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## Review Article

# 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

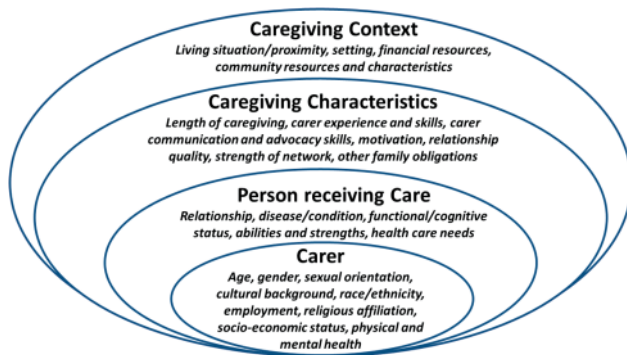


Figure 1. Heterogeneity of caregiving.

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, & Khillan, 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 & Lauer, 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

**Table 1. Search Terms**

aged	caregiving	family	Hospice
Alzheimer	dement*	family caregiving	palliative care
cancer	dementia	family counseling	intervent*
caregiv*	education	geriatric	Intervention
caregiver	elderly	home care	interventions for
caregiver	elderly care	home nursing	caregiver support
burden			

(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.

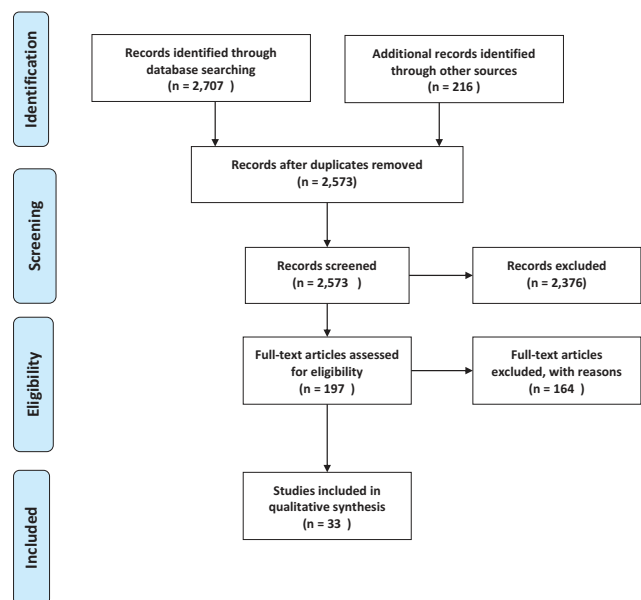
**Results**

**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



**Figure 2.** PRISMA flow chart for study selection.

**Table 2.** Systematic Review Descriptions (*n* = 33)

Authors	Target condition	Meta-analysis	Included studies ( <i>n</i> )	Caregivers ( <i>n</i> )	% Randomized controlled trial (RCT)	Types of interventions	Outcomes	AMSTAR 2 total score <sup>a</sup>
Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014	Dementia	No	12	>1,000	2.5	SB, PS	MH, SE, QoL, PH, S, B	5
Brereton, Carroll, & Barnston, 2007	Stroke	No	8	>1,000	100	SB, PS, E	MH, SE, S, B, SK	6
Corbett et al., 2012	Dementia	Yes	13	501–1,000	100	Education	QoL, B	6
Corry, While, Neenan, & Smith, 2015	Stroke	No	8	>1,000	100	SB, PS	MH, QoL, S, SK, other	6
Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016	Dementia	No	39	>1,000	72	PS	MH, S	6
Dickinson, Gibson, Gotts, Stobbart, & Robinson, 2017	Dementia	No	13	Not specified	100	PS	MH, Other	3
Evangalista, Stromberg, & Dionne-Odom, 2016	CHF	No	8	501–1,000	100	PS, E	MH	2
Greenwood, Pelone, & Hassenkamp, 2016	Dementia	No	4	<500	50	PS, E, CB, other	MH, PH, QoL, S, B, SK	7
Hempel, Norman, Golder, Aguiar-Ibañez, & Eastwood, 2008	Parkinson's disease	No	30	>1,000	10	SB, PS, E, R, CM	MH, PH, SE, S, SK, Sat, other	3
Jackson, Roberts, Wu, Ford, & Doyle, 2016	Dementia	No	22	>1,000	73	PS, E	MH, PH, SE, QoL, B, Sat, other	2
Khanassov & Vedel, 2016	Dementia	Yes	54	Not specified	9	CM, Other	MH, B, SK, CR, other	7
Lee, Soeken, & Picot, 2007	Stroke	Yes	4	501–1,000	100	SB, PS, E	MH	6
Legg et al., 2011	Stroke	No	8	>1,000	100	SB, PS, E	MH, PH, QoL, Sat	8
Lui, Ross, & Thompson, 2005	Stroke	No	11	>1,000	55	SB	MH, PH, SK, S, B, other	3
Mason et al., 2007	Frailty/cognitive impairment	Yes	22	Not specified	45	R	MH, QoL, Sat	3
Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016	Dementia	No	3	<500	33	Other	MH, PH, SE, B, other	8
Piersol et al., 2017	Dementia	No	43	Not specified	65	PS, E, CM, R/PA, other	MH, PH, SE, SK, CR, RQ, other	4

Table 2. Continued

Authors	Target condition	Meta-analysis	Included studies (n)	Caregivers (n)	%	Randomized controlled trial (RCT)	Types of interventions		Outcomes	AMSTAR 2 total score <sup>a</sup>
							Types of interventions	Outcomes		
Rausch, Caljouw, & van der Ploeg, 2017	Dementia	No	7	501–1,000	57		PS, E, Other	SK, RQ	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, Lyketos, & 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		PS	MH, PH, SE, QoL, S, B, SK, CR	7	
Sousa, Sequeira, Ferre-Grau, Neves, & Lleixa-Fortunó, 2016	Dementia	No	8	501–1,000	50		SB, E, R/PA	MH, SE, B, S, SK, CR	4	
Stoltz, Uden, & Willman, 2004	Dementia	No	26	501–1,000	5		S, R	MH, SE, S, B, SK, Sat, CR	4	
Tretteig, Vame, & 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, CB, 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, CB, 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, & Downs, 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, CB, R	MH, PH, SE, QoL, S, B SK	5	
Wasilewski, Strinson, & Cameron, 2017	Multiple	No	53	>1,000	34		SB, PS, E, Other	PH, MH, SE, QoL, B, SK, other	2	

Notes: <sup>a</sup>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

**Table 3.** Percentage and Details of Caregiver Social Determinants of Health Specified in Systematic Reviews<sup>a</sup>

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	NS	8	75	75	NS
		Male 11–58%		≥ College Degree 65%	Mean age 46.9–73 <sup>b</sup>	Partner 7–100% Child 0–75% Other 0–23%	
Brereton et al., 2007	8	13 <sup>b</sup>	38 <sup>b</sup>	75 <sup>b</sup>	100 <sup>b</sup>	NS	100 United States (50%) United Kingdom (13%) Europe (23%)
Corbett et al., 2012	13	NS	NS	NS	NS	NS	100 United States (62%) Asia (15%) Europe (23%) NS
Corry et al., 2015	8	NS	NS	NS	NS	NS	NS
Dam et al., 2016	29	NS	21 Chinese 0–100% <sup>b</sup>	NS	NS	NS	100 United States (52%) United Kingdom (10%) Europe (14%) Asia (14%) Canada (7%) Australia (3%) NS
Dickinson et al., 2017	13	NS	NS	NS	NS	38 <sup>b</sup>	NS
Evangelista et al., 2016	8	54 Male 20–35%	NS	54 ≥ College 12–54% <sup>b</sup>	100 Mean age 47.1–68.5 <sup>b</sup>	NS	100 United States (50%) Europe (25%) Asia (2.5%)
Greenwood et al., 2016	4	100 Male 7–55%	NS	NS	100 Mean age 62.4–71.6	NS	100 United States (75%) Europe (25%) NS
Hempel et al., 2008	30	NS	NS	NS	NS	NS	NS
Jackson et al., 2016	22	NS	NS	NS	NS	NS	100 United States (73%) Europe (14%) Canada (5%) Asia (9%)



**Table 3.** Continued

Authors	Studies in review (n)	Sex (%)	Race/ethnicity (%)	Socioeconomic status (%)	Age (%)	Relationship to care recipient (%)	Geographic setting (%)
<a href="#">Khanassov et al., 2016</a>	54	63 Male 8–71%	NS	NS	59 Mean age 49–80 <sup>b</sup>	NS	100 United States (28%) Canada (2%) Europe (39%) Asia (13%) Africa (2%) Other (15%)
<a href="#">Lee et al., 2007</a>	4	NS	NS	NS	100 Mean age 57–65	NS	100 United States (25%) Europe (75%)
<a href="#">Legg et al., 2011</a>	8	63 Male 9–33%	NS	NS	50 Mean age 58–67	NS	100 United States (38%) Australia (12%) United Kingdom (25%) Europe (12%) Asia (12%)
<a href="#">Lui et al., 2005</a>	11	45 Male 8–37%	18 White 40–50% Black 50–60%	36 Mean years of education 11–13 <sup>b</sup>	45 Mean age 47.9–64	9 Partner 95% Child NS Other NS	100 United States (64%) United Kingdom (27%) Europe (9%)
<a href="#">Mason et al., 2007</a>	22	95 Male 12–38%	NS	NS	86 Mean age 54–73 <sup>b</sup>	NS	100 United States (50%) Australia (9%) Canada (9%) Europe (9%) United Kingdom (23%)
<a href="#">Petrowskyj et al., 2016</a>	3	100 Male 15–35%	50 White 95%	50 ≥ College degree 60%	100 Mean age 60.2 <sup>b</sup>	33 Partner 38% Child 62% Other NS	NS
<a href="#">Pierzol et al., 2017</a>	43	79 Male 0–47%	44 White 0–100% Asian 0–100% Black 0–100% Hispanic 0–34%	NS	79 Mean age 44–71 <sup>b</sup>	NS	NS

Table 3. Continued

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 Partner 0–100% Child 0–100% Other NS	NS
Scott et al., 2016	4	100 Male 13–27%	NS	NS	100 Mean age 47–65	100 Partner 7–55% Child 36–74% Other NS	NS
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%)
Stoltz et al., 2004	26	NS	NS	NS	NS	NS	100 United States (77%) Europe (12%) Canada (8%) Asia (4%)
Tretteireig et al., 2016	19	89 Male 0–80%	NS	NS	95 Mean age 51–71	79 Partner 25–78% Child 28–76% Other 2–30%	100 United States (58%) Europe (37%) Australia (5%)
Van't Leven et al., 2013	23	NS	NS	NS	NS	NS	NS
Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Faes, et al., 2016a	53	NS	NS	NS	NS	15 Partner 100% <sup>b</sup>	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%	27 White 80–81% Black 4–19% Hispanic 0–8% Other 0–8%	45 Mean years of education 11–14 ≥ College 90%	91 Mean age 47–70	91 Partner 7–89% Child 41–67% Other 5–26%	NS
Waller et al., 2017	23	NS	NS	NS	NS	NS	100 United States (87%) Europe (35%) Asia (13%) Canada (9%) United Kingdom (4%)
Wasilewski et al., 2017	53	77 Male 0–70%	NS	NS	68 Mean age 45–70	66 Partner 0–100% Child NS Other NS	100 United States (53%) Canada (26%) Europe (19%) Asia (2%) Australia (2%)

Notes: NS = not significant. \*Caregiver rurality not included because no reviews reported. <sup>a</sup>Some studies in the review reported this characteristic but did not quantify (e.g., mean or % of the sample).

**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)

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 (Apesoa-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 be 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 & Sørensen, 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 & Sørensen, 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

care recipient's condition and/or caregiver characteristics? This has implications for both design and generalizability. 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.

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