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

# 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 Aging 101.

**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.

## Advances in Psychotherapy - Evidence-Based Practice

#### **Series Editor**

Danny Wedding, PhD, MPH, Professor Emeritus, University of Missouri-Saint Louis, MO

#### **Associate Editors**

**Jonathan S. Comer**, PhD, Professor of Psychology and Psychiatry, Director of Mental Health Interventions and Technology (MINT) Program, Center for Children and Families, Florida International University, Miami, FL

**J. Kim Penberthy**, PhD, ABPP, Professor of Psychiatry & Neurobehavioral Sciences, University of Virginia, Charlottesville, VA

**Kenneth E. Freedland**, PhD, Professor of Psychiatry and Psychology, Washington University School of Medicine, St. Louis, MO

**Linda C. Sobell**, PhD, ABPP, Professor, Center for Psychological Studies, Nova Southeastern University, Ft. Lauderdale, FL

The basic objective of this series is to provide therapists with practical, evidence-based treatment guidance for the most common disorders seen in clinical practice – and to do so in a reader-friendly manner. Each book in the series is both a compact "how-to" reference on a particular disorder for use by professional clinicians in their daily work and an ideal educational resource for students as well as for practice-oriented continuing education.

The most important feature of the books is that they are practical and easy to use: All are structured similarly and all provide a compact and easy-to-follow guide to all aspects that are relevant in real-life practice. Tables, boxed clinical "pearls," marginal notes, and summary boxes assist orientation, while checklists provide tools for use in daily practice.

# **Continuing Education Credits**

Psychologists and other healthcare providers may earn five continuing education credits for reading the books in the *Advances in Psychotherapy* series and taking a multiple-choice exam. This continuing education program is a partnership of Hogrefe Publishing and the National Register of Health Service Psychologists. Details are available at https://www.hogrefe.com/us/cenatreg

The National Register of Health Service Psychologists is approved by the American Psychological Association to sponsor continuing education for psychologists. The National Register maintains responsibility for this program and its content.

# Family Caregiver Distress

# **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



**Library of Congress of Congress Cataloging in Publication** information for the print version of this book is available via the Library of Congress Marc Database under the Library of Congress Control Number 2023934039

#### Library and Archives Canada Cataloguing in Publication

Title: Family caregiver distress / 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).

Names: Gallagher-Thompson, Dolores, author. | Bilbrey, Ann Choryan, author. | Qualls, Sarah Honn, author. | Ghatak, Rita, author. | Trivedi, Ranak, 1975- author. | Waelde, Lynn C., author.

Series: Advances in psychotherapy--evidence-based practice; v. 50.

Description: Series statement: Advances in psychotherapy--evidence-based practice; volume 50 | Includes bibliographical references.

Identifiers: Canadiana (print) 20230193978 | Canadiana (ebook) 20230194001 | ISBN 9780889375178

(softcover) | ISBN 9781613345177 (EPUB) | ISBN 9781616765170 (PDF)

Subjects: LCSH: Dementia—Patients—Home care—Psychological aspects. | LCSH: Caregivers—Mental health

services. | LCSH: Caregivers—Mental health. | LCSH: Caregivers—Care. | LCSH: Caregivers—

Psychology. | LCSH: Stress management.

Classification: LCC RC521 .G35 2023 | DDC 362.1968/31-dc23

#### © 2023 by Hogrefe Publishing

#### www.hogrefe.com

The authors and publisher have made every effort to ensure that the information contained in this text is in accord with the current state of scientific knowledge, recommendations, and practice at the time of publication. In spite of this diligence, errors cannot be completely excluded. Also, due to changing regulations and continuing research, information may become outdated at any point. The authors and publisher disclaim any responsibility for any consequences which may follow from the use of information presented in this book.

Registered trademarks are not noted specifically as such in this publication. The use of descriptive names, registered names, and trademarks does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The cover image is an agency photo depicting models. Use of the photo on this publication does not imply any connection between the content of this publication and any person depicted in the cover image.

Cover image: © SB Arts Media - iStock.com

#### PUBLISHING OFFICES

USA: Hogrefe Publishing Corporation, 44 Merrimac St., Suite 207, Newburyport, MA 01950

Phone 978 255 3700; E-mail customersupport@hogrefe.com

EUROPE: Hogrefe Publishing GmbH, Merkelstr. 3, 37085 Göttingen, Germany

Phone +49 551 99950 0, Fax +49 551 99950 111; E-mail publishing@hogrefe.com

#### SALES & DISTRIBUTION

USA: Hogrefe Publishing, Customer Services Department,

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.,

Milton Park, Abingdon, OX14 4SB

Phone +44 1235 465577, Fax +44 1235 465556; E-mail direct.orders@marston.co.uk

EUROPE: Hogrefe Publishing, Merkelstr. 3, 37085 Göttingen, Germany

Phone +49 551 99950 0, Fax +49 551 99950 111; E-mail publishing@hogrefe.com

OTHER OFFICES

CANADA: Hogrefe Publishing Corporation, 82 Laird Drive, East York, Ontario, M4G 3V1

SWITZERLAND: Hogrefe Publishing, Länggass-Strasse 76, 3012 Bern

#### Copyright Information

The eBook, including all its individual chapters, is protected under international copyright law. The unauthorized use or distribution of copyrighted or proprietary content is illegal and could subject the purchaser to substantial damages. The user agrees to recognize and uphold the copyright.

#### License Agreement

The purchaser is granted a single, nontransferable license for the personal use of the eBook and all related files.

Making copies or printouts and storing a backup copy of the eBook on another device is permitted for private, personal use only. This does not apply to any materials explicitly designated as copyable material (e.g., questionnaires and worksheets for use in practice).

Other than as stated in this License Agreement, you may not copy, print, modify, remove, delete, augment, add to, publish, transmit, sell, resell, create derivative works from, or in any way exploit any of the eBook's content, in whole or in part, and you may not aid or permit others to do so. You shall not: (1) rent, assign, timeshare, distribute, or transfer all or part of the eBook or any rights granted by this License Agreement to any other person; (2) duplicate the eBook, except for reasonable backup copies; (3) remove any proprietary or copyright notices, digital watermarks, labels, or other marks from the eBook or its contents; (4) transfer or sublicense title to the eBook to any other party.

These conditions are also applicable to any files accompanying the eBook that are made available for download.

Should the print edition of this book include electronic supplementary material then all this material (e.g., audio, video, pdf files) is also available with the eBook edition.

Format: PDF

ISBN 978-0-88937-517-8 (print) • ISBN 978-1-61676-517-0 (PDF) • ISBN 978-1-61334-517-7 (EPUB) https://doi.org/10.1027/00517-000

This document is for personal use only. Reproduction or distribution is not permitted.

From Dolores Gallagher-Thompson et al.: Family Caregiver Distress (ISBN 9781616765170) © 2023 Hogrefe Publishing.

# **Acknowledgments**

We thank the many caregivers whose lived experience provided the basis for our passion to work in this field. We also thank collaborators who provided expertise on specific chapters: Jennifer Ramsey, PhD (Chapter 1), Maureen Ross, LMFT (Chapter 2), and Victoria Ngo, PhD (Chapter 9). We are grateful for their contributions.

# **Contents**

|       | wledgmentse  |
|-------|--|
| 1     | Description  |
| 1.1   | Terminology  |
| 1.1.1 | Individuals Providing and Receiving Care                     |
| 1.2   | Caregiver Demographics                                       |
| 1.2.1 | Ethnic and Racial Diversity of Caregivers                    |
| 1.2.2 | Age, Relationship to Care Recipient, and Gender              |
| 1.2.3 | Reasons for Providing Care                                   |
| 1.3   | The Emotional and Physical Impacts of Caregiving             |
| 1.3.1 | Common Caregiver Responses to Stress: Mental Health Issues   |
| 1.3.2 | Common Caregiver Responses to Stress: Physical Health Issues |
| 1.3.3 | Other Stressors Most Caregivers Face                         |
| 1.3.4 | Positive Aspects of Caregiving                               |
| 1.4   | Knowledge of the Care Recipient's Dementia                   |
| 1.4.1 | Neurocognitive Disorders: Basics About Dementia              |
| 2     | Theories and Models  |
| 2.1   | Stress and Coping Model                                      |
| 2.2   | Sociocultural Model  |
| 2.3   | Trajectory of Illness Model                                  |
| 2.4   | Transition Into Early-Stage Caregiving                       |
| 2.4.1 | Description  |
| 2.4.2 | Interventions  |
| 2.5   | Early-Stage Caregiving                                       |
| 2.5.1 | Description  |
| 2.5.2 | Intervention   |
| 2.6   | Transition Into Middle Stage                                 |
| 2.6.1 | Description  |
| 2.6.2 | Interventions  |
| 2.7   | Transition Into Late Stage                                   |
| 2.7.1 | Description  |
| 2.7.2 | Interventions  |
| 2.8   | Postcaregiving Life  |
| 2.8.1 | Description  |
| 2.8.2 | Interventions  |
| 2.9   | Interventions With Family Systems                            |
| 2.9.1 | Rationale for the Family Systems Approach                    |
| 2.9.2 | Theories of Family Therapy and Applications to Caregiving    |
| 2.10  | Dyadic Models  |

| 3     | Assessment   | 26 |
|-------|--|----|
| 3.1   | Caregiver Core Assessment Battery                              | 26 |
| 3.1.1 | Overall Mental Health  | 26 |
| 3.1.2 | Caregiver Specific Challenges                                  | 27 |
| 3.1.3 | Caregiver Supports   | 27 |
| 3.2   | Optional Measures to Address Unique Needs                      | 29 |
| 3.2.1 | Assessment of Suicidality                                      | 29 |
| 3.2.2 | Screening for Cognitive Function                               | 31 |
| 3.2.3 | Other Specific Measures  | 31 |
| 3.2.4 | Assessing Domains Not Listed                                   | 31 |
| 3.2.5 | Working With Diverse Caregivers                                | 31 |
| 3.2.6 | Monitoring Change  | 32 |
| 3.3   | Assessment Tools in Depth                                      | 32 |
| 3.3.1 | Overall Mental Health  | 32 |
| 3.3.2 | Caregiving Challenges  | 33 |
| 3.3.3 | Caregiving Supports  | 34 |
| 3.3.4 | Optional Measures  | 35 |
| 4     | Interventions to Reduce Caregiver Distress                     | 39 |
| 4.1   | Introduction of Stepped Approach                               | 39 |
| 4.1.1 | Levels of Intervention   | 39 |
| 4.1.2 | Supporting Evidence for Interventions                          | 41 |
| 4.1.3 | Diversity and Inclusion Issues                                 | 42 |
| 4.2   | Psychoeducational Interventions                                | 44 |
| 4.2.1 | Coping With Caregiving (CWC)                                   | 45 |
| 4.2.2 | Savvy Caregiver Program  | 46 |
| 4.2.3 | Inner Resources for Stress (IR)                                | 47 |
| 4.2.4 | Building Better Caregivers (BBC)                               | 48 |
| 4.2.5 | iSupport   | 49 |
| 4.3   | Specialized Care: Psychotherapeutic Interventions              | 49 |
| 4.3.1 | Cognitive Behavioral Therapy (CBT)                             | 50 |
| 4.3.2 | Acceptance and Commitment Therapy (ACT)                        | 51 |
| 4.4   | Multicomponent Intervention Programs                           | 52 |
| 4.4.1 | Resources for Enhancing Alzheimer Caregivers Health (REACH II) | 53 |
| 4.4.2 | New York University Caregiver Intervention (NYUCI) Program     | 53 |
| 4.5   | Family Systems Approach  | 54 |
| 4.5.1 | Family Interventions   | 54 |
| 4.5.2 | Dyadic Therapy   | 56 |
| 4.6   | Technology-Enabled Interventions                               | 57 |
| 4.6.1 | Caregiver Wellness and Self-Care                               | 58 |
| 4.6.2 |  | 58 |
| 4.6.3 | Caregiver Support  | 58 |
| 4.6.4 | Caregiving Task Management                                     | 59 |

| 4.6.5 | Adaptive Home Products   | 59 |
|-------|--|----|
| 4.6.6 | Using Technology in Session  | 60 |
| 4.7   | Other Interventions  | 60 |
| 4.7.1 | Care Management  | 61 |
| 4.7.2 | Palliative Care  | 63 |
| 4.8   | Ethical Dilemmas Often Experienced by Caregivers                         | 63 |
| 4.8.1 | Over-Arching Themes  | 64 |
| 4.8.2 | Practical Issues Rooted in Ethical Dilemmas in the Caregiving Trajectory | 65 |
| 4.9   | Summary of Critical Points to Effectively Treat Distressed Caregivers    | 66 |
| 5     | Professional Practice Issues   | 68 |
| 5.1   | Training Content and Competencies  | 68 |
| 5.2   | Education and Training Resources   | 68 |
| 5.3   | Billing for Caregiver Services   | 69 |
| 6     | Case Vignette  | 74 |
| 7     | Further Reading  | 79 |
| 8     | References   | 81 |
| 9     | Appendix: Tools and Resources  | 90 |