Social Determinants of Health: Underreported Heterogeneity in Systematic Reviews of Caregiver Interventions

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Abstract

Background and Objectives: Although most people have some experience as caregivers, the nature and context of care are highly variable. Caregiving, socioeconomic factors, and health are all interrelated. For these reasons, caregiver interventions must consider these factors. This review examines the degree to which caregiver intervention research has reported and considered social determinants of health.

Research Design and Methods: We examined published systematic reviews and meta-analyses of interventions for older adults with age-related chronic conditions using the PRISMA and AMSTAR 2 checklists. From 2,707 papers meeting search criteria, we identified 197 potentially relevant systematic reviews, and selected 33 for the final analysis.

Results: We found scant information on the inclusion of social determinants; the papers lacked specificity regarding race/ethnicity, gender, sexual identity, socioeconomic status, and geographic location. The majority of studies focused on dementia, with other conditions common in later life vastly underrepresented.

Discussion and Implications: Significant gaps in evidence persist, particularly for interventions targeting diverse conditions and populations. To advance health equity and improve the effectiveness of interventions, research should address caregiver heterogeneity and improve assessment, support, and instruction for diverse populations. Research must identify aspects of heterogeneity that matter in intervention design, while recognizing opportunities for common elements and strategies.

Keywords: Intervention specificity, AMSTAR 2, Health disparities

Although most people have some experience as caregivers, the nature and context of care are highly variable. In designing caregiving interventions, it is vital to distinguish elements that might be broadly applicable to all family caregivers from those that are specific to the caregiver, care recipient’s condition and context of care. This is particularly important considering the increasing age and diversity of the U.S. population (Colby & Ortman, 2014; Mather, Jacobsen, & Pollard, 2015).

Interventions that contain common elements may be more broadly applicable to all caregivers and could be more readily adopted by agencies serving the general population of older adults. However, caregivers themselves are diverse and have heterogeneous needs, and some elements within an intervention must be context specific. For example, most caregivers experience emotional strain, but the particular sources of strain may vary according to such factors as the care recipient’s condition and the demographic
characteristics and social determinants of health for both the care recipient and the caregiver (see Figure 1).

The 2016 Families Caring for an Aging America report issued by the National Academies of Science, Engineering and Medicine (NASEM) identified the challenge of developing interventions that are tailored for and accessible to diverse caregivers, in part because of limited evidence among subgroups of the population (NASEM, 2015). They note the increasing relevance of diversity in both racial/ethnic and sexual identity to health disparities among caregivers and those for whom they care. Others have highlighted disparities within demographic subgroups of the population, including gender, ethnicity, LGBT status, and rurality (Berg & Woods, 2009; Castro et al., 2007; Dilworth-Anderson, Pierre, & Hilliard, 2012; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). With the emergence of caregiving as a public health issue (Talley & Crews, 2007), inclusion of social determinants of health such as gender, race/ethnicity, and socioeconomic status in caregiving research is vital to addressing health disparities.

Indeed, the first recommendation produced by the National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers (Gitlin, Maslow, & Khillian, 2018) pertains to the imperative of recognizing heterogeneity in developing research, services, and supports for family caregivers. This consensus body used the term heterogeneity to reflect the array of differences among caregivers that go beyond race and ethnicity and contribute to health disparities for both the care recipient and the caregiver. Summit participants focused on characteristics that might influence the experience of dementia, caregiver capacity and needs, and the accessibility and appropriateness of services and supports. The summit’s recommendation was that researchers identify heterogeneity and reduce health disparities among caregivers by developing culturally appropriate interventions.

A growing body of evidence suggests that interventions targeted to address characteristics of a group (e.g., age, sex, diagnosis, race/ethnicity) or specifically tailored to address individual needs, preferences, resources, or personality characteristics may be more effective—in terms of outcomes, patient satisfaction, adherence, and cost—when compared with standard interventions that do not take these characteristics into account (Beck et al., 2010; Ryan & Lauver, 2002). Applied to family caregiving interventions, a recent systematic review of 31 randomized controlled trials in the context of dementia or Alzheimer’s disease found insufficient evidence to endorse the use of most interventions but noted larger trials that employed tailored interventions had higher quality ratings and significant effects on at least one outcome (Griffin et al., 2013).

Investigators and clinicians rely on systematic reviews and meta-analyses of intervention trials as “gold standards” of evidence, providing valuable information about the efficacy of interventions, whether standard or tailored. At the same time, systematic reviews offer clues as to which subgroups may benefit most from specific interventions and, in reporting population characteristics, also reveal omissions of subgroups from intervention research. The purpose of this article was to explore the extent to which systematic reviews include and report common categories of social determinants linked to known health disparities. Specifically, we searched the health sciences literature for systematic reviews and meta-analyses of caregiving research—conducting a systematic review of reviews—to examine and enumerate the incorporation of specific population characteristics known to be associated with disparities. The overarching goal was to ignite consideration of the inclusion of social determinants of health in future caregiving studies. The genesis of this manuscript was a discussion paper prepared for the Research Priorities in Caregiving Summit: Advancing Family-Centered Care across the Trajectory of Serious Illness, convened by the Family Caregiving Institute at the Betty Irene Moore School of Nursing.

Methods
Search Strategy and Study Selection
We conducted a literature search for systematic reviews and meta-analyses of interventions for caregivers of older adults, published from 1990 to June 2018, in the following search engines: Scopus, PubMed, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). We focused on articles since 1990, as this was the general advent of published review papers of caregiving intervention research, following seminal caregiving intervention research during the 1980s. We only included review papers (i) because of their salience to the field in determining intervention effectiveness; (ii) because of their ability to identify related patterns within subgroups, and (iii) because the volume of individual intervention studies far exceeds the threshold for a feasible or publishable systematic review.

Inclusion criteria were as follows: systematic reviews and meta-analyses of intervention studies, published in English, targeting caregivers of older adults with dementia, stroke, Parkinson’s disease, cancer, heart failure, multiple chronic conditions, or other serious illnesses associated with aging. We excluded reviews that focused solely on...
care recipient outcomes or care recipients under 50 years of age. We also excluded end-of-life interventions because caregiving needs and approaches at this stage of the illness trajectory are unique and warrant a separate review and discussion. We completed the full search by August 1, 2018. Table 1 provides a list of search terms. We identified additional review papers through iterative examination of the bibliographies of all papers that met review criteria, and through the review of related book chapters.

One author (J.B.) screened the titles and abstracts of all articles identified in the search to determine whether they met inclusion criteria, then a second author (R.W.) confirmed inclusion/exclusion for each article. All the authors (J.B., R.W., R.R., S.R., P.P.V., and H.M.Y.) worked in pairs for the next round of selection, with each pair assigned a set of full texts of the articles to review against inclusion/exclusion criteria. The paired authors screened the articles independently and then the full team reviewed the results of this more intensive screening, resolving discrepancies through discussion until all agreed on the final selection.

Data Extraction
As a group, the authors developed, tested, and refined an extraction spreadsheet. The spreadsheet incorporated the following salient descriptive data: full citation, review objectives, care recipient conditions, number of studies included, aggregate sample size, design, meta-analyses, restriction to publications in English, intervention type, caregiver age, caregiver’s relationship to the care recipient, geographic setting, race/ethnicity, sexual identity, rural/urban, socioeconomic status (SES), use of a theory, unit of intervention (caregiver only, care recipient only, dyad, mixed, other), and study outcomes. We used the typology developed by Gaugler, Jutkowitz, Shippee, and Brasure (2017; specifically: skill building, psychosocial support, education, cognitive/behavioral approaches, respite, care/case management, and relaxation/physical activity) to categorize the intervention type.

We assessed the quality of each review using the AMSTAR 2 tool (Shea et al., 2017), designed for rating the quality of systematic reviews and meta-analyses that include both randomized and nonrandomized studies. Because most of the studies we included were not meta-analyses, we only used the first eight AMSTAR 2 criteria: use of population/intervention/comparator/outcomes (PICO) to frame the review; use of a written protocol; explanation for design inclusion; search strategy; duplicate study selection; duplicate study abstraction; list of excluded studies; and PICO description. Again, working in pairs, we independently extracted data using the spreadsheet and rated the reviews according to the AMSTAR 2 criteria. Paired authors conferred on their coding of the data, resolved discrepancies, and identified issues for further discussion. The entire team reviewed the coding of the pairs and discussed outstanding concerns, coming to consensus.

Data Synthesis
We reviewed and summarized the descriptive characteristics of the systematic reviews and developed a narrative synthesis to describe the heterogeneity of the studies in terms of care recipient condition, caregiver relationship, and characteristics of the populations studied.

Results

Literature Search
From 2,707 papers meeting search criteria, we identified 197 potentially relevant systematic reviews, and after applying inclusion and exclusion criteria, selected 33 reviews for the final analysis. Figure 2 displays the PRISMA flow chart of the selection process (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009).

Description of the Reviews
Table 2 provides a descriptive summary of the included reviews. Together, the reviews included 736 papers (mean

| Table 1. Search Terms |
|-----------------------|
| aged Alzheimer care  |
| caregiver dementia   |
| caregiving family    |
| dement* cancer       |
| dementia caregiv*    |
| education elderly    |
| burden elderly care  |
| care home home care  |
| counseling geriatric |
| interventions for    |
| Hospice palliative   |
| Care intervent*      |
| intervention comparator/outcomes |

Figure 2. PRISMA flow chart for study selection.
### Table 2. Systematic Review Descriptions (n = 33)

| Authors                                      | Target condition       | Meta-analysis | Included studies (n) | Caregivers (n) | Types of interventions                                                                 | Outcomes                                                                 | AMSTAR 2 total score |
|----------------------------------------------|------------------------|---------------|---------------------|----------------|----------------------------------------------------------------------------------------|---------------------------------------------------------------------------|----------------------|
| Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014 | Dementia               | No            | 12                  | >1,000         | SB, PS                                                                                  | MH, SE, QoL, PH, S, B                                                    | 5                    |
| Berreton, Carroll, & Barnston, 2007          | Stroke                 | No            | 8                   | >1,000         | SB, PS                                                                                  | MH, SE, S, B, SK                                                         | 6                    |
| Corbett et al., 2012                        | Dementia               | Yes           | 13                  | 501–1,000      | Education                                                                               | QoL, B                                                                   | 6                    |
| Corry, While, Neenan, & Smith, 2015          | Stroke                 | No            | 8                   | >1,000         | SB, PS                                                                                  | MH, QoL, S, SK, other                                                    | 6                    |
| Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016 | Dementia               | No            | 39                  | >1,000         | PS                                                                                      | MH, S                                                                    | 6                    |
| Dickinson, Gibson, Gotts, Stobart, & Robinson, 2017 | Dementia               | No            | 13                  | Not specified  | PS                                                                                      | MH, Other                                                                | 3                    |
| Evangelista, Stromberg, & Dionne-Odom, 2016  | CHF                    | No            | 8                   | 501–1,000      | PS, E                                                                                   | MH                                                                        | 2                    |
| Greenwood, Pelone, & Hasenkamp, 2016         | Dementia               | No            | 4                   | <500           | PS, E, CB, other                                                                        | MH, PH, QoL, S, B, SK                                                    | 7                    |
| Hempe, Norman, Golder, Aguiar-Ibáñez, & Eastwood, 2008 | Parkinson's disease   | No            | 30                  | >1,000         | SB, PS, E, R, CM                                                                       | MH, PH, SE, S, SK, Sat, other                                           | 3                    |
| Jackson, Roberts, Wu, Ford, & Doyle, 2016    | Dementia               | No            | 22                  | >1,000         | PS, E                                                                                   | MH, PH, SE, QoL, B, Sat, other                                          | 2                    |
| Khanassov & Vedel, 2016                      | Dementia               | Yes           | 54                  | Not specified  | CM, Other                                                                               | MH, B, SK, CR, other                                                    | 7                    |
| Lee, Soeken, & Picot, 2007                   | Stroke                 | Yes           | 4                   | 501–1,000      | SB, PS, E                                                                               | MH                                                                        | 6                    |
| Legg et al., 2011                            | Stroke                 | No            | 8                   | >1,000         | SB, PS, E                                                                               | MH, PH, QoL, Sat                                                        | 8                    |
| Lui, Ross, & Thompson, 2005                  | Stroke                 | No            | 11                  | >1,000         | SB                                                                                      | MH, PH, SK, S, B, other                                                 | 3                    |
| Mason et al., 2007                           | Frailty/cognitive impairment | Yes         | 22                  | Not specified  | R                                                                                       | MH, QoL, Sat                                                            | 3                    |
| Petriwskyj, Parker, O'Dwyer, Moyle, & Nuñofora, 2016 | Dementia               | No            | 3                   | <500           | Other                                                                                   | MH, PH, SE, B, other                                                    | 8                    |
| Piersol et al., 2017                         | Dementia               | No            | 43                  | Not specified  | PS, E, CM, R/PA, other                                                                 | MH, PH, SE, SK, CR, RQ, other                                           | 4                    |
| Authors                                    | Target condition | Meta-analysis | Included studies (n) | Caregivers (n) | % Randomized controlled trial (RCT) | Types of interventions | Outcomes | AMSTAR 2 total score |
|-------------------------------------------|------------------|---------------|----------------------|----------------|------------------------------------|------------------------|----------|---------------------|
| Rausch, Caljouw, & van der Ploeg, 2017   | Dementia         | No            | 7                    | 501–1,000      | 57                                 | Skill building (SB), psychosocial support (PS), education (E), cognitive behavioral (CB), respite (R), care/case management (CM), relaxation/physical activity (R/PA) | CG mental health (MH), CG physical health (PH), self-efficacy (SE), quality of life (QoL), support (S), burden (B), skill/knowledge (SK), satisfaction (Sat), relationship quality (RQ), CR outcomes (CR) | 2        |
| Schoenmakers, Buntinx, & DeLepeleire, 2010 | Dementia         | Yes           | 29                   | >1,000         | 93                                 | SB, PS, E, R, CM, other | MH, SK, B, Sat | 2        |
| Schulz, Martire, & Klinger, 2005          | Multiple         | Yes           | 51                   | Not specified  | 100                                | PS, E                  | MH, PH, QoL, B, RQ, Sat, other | 4        |
| Scott et al., 2016                        | Dementia         | Yes           | 4                    | 501–1,000      | 50                                 | CBT                    | MH, SE, B, QoL | 6        |
| Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007 | Dementia         | No            | 62                   | >1,000         | 56                                 | SB, PS, E, CBT         | MH, QoL, SK, B | 2        |
| Smits et al., 2007                        | Dementia         | No            | 25                   | >1,000         | NS                                 | SB, PS, E, CBT, CM, R, other: Recreation & Outings | MH, PH, SE, SK | 3        |
| Sorensen, Pinquart, & Duberstein, 2002    | Dementia         | Yes           | 23                   | <500           | 100                                | Rec, PS                | MH, PH, SE, QoL, S, B, SK, CR | 7        |
| Sousa, Sequeira, Ferre-Grau, Neves, & Lleix Fortuny, 2016 | Dementia         | No            | 8                    | 501–1,000      | 50                                 | SB, E, R/PA            | MH, SE, S, SK, CR | 4        |
| Stoltz, Uden, & Willman, 2004             | Dementia         | No            | 26                   | 501–1,000      | 5                                  | S, R                   | MH, SE, S, B, Sat, CR | 4        |
| Tretteteig, Vatne, & Rokstad, 2016        | Dementia         | No            | 19                   | >1,000         | 0                                  | S, R                   | MH, B, other          | 3        |
| Van’t Leven et al., 2013                  | Dementia         | Yes           | 23                   | <500           | 100                                | SB, PS, E, CBT, R, R/PA, other | MH, PH, SE, QoL, B, S, SK, CR | 6        |
| Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Faes, et al., 2016a | Dementia         | No            | 53                   | >1,000         | 85                                 | PS, E, CBT, R, other   | MH, PH, SE, QoL, B, S, other | 5        |
| Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Verdonck, et al., 2016b | Dementia         | No            | 17                   | >1,000         | 18                                 | Respite                | MH, PH, S, B, CR, other | 6        |
| Vernooij-Dassen, Draskovic, McCleery, & Downes, 2011 | Dementia         | Yes           | 11                   | >1,000         | 100                                | SB, PS, E, CB, other  | MH, SE, QoL, B, CR | 6        |
| Waller, Dilworth, Mansfield, & Sanson-Fisher, 2017 | Dementia         | No            | 23                   | >1,000         | 88                                 | SB, PS, E, CBT, R     | MH, PH, SE, QoL, S, B SK | 5        |
| Wasilewski, Stinson, & Cameron, 2017      | Multiple         | No            | 53                   | >1,000         | 34                                 | SB, PS, E, Other      | PH, MH, SE, QoL, B, SK, other | 2        |

Notes: Based on items 1–8 of the AMSTAR 2 tool. Each item scored 0–1 with 1 point given for “yes” or “partial yes.” Total possible score range 0–8; median score: 5.
22, range 3–62). More than half of the reviews (17) included over 1,000 caregivers in their cumulative samples across the underlying papers. Nine of the reviews involved meta-analysis. The majority of the reviews addressed interventions for caregivers of persons with dementia and cognitive impairment (\(n = 23\)), followed by stroke (5), multiple conditions (3), Parkinson’s disease (1), and heart failure (1). The reviews varied in their inclusion criteria for design, with 11 featuring 100% randomized controlled trials, and the remaining including quasiexperimental and descriptive designs. The tactics addressed in the reviews were highly variable, but we found particular emphasis on psychoeducational approaches to care and management of care recipient behavioral symptoms. Most reviews (24) included multicomponent interventions, and nine reviews used a single approach. Reviews reported diverse outcomes; however, most focused on caregivers’ mental health, addressing depression, anxiety, stress, strain, or well-being.

The study descriptions overall did not provide sufficient information to quantify the heterogeneity of the samples. Table 3 provides summary data for all reviews and for meta-analyses. The table also provides systematic review/meta-analysis-level data regarding percentage of studies within the review that specify sample characteristics and a summary of the aggregate data when specified. The most frequently reported caregiver characteristic was geographic setting, operationalized as country of origin for the study, reported in 52% of all reviews and 44% of meta-analyses. The authors reported caregiver age in 45% of all reviews and 56% of meta-analyses, caregiver sex in 42% of all reviews and 44% of meta-analyses, and relationship to care recipient in 30% of all reviews and 22% of meta-analyses. Only a small proportion of reviews reported caregiver race/ethnicity or socioeconomic status (18% of all reviews and 11% of meta-analyses), and no reviews reported rurality. The meta-analyses did not provide greater specificity than the systematic reviews. Importantly, there were considerable missing data; even when reviews addressed caregiver characteristics, they did not present these data for every study included in the review. For example, among the reviews that reported caregiver sex, the proportion of individual studies within reviews reporting caregiver sex ranged from 13% to 100% (Table 3).

Table 4 summarizes the results of the AMSTAR 2 ratings. About half (18) specified the population, intervention, comparator, and outcome targeted in the review. With the eight criteria summed, the median total score across the reviews was 5, with a range of 2–8 out of a possible 8 points (Table 3). The lowest scoring items were the following: providing a list of excluded studies and providing a rationale for included study designs, with only six reviews (18%) and 17 reviews (52%) fulfilling AMSTAR 2 criteria, respectively (Table 4).

**Discussion**

In this review of 33 peer-reviewed, published systematic reviews and meta-analyses of interventions for older adults with chronic conditions associated with aging, we found very little attention to social determinants of health among caregivers. The body of literature represented in this article encompasses 736 individual studies and more than 20,000 caregivers, yet, as described in the review papers, the populations are presented as though they were homogeneous in race/ethnicity, gender, SES, and geographic location. Importantly, many reviews did not mention these common variables of heterogeneity at all, even when the underlying papers identified them. This is of particular concern because investigators and practitioners rely on systematic reviews and meta-analyses, as these are considered to be the “gold standards” of evidence.

The systematic reviews included in our analysis did not consider factors related to diversity and health inequalities (Berg & Woods, 2009; Castro et al., 2007; Dilworth-Anderson et al., 2012; Fredriksen-Goldsen et al., 2013; NASEM, 2015; Talley & Crews, 2007). Overall, few reviews reported any data specific to participants’ race/ethnicity, SES, rural versus urban, or LGBTQ status. Only six reviews addressed the racial/ethnic composition of the underlying papers; of those, most reported that race/ethnicity was not specified in any of the underlying studies or that the papers included majority Caucasian samples. Geographic location was operationalized as the country of origin of the study, with none specifying residential rurality. Rurality is a known source of disparity, given that residents of rural communities tend to be older and have more chronic conditions and also have less access to geriatric expertise and community resources for caregivers. None of the reviews explicitly considered the needs of LGBTQ older adults and their caregivers. To address racial, economic, and social disparities in health, we must first include, represent, and report on diverse populations of caregivers. Further effort is required to understand and remove barriers to care for underrepresented groups and ensure that interventions are culturally and linguistically appropriate and accessible.

Less than half of reviews identified caregivers’ relationships to care recipients, despite evidence that the caregiving experiences of spouses/partners differ from those of adult children or siblings in multiple ways and by gender (Hooker, Manoogian-O’Dell, Monahan, Frazier, & Shifren, 2000; Lutzky & Knight, 1994; Pinquart & Sörensen, 2011; Savundranayagam, Montgomery, & Kosloski, 2011; Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993). Beyond social determinants of health, other aspects of the caregiving situation could influence disparities in caregiver health and/or access to resources to support their efforts. Since 1990, research has focused primarily on dementia caregivers. Fewer studies have concentrated on the needs of those caring for older persons with such conditions as cancer, stroke, chronic disease, Parkinson’s...
| Authors                | Studies in review (n) | Sex (%)  | Race/ethnicity (%) | Socioeconomic status (%) | Age (%)  | Relationship to care recipient (%) | Geographic setting (%) |
|-----------------------|----------------------|----------|--------------------|--------------------------|----------|------------------------------------|------------------------|
| All reviews (n = 33)  | 726                  | 42       | 18                 | 18                       | 45       | 30                                 | 52                     |
| Meta-analyses (n = 9) | 183                  | 44       | 11                 | 11                       | 56       | 22                                 | 44                     |
| Boots et al., 2014    | 12                   | 83       | Male 11–58%        |                         | 8        | ≥ College Degree 65%                |                        |
|                       |                      |          |                    |                           |          | Mean age 46.9–73b                  | Partner 7–100%          |
|                       |                      |          |                    |                           |          |                                    | Child 0–75%            |
|                       |                      |          |                    |                           |          |                                    | Other 0–23%            |
| Brereton et al., 2007 | 8                    | 13b      | 38b                | 75b                      | 100b     | NS                                 | NS                     |
| Corbett et al., 2012  | 13                   | NS       | NS                 | NS                       | NS       | NS                                 | NS                     |
| Corry et al., 2015    | 8                    | NS       | NS                 | NS                       | NS       | NS                                 | NS                     |
| Dam et al., 2016      | 29                   | NS       | 21                 | Chinese 0–100%            | NS       | NS                                 | NS                     |
| Dickinson et al., 2017| 13                   | NS       | NS                 | NS                       | NS       | 38b                                | NS                     |
| Evangelista et al., 2016| 8                  | 54       | NS                 | 54                       | 100      | NS                                 | NS                     |
| Greenwood et al., 2016| 4                    | 100      | NS                 | NS                       | 100      | NS                                 | NS                     |
| Hempel et al., 2008   | 30                   | NS       | NS                 | NS                       | NS       | NS                                 | NS                     |
| Jackson et al., 2016  | 22                   | NS       | NS                 | NS                       | NS       | NS                                 | NS                     |

The Gerontologist, 2020, Vol. 60, No. S1
| Authors                        | Studies in review (n) | Sex (%)     | Race/ethnicity (%) | Socioeconomic status (%) | Age (%)       | Relationship to care recipient (%) | Geographic setting (%) |
|-------------------------------|-----------------------|-------------|--------------------|--------------------------|---------------|-------------------------------------|------------------------|
| Khanassov et al., 2016        | 54                    | 63          | NS                 | NS                       | 59            | NS                                  | United States (28%)    |
|                               |                       | Male 8–71%  |                    |                          | Mean age 49–80\(^b\) |                                      | Canada (2%) Asia (13%) |
|                               |                       |             |                    |                          |               |                                     | Europe (39%) Africa (2%) |
|                               |                       |             |                    |                          |               |                                     | Other (15%)             |
| Lee et al., 2007              | 4                     | NS          | NS                 | NS                       | 100           | NS                                  | United States (25%)    |
|                               |                       |             |                    |                          | Mean age 57–65 |                                      | Europe (75%)           |
| Legg et al., 2011             | 8                     | 63          | NS                 | NS                       | 50            | NS                                  | United States (38%)    |
|                               |                       | Male 9–33%  |                    |                          | Mean age 58–67 |                                      | Australia (12%)         |
|                               |                       |             |                    |                          |               |                                     | United Kingdom (25%)   |
|                               |                       |             |                    |                          |               |                                     | Europe (12%) Asia (12%)|
|                               |                       |             |                    |                          |               |                                     | Other (9%)              |
| Lui et al., 2005              | 11                    | 45          | 18                 | 36                       | 45            | 9                                   | United States (64%)    |
|                               |                       | Male 8–37%  | White 40–50%       | Mean years of education 11–13\(^b\) | Mean age 47.9–64| Partner 95%                          | United Kingdom (27%)   |
|                               |                       |             | Black 50–60%       |                          |               | Child NS                             | Europe (9%)            |
| Mason et al., 2007            | 22                    | 95          | NS                 | NS                       | 86            | NS                                  | United States (50%)    |
|                               |                       | Male 12–38% |                    |                          | Mean age 54–73\(^b\) |                                      | Australia (9%) Canada (9%) Europe (6%) |
| Petriwskyj et al., 2016       | 3                     | 100         | 50                 | 50                       | 100           | 33                                  | United Kingdom (23%)   |
|                               |                       | Male 15–35% | White 95%          | ≥ College degree 60%     | Mean age 60.2\(^b\) | Partner 38%                          | NS                     |
|                               |                       |             |                    |                          |               | Child 62%                            | Other NS               |
| Piersol et al., 2017          | 43                    | 79          | 44                 | NS                       | 79            | 79                                  | NS                     |
|                               |                       | Male 0–47%  | White 0–100%       |                          | Mean age 44–71\(^b\) |                                      | Other NS               |
| Authors                        | Studies in review (n) | Sex (%) | Race/ethnicity (%) | Socioeconomic status (%) | Age (%) | Relationship to care recipient (%) | Geographic setting (%)           |
|-------------------------------|-----------------------|---------|--------------------|--------------------------|---------|------------------------------------|----------------------------------|
| Rausch et al., 2017          | 7                     | NS      | NS                 | NS                       | NS      | NS                                 | 100                              |
|                               |                       |         |                    |                          |         | United States (43%)                | United Kingdom (57%)               |
| Schoenmakers et al., 2010    | 29                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                               |
| Schulz et al., 2005          | 51                    | NS      | NS                 | NS                       | NS      | 75                                 | NS                               |
|                               |                       |         |                    |                          |         | Partner 0–100%                      | Child 0–100%                      |
|                               |                       |         |                    |                          |         | Other NS                           |                                  |
| Scott et al., 2016           | 4                     | 100     | NS                 | NS                       | 100     | Mean age 47–65                      | NS                               |
|                               |                       | Male 13–27% |                |                          |         |                                    |                                  |
| Selwood et al., 2007         | 62                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                               |
| Smits et al., 2007           | 25                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                               |
| Sorensen et al., 2002        | 23                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                               |
| Sousa et al., 2016           | 8                     | NS      | NS                 | NS                       | NS      | NS                                 | 100                              |
|                               |                       |         |                    |                          |         | United States (63%)                | Canada (12%)                      |
|                               |                       |         |                    |                          |         | Europe (12%)                        | Asia (12%)                        |
|                               |                       |         |                    |                          |         |                                    | 100                              |
| Stoltz et al., 2004          | 26                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                               |
|                               |                       |         |                    |                          |         | United States (77%)                | Europe (12%)                      |
|                               |                       |         |                    |                          |         | Canada (8%)                         | Asia (4%)                         |
|                               |                       |         |                    |                          |         |                                    | 100                              |
| Tretteteig et al., 2016      | 19                    | 89      | NS                 | NS                       | 95      | 79                                 | United States (58%)               |
|                               |                       | Male 0–80% |                |                          |         | Partner 25–78%                     | Europe (37%)                      |
|                               |                       |         |                    |                          |         | Child 28–76%                       | Australia (5%)                    |
|                               |                       |         |                    |                          |         | Other 2–30%                        |                                  |
| Van‘t Leven et al., 2013     | 23                    | NS      | NS                 | NS                       | NS      | NS                                 | 100                              |
| Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Faes, et al., 2016a | 53 | NS | NS | NS | NS | Partner 100% | United States (43%) |
|                               |                       |         |                    |                          |         | United Kingdom (8%)                | Europe (42%)                      |
|                               |                       |         |                    |                          |         | Canada (6%)                         | Australia (2%)                    |
### Table 3. Continued

| Authors                                      | Studies in review (n) | Sex (%) | Race/ethnicity (%) | Socioeconomic status (%) | Age (%) | Relationship to care recipient (%) | Geographic setting (%) |
|----------------------------------------------|-----------------------|---------|--------------------|--------------------------|---------|------------------------------------|-----------------------|
| Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Verdonck, et al., 2016b | 17                    | NS      | NS                 | NS                       | NS      | NS                                 | 100 United States (29%) Canada (12%) Australia (12%) Europe (29%) United Kingdom (6%) Asia (12%) |
| Vernooij-Dassen et al., 2011                  | 11                    | 82      | Male 0–31%         | White 80–81% Black 4–19% Hispanic 0–8% Other 0–8% | 45      | Mean years of education 11–14 ≥ College 90% | 91 Partner 7–89% Child 41–67% Other 5–26% |
| Waller et al., 2017                          | 23                    | NS      | NS                 | NS                       | NS      | NS                                 | NS                    |
| Wasilewski et al., 2017                      | 53                    | 77      | Male 0–70%         | NS                       | 68      | Mean age 45–70                      | 66 Partner 0–100% Child NS Other NS |

**Notes:** NS = not significant. aCaregiver rurality not included because no reviews reported. bSome studies in the review reported this characteristic but did not quantify (e.g., mean or % of the sample).
disease, and depression. Notably, our review identified no studies of caregivers of persons with cancer even though it is a common chronic condition in late life. It is possible that our exclusion of studies at the end of life contributed to this omission; however, this neglects the important care that families provide to persons with cancer in the acute and chronic phases of treatment.

Although caregiving roles such as assistance with activities of daily living or instrumental activities of daily living might be considered generic, specific conditions present specific demands. For example, in the case of stroke, caregivers might be managing significant mobility deficits along with speech and swallowing difficulties. On the other hand, an older adult with cancer may experience distressing symptoms such as nausea and fatigue, and the caregiver, depending on the treatment, may have to care for wounds, prepare a special diet, and manage pain. With Parkinson’s disease, the medication regimen can dominate, along with mobility, swallowing, and safety issues. Medical/nursing tasks are relatively unexplored in these studies, an obvious omission given the results of the AARP Home Alone (Reinhard, Levine, & Samis, 2012) and the Home Alone Revisited (Reinhard et al., 2019), which indicated that almost half of caregivers perform such tasks, often without adequate preparation. Still, we found that most reviews featured multicomponent approaches, which are clearly indicated given the diverse needs of family caregivers regardless of care recipients’ condition.

All of the reviews considered interventions that focused on caregivers or caregiver-care recipient dyads, yet caregiving takes place in the context of a family unit that contains multiple relationships, and within a broader social network and community. Presently, there is a dearth of studies designed to mobilize and sustain the caregiving network, improve communications, resolve conflicts, and conduct advance planning (A pesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2016). However, caregivers face known challenges in the resolution of family conflicts, mobilization of adequate support, and navigation of community resources, and these issues contribute to health disparities. As such, future research in these areas is crucial.

The issue of a designated caregiver and inclusion of multiple caregivers in a study remains a challenge, particularly in light of multicultural caregiving patterns. The identification of a primary caregiver may be arbitrary, particularly in families where several individuals are contributing in different ways—contributions that may change over time. Some family members, for example, may by pitching in from a distance. Not only do interventions often fail to include the network of caregivers, they may also overestimate the demands on a caregiver whose role is shared by others. Such differences may be confounded in multi-generational households with varied familial expectations for caregiving or financial constraints for securing additional help.

In reviewing both the caregiver characteristics and the outcomes identified in the reviews, the physical health of the caregiver was another area of neglect. Indeed, existing chronic conditions such as cardiovascular disease tend to worsen over the course of caregiving, as demonstrated by metabolic variables (Vitaliano, Russo, Bailey, Young, & McCann, 1993; Vitaliano, Zhang & Scanlan, 2003). Caregivers’ health—an important factor that influences their physical and mental ability to care—is a variable that is potentially changed by the experience of caregiving, the accumulation of chronic stressors, and neglect of one’s own health. And although the effects of caregiving on the mental, physical, and cognitive health of dementia caregivers are well known (Pinquart & Sörensen, 2003; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011; Vitaliano, Zhang, & Scanlan, 2003), the majority of reviews focused on improving caregivers’ mental health, with a relatively small number aiming to reduce caregiver stress through self-care. Few considered preexisting psychological problems (early childhood trauma, depression, anxiety), which may influence the caregiving experience and obscure interpretation of the findings from intervention studies (Russo, Vitaliano, Brewer, Katon, & Becker, 1995). Again, social determinants of health play a role in the resulting disparities. For example, caregiver gender differences influence both reporting of health problems, development of metabolic imbalances, and negative health outcomes (Berg & Woods, 2009; Pinquart & Sörensen, 2006; Schulz & Beach, 1999; Vitaliano, Zhang & Scanlan, 2003). Yet the exacerbation of a caregiver’s preexisting health problems—while crucial—has received minimal attention.

This review raises the following question: to what extent is caregiving generic and to what extent is it specific to the

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**Table 4. AMSTAR 2 Ratings in Reviews (n = 33)**

| AMSTAR 2 item                          | Yes, n (%) | Partial yes, n (%) | No, n (%) |
|----------------------------------------|------------|--------------------|-----------|
| 1. Includes PICO                       | 18 (55)    | 0 (0)              | 15 (45)   |
| 2. Guided by Written Protocol          | 8 (24)     | 16 (48)            | 9 (27)    |
| 3. Explanation for Included Study Designs | 17 (52)   | 0 (0)              | 16 (48)   |
| 4. Search strategy                     | 6 (18)     | 24 (73)            | 3 (9)     |
| 5. Study Selection in Duplicate        | 19 (58)    | 1 (3)              | 13 (39)   |
| 6. Study Abstraction in Duplicate      | 20 (61)    | 0 (0)              | 13 (39)   |
| 7. List of excluded studies            | 6 (18)     | 0 (0)              | 27 (82)   |
| 8. Detailed PICO described for each study | 9 (27)    | 11 (33)            | 13 (39)   |
Some common elements of caregiving may be universal regardless of the demographic characteristics of the caregiver and the condition precipitating care (e.g., hours of care, duration of care, care-recipient negative behaviors), while others warrant customization (e.g., heavy lifting, organization, home repairs). Given the difficulties in gleaning information about important variables such as race/ethnicity, caregiver relationship, SES, and geographic location, accounting for social determinants of health and their effects on outcomes in intervention studies will be challenging.

AMSTAR 2 results across the reviews suggest that this body of work is unevenly rigorous, reported in insufficient detail, or both. The first question on the AMSTAR 2 evaluation tool pertains to specifying PICO. Yet, “population” is operationalized as the targeted clinical condition rather than descriptors of the sample that reflect population characteristics such as sex, race/ethnicity, age, or geographic location. Although we identified numerous reviews of caregiving interventions, many lacked details about the populations in the included studies, making it difficult to generalize findings across multiple caregiving contexts. This constitutes a major limitation in these systematic reviews, which are considered to be the most rigorous and evidence-based forms of research. These findings point to opportunities for authors of guidelines such as AMSTAR to advocate for explicit reporting of population characteristics associated with the social determinants of health and to assure reporting in detail beyond clinical population descriptions.

A limitation of this review was our reliance on what the authors of the review papers chose to report, with the likelihood that the underlying studies better represented social determinants of health (e.g., race/ethnicity or SES). This is of concern because both researchers and clinicians rely on systematic reviews and meta-analyses for advancing research and practice. The restriction of our search to reviews published in English potentially limited access to a broader and more diverse sample, although some of the reviews did include papers in other European languages. The decision to exclude studies that focused on end-of-life caregiving may have biased the types of interventions evaluated, particularly those focusing on cancer care. As with all systematic reviews, our search criteria may have resulted in missing some reviews thereby limiting our findings. Finally, the context of caregiving may be heterogeneous in countless ways beyond the characteristics we selected here. However, the characteristics we examined are commonly associated with health disparities and provide useful information to advance the dialogue about targeting interventions for optimal outcomes for both the caregiver and care recipient.

Implications
Our findings have important implications for theory-driven caregiver intervention research that fully considers caregiver social determinants of health. To advance health equity, future research should include diverse populations and explicitly consider caregiver physical and mental health as a descriptor of the population, as a focus of intervention, and as an outcome of importance. It must also be expanded to generate knowledge about caregivers caring for older adults with a variety of diseases associated with aging, including cancer, depression, Parkinson’s disease, and stroke. Research could improve health system and community capacity to support caregivers in culturally appropriate ways, formally recognizing them as integral to the care team. These efforts would increase the visibility of caregivers as partners in care with health professionals (Reinhard & Ryan, 2017) and as a vulnerable population within our communities.

The 2016 Families Caring for an Aging America report issued by the NASEM identified elements of interventions that resulted in improved caregiver outcomes (NASEM, 2015). These included assessing caregiver needs; considering risks and preferences; providing appropriate education, skills training, counseling, and self-care strategies; and actively engaging the caregiver in all aspects of learning. As recommended in the report, the foundation for any intervention should be an assessment of risk, need, and preference. This assessment clearly should be informed by characteristics of the caregiver that contribute to disparities in health, experience, and/or access to services. With this basis, research could test whether caregivers who are at “high risk” benefit from more resource-intensive approaches.

There are many variables potentially relevant in caregiving intervention research, as suggested in Figure 1, including characteristics of the care recipient, the caregiver, the caregiving experience, and the context for care. Based on the current review, there remain many gaps in research within this broad caregiving ecology, including how to determine which variables are most salient for a particular study. Given the pressing need for support for family caregivers (Reinhard et al., 2019), an essential direction for research would be to identify “common elements” across interventions and test how effective these are across conditions. Every caregiver is at a different point in the experience, with his or her unique preparation for and attitude toward the situation, yet this is rarely captured in study design. Particularly with older couples, the role of caregiver and care recipient might alternate, with each member of the couple bringing different skills and posing different challenges to the other.

Research guided by theoretical models of stress could target vulnerable caregivers more effectively, building on decades of research using the diathesis-stress model (Monroe & Simons, 1991; Russo and Vitaliano, 1995). This framework posits that distress and disorders can be understood by considering interactions of preexisting and current vulnerabilities and life stressors onto psychological and physical responses. For example, we know that caregivers with chronic illnesses are at heightened risk for
exacerbations of their illnesses (e.g., coronary disease and metabolic syndrome, cancer and natural killer cell activity, current depression with depression history; Russo and Vitaliano, 1995; Vitaliano, Zhang, et al., 2003). A one-size-fits-all approach to caregiving interventions may not be sustainable; caregivers who experience health disparities and who are most likely to relinquish their activities may need to be identified and prioritized. This approach would improve tailoring, thus increasing the likelihood of having the intended impact as well as promoting more cost effective use of resources. One example of the value of the Diathesis-Model for interventions was applied by Hatch, DeHart, and Norton (2014).

Because caregivers experience their roles differently, interventions must be tailored to provide the most relevant support given caregiver heterogeneity and the context. This suggests the usefulness of a more comprehensive and standardized assessment of each situation. Such a measure might be helpful across studies that target different conditions, settings, and trajectories. It will be vital to identify aspects of heterogeneity that matter in design, and recognize opportunities for common elements and strategies. This will drive the scalability and sustainability of interventions.

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Conflict of Interest
None reported.

References
Apesoa-Varano, E., Tang-Feldman, Y., Reinhard, S., Choula, R., & Young, H. M. (2016). Multi-cultural caregiving and caregiver interventions: A look back and a call for future action. Generations, Winter/Spring. Retrieved from https://search.proquest.com/docview/1764312946?accountid=14505
Beck, C., McSweeney, J. C., Richards, K. C., Roberson, P. K., Tsai, P. F., & Soudere, E. (2010). Challenges in tailored intervention research. Nursing Outlook, 58, 104–110. doi:10.1016/j.noutlook.2009.10.004
Berg, J. A., & Woods, N. F. (2009). Global women’s health: A spotlight on caregiving. The Nursing Clinics of North America, 44, 375–384. doi:10.1016/j.cnur.2009.06.003
Boots, L. M., de Vugt, M. E., van Knippenberg, R. J., Kempen, G. I., & Verhey, F. R. (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. International Journal of Geriatric Psychiatry, 29, 331–344. doi:10.1002/gps.4016
Brereton, L., Carroll, C., & Barnston, S. (2007). Interventions for adult family carers of people who have had a stroke: A systematic review. Clinical Rehabilitation, 21, 867–884. doi:10.1177/0269215507078313
Castro, C. M., King, A. C., Housemann, R., Bacak, S. J., McMullen, K. M., & Brownson, R. C. (2007). Rural family caregivers and health behaviors: Results from an epidemiologic survey. Journal of Aging and Health, 19, 87–105. doi:10.1177/0898264306296870
Colby, S., & Ortmann, J. (2014). Projections of the size and composition of the U.S. population: 2014 to 2060. Retrieved from http://wedocs.unep.org/bitstream/handle/20.500.11822/20152/colby_population.pdf
Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R.,...Ballard, C. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. International Journal of Geriatric Psychiatry, 27, 628–636. doi:10.1002/gps.2762
Corry, M., While, A., Neenan, K., & Smith, V. (2015). A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. Journal of Advanced Nursing, 71, 718–734. doi:10.1111/jan.12523
Dam, A. E., de Vugt, M. E., Klinkenberg, I. P., Verhey, F. R., & van Boxtel, M. P. (2016). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? Maturitas, 85, 117–130. doi:10.1016/j.maturitas.2015.12.008
Dilworth-Anderson, P., Pierre, G., & Hillard, T. S. (2012). Social justice, health disparities, and culture in the care of the elderly. The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics, 40, 26–32. doi:10.1111/j.1748-720X.2012.00642.x
Dickinson, C., Gibson, G., Gotts, Z., Stobbart, L., & Robinson, L. (2017). Cognitive stimulation therapy in dementia care: Exploring the views and experiences of service providers on the barriers and facilitators to implementation in practice using Normalization Process Theory. International Psychogeriatrics, 29, 1869–1878. doi:10.1017/S1041610217001272
Evangelista, L. S., Stromberg, A., & Dionne-Odom, J. N. (2016). An integrated review of interventions to improve psychological outcomes in caregivers of patients with heart failure. Current Opinion in Supportive and Palliative Care, 10, 24–31. doi:10.1097/SPC.0000000000000182
Fredriksen-Goldsen, K. I., Kim, H. J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based epidemiologic survey. International Journal of Geriatric Psychiatry, 29, 331–344. doi:10.1002/gps.4016
Gaugler, J.E., Jutkowitz, E., Shippee, T. P., & Brasure, M. (2017). Consistency of dementia caregiver intervention classification:
An evidence-based synthesis. *International Psychogeriatrics*, 29, 19–30. doi:10.1017/S1041610216001514

Girlin, L., Maslow, K., & Khillan, R. (2018). National Research Summit on care, services, and supports for persons with dementia and their caregivers. Office of the Assistant Secretary for Planning and Evaluation. Retrieved from https://aspe.hhs.gov/system/files/pdf/2539156/FinalReport.pdf

Greenwood, N., Pelone, F., & Hassenkamp, A. M. (2016). General practice based psychosocial interventions for supporting carers of people with dementia or stroke: A systematic review. *BMC Family Practice*, 17, 3. doi:10.1186/s12875-015-0399-2

Griffin J. M., Meis, L., Greer, N., Jensen, A., MacDonald, R., Rutks, I., ... Wilt, T. J. (2013). Effectiveness of Family and Caregiver Interventions on Patient Outcomes Among Adults with Cancer or Memory-Related Disorders: A Systematic Review [Internet]. Washington, DC: Department of Veterans Affairs (US). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK148475/

Hatch, D. J., DeHart, W. B., & Norton, M. C. (2014). Subjective differences among Alzheimer’s and Parkinson’s disease spouse caregivers: A systematic review. *The Gerontologist*, 66, 568–573. doi:10.1093/geront/gnt048

Hempel, S., Norman, G., Golder, S., Aguilar-Ibáñez, R., & Eastwood, A. (2008). Psychosocial interventions for non-professional carers of people with Parkinson’s disease: A systematic scoping review. *Journal of Advanced Nursing*, 64, 214–228. doi:10.1111/j.1365-2648.2008.04806.x

Hooker, K., Manoogian-O’Dell, M., Monahan, D. J., Frazier, L. D., & Shifren, K. (2000). Does type of disease matter? Gender differences among Alzheimer’s and Parkinson’s disease spouse caregivers. *The Gerontologist*, 40, 568–573. doi:10.1093/geront/40.5.568

Jackson, D., Roberts, G., Wu, M. L., Ford, R., & Doyle, C. (2016). A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer’s, vascular or mixed dementia in the community. *Archives of Gerontology and Geriatrics*, 66, 218–236. doi:10.1016/j.archger.2016.06.013

Khanassov, V., & Vedel, I. (2016). Family physician-case manager collaboration and needs of patients with dementia and their caregivers: A systematic mixed studies review. *Annals of Family Medicine*, 14, 166–177. doi:10.1370/afm.1898

Lee, J., Soeken, K., & Picot, S. J. (2007). A meta-analysis of interventions for informal stroke caregivers. *Western Journal of Nursing Research*, 29, 344–356; discussion 357. doi:10.1177/0193945906296564

Legg, L. A., Quinn, T. J., Mahmood, F., Weir, C. J., Tierney, J., Stott, D. J., Smith, L. N., Langhorne, P. (2011). Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database of Systematic Reviews*, 10, CD008179. doi:10.1002/14651858.CD008179.pub2

Lui, M. H., Ross, F. M., & Thompson, D. R. (2005). Supporting family caregivers in stroke care: A review of the evidence for problem solving. *Stroke*, 36, 2514–2522. doi:10.1161/01.STR.0000185743.41231.85

Lutzky, S. M., & Knight, B. G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9, 513–519.

Mason, A., Weatherly, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J., & Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. *Journal of the American Geriatrics Society*, 55, 290–299. doi:10.1111/j.1532-5415.2006.01017.x

Mather, M., Jacobsen, L., & Pollard, K. (2015). Aging in the United States. *Population Bulletin*, 70. Retrieved from https://stage.prb.org/wp-content/uploads/2011/07/reports-on-america-2010-census.pdf

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G.; PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLOS Medicine*, 6, e1000097. doi:10.1371/journal.pmed.1000097

Monroe, S. M., & Simons, A. D. (1991). Diathesis-stress theories in the context of life stress research: Implications for the depressive disorders. *Psychological Bulletin*, 110, 406–425. doi:10.1037/0033-2909.110.3.406

NASEM. (2015). *Families caring for an aging America*. Washington, DC: National Academies of Science, Engineering and Medicine Press. doi:10.17226/23606

Petriwskyj, A., Parker, D., O’Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 14, 238–273. doi:10.11124/JBISRIR-2016-002555

Pieris, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., & Sager, S. (2017). Effectiveness of interventions for caregivers of people with Alzheimer’s disease and related major neurocognitive disorders: A systematic review. *The American Journal of Occupational Therapy*, 71, 7105180020p1–7105180020p10. doi:10.5014/ajot.2017.027581

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18, 250–267.

Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 61, P33–P45. doi:10.1093/geronb/b61.l.p33

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26, 1–14. doi:10.1037/a0021863

Rausch, A., Caljouw, M. A., & van der Ploeg, E. S. (2017). Keeping the person with dementia and the informal caregiver together: A systematic review of psychosocial interventions. *International Psychogeriatrics*, 29, 583–593. doi:10.1017/S1041610216002106

Reinhard, S., Levine, C., & Samis, S. (2012). *Home alone revisited: Family caregivers providing complex chronic care*. Washington, DC: AARP Public Policy Institute.

Reinhard, S. C., Young, H. M., Levine, C., Kelly, K., Choulia, R., & Accius, J (2019). *Home alone revisited: Family caregivers providing complex care*. Washington, DC: AARP Public Policy Institute. Retrieved from www.aarp.org/homealone

Reinhard, S., & Ryan, E. (2017). From home alone to the CARE Act: Collaboration for family caregivers. Retrieved from https://www.aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html
Russo, J., Vitaliano, P. P., Brewer, D. D., Katon, W., & Becker, J. (1995). Psychiatric disorders in spouse caregivers of care recipients with Alzheimer’s disease and matched controls: A diathesis-stress model of psychopathology. *Journal of Abnormal Psychology, 104*, 197–204. doi:10.1037/0021-843X.104.1.197

Russo, J., & Vitaliano, P. P. (1995). Life events as correlates of burden in spouse caregivers of persons with Alzheimer’s disease. *Experimental Aging Research, 21*, 273–294. doi:10.1080/03610739508233985

Ryan, P., & Lauver, D. R. (2002). The efficacy of tailored interventions. *Journal of Nursing Scholarship, 34*, 331–337.

Savundranayagam, M., Montgomery, R., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist, 51*, 321–331. doi:10.1093/geront/nq102

Schoenmakers, B., Buntinx, F., & DeLepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging and Mental Health, 14*, 44–56. doi:10.1080/13607860902845533

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association, 282*, 2215–2260. doi:10.1001/jama.282.23.2215

Schulz, R., Martire, L. M., & Klinger, J. N. (2005). Evidence-based caregiver interventions in geriatric psychiatry. *The Psychiatric Clinics of North America, 28*, 1007–1038. doi:10.1016/j.psc.2005.09.003

Scott, J. L., Dawkins, S., Quinn, M. G., Sanderson, K., Elliott, K. E., Stirling, C.,...Robinson, A. (2016). Caring for the carer: A systematic review of pure technology-based cognitive behavioral therapy (CBT) interventions for dementia carers. *Aging and Mental Health, 20*, 793–803. doi:10.1080/13607863.2015.1040724

Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livington, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101*, 75–89. doi:10.1016/j.jad.2006.10.025

Shea, B., Reeves, B., Wells, G., Thuku, M., Hamel, C., Moran, J.,...Henry, D. (2017). AMSTAR 2: A critical appraisal tool for systematic reviews that include randomised or non-randomised controlled trials. *Systematic Reviews, 6*, 20. doi:10.1186/s13643-017-0408-2

Stoltz, P., Uden, G., & Willman, A. (2004). Support for family carers who care for an elderly person at home – A systematic literature review. *Scandinavian Journal of Caring Sciences, 18*, 111–119. doi:10.1111/j.1471-6712.2004.00269.x

Trettetteig, S., Vatne, S., & Rokstad, A. M. (2016). The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature. *Aging and Mental Health, 20*, 450–462. doi:10.1080/13607863.2015.1023765

Talley, R., & Crews, J. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*, 224–228. doi:10.2105/ajph.2004.059337

Van’t Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics, 25*, 1581–1603. doi:10.1017/S1041610213000860

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K., & Annemans, L. (2016a). Effectiveness of supporting informal caregivers of people with dementia: A systematic review of randomized and non-randomized controlled trials. *Journal of Alzheimer’s Disease, 52*, 929–963. doi:10.3233/jad-151011

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016b). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *International Journal of Geriatric Psychiatry, 31*, 1277–1288. doi:10.1002/gps.4504

Vernooij-Dassen, M., Draskovic, I., McClery, J., & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews (Online), 11*, CD005318. doi:10.1002/14651858.CD005318.pub2

Vitaliano, P., Murphy, M., Young, H. M., Echeverria, D., & Borson, S. (2011). Does caring for a demented spouse promote cognitive decline? A hypothesis and proposed mechanisms. *Journal of the American Geriatrics Society, 59*, 900–908. doi:10.1111/j.1532-5415.2011.03368.x

Vitaliano, P., Zhang, J., & Scanlan, J. (2003). Is caregiving hazardous to one’s physical health? A meta-analysis. *Psychological Bulletin, 129*, 946–972. doi:10.1037/0033-2909.129.6.946

Vitaliano, P. P., Young, H. M., Russo, J., Romano, J., & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer’s disease? *Journal of Gerontology, 48*, P202–P209. doi:10.1093/geronj/48.4.p202

Vitaliano, P. P., Russo, J., Bailey, S. L., Young, H. M., & McCann, B. S. (1993). Psychosocial factors associated with cardiovascular reactivity in older adults. *Psychosomatic Medicine, 55*, 164–177. doi:10.1097/00006842-199303000-00005

Waller, A., Dilworth, S., Mansfield, E., & Sanson-Fisher, R. (2017). Computer and telephone delivered interventions to support caregivers of people with dementia: A systematic review of research output and quality. *BMC Geriatrics, 17*, 265. doi:10.1186/s12877-017-0654-6

Wasilewski, M. B., Stinson, J. N., & Cameron, J. I. (2017). Web-based health interventions for family caregivers of elderly individuals: A Scoping Review. *International Journal of Medical Informatics, 103*, 109–138. doi:10.1016/j.ijmedinf.2017.04.009