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RESPITE CARE FOR PEOPLE WITH DEMENTIA AGING IN PLACE: A SYSTEMATIC REVIEW AND NARRATIVE ANALYSIS

by

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ABSTRACT

AMANDA WEIR-GERTZOG. Respite care for people with dementia aging in place:
A systematic review and narrative synthesis. (Under the direction of
DR. MICHAEL J. TURNER)

Respite care, including adult day care, residential respite, and home services, offers integral life-enhancing benefits to people with dementia aging in place: peer interaction, diminished social isolation, and enhanced feelings of purpose and occupation. Policy provisions, particularly within dementia strategies, which include ancillary supports to people with dementia and their caregivers are becoming increasingly common. A systematic review was undertaken, and a narrative synthesis of 15 qualitative, quantitative and mixed-methods studies that examined the role of respite care for people with dementia was conducted. Experiences of people with dementia aging in place utilizing respite care were examined, particularly the potential psychosocial benefits, and expressed limitations to usage. Respite care was viewed favorably by people with dementia, especially as those interviewed often emphasized the relationships, meals, and shared experiences. While some users and caregivers communicated hindrances to respite care, including flexibility of scheduling, and continuity of care, emphasis was placed on positive outcomes to respite care for people with dementia.

Key words: respite care, dementia, Alzheimer’s disease, aging in place, social isolation.

DEDICATION

This thesis is dedicated to my mother, Susan Huston Jones, who devoted her entire career to education and access, retiring from George Mason University in 2012 as University Registrar and Associate Provost. She never doubted that I could complete a graduate degree, and wholeheartedly believed that online education would be my entry back. Her ceaseless faith, long-distance encouragement, superior editing skills, and sage, methodical advice contributed appreciably. For believing that I would find my way to graduate school years later: thanks, ma mere. This one is, and always has been, for you.

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Instructions for living a life.
Pay attention.
Be astonished.
Tell about it.
Mary Oliver, 2008

Pay attention

A shout out and top billing to the unflappable Dr. Mike Turner for his manifold roles as my master's thesis advisor, professor, graduate research coordinator, and UNC Charlotte consigliere. Suffering no fools, but with a propensity to jest with the best, Dr. Turner's hands-on research expertise also contributed to his direction of my oft curious, and verbose inquiries.

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Be astonished

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Tell about it

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CHAPTER 1: INTRODUCTION

Older adults are increasingly aging in place, including people with dementia, as societal, economic, and demographic shifts of the past three decades impact family size, health care, and social assistance programs (Alzheimer's Association, 2018; Kaplan, Anderson, Lehning, & Perry, 2015; Mather, Jacobsen, & Pollard, 2015). Aging in place refers to older adults consciously choosing to remain in their homes with the potential addition of complementary supports (e.g. social services, interpersonal, and health care) to facilitate comfort and safety (NIA, 2017). Home may be an apartment, mobile home, house, or residence in a 55+ living community. Respite care relieves some of the psychosocial stressors of dementia such as social isolation, and feelings of exclusion, that can occur with people with dementia. According to the National Alliance on Caregiving (2017) approximately 74% of people with dementia in the United States are aging in place and receiving the bulk of their care from a family member (most commonly a spouse or an adult child) which emphasizes the role that family can play as long-term dementia care providers, and the obligations of surrounding communities to provide coordinated health and social services (Blackburn & Dulmus, 2007; Silverstein, Wong, and Brueck, 2010).

Dementia, of which 60-70% of cases are Alzheimer's disease, is a syndrome that impacts the thinking, language, attention, memory and other challenges of the diagnosed (NIA, n.d.a; Sabat, 2018). The symptoms need to evince additional decline of prior abilities and impact daily living for a dementia diagnosis (Dementia Australia, 2012; Sabat, 2018). Age, family history, and genetics are risk factors of dementia. Head injuries, overall health (particularly diabetes, hypertension, tobacco use), and an elevated likelihood of diagnosis in black and Latinx communities are also considered contributing factors (Alzheimer's Association, 2018; WHO, 2018). Populations and geographic areas disproportionately affected by socioeconomic disparities, limited health care access, and comorbidities, are especially in need of flexible respite care options, information, and bilingual, culturally sensitive provisions (Alzheimer's Association, 2018).

Although dementia is not a "normal" part of aging, worldwide dementia statistics currently estimate: 50 million people experience dementia, with a predicted 82 million people with dementia diagnoses expected by 2030, and 152 million by 2050 (Alzheimer's Association, 2018; WHO, 2018). Health care throughout the continuum of the dementia experience contributes to earlier diagnoses, and provision of meaningful community services, contacts, and assistance, such as respite care inclusive of people with dementia

Objectives

The primary objective of this systematic review focuses on exploring the experiences of people with dementia aging in place and their participation in respite care. Ancillary objectives encompass examining user and caregiver needs and impediments to respite care. Lastly, determining potential implications to health and social care policies are also a consideration.

CHAPTER 2: LITERATURE REVIEW

2.1 Social isolation and dementia

Respite care, including adult day care, home respite, and short stay residential programs, is often necessitated by heightened feelings of psychosocial stress, especially sentiments of loneliness, and desire for companionship and daily activities, as expressed by people with dementia (Dabelko-Schoeny & King, 2009; Moholt, Friborg, Blix, & Henriksen, 2018). Social isolation in older adults has several risk factors including being widowed, living alone, poor health, psychological difficulties, and cognitive challenges (Machielse, 2015; Walker et al., 2013). Retirement, financial hardship, moving, and the reduction in size of social networks or familiarity of community can also stimulate long-lasting reverberations of isolation in older adults. Machielse's (2015) definition of social isolation highlights those who have limited to no assistance for companionship or emotional and practical support. Not only are older adults with dementia at an increased risk for isolating themselves for a myriad of reasons (embarrassment, altering social ties, changes in cognitive function), but their diagnoses may lead to the potential prospect of depression (Lange, 2012).

Loneliness, the subjective feeling of being alone, and social isolation, the objective experience of limited to no social relationships, corresponds with heightened health risks, including mortality, morbidity, and an increased risk of dementia (Pillemer, Schoen, & Sheldon, 2019). The augmented dementia risks may be specifically related to an absence of social interaction, which activates brain health (Kaye & Singer, 2019).

2.2 Theory of personhood

Personhood, Kitwood (1997a) proffered, is relative social status awarded someone by others that suggests dignity, respect, and trust. However, just as personhood is granted and positive feelings of comfort and prosperity induced while standard, abled indicators of the status quo are projected on an individual, when the effects of ill health, or increased need for assistance occur, a reduction in the benefits of personhood commence (Mitchell & Agnelli, 2015; Kitwood, 1997a). People with dementia may be regarded as "less than" due to myriad factors including westernized focus on individualism, fear of aging, fear of death, and fear of perceived mental illness, which may lead to people with dementia being excluded, activating feelings and experiences of social isolation (Kitwood, 1997a).

Positive person work, a component of person-centered care for people with dementia, incorporates several types of interactions that focus on maintaining individuality, nourishing feelings of well-being, and enhancing abilities, while strengthening core components of personhood (Fazio, Pace, Filnner, & Kallmyer, 2018; Kitwood, 1997a). Interactions in positive person work for people with dementia include recognition, collaboration, celebration, and negotiation (Kitwood, 1997a). Additionally, the attendance to the psychosocial needs of comfort, inclusion, attachment, occupation, and identity, also comprise a framework that recognizes love and nourishing relationships as integral elements in person-centered care for people with dementia (Kitwood, 1997a; Kitwood, 1997b)

Kitwood's (1997a) theory of personhood also aligns with his concept of malignant social psychology, which he described as the challenges and communication concerns that people encountered when their personhood was undermined (Mitchell & Agnelli, 2015). Malignant social psychology, however unintentional, contains numerous components such as infantilization, disempowerment, and banishment (Kitwood, 1997a). Kitwood (1997b) identified malignant social psychology as dehumanizing, and restrictive to the sense of self, in stark contrast to positive person work, which is utilized to embrace the unique personhood of each individual with dementia and their lived experience.

2.3 Respite care definition

Respite care is a hallmark of caregiver and aging in place supports, particularly for people with dementia. However, even the definition of *respite* or *respite care* lacks standardization across aging fields which breeds confusion, not only in research endeavors, but clarity of message. In the United States the Alzheimer's Association, National Institute of Aging, and Medicare define respite care as offering short-term relief of caregiving duties to a primary caregiver via an adult day center, home, or in a health care facility (Alzheimer's Association, 2019; Centers for Medicare and Medicaid, 2018; NIA, n.d.b). This construct of respite is also depicted in America's current dementia strategy, which offers minimal related adult day programming opportunities in its initial presentation or updates (U.S. Department of Health and Human Service, 2018).

In contrast, Australia, home to one of the first dementia policies in 1992 with their National Plan for Dementia Care, regards respite care as intrinsic to the continued health and fortification of people with dementia as well their caregivers (Australia Health Ministers Conference, 2015; Hunter & Doyle, 2014). Australia also extends the National Respite Program for Caregivers supplying daily, weekend, and long-term respite for users, while accentuating the myriad goals of respite, including maintenance of aging in place, and reinforcement of the partnered relationship (Alzheimer's Australia, 2016; Howe, 2013; Tang, Ryburn, Doyle, & Wells, 2010). Comparatively, Norway's Dementia Plan 2020 also characterizes respite care as primarily a domain of caregivers though it emphasizes day activity services for people with dementia and the successful synthesis of the two programs, funded and provided by municipalities, as ways to offer coping strategies, social integration, and meaningful activity to both care partner and person with dementia (Norwegian Ministry of Health and Care Service, 2015). Moholt et al. (2018) respite care survey of home-based and out-of-home respite care services for dementia in Norway expounds upon this understanding of respite to encompass both home-based and out-of-home respite services for people with dementia.

Another semantic conundrum regarding respite is that it is both an outcome and a service: a person with dementia attends day *respite services* to *receive respite* from their experience and the service (if living with family or a loved one) *provides respite* to their care partner (Chappell, Read, & Dow, 2001; Neville, Beattie, Fielding, & MacAndrew, 2013). A study of typological meaning of respite argued for the reconceptualization of respite care as an outcome for care providers, incorporating the voice of caregivers, instead of its presentation as a service developed by policy and health care providers (Chappell et al., 2001). In his 2013 review, Evans analyzed the concept of respite, acknowledged the difficulties of definition, and even inserted another: respite as a location.

For the purpose of this paper, respite, in its many variations, will be understood as an option for people with dementia. The nature of respite as a service or an outcome is recognized, though will not be rectified within the confines of this study.

CHAPTER 3: METHODS

3.1 Search and information sources

In April 2019 database searches utilizing EBSCohost via Abstracts in Gerontology, Academic PsycInfo, and Social Work Abstracts, as well as the Web of Science (hosted by Clarivate Analytics) . The broad swath of health, social science, and academic database searches speaks to the diverse range of professions that may write and study dementia, contrasted with the potentially dichotomous issue of limited information or research on respite programs for people with dementia aging in place. Search terms included were dementia, people with dementia, Alzheimer's, policy, adult day care, adult day service or program, respite care, respite services, dementia strategy, as well as United States, England, Britain, and Australia. Application of Boolean operators allowed for greater emphasis on people with dementia instead of the care provider (Alliant libraries, n.d.). For example, several searches included the following combination or a variation of (respite care or respite or respite services) (people with dementia) NOT (caregivers). Caregivers are integral to the maintenance of people with dementia aging in place, however, in extrapolating data with the highest likelihood of perspectives from people with dementia themselves this appeared a sensible strategy. Full search syntax for each database search is included in Table 1.

Table 1

Search Syntax: Respite Care for People with Dementia

Database	**Search syntax**
Abstracts in Social Gerontology	(dementia or Alzheimer's) (respite or respite care or respite services) NOT (systematic review or meta-analysis); (people with dementia) (respite or respite care or respite services) (policy) (respite or respite care or respite services) (dementia or Alzheimer's) (adult day services or program) (respite or respite care or respite services) (dementia or Alzheimer's) (policy) (people with dementia) (adult day care) (respite or respite care or respite services)
Academic Search Complete	(dementia) (respite or respite care or respite services) (dementia or Alzheimer's) (respite or respite care or respite services) (dementia or Alzheimer's) (respite or respite care or respite services) (policy) (dementia or Alzheimer's) (respite or respite services or respite care) (policy or policies) (respite or respite care or respite services) (people with dementia) NOT (caregivers)
CINAHL Plus with Full Text	(dementia) (policy) (United States) (people with dementia) (respite care or respite or respite services) NOT (caregiver) (dementia capable) (services or programs or interventions or resources) (dementia) (respite care or respite or respite services) (policy) (dementia) (policy) (Australia) (dementia) (policy) (England or Britain)
PsycInfo	(dementia strategy) (policy) (respite or respite care or respite services) (dementia or Alzheimer's) (dementia) (respite or respite care or respite services) (policy) (dementia capable) (dementia or Alzheimer's)

Table 1

Search Syntax: Respite Care for People with Dementia (continued)

Database	**Search syntax**
	(respite or respite care or respite services) (people with dementia) NOT (caregivers)
Social Work Abstracts	(dementia or Alzheimer's) (respite) (respite care or respite or respite services) (people with dementia) NOT (caregivers) (dementia) (adult day) (dementia) (program) (people with dementia) (policy)
Web of Science	(dementia or Alzheimer's) (respite) NOT (caregiver) (respite care) (people with dementia) (policy) (people with dementia) (respite or respite care or respite services) (programs or programmes) (respite care or respite or respite services) (dementia or Alzheimer's) (programs or programmes) (Australia) (policy) (dementia) (United States)

Note, database searches initially occurred in April 2019

Further studies and sources were acquired via article reference lists, related studies, and means of hand searching. Hand searching is the process of manually scanning designated journals page by page in efforts to gather articles missed by online indexing (Rutgers University Libraries, 2019). Rutgers (2019) also indicates that hand searching incorporates scanning the reference lists of selected articles to locate additional papers, which is also referred to as snowballing. Supplemental searching of grey literature occurred in September 2019. Grey literature represents the copious print and electronic, intellectually protected, documents of business, government, and academia that are of high enough quality for preservation and collection in repositories and libraries, though whose primary aim was not commercial publication (Duke, 2019). Greynet.org was founded in 1992 to distribute and assist in the dissemination of a variety of government, academic, and business documents, and publications that are often restricted from view behind publisher paywalls and sites (Grey Net, n.d.). The social sciences section of Greynet included a link to Analysis and Policy Observatory (APO), an Australian open access site focused on making public policy and practice accessible (APO, n.d.). This led to several searches (though none with the database Boolean operator search potential of EBSCOhost), consisting of the following terms: adult day care, dementia, and respite (APO, n.d.).

3.2 Eligibility criteria

Initial eligibility criteria for database search study characteristics encompassed the following factors: publication dates from 2009-2019, availability in English, peer-review, compatibility with search terminology. The explanation for examining papers from the past two decades (aside from foundational texts) resides in the desire to relay contemporary information, as well as focus on studies that may directly tie to policies initiated after (or concurrently with) the formulation of many dementia strategies, such as Australia's *The Dementia Initiative* (2005), England's *Living Well with Dementia* (2009), and Norway's *Dementia Plan* (2007). The understanding of respite care services as inclusive of people with dementia and not solely relegated to caregivers appears specific to certain countries. For example. Australian policy speaks intentionally about respite as a service for people with dementia as well as their caregivers (Alzheimer's Australia, 2016; U.S. Department of Health and Human Services, 2018).

3.3 Study selection

The database searches with selected eligibility criteria identified 1,110 records of potentially relevant studies. After additional records were identified through other sources (hand searching and grey literature) the total records count equaled 1,122. Once duplicate records were removed in EndNote, online software developed to assist with bibliographic, reference, and citation management, the remaining records totaled 759 (Boland, Cherry, & Dickson, 2017; Clarivate, 2019). To winnow the field of articles, the author narrowed the date range from twenty years (1999-2019) to ten (2009-2019) thus reducing the records to 545 to be screened and introducing the exclusion criteria of studies prior to 2009, as well as one page “In Brief” or Review articles . At this stage assuring the inclusion of studies that focused on people with dementia, respite programs, and primarily older adults with dementia (65+) was integral and led to an additional exclusion of 403 studies. 142 full-text articles were then assessed for suitability, with parameters of encompassing respite care programming for older adults aging in place, even short-term residential respite care, if the emphasis was on the impact on the person with dementia. Additionally, young onset dementia was not excluded, but only included if older people with dementia also participated in the study. The searching, selecting, and eligibility process reduced the field of records from 1,122 to 15.

3.4 Data collection and items

Information extracted from database searching was collected in EndNote, as well as Zotero, which is open access citation organization software (Boland et al., 2017; Clarivate, 2019; Zotero, n.d.). Data extracted from studies was placed into multiple spreadsheets comprised of recommended components via PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), Cochrane Database of Systematic Reviews, as well as current texts on systematic reviews in the social sciences (Beller et al., 2001; Boland et al., 2017; Cochrane Library, 2019; Petticrew & Roberts, 2006;

PRISMA, n.d.). Thesis data tables were developed and include the following three individual spreadsheets: participant characteristics, study characteristics, and study results. The participant characteristic table includes the following sections for each study, however, not every study applied to each section since the 15 selected articles entailed qualitative, quantitative, and mixed methods approaches:

- N=the total number of study participants
- Mean Age
- Sex
- Geography (urban, metro, suburban, rural)
- Education
- Race/ethnicity
- Diagnosis

The study characteristics table contains columns for country (where the study took place), design (what type of study), general focus (e.g., how an adult day care program one day per week for seven weeks for a person with dementia is experienced), and source of funding. The third thesis data table is the study results spreadsheet and displays sections for primary outcomes, secondary outcomes, and thematical analysis (themes, sub-themes).

3.5 Risk of bias in individual studies

The mixed methods appraisal tool (MMAT), developed by Pluye and Hong (2009) offers a way to review the viability and reliability of qualitative, quantitative, and mixed methods studies without employing a different assessment tool for each style of study (Boland et al., 2017; Hong et al., 2018; Pluye & Hong, 2009). Available online, open access, with accompanying literature and instructions, the MMAT was downloaded, and applied to address individual risk of bias in this systematic review.

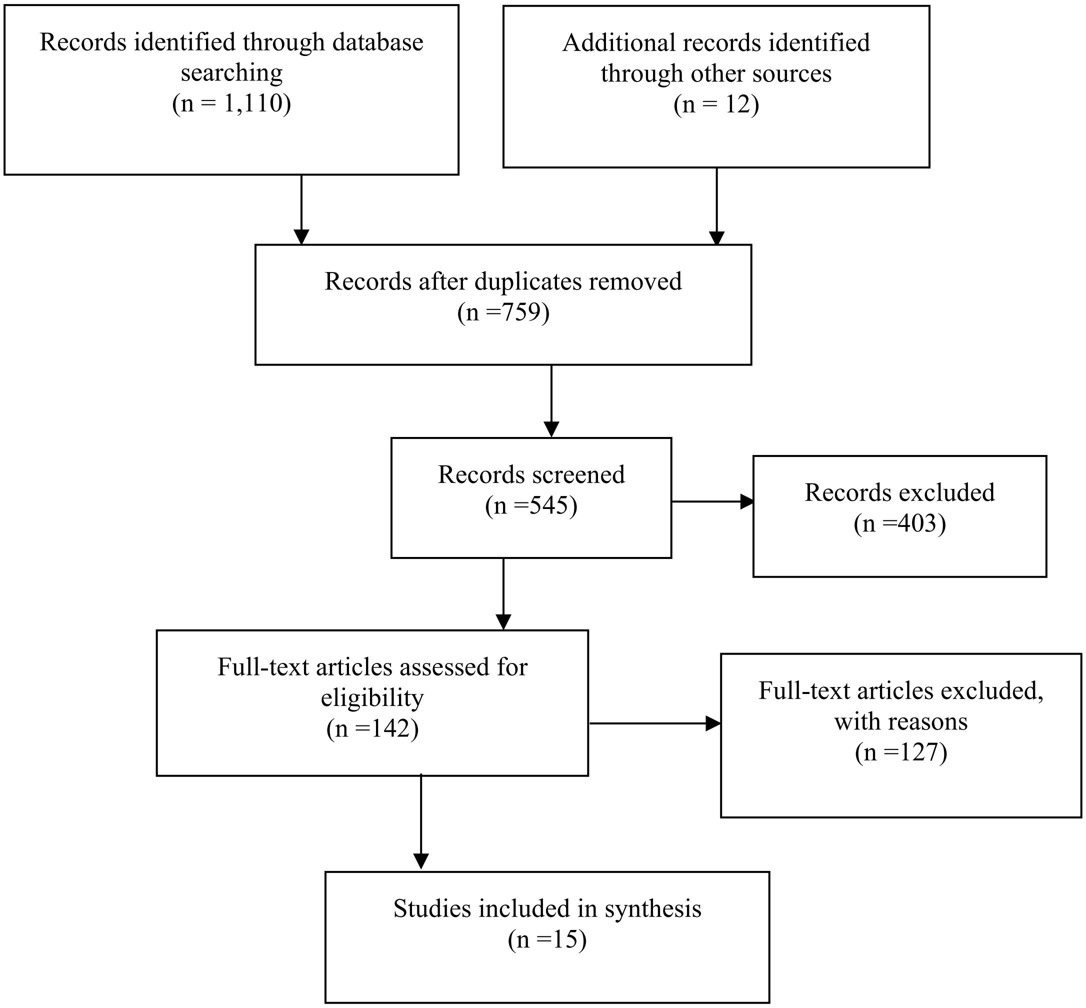
CHAPTER 4: RESULTS

4.1 Study selection

The PRISMA flow diagram (Figure 1) includes studies screened, assessed, and selected for review (Moher, Liberati, Tetzlaff, & Altman, 2009).

Figure 1.

Study Selection: Respite Care for People with Dementia



4.2 Study characteristics

Details on study participants, as contributed by their authors, such as total participants of each study, age, sex, geography, education, and diagnosis are found in Table 2 Participant Characteristics. Study characteristics (country, design of study, general focus, and funding source) are in Table 3.

Table 2

Participant Characteristics: Respite Care for People with Dementia

Study	**N=**	**Mean Age (and/or Range)**	**Sex**	**Geography**	**Education**	**Race/ Ethnicity**	**Diagnosis**
Brataas, H.V., Bjugan, H., Wille, T., & Hellzen, O. (2010)	9 PWD	77-88	F: 7 M:2	rural			mild dementia
Gresham, M., Hefferman, M., & Brodaty, H. (2018)	90: 45 dyads 85: @ 6-month follow up 84: @ 12 month follow up	PWD: 49-90 caregiver: 36-89	PWD: F 28.9% Caregiver: F 77.8%	Metro: 75% Non-metro: 14% Remote: 11%			AD: 58% FTD: 12% Lewy body: 5% Other: 14% Unknown: 10%
Hochgraeber, I., von Kutzleben, M., Bartholomeyczik, S., & Holle, B. (2017)	31 stakeholders caregivers: 6 PWD: 3 volunteers: 12 coordinators: 7 providers: 3		F: 28 M: 3				

Table 2

Participant Characteristics: Respite Care for People with Dementia (continued)

Study	**N=**	**Mean Age (and/or Range)**	**Sex**	**Geography**	**Education**	**Race/ Ethnicity**	**Diagnosis**
Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. & Bond, J. (2011).							
Miranda-Castillo, C. Woods, B., & Orrell, M. (2013)	152: 125 dyads; 27 professionals	PWD: 79.2 (60-94)	PWD: F: 51.3% M: 48.7% Caregiver: F: 71.1% M: 28.9%		PWD: Higher Educ: 20.3% Secondary: 75.6% Below Secondary 4.1%	PWD: White: 98.7% Black: 0.7% Asian: 0.7% Caregivers: N/A	
Morrisby, C., Joosten, A., & Ciccarelli, M. (2018)	7,212: 5,069 caregivers 2,089 PWD 54 care workers/ providers						Included Alzheimer's disease;vascular dementia; and young onset dementia (2 cases)

Table 2

Participant Characteristics: Respite Care for People with Dementia (continued)

Study	**N=**	**Mean Age (and/or Range)**	**Sex**	**Geography**	**Education**	**Race/ Ethnicity**	**Diagnosis**
Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015)							
Phillipson, L. & Jones, S.C. (2011)	36 caregivers	71 (43-87)	F:26 M:10		Primary: 5 Secondary: 16 Technical: 5 University: 8	Non-English speaking country of origin: 3 (Malta, Germany, Finland)	AD:15 Vascular dementia:6 LBD:3 FTD:2 Other/unknown/no diagnosis:10
Silverstein, N.M., Wong, C.M., & Brueck, K.E. (2010)	93 Adult Day Health Care providers			MA, USA			
Strandenaes, M.G., Lund, A. & Rokstad, A.M.M. (2018)	17 PWD	80.5	F:10 M: 7				very mild: 3 mild: 11 moderate: 3

Table 2

Participant Characteristics: Respite Care for People with Dementia (continued)

Study	**N=**	**Mean Age (and/or Range)**	**Sex**	**Geography**	**Education**	**Race/ Ethnicity**	**Diagnosis**
Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D., & Challis, D.J. (2015)	27 caregivers and PWD	Age Range: PWD: 54-94 Caregivers: 58-87	Caregivers: F: 17 M: 10			White: 100%	
Tang, J., Ryburn, E., Doyle, C., & Wells, Y. (2010)							
Whitelatch, C. & Orsulic-Jeras, S. (2018)							

Note, *Key: Metro=metropolitan; Alzheimer's disease=AD; frontotemporal dementia=FTD; ADHC Adult Day Health Care

Table 3

Study Characteristics: Respite Care for People with Dementia

Study	Country	Design	General focus	Source of funding
Brataas, H.V., Bjugan, H., Wille, T., & Hellzen, O. (2010)	Norway	qualitative interview study in a narrative content design	How a day care program 1 day per week for 7 weeks by the PWD is experienced	Nord-Trønedelag University College and FOLK2
Gresham, M., Hefferman, M., & Brodaty, H. (2018)	Australia	Mixed methods (survey, interviews, observations) 5-day residential caregiver training with parallel respite programming for PWD	How caregiver psychological health, unmet needs and measures of burden could be improved with specific supports impacting the PWD challenges and potential institutionalization	Australian Government Department of Social Services (Aged Care Services Improvement and Healthy Ageing Grants Flexible Fund)
Hochgraeber, I., von Kutzleben, M., Bartholomeyczik, S., & Holle, B. (2017)	Germany	qualitative (guided interviews, group discussions)	How low-threshold support services for PWD are viewed from caregiver, PWD, and provider positions	

Table 3

Study Characteristics: Respite Care for People with Dementia (continued)

Study	**Country**	**Design**	**General focus**	**Source of funding**
Hochgraeber, I. and Riesner, C., & Schoppman, S. (2012)	Germany	qualitative (interviews, observation)	How do PWD experience social care groups	
Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. & Bond, J. (2011).	United Kingdom	qualitative (phone interviews, focus groups, face-to-face interviews, thematic analysis of transcripts), though the journal article homes in on service providers	How person-centered respite services for people with dementia is assessed and how its organizational culture impacts its dissemination	Commissioned by the National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) Programme and funded by the Department of Health.
Miranda-Castillo, C. Woods, B., & Orrell, M. (2013)	Chile	qualitative (professional interviews, statistical analysis)	How differences in the perceived needs of community dwelling PWD vary from caregiver, professional, and PWD perspectives	

Table 3

Study Characteristics: Respite Care for People with Dementia (continued)

Study	**Country**	**Design**	**General focus**	**Source of funding**
Moholt, J., Friborg, O., Blix, B.H., & Henriksen, N. (2018)	Norway	quantitative descriptive (cross-sectional)	How in-home and community respite care services are utilized by older PWD, and what predictors may exist of respite services usage	The Research Council of Norway
Morrisby, C., Joosten, A., & Ciccarelli, M. (2018)	Australia	qualitative (scoping review and thematic analysis)	How community services for PWD aging in place are meeting the needs of families, and how evidence can inform policy internationally	
Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015)	Australia	qualitative descriptive (literature review with levels of evidence)	How PWD and caregivers determined respite care usage and what contributed to its low rate	Trust Company

Table 3

Study Characteristics: Respite Care for People with Dementia (continued)

Study	**Country**	**Design**	**General focus**	**Source of funding**
Phillipson, L. & Jones, S.C. (2011)	Australia	qualitative (focus groups, face-to-face interviews)	How caregivers of PWD make decisions about residential respite care and how these details may improve models of care	
Silverstein, N.M., Wong, C.M., & Brueck, K.E. (2010)	United States	mixed-methods (surveys, in-person interviews)	How providers of adult day health care tend to the psycho-social needs of PWD and related disorders	Not externally funded. Small stipend from UMass Boston College of Public and Community Service, and Alzheimer's Association MA/NH Chapter

Table 3

Study Characteristics: Respite Care for People with Dementia (continued)

Study	**Country**	**Design**	**General focus**	**Source of funding**
Strandenaes, M.G., Lund, A. & Rokstad, A.M.M. (2018)	Norway	qualitative (individual interviews)	How do PWD view their experiences with adult day care	Research Council of Norway
Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D., & Challis, D.J. (2015)	United Kingdom	qualitative (focus groups)	How PWD and caregivers experience dementia care and community services	European Commission within the 7th framework programme
Tang, J., Ryburn, E., Doyle, C., & Wells, Y. (2010)	Australia	qualitative	How does respite care for PWD meet the needs of caregivers and what is the reason for its low usage	

Table 3

Study Characteristics: Respite Care for People with Dementia (continued)

Study	**Country**	**Design**	**General focus**	**Source of funding**
Whitelatch, C. & Orsulic-Jeras, S. (2018)	United States	qualitative	How to meet the evolving changes of PWD and caregivers when education, social supports, and health services are diverse	Alzheimer's Association

4.3 Results

Outcomes and themes of the individual studies are exhibited in Table 4 and consist of primary outcomes, secondary outcomes, themes and subthemes interpreted by each paper's authors.

The positive impact of respite care on the daily living and social interactions of people with dementia was a predominant focus of numerous included papers (Brataas, Bjugan, Wille, & Hellzen, 2010; Gresham, Hefferman, & Brodaty, 2018; Hochgraeber, von Kutzleben, Bartholomeyczik, & Holle, 2017; Hochgraeber and Riesner, & Schoppman, 2012; Strandenaes, Lund, & Rokstad, 2018.) Studies focused on unmet needs of caregivers and people with dementia, low respite usage, and variations in dementia services in the community (Miranda-Castillo, Woods, & Orrell, 2013; Moholt, Friborg, Blix, & Henriksen, 2018; Morrisby, Joosten, & Ciccarelli. 2018; Neville, Beattie, Fielding, & MacAndrew, 2015; Phillipson & Jones, 2011; Tang, Ryburn, Doyle, & Wells, 2010). They ascertained similarities in the needs of caregivers and people with dementia, as well as some commonalities of inflexible adult programming hours, limited communication of information, and fear of change in routine. Professionals in these studies valued early diagnosis, person-centered care, and the discretion (and funding) to adapt facilities, for example, to accommodate people with later stage dementia (Kirkley, Bamford, Poole, Arksey, Hughes, & Bond, 2011; Silverstein, Wong, & Brueck, 2010).

Table 4

Study Results: Respite Care for People with Dementia

Study	Primary Outcomes	Secondary Outcomes	Thematic Analysis
Brataas, H.V., Bjugan, H., Wille, T., & Hellzen, O. (2010).			1) 'Ambivalence shifts to interest' 2) 'Meaningful engagement engenders wellbeing' 3) 'Social fellowship promotes life contentment'
Gresham, M., Hefferman, M., & Brodaty, H. (2018).	Significant change in caregiver QOL, burden, and psychological distress did not occur	Increase in caregiver needs being met; PWD admission rate to permanent care at 12 months was 17.6% compared to 52.9%; Cognitive loss symptoms of PWD improved	
Hochgraeber, I., von Kutzleben, M., Bartholomeyczik, S., & Holle, B. (2017).			1) organization of low-threshold support services (LSS) 2) overall value of LSS

Table 4

Study Results: Respite Care for People with Dementia (continued)

Study	Primary Outcomes	Secondary Outcomes	Thematic Analysis
Hochgraeber, I. and Riesner, C., & Schoppman, S. (2012).			Main themes: familiar community and personal meaning. Sub-themes: working together, being needed, knowing one another, becoming one of us, drop-out group members, adapting, wrong title, personal appearance, family, and domestic service.
Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. & Bond, J. (2011).			Comprehension of person-centered care; value of staff; results-focused approach; views on service improvement; priorities of service
Miranda-Castillo, C. Woods, B., & Orrell, M. (2013).	Frequent unmet needs of both PWD and caregivers are psychological distress, daytime activities (that occupy PWD), and companionship.	When PWD and caregivers are both involved in in their care, self-esteem improves for PWD.	

Table 4

Study Results: Respite Care for People with Dementia (continued)

Study	**Primary Outcomes**	**Secondary Outcomes**	**Thematic Analysis**
Moholt, J., Friborg, O., Blix, B.H., & Henriksen, N. (2018).	Usage of home-based respite services increased with the age of PWD and caregiver, higher educational level, residence in urban areas, and if PWD lived alone or with people other than a spouse.	Family caregivers were more likely to integrate home-based respite services when they did not view caregiving negatively, their health and well-being was good, and they had been in a caregiving role for a significant amount of time.	
Morrisby, C., Joosten, A., & Ciccarelli, M. (2018).	Lack of available dementia service provisions; limitations to quality services; person-centered care; information and education; peer support		

Table 4

Study Results: Respite Care for People with Dementia (continued)

Study	**Primary Outcomes**	**Secondary Outcomes**	**Thematic Analysis**
Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015).	Predicting usage of respite care almost impossible due to diversity of diagnoses, services, research, socioeconomic statuses, government provisions, etc.	Respite may have greater potential when caregivers recognize it as beneficial to themselves and PWD	
Phillipson, L. & Jones, S.C. (2011).	Non-users expressed concerns about loss of control, routine being disrupted, and access and flexibility (often on past poor experiences)	Users of respite services either realized they had reached their stress point, or were preparing for long-term care	
Silverstein, N.M., Wong, C.M., & Brueck, K.E. (2010).	41% of ADHC sites provided specifically for PWD while 78% offered training to their staff on dementia. Early-onset dementia and late/end stage dementia services were most limited.	Some sites incorporated environmental design for later-stage PWD who may require more rest, ambulatory space, and nursing care	

Table 4

Study Results: Respite Care for People with Dementia (continued)

Study	**Primary Outcomes**	**Secondary Outcomes**	**Thematic Analysis**
Strandenaes, M.G., Lund, A. & Rokstad, A.M.M. (2018).	PWD were positive about day care, especially the routine it provided their days, the socialization, and that it was beneficial to home life	PWD noted that food, laughter, and company was more important than selecting certain activities.	
Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D., & Challis, D.J. (2015).	Timely diagnosis; flexible support for caregivers; training/quality of care for PWD; awareness of dementia and related issues; desire for one point of contact		

Table 4

Study Results: Respite Care for People with Dementia (continued)

Study	**Primary Outcomes**	**Secondary Outcomes**	**Thematic Analysis**
Tang, J., Ryburn, E., Doyle, C., & Wells, Y. (2010).	Respite services in Australia do not always offer providers available for PWD; caregivers are concerned about lack of staffing at residential respite; limited culturally and linguistically diverse employees and venues keep some caregivers away.	Increased psychological supports and interventions (art/music therapy, mediation) might alleviate stressors, as well as heighten socialization.	
Whitelatch, C. & Orsulic-Jeras, S. (2018).	Efforts to ensure evidence-based, person-centered information, education, and support services to PWD and their caregivers can help maintain consistency, family, and esteem.		

Note, QOL (quality of life); PWD (people/person with dementia)

4.4 Risk of bias

The MMAT asked two initial questions regarding each paper: is the research question under scrutiny clear, and does the data collected permit that question to be answered (Howe & Pluye, 2009). 13 of the 15 studies in this review answered those initial questions in the affirmative, or with one in the affirmative and one in the "can't tell" category. Following are the tables for the qualitative (Table 5), and mixed methods (Table 6) risk of bias questions from the MMAT applied to each study in this review.

Table 5

MMAT Qualitative Portion: Respite Care for People with Dementia

Study	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Brataas, H.V., Bjugan, H., Wille, T., & Hellzen, O. (2010)	Yes	Yes	Yes	Yes	Yes
Hochgraeber, I., von Kutzleben, M., Bartholomeyczik, S., & Holle, B. (2017)	Yes	Yes	Yes	Yes	Yes
Hochgraeber, I. and Riesner, C., & Schoppman, S. (2012)	Yes	Yes	Yes	Yes	Yes

Table 5

MMAT Qualitative Portion: Respite Care for People with Dementia (continued)

Study	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. & Bond, J. (2011).	Yes	Yes	Yes	Yes	Yes
Miranda-Castillo, C. Woods, B., & Orrell, M. (2013)	Yes	Yes	Yes	Yes	Yes
Morrisby, C., Joosten, A., & Ciccarelli, M. (2018)	Yes	Yes	Yes	Yes	Yes
Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015)	Yes	Yes	Yes	Yes	Can't tell
Phillipson, L. & Jones, S.C. (2011)	Yes	Yes	Yes	Yes	Yes
Strandenaes, M.G., Lund, A. & Rokstad, A.M.M. (2018)	Yes	Yes	Yes	Yes	Yes

Table 5

MMAT Qualitative Portion: Respite Care for People with Dementia (continued)

Study	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D., & Challis, D.J. (2015)	Yes	Yes	Yes	Yes	Can't tell

Note, Pluye, P. & Hong, Q.N. (2009). Mixed methods appraisal tool. Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage

Table 6

MMAT Mixed Methods: Respite Care for People with Dementia

Study	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Gresham, M., Hefferman, M., & Brodaty, H. (2018)	Yes	Yes	Can't tell	Can't tell	Yes
Silverstein, N.M., Wong, C.M., & Brueck, K.E. (2010)	Yes	Yes	Can't tell	Can't tell	Yes

Note, Pluye, P. & Hong, Q.N. (2009). Mixed methods appraisal tool. Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage

CHAPTER 5: DISCUSSION

This systematic review examined the experiences of people with dementia aging in place and their participation with respite care. Secondary objectives included investigating the models of respite care that offered the most beneficial impact to people with dementia and their caregivers, essentials to boost respite care usage, and suggesting policy implications.

5.1 Summary of evidence

Experience of respite care by people with dementia. 204 people with dementia (of the 2,293 people with dementia total in this review) were interviewed, participated in group discussions, and/or focus groups and communicated the portions of their respite that they found pleasurable, useful, or lacking (Brataas et al., 2010; Gresham et al., 2018; Hochgraeber et al., 2017). The plurality of the evidence available from the 15 included studies observed that people with dementia enjoyed respite care once adjustments about initial hesitation about attendance were considered (Brataas et al., 2010; Hochgraeber et al., 2017; Hochgraeber et al., 2012). Brataas et al. (2010) thematic analysis identifies three themes of people with dementia's psychosocial course to and during respite care:

- "Ambivalence shifts to interest
- Meaningful engagement engenders wellbeing
- Social fellowship promotes life contentment" (pp 2842-2844).

These not only connote the pathways that interviewees encountered, but that similarly mirror Hochgraeber et al. (2012) main themes of "familiar community" and "personal meaning," as well as sub-themes which included "becoming one of us," "being needed," and "knowing each other" (p 758). These themes, particularly *being needed* and *meaningful engagement* address components of Kitwood's theory of personhood, especially inclusion and engagement, which may assuage feelings of social isolation, and declining ability (Fazio et al., 2018; Kitwood, 1997a; Strandenaes, Lund, & Rokstad, 2018).

Participants also emphasized food and meal sharing as a favored, communal activity. Community meals became a focal point for almost every person with dementia that was questioned about their preferred part of the day. As Strandeanaes et al. (2018), and both Hochgraeber (2012, 2017) led studies reinforced, mealtime represents more than sustenance for people with dementia in respite care: meals are part of establishing a familiar, predictable routine outside of the home that not only could be replicated, but contributes social engagement, nutrition, and community. Encouraging schedules and familiarity, especially for people with mild and moderate dementia, with equally pleasurable activities, such as eating, laughing and conversing, galvanizes social engagement and peer support (Strandenaes et al., 2018).

Whether via adult day care, didactic programming for caregiver training and respite for people with dementia, or adult day services, Brataas et al. (2010), Gresham et al. (2018), and Strandenaes et al. (2018) studies aimed to evaluate the respite care experiences of people with dementia. Each of the three investigations stated that respite was essential to meaningful social engagement, and integration of person-centered care (Brataas et al., 2010; Brooker & Latham, 2016; Gresham et al., 2018; Strandenaes et al., 2018). Psychosocial impacts of respite care to people with dementia included diminished social isolation, increased engagement of occupation and purpose, feelings of contentment, preservation of routine, positive impact on home life, and heightened sense of autonomy (Brataas et al., 2010; Gresham et al., 2018; Neville et al., 2015; Strandenaes et al., 2018; Whitelach & Orsulic-Jeras, 2018).

Regardless of the official group construct (social care group or low threshold support services in Germany, day care services in Norway, or focus groups in the United Kingdom), the continuity of participants' trajectories across national and policy borders speaks to commonalities of experience. The pleasures of communal meals, walks, and companionship that are prevalent across these studies, are salubrious to people with dementia aging in place.

Respite user needs and concerns. Understanding the diverse needs of a varied dementia populace, as well as how they and their families experience respite care, furnishes narratives which may further impact policy decisions, dementia strategies, and community resources, especially as underutilized social services are often eradicated. While this review incorporates studies that emphasize the contemporary experiences of people with dementia in respite care, the opinions of their caregivers, and varied dementia and health care providers, also proffer practicable details. For example, Miranda-Castillo et al. (2013) study administered The Camberwell Assessment of NEED for the Elderly (CANE) to 125 dyadic pairs (person with dementia and family caregiver), and 27 professionals, to discern each person's perspective of the level of met and unmet needs for the person with dementia via community health provisions. Caregivers, people with dementia, and professionals all identified the highest (or their highest) unmet needs in the *exact same areas*: daytime activities, psychological distress, and company for the PWD (Miranda-Castillo et al., 2013; Morrisby et al., 2018).

Central contact person, flexibility of services, worries about cognitive losses, and continuity of care were prominent points of lack of, limited, or discontinued respite care usage by people with dementia and their caregivers (Phillipson & Jones, 2011; Tang et al., 2011). For example, respite care services may list availability to accommodate people with dementia, but several caregivers expressed that staff contacted them within two or three hours after their loved one was in respite to discuss his or her inability to "settle," or how they were "wandering" (Phillipson & Jones, 2011; Sutcliffe et al., 2015). Some respite services (particularly due to varieties of respite options across insurance, state, and national borders) may not have the training and staff to facilitate varied levels of dementia diagnoses. They may offer a medical model of care where dementia is viewed through the lens of disease, with wandering judged an "ill behavior" (Kitwood, 1997a). But additional health organizations are entering the person-centered care arena, as evidenced in Silverstein et al. (2010) study of respite care (adult day health care) in Massachusetts. Some locations have begun to incorporate environmental design in their facilities to ameliorate later-stage symptoms of dementia, as well as provide more ambulatory space, nursing care, and rest (Silverstein et al., 2010).

Moholt et al. (2018) identified several determinants that increased in-home respite usage in Norway, including the caregiver's full-time employment, advanced age, higher educational level, and non-spousal relationship to the person with dementia, while higher age, urban locale and living alone were factors for people with dementia. Community respite care heightened if the caregiver was female, caregiving provisions were longer-term, and the location was urban (Moholt et al. 2018). Respite care was minimally utilized by the Sami population (indigenous people of Northern Norway, Russia, Finland,

and Sweden with an estimated population of 80,000, and varied languages and dialects), 7% of the caregivers and 10.2% of the people with dementia in Moholt et al. (2018) study (UNRIC, 2019). Tang et al. (2011) also addressed barriers to respite care for culturally diverse populations in Australia. Potential barriers to minority or indigenous usage of respite services and community supports for older adults include language proficiency, rural locations, socioeconomic status, and cultural norms (Moholt et al., 2018; Tang et al., 2011).

5.2 Limitations

There are limitations to this study including the influence of the author on review criteria, inclusion, and exclusion decisions. Reporting bias, specifically language bias, and citation bias (due to methods of handsearching) also likely occurred.

The 15 studies in this review incorporated an international perspective with authorship from the United States, Europe, Australia, and South America. Although male and female perspectives were included, they did not appear to encompass varied gender or sexual identities other than heteronormative. Just three studies mentioned the racial and ethnic makeup of their participants; two studies noted educational attainment; and four studies reported if participants lived in rural, suburban or urban areas.

Conclusion

People with dementia aging in place often benefit from respite care services available in their communities, especially in maintenance of purposeful activity, social engagement, and lessened feelings of psychological distress (Brataas et al., 2010; Miranda-Castillo et al., 2013; Morrisby et al., 2018; Whitelach & Orsulic-Jeras, 2018). Person- and family-centered care provisions and dementia strategies inclusive and cognizant of the lived experiences of people with dementia, and their caregivers, engenders a less ableist approach that invites holistic wraparound supports. Although great care and time has been invested to develop dementia strategies across the world inclusive of ancillary services (such as respite care) a paucity of research of the very participants many of these strategies are trying to serve speaks to issues of access, and autonomy. Some of the continued invisibility of the voices of people with dementia endures through their limited involvement in research, caregiver participation on their behalf, and studies that recognize people with dementia as “silent participants” (Moholt et al., 2018; Sutcliffe et al., 2015). Kitwood’s foundational positive-person work for people with dementia can only be extended as far as related aging education, research, and policies reach. Further mixed-method studies, that include comparison groups if not randomized control studies, for example, would benefit the continued development of, and amendments to, national and statewide dementia strategies.

Additionally, health care policies that incorporate aging, diverse sexual and gender identities, racial and ethnic diversity, varied socioeconomic strata, myriad educational backgrounds, and dementia-friendly approaches are essential to providing services to the current and burgeoning dementia community. Dementia-Capable North Carolina, with its emphasis on access to medical and community supports via public transportation in all 100 North Carolina counties provides an example and a potential starting point for others (North Carolina Institute of Medicine, 2016).

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APPENDIX: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	

APPENDIX: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	

APPENDIX: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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