

Dolores Gallagher-Thompson
Ann Choryan Bilbrey
Sara Honn Qualls
Rita Ghatak
Ranak B. Trivedi
Lynn C. Waelde

Advances in Psychotherapy –
Evidence-Based Practice

Family Caregiver Distress



Family Caregiver Distress

About the Authors

Dolores Gallagher-Thompson, PhD, ABPP, is active professor emerita in the Department of Psychiatry/Behavioral Sciences at Stanford. For 30+ years she conducted intervention research with caregivers of older adults experiencing memory loss.

Ann Choryan Bilbrey, PhD, is the CEO of the Optimal Aging Center for Training and Research Consultation. Along with Dr. Gallagher-Thompson, she is co-developer of the CWC2.0 Workshop series.

Sara Honn Qualls, PhD, ABPP, is Kraemer Family Professor of Aging Studies and Professor of Psychology at the University of Colorado Colorado Springs. She publishes on mental health and aging, caregiving, and geropsychology.

Rita Ghatak, PhD, is active in direct care, research, and education. Founder of Aging Adult Services at Stanford University Medical Center, she developed many care models. She is the CEO of Aging101.

Ranak B. Trivedi, PhD, assistant professor at Stanford University has sought to improve the self-management of serious illnesses by enhancing the collaboration and coping of patient-caregiver dyads. She is a director of education and training in the VA Palo Alto Health Care System.

Lynn C. Waelde, PhD, is a professor emeritus at Palo Alto University. Her work addresses the use of mindfulness/meditation to promote resilience/recovery from stress and trauma. She is the developer of Inner Resources for Stress, named a best practice by the Benjamin Rose Institute on Aging.

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Dolores Gallagher-Thompson

Department of Psychiatry and Behavioral Sciences,
Stanford University School of Medicine, Palo Alto, CA

Ann Choryan Bilbrey

Optimal Aging Center for Training and Research Consultation,
Sunnyvale, CA

Sara Honn Qualls

University of Colorado Colorado Springs, CO

Rita Ghatak

Aging 101, Center for Care and Innovation, Los Altos, CA

Ranak B. Trivedi

Department of Psychiatry and Behavioral Sciences,
Stanford University School of Medicine, Palo Alto, CA

Center for Innovation to Implementation,
VA Palo Alto Health Care System, Palo Alto, CA

Lynn C. Waelde

Palo Alto University, Palo Alto, CA

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30 Amberwood Parkway, Ashland, OH 44805
Phone 800 228 3749, Fax 419 281 6883; E-mail customersupport@hogrefe.com

UK: Hogrefe Publishing, c/o Marston Book Services Ltd., 160 Eastern Ave.,
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EUROPE: Hogrefe Publishing, Merkelstr. 3, 37085 Göttingen, Germany
Phone +49 551 99950 0, Fax +49 551 99950 111; E-mail publishing@hogrefe.com

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Preface

Caring for older adult friends or family members with chronic illness is demanding and strenuous. Caregiving can have serious negative effects on caregivers' physical and mental health, particularly if the care recipient is experiencing Alzheimer's disease or another form of dementia (ARD). At the same time, caregiving provides its own rewards and satisfactions. However, since our health care systems generally focus on care recipients and not caregivers, many of their specific needs for education, support, and treatment are not addressed. Recent legislation such as the BOLD Infrastructure for Alzheimer's Act (2018) and the newly enacted National Strategy to Support Family Caregivers (2022) provide leadership and funding so these efforts can and will move forward. Caregivers are the backbone of long-term care in the US.

Providing services to family caregivers of persons with dementia (or other forms of chronic illness) requires that we think of caregivers in relation to their care recipients since their difficulties and strengths are inextricably linked. Over time, we need to understand their changing needs and those of their larger family/friend social network. We focus on ARD caregivers in this book because they are the most distressed, the most well-studied, and the persons with whom we have the most clinical experience.

We invite you to dive deeply into this book and to utilize the many resources provided in the appendices. We welcome your feedback as you put these recommendations into practice!

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a person spends in each phase varies across individuals. Physical changes in the brain damage and destroy nerve cells. In early stages, the brain can compensate; however, as damage progresses, the brain is less able to compensate, resulting in increasing symptoms and gradual, steady decline over time. Depending on when in the course of illness the diagnosis is made, the person with dementia may survive for 10–20 years which correlates with the amount of time that family members will be in the caregiving role.

A combination of methods and tests are used to detect AD (National Institute on Aging, 2021). However, a conclusive diagnosis is possible only after the person’s death when confirmed through examination of the brain postmortem. Alzheimer Disease Research Centers (ADRC) are a nationwide network of congressionally mandated Centers of Excellence supported by the National Institutes of Health. ADRCs, located in major medical institutions across the United States, are an excellent resource for obtaining a diagnosis. Their locations are found at <https://www.nia.nih.gov/health/alzheimers-disease-research-centers>.

Pre-clinical phase: measurable brain changes, no cognitive symptoms of AD

In the *pre-clinical* phase, an individual may have measurable evidence of brain changes but has not yet exhibited the cognitive symptoms of AD (see Figure 2). These changes include the abnormal accumulation of beta amyloid plaque in areas between nerve cells, and tangling of a protein called tau within cells. In a meta-analysis of 36 longitudinal studies with over 6,600 subjects, the pooled risk of progression to the next stage was shown to be 73% (Parnetti et al., 2019). Therefore, not all persons with these biomarkers will exhibit memory or thinking difficulties, or progress to AD. In fact, autopsies reveal in individuals with normal cognition that the prevalence of amyloid at 70 years of age is 23%, increasing to 43% in those at 90-years-old (Jansen et al., 2015). Other factors, such as lifestyle, are also strongly implicated in whether or not older adults actually develop diagnosable cognitive disorders (Livingston et al., 2020).

MCI due to AD: brain changes, mild issues in memory or thinking, but still functional in IADL

In the next stage, *mild cognitive impairment (MCI) due to AD*, an individual has biomarker evidence of AD and is exhibiting mild or subtle difficulties with their memory and thinking significant enough that those close to them notice changes. However, the individual is still able to function and carry out their *independent activities of daily living (IADL)* such as managing their money and

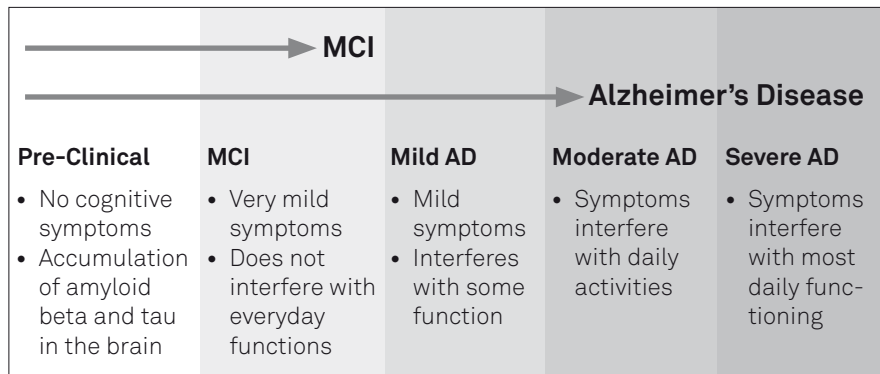


Figure 2

Alzheimer’s disease progression and stages. MCI = mild cognitive impairment.

may be present, and clinicians may use other assessments to get more in-depth information. However, in our experience, depression and anxiety are the most common problems bringing caregivers into treatment. Also essential is the *Caregiver Self-Assessment Questionnaire* – a set of questions about stress related to caregiving. These are the Top 3 to administer and score when time is very short.

Key Takeaway

Even if time is limited, clinicians should always administer:

1. PHQ-2 and 9 if indicated
2. GAD-2 and 7 if indicated
3. Caregiver Self-Assessment Questionnaire

These three self-report measures will take about 10 minutes.

3.1.2 Caregiver Specific Challenges

If a full hour is available for the baseline assessment, we recommend incorporating additional measures to get a fuller picture of the CG's strength and challenges. Clinicians should select either the *Revised Memory and Behavior Problem Checklist*, where questions are specific to dementia, or the *Caregiver Reaction Scale*, which has a broader focus in that it is multifactorial and can be used with caregivers of persons with other chronic illnesses. For a caregiver of PLWD, administering both can be very informative, if time permits.

Allowing for sufficient time is critical for a CG-focused assessment

All caregivers should complete two indices of care recipient functioning: *Lawton Instrumental Activities of Daily Living* and the *Katz Activities of Daily Living*. This information helps clinicians understand specific care needs of the PLWD and provides a basis for asking about what the caregiver actually does for that individual, what about it is causing stress, and what other help may be needed.

3.1.3 Caregiver Supports

The *Positive Aspects of Caregiving Scale* assesses perceived benefits from caregiving. Extent of support from other is also vital to understanding current needs as many caregivers lack sufficient support to mitigate the stressors involved. Their sense of resilience in the face of adversity is another dimension that can be assistive, or, if lacking, can suggest an area for intervention. Taken together, this information gives mental health providers a good sense of what the problems are and where to begin in terms of intervention.

3.2.2 Screening for Cognitive Function

For caregivers who may themselves be experiencing mild cognitive dysfunction (e.g., inability to give specific dates and sequences of events), administering a quick screen for cognitive impairment such as the Mini-Cog or SLUMS is appropriate and helps clarify the situation. If the caregiver is experiencing mild cognitive decline themselves, PHQ-9 may be too complicated for them to complete accurately. Use of the Geriatric Depression Scale in those cases is recommended as it has a simple yes/no response format and is a more accurate way to assess depression in these persons.

3.2.3 Other Specific Measures

Clinicians interested in evaluating the caregiver's sense of self-efficacy for managing challenging aspects of caregiving may want to include such questions in their interview. To understand the caregiver's social support network we recommend the *Atlas CareMap*. Some caregivers describe their situation in terms of *burden*; for them, the *Zarit Burden Inventory* can help quantify its extent. The *UCLA Loneliness Scale* taps into the caregiver's sense of isolation which may be present despite having some supports, and the *Marwit-Meuser Caregiver Grief Inventory* captures the caregivers' experience of grief both in anticipation of, and following, the death of their care recipient.

3.2.4 Assessing Domains Not Listed

Clinicians may find it necessary to assess other domains not listed here; for that, the American Psychological Association's Caregiver Briefcase can be consulted.

3.2.5 Working With Diverse Caregivers



DEI Spotlight!

- Most measures are not validated on racial/ethnic, sexual, or other minorities.
- Clinicians should try to find tools that may be culturally suited, and use interpreters as needed.

Throughout the book we will highlight diversity, equity, and inclusion notes in the DEI Spotlight. Many of the most commonly used measures described above have not been validated with diverse groups, although translated versions are often available. Clinicians working with caregivers who identify as Black, Indigenous, or Persons of Color (BIPOC) and/or as sexual or gender minorities, should do their due diligence to identify optimal measures for assessment. When the first language of the caregivers is not English and a validated measure is not available, clinicians may do their best to translate

4

Interventions to Reduce Caregiver Distress

4.1 Introduction of Stepped Approach

A variety of interventions can be used, singly or in combination, sequentially or simultaneously, to improve caregivers' quality of life and provide treatment for their mental health concerns. We use the term *intervention* rather than *treatment* in several places below and reserve the term *treatment* for those programs that have a published, data-driven evidence base. This reflects our experience that caregivers have multiple unmet needs and so require multiple levels of intervention for best results. Their needs vary according to where their care recipient is the trajectory of their illness, as well as where the caregiver is in terms of knowledge, support, and their own psychological distress. We propose an integration of the *trajectory* model of caregiving (Table 1 in Chapter 2) with the *stepped* approach (Figure 4) to help clinicians make appropriate intervention selections. The latter is adapted and modified from the Inter-Agency Standing Committee guidelines for mental health and psychosocial support in emergency settings (Inter-Agency Standing Committee, 2021) which are widely followed with regard to intervention selection for trauma victims (<https://reliefweb.int/report/world/iasc-guidelines-mental-health-and-psychosocial-support-emergency-settings>).

In this approach, different interventions are used based on differing levels of need, with the most minimally invasive or least expensive level tried first. Virtually all caregivers benefit from Levels 1 and 2. Level 3 psychoeducational programs focus on learning to employ effective coping strategies, and the various forms of psychotherapy and multicomponent programs on Level 4 treat significant psychological distress.

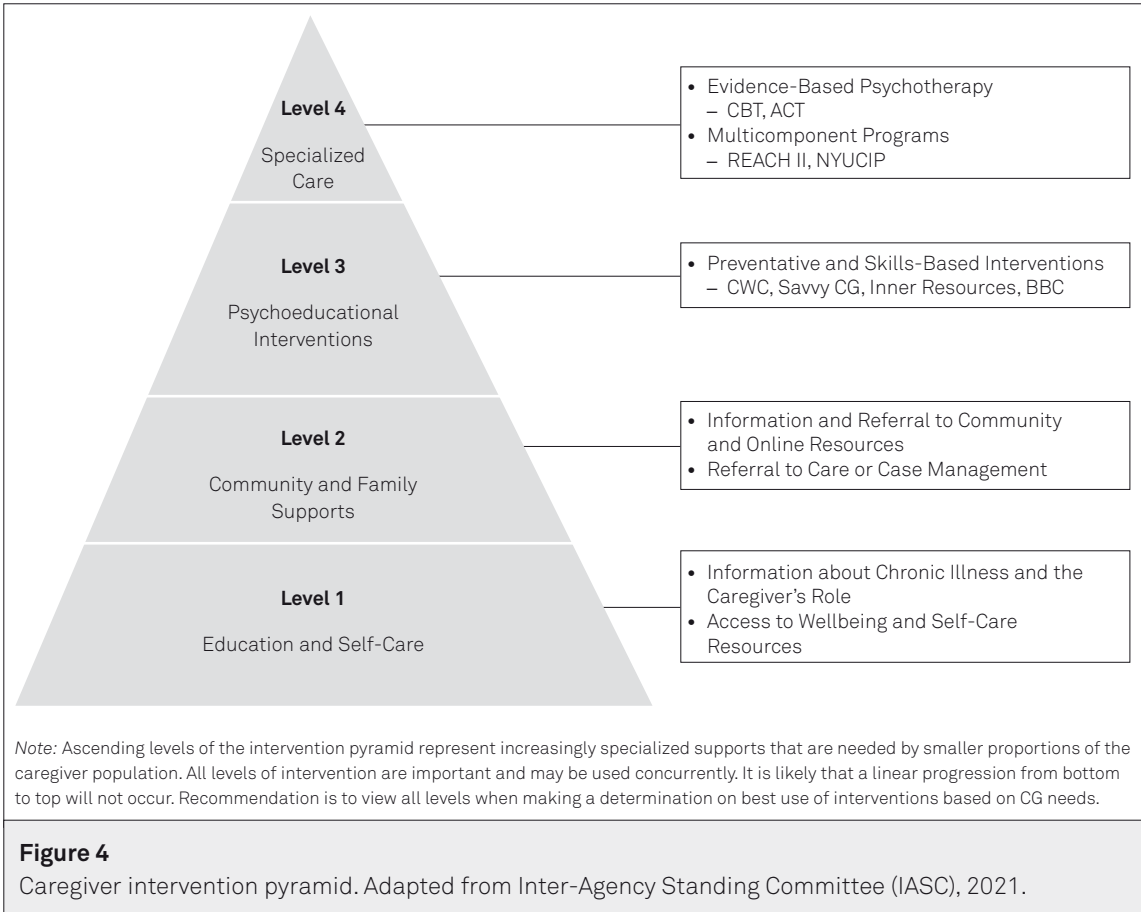
In a tiered approach the most minimally invasive or least expensive is tried first

4.1.1 Levels of Intervention

Level 1

The pyramid base depicts the foundational importance of education and self-care. If caregivers do not know what is happening to their loved one, what is likely to happen in the future, and what is expected of them over time, they are ill-equipped to deal with challenges ahead. Of course, information needs change as their care recipients' care needs change. Caregivers can be directed to vetted websites and sources such as print, online, videos, books, and research sites. The National Institute on Aging ADEAR Center's website and the national website of the Alzheimer's Association are excellent. Both

Level 1 focuses on education and self-care, vital to CG mental health



contain information in several languages which is helpful for caregivers who prefer information in their native language. Appendix 1 gives descriptions of curated resources for caregivers. Websites and other sources of information for providers are found in Appendix 4.

Level 2

Level 2 focuses on community & family supports which all CGs need eventually

Community and family supports are vital to caregivers' mental health. It is simply not possible to be a long-term caregiver to a PLWD and not utilize community-based services at different points along the way. Services at this level take many forms including in-home help to assist with management of the PLWD as well as engaging the PLWD in a licensed day care or day health program. Caregivers may attend dementia-focused support groups sponsored by a reliable source such as local chapters of the Alzheimer's Association and similar organizations. In order to determine which specific supports each caregiver needs, clinicians must become familiar with what resources are available, and think through, with the client, which are most relevant to meet current needs. Of note is that community-based resources vary greatly by state, and within states, on the local level. Providers should become familiar with local Area Agencies on Aging (AAAs) as a starting point to learn about these resources.

9

Appendix: Tools and Resources

The following materials for your book can be downloaded free of charge once you register on the Hogrefe website:

Appendix 1: Curated Resources for Caregivers

Appendix 2: Caregiver Intake Interview

Appendix 3: Assessment Recommendations Links Listed in the Book

Appendix 4: Curated National Resources for Providers

Appendix 1: Curated Resources for Caregivers

Books About Caregiving Authored by Caregivers

- Comer, M. (2014). *Slow dancing with a stranger: Lost and found in the age of Alzheimer's*. Harper Collins.
- Davidson, A. (1997). *Alzheimer's, a love story: One year in my husband's journey*. Birch Lane Press.
- Davidson, A. (2015). *A curious kind of widow: Loving a man with advanced Alzheimer's*. Daniel & Daniel Publishers.
- Graboys, T. B., & Zheutlin, P. (2008). *Life in the balance: A physician's memoir of life, love, and loss with Parkinson's disease and dementia*. Union Square Press.
- Jacobs, B. J. & Mayer, J. L. (2016). *Meditations for caregivers: Practical, emotional, and spiritual support for you and your family*. Da Capo Press.
- Kleinman, A. (2019). *The Soul of care: The moral education of a husband and a doctor*. Penguin Books.
- Mace, N. L., & Rabins, P. V. (2011). *The 36-hour day: A family guide to caring for people who have Alzheimer disease, related dementias, and memory loss*. JHU Press.
- Thelwell, D. (2014). *The dance: Our journey through frontotemporal degeneration*. CreateSpace Independent Publishing Platform.
- Thomas, D. & White, Z. (2019). *The unexpected journey of caring: The transformation from loved one to caregiver*. Rowman & Littlefield.

Films About Caregiving

- *Still Alice* (2014). Sony Pictures Classics.
- *Iris* (2001). Miramax Films.
- *On Golden Pond* (1981). Universal Pictures.
- *Robin's Wish* (2020). Quotable Pictures.
- *The Father* (2020). Sony Pictures Classics.

Online Resources

AARP local resources	Find local resources on in-home care, medical services, housing options, community services for AD by US city https://www.aarp.org/caregiving/local/
AARP's CG Resources	Access site to articles, videos, & resources https://www.aarp.org/caregiving/
Alzheimer's Association: National Website	Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. https://www.alz.org
Alz Assn: 24/7 Helpline	Alz Assn's 24/7 Helpline: professionals offer confidential support and information to PLWD, CGs, & families. https://www.alz.org/help-support/resources/helpline
AFA: Caregiving Resources	List of resources available for caregivers from the Alzheimer's Foundation of America (AFA) contains: Helpline, support groups, fact sheets, webinars, and daily activities. https://alzfdn.org/caregiving-resources/
AFA: National Memory Screening Program	Alzheimer's Foundation of America's National Memory Screening Program provides free, confidential memory screenings throughout the country on an ongoing basis. https://alzfdn.org/memory-screening/
AngelSense App	Subscription based GPS tracking app to help locate people. https://www.angelsense.com