for psychiatric or psychological evaluation.

Slide 16:

- This slide summarizes the scoring of the PHQ-9 for severity of depression. It shows different levels of potential severity although these are not diagnostic classifications. Providers can use the score to determine the urgency of further evaluation.

Slide 17:

- The Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) is a culturally sensitive protocol based on an individualized assessment of caregiver needs. It is a multi-component caregiver intervention, tailored to individualized risk profiles based on a caregiver assessment of depression, burden, self-care and healthy behaviors, social support, and problem behaviors. It is available in an 8-item and a 16-item form. The link provided at the bottom of the slide gives details for how to score the shorter form. The link on this slide was last accessed on June 15, 2017.

Slide 18:

- This slide shows the eight items in the short form of the REACH II. It includes a mixture of items that address resources available to the caregiver, issues about specific risks to the person living with dementia, caregiver satisfaction with the amount of help received, and a series of potential symptoms associated with stress.

Slide 19:

- The GAD-7 Scale identifies whether a complete assessment for anxiety is indicated. Details for using and scoring the GAD-7 can be found at the link on the slide. The link on this slide was last accessed on June 15, 2017.

Slide 20:

- These are the questions in the GAD-7 that can be found at the link in the previous slide.

Slide 21:

- Providers can choose from among a number of scales to assess caregiver stress. The best known, developed by Zarit, has been shown to work well and is copyrighted. As an alternative, providers can use a short tool developed by two family physicians, Drs. Parks and Novelli. Shown in the next slide, the tool reviews a number of areas where problems might exist. Their article offers a number of helpful suggestions.

Slide 22:

- This tool identifies potential areas related to caregiver stress. Positive responses require further investigation with the caregiver to determine if referrals, counselling, or supports such as respite care are necessary.

Slide 23:

- Respite or regular time off for the caregiver is very important to caregiving. Encourage caregivers to take breaks at least weekly. Recommend that caregivers build time for themselves into their routine and refer caregivers to resources that can provide respite both in and outside of the home. Explain the reality of burnout and the consequences for both the caregiver and the person living with dementia and reassure the caregiver that personal time off is actually in the best interest of the person living with dementia. Providers can encourage caregivers to take vacations and formally prescribe home help. Providers should also encourage caregivers to arrange for longer periods of coverage, with the help of family members or hired help. In some cases, a short-term nursing home or assisted living stay may be used. Emphasize how the benefits of respite offset the loss of someone new providing slightly less individualized care, slightly less well.

Slide 24:

- Respite care can help in many ways and come in a variety of different forms. Encourage caregivers to ask family members to contribute to caregiving weekly and remind caregivers that it is also possible to pay for assistance inside and outside of the home. Some agencies provide assistance in the home while day care and residential care agencies provide care outside the home. When a caregiver becomes ill, caregivers can arrange emergency respite care through homecare agencies, adult day care, health centers, and residential care facilities. Using each of these agencies in non-emergency situations will allow caregivers to test out the services and pick one or two for emergency purposes.

Slide 25:

- Let us now address Learning Objective #1: Describe your roles in maintaining caregiver's health when the caregiver is your patient.
 - The daughter of a 78-year old man with moderate dementia brings her father to see you.
 - She is also your patient. She complains of feeling anxious and tired.
 - How do you respond to this caregiver?

- Take a moment to compile your answer and compare it to the response on the next slide.

Slide 26:

- Ask for details about how she is doing. What makes the caregiving stressful? How is she balancing the role with her other responsibilities? Does she feel she is getting enough help and support? Ask about sleep problems and eating. Is there a problem with her father's behavior? Screen for stress, anxiety, and depression and use the results of those screenings as a basis for discussing the issues and referring the caregiver for additional care. Review her medical condition and ask about problems in adhering to regimens and make changes as indicated.

Slide 27:

- The caregiver who accompanies a person living with dementia may not be your patient. However, when he/she is in your office you have an opportunity to inquire about her health and to encourage a visit to his or her own primary care provider. You may want to be proactive and use your office staff to help make appointments with the appropriate providers. You should ask at each follow-up visit whether the caregiver has seen a primary care provider. It is important to take every opportunity to talk with any caregiver about the need to take care of him/herself.

Slide 28:

- Let us now consider Objective #2: Describe your roles in maintaining the caregiver's health when the caregiver is not your patient.
 - For the scenario where the daughter of a 78-year old man with moderate dementia brings her father to see you and she is not your patient, what do you say to this caregiver?
 - Once you have considered your response, compare it to the one listed on the next slide.

Slide 29:

- Ask her how she is feeling. Acknowledge the strains of caregiving.
- Inquire about how well she feels because she is balancing the caregiving role with her other responsibilities.
- Ask her if she feels she is getting enough help and support.
- Inquire directly about any feelings of stress and depression she may be experiencing.
- Ask what she is doing to relieve stress and what time she has for herself. If appropriate, encourage her to consider respite.
- Ask if she is getting treatment for her own medical issues and following that advice. If she has been neglecting her own health, remind her that she will be a better caregiver if she is healthy. Ask if your staff can assist her with making an appointment with her own primary care provider.

Slide 30:

- In summary, caregiving is associated with poorer caregiver physical and mental health. The stress of caregiving can result in new disease or exacerbation of existing conditions that go unattended. Therefore, it is essential to work with caregivers to help them maintain their health.

Screening tools are available to monitor depression, anxiety, and stress. You should be proactive in attending to early signs of stress by inquiring about the burdens of caregiving and encourage the use of respite care.

Slide 31:

- This and the next two slides provide the full references for information found in this module. The links on this slide were last accessed on June 15, 2017.

Slide 32:

- The links on this slide were last accessed on June 15, 2017.

Slide 33:

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Slide 34:

- This slide provides links to several informative videos and webinars on dementia care. Check your local chapter of the Alzheimer's Association for other useful videos. Other resources from the Alzheimer's Association are available at the links provided. The links on this slide were last accessed on June 15, 2017.

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