*Figure*

Recommendations for Clinicians who Work with Caregivers of Persons Living with Dementia

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| Domain | Recommendations |
| Race | 1. Do not assume that Black caregivers are less distressed by their PLWDs’ symptoms because of their cultural values of filial obligation and cultural expectation of unquestionable responsibility for their older relatives. 2. Assess PLWDs’ symptoms using validated instruments and via discussions with caregivers. |
| Gender | 1. Recognize that most caregivers are female. Expect that female caregivers are likely to be more distressed. 2. If male caregivers do not show distress or downplay it, however, do not assume they are not distressed. In Western culture, men are socialized to emphasize self-efficacy and assertiveness which may lead to under-reporting depression.1 Attention to male caregivers is particularly important because White males have the most suicides.2 |
| Age | 1. Attend to younger caregivers who may appear less distressed as they may seem to have more energy and other aspects of life beyond caregiving (e.g., job, family, live apart from their PLWD). |
| Relationship configuration | 1. Adult children caregivers are likely to be highly distressed from sources of stress beyond caregiving. Stressors from employment, their own family, and more may compound the stress of caregiving. 2. Recognize that family conflict is highly prevalent in caregiving families.2 Initiate the conversation about family conflict and possible disagreements about caregiving. Encourage the caregiver who is providing the majority of care to set boundaries on caregiving and in relationships with family members who do not provide hands-on or financial help. Explain that caregiving is a full-time job that will become progressively more difficult. 3. Encourage caregivers to start discussions with family members about caregiving responsibilities and legal and financial planning. Recommend books/resources on initiating and handling complex discussions (e.g., *“Crucial Conversations: Tools for Talking when Stakes are High.”*)3 |
| Employment | 1. Provide information about financial expenditures associated with caregiving. Discuss the possibility of the caregiver re-appraising his/her financial situation to allow for paid help (e.g., brainstorm ways to generate additional income to supply additional help). 2. Forewarn caregivers who are employed that it is very common for caregivers to experience employment disruption as a result of caregiving.4 Discuss with caregivers possible consequences of relinquishing employment such as diminished financial security but also a changed social role with the potential of social isolation, perceived loneliness, and lower self-worth. Future employment may also be jeopardized. Discuss options to find a compromise between caregiving and employment (e.g., part-time employment, asking for paid or unpaid help with caregiving). 3. Arrange a meeting with a social worker who may assist with applying for respite and financial assistance for caregivers. Caregivers may not be able or willing to find help themselves (e.g., low health literacy, too busy, lacking knowledge about navigating the healthcare system). |
| Time since Dementia Onset | 1. Recognize that PLWDs’ quality of life will decrease with dementia progression. Formally assess cognition5,6 and dementia stage7,8 and provide resources appropriate for the dementia stage. |
| Comorbidities | 1. Ensure comprehensive care provision to PLWD, recognizing that PLWD are likely to have numerous comorbidities that are difficult to manage. Managing comorbidities is further complicated as PLWDs’ capacity to communicate and care for self diminishes. 2. Employ geriatric care guidelines and prescribe medications and treatments in concordance with the person’s dementia stage and adhering to geriatric pharmacotherapy guidelines (Beer’s criteria).9 |
| Dementia type | 1. Ascertain specific type of dementia (e.g., Alzheimer’s disease, vascular dementia, frontotemporal dementia).4 2. Tailor information to the specific dementia diagnosis, recognizing that caregivers of persons with non-Alzheimer’s dementia are likely to have insufficient information. Refer to specialists. |
| General recommendations | 1. Confirm whether adults who may possibly be caregivers are indeed caregivers. Without direct questioning, many persons may not think of themselves as caregivers or they may not volunteer this information. 2. Supplement discussions with administering validated survey instruments that measure important PLWD- and caregiver-centered variables, including but not limited to: Zarit Burden Interview,10,11 Perceived Stress Scale,12 Center for Epidemiologic Studies – Depression,13 Patient-Reported Outcomes Measurement Information System – Anxiety,14 Pearlin’s Caregiver Stress Scales,15 and Neuropsychiatric Inventory.16 3. Carefully assess information derived from discussions and analyzing findings from the survey instruments to create a more comprehensive view of the caregivers’ situation and offer individualized solutions. Follow up on the implementation of these solutions and whether they are effective. 4. Explain the various neuropsychiatric symptoms, their etiology, and pharmacologic and nonpharmacologic management.17 5. Forewarn caregivers that dementia will progress despite the caregivers’ best efforts and clarify prognostic information. Reinforce that progress of dementia is the expected course, not a reflection of anything the caregiver did or did not do. |

*Note.* PLWD – person living with dementia.1Oksuzyan et al., (2008) 2Centers for Disease Control and Prevention (2019) 2Fukui et al., (2017) 3Grenny et al., (2013) 4Alzheimer’s Association (2021) 5Borson et al., (2003) 6Nasreddine et al., (2005) 7Reisberg et al., (1984) 8Morris (1993) 92019 American Geriatrics Society Beers Criteria® Update Expert Panel 10Zarit et al., (1980) 11Bédard et al., (2001) 12Cohen et al., (1983) 13Radloff et al., (1977) 14PROMIS (n.d.) 15Pearlin et al., (1990) 16Kaufer et al., (2000) 17Desai et al., (2012)