

Measures of religion and spirituality in dementia: An integrative review

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Abstract

Introduction: Literature on the association of religion and spirituality (R/S) and health is growing. However, it is unclear how R/S affects outcomes and is assessed in persons with dementia (PWDs). In this integrative review, we evaluate published R/S measures and synthesize R/S findings for PWDs.

Methods: We searched five databases (ATLA Religion, CINAHL, PsychInfo, PubMed, SocIndex) and identified 14 of 1043 studies for review. We assess the studies' information, quality, measures, and results.

Results: We identified 17 measures for R/S: six were adapted for use with PWDs and only two were validated for PWDs; most studies reported only measures' reliability, with Cronbach's alpha. The studies' findings support significant positive associations between R/S and cognitive function and negative associations between R/S and depression and behavioral expressions.

Discussion: The two validated scales indicated acceptable validity with overall good reliability. Nevertheless, diverse samples and rigorous study designs are needed to improve R/S measures and to examine associations over time for PWDs.

KEY WORDS

Alzheimer's disease, behavioral expressions, cognitive function, coping, depression, faith, neuropsychiatric symptoms, scales, quality of life

Highlights

- Few scales for measuring religion and spirituality (R/S) have been validated in persons with dementia (PWD); additional testing is needed.
- Most R/S measures only reported scale reliability with Cronbach's alpha.
- Studies supported positive associations between R/S and health yet few studies exist conducted.
- Only one spiritual intervention, spiritual reminiscence, was found for PWD.
- More rigorous R/S studies are needed to examine health outcomes in dementia.

RESEARCH IN CONTEXT

- **Systematic Review:** The authors searched five databases for studies using measures for assessing religion and spirituality (R/S) in persons with dementia (PWDs) and assessed study quality and health associations using established tools. Psychometric properties, measures, and findings were collated and reported narratively.
- **Interpretation:** Few high-quality studies were identified due to study design limitations. Some R/S measures were validated in dementia but most were from the general population with limited adaptation, reporting reliability with Cronbach's alpha. Findings indicate positive associations between R/S and cognitive and mental health and in use for coping with disease in this population.
- **Future Directions:** Study quality issues can be addressed and measures validated in future studies using rigorous methods. Consistency in reporting R/S dimensions, testing spiritual interventions, and developing more spiritual tools are needed.

1 | INTRODUCTION

Dementia is an increasingly prevalent terminal illness that cannot be prevented or cured. Estimated to reach 152 million people by 2050, it is a public health priority with huge financial costs—the United States spent >\$800 billion on dementia care globally in 2015, and that number is expected to rise.¹ Dementia leaves many people unable to care for themselves, which affects not only older adults with dementia, but also dementia caregivers. Persons newly diagnosed with dementia may experience an array of emotional responses such as shock, distress, fear, anxiety, depression, anger, and despair.²

When individuals face the uncertainties of advanced, terminal illness, as they do in the case of dementia, they may turn to religion or spirituality to cope.³ Although definitions vary, spirituality can be broadly defined as an individual's focus on a search for meaning, purpose, and connectedness with respect to the self, the moment, others, nature, and God,⁴ whereas religion represents systematic ways in which people conduct their search, which involve beliefs, rituals, and practices related to the sacred, often stemming from an established tradition.⁵ When their religious or spiritual needs are not met, patients are at greater risk for spiritual distress, which has been associated with poorer patient outcomes: depression,⁶ diminished quality of life (QOL),⁷ increased anxiety and greater physical pain,⁸ and decreased emotional well-being.⁹ However, research on the topic of religion and spirituality is limited in reference to persons living with dementia.

Because of their diminished cognitive capacity, persons with dementia (PWDs) often rely on others to support their identity (personhood) and spiritual well-being.¹⁰ Managing distress in this population is important; however, findings indicate an absence (or minimal presence)

of spiritual care in clinical practice guidelines for dementia care¹¹ and a lack of religious and spiritual support at end of life,^{12,13} such that PWDs are at risk of not having their religious and spiritual needs met.¹⁴ There is a need for further study of religion and spirituality (R/S) among PWDs, beginning with the identification of tools to measure R/S that have been validated specifically for this population. Of the literature reviews touching on R/S measures, none have assessed these measures with respect to dementia.

This is an integrative review to identify and critically examine the literature on measures of R/S in PWDs by answering the following questions: (1) "How is R/S measured in PWDs?" (2) "What are the psychometric properties of R/S measures used in dementia?" (3) and "What do these measures report about R/S in PWDs?" Although religion and spirituality are distinguishable, scholars often use these concepts interchangeably. Formal religiosity is included under religion (i.e., frequency of church attendance), and it is assumed to represent an individual's level of religious commitment.⁵ Spirituality, on the other hand, might describe individuals who consider themselves spiritual but not religious, with beliefs and values apart from those of faith-based institutions or organizations.¹⁵ However, given the overlapping nature of religion and spirituality in research, we consider these concepts together as R/S. We also evaluate R/S measures according to (1) the stage of dementia (mild, moderate, and severe) of PWDs in the studies that we review; (2) key R/S categories—the centrality of R/S including religiosity and spirituality, R/S resources, R/S needs and preferences, R/S coping, and spiritual well-being; and (3) R/S findings reported in the reviewed studies.

This review is guided by the vulnerability stress model of religiosity and spirituality (VSM-RS)¹⁵ as a heuristic framework for illustrating the pathway from R/S to health (see Figure 1). The VSM-RS displays multiple dimensions of R/S, which inform the five key R/S constructs that we identified and used in this review. The VSM-RS^{15–17} framework is based on two established theories: the psychological diathesis-stress model^{18,19} and the transactional theory of stress and coping.²⁰ The diathesis-stress model posits that psychological disorders are the result of a vulnerability that is predispositional (the diathesis can be genetic, situational, etc.) and stress caused by life experiences (e.g., environmental stressors). If the combination of a person's vulnerability and stress exceeds a threshold, the person will develop a disorder. Lazarus and Folkman's²⁰ transactional theory of stress and coping posits that coping involves thoughts and actions with which individuals attempt to manage internal and external threats/stressors perceived to exceed their personal resources. The VSM-RS framework posits that health is the result of an individual's reactions to diverse stressors, including advanced illness, with the result depending on the interaction of several factors such as predispositions, health resources, and coping behaviors.¹⁵ Within this framework, an individual who identifies as religious or spiritual uses R/S resources to support the individual's beliefs and practices; people with such resources are more likely to have their spiritual needs fulfilled and may use religious coping behaviors and strategies to overcome a stressor or in response to spiritual needs. Positive religious coping can result in well-being; however, if the individual does not have religious resources and the

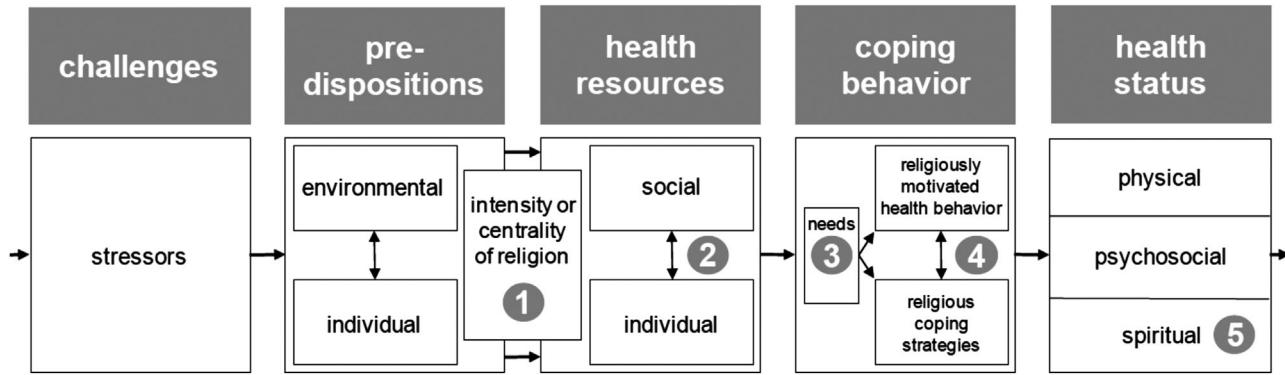


FIGURE 1 The vulnerability-stress model incorporating religiosity/spirituality (VSM-RS).¹⁵

individual's spiritual needs are not met, distress and decreased well-being may result.

The VSM-RS framework includes 5 R/S constructs:

- Centrality of R/S: The importance of religiosity or spirituality in one's life, devoted participation in organizational worship or practice, or disposition representing a resource, which includes general religiosity, spirituality, religious and spiritual beliefs, and religiousness.¹⁵ R/S centrality represents a predisposition and/or a health resource.¹⁵
- R/S resources: How individuals use their faith, strong beliefs, and deeds to deal with stressors or difficult life circumstances. These resources include individual factors such as a close relationship with the sacred and social support from a congregation or religious community.
- Spiritual needs: Religious or spiritual expectations an individual has to find meaning, purpose, and value in life.²¹
- Religious coping: Religious or spiritual ways of understanding and viewing stressors or difficult life circumstances²² and how individuals deal with crises to overcome them, which may include behaviors and strategies.
- Spiritual well-being (QOL): One's sense of well-being based on satisfaction or dissatisfaction with a particular aspect of life that one has identified as important,²³ which may include aspects of faith, peace, and meaning.²⁴

2 | METHODS

2.1 | Study design

This is an integrative review,²⁵ including studies with diverse methodologies owing to variability in study purposes, designs (qualitative and quantitative), sample characteristics, and R/S measures. This approach allows a thorough review of R/S measures in the relatively small number of studies available (i.e., a total of 14 studies). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines²⁶ inform our analysis and report (Table S1 in supporting information).

2.2 | Search strategy

The medical and psychological literature was searched for empirical studies reporting assessment of R/S in PWDs. The databases searched were ATLA Religion, CINAHL, PsychInfo, PubMed, and SocIndex (Table S2 in supporting information). Search strategies combined common terminology of dementia, religion and spirituality, and assessment. The search period was limited to the last 22 years (2000–2022), to minimize inclusion of the narrower interpretation of spirituality²⁷ more common in older publications.

2.3 | Inclusion/exclusion criteria

After the initial search, articles were exported into Endnote X9, where duplicates were removed. The remaining articles were exported into Rayyan software for screening. Titles and abstracts were vetted for inclusion and exclusion criteria and independently evaluated by two of this study's authors. When an article's title and abstract were insufficient to make a decision, the article's full text was retrieved and reviewed. Only literature written in English, peer reviewed, focused on assessment (e.g., tools or measures) of religion or spirituality, and focused on persons with dementia were included. Articles were excluded if (1) they were not original empirical research, (2) they were literature reviews or case studies, (3) participants were nonadults (i.e., younger than 18 years of age), (4) participants had psychiatric disorders, (5) the concept of spirituality was not reported discreetly (i.e., not embedded in other psychosocial terms), or (6) a measure was limited to a single item for collecting religion or spirituality in participants. Discrepancies regarding the inclusion of articles were discussed and resolved among the authors.

2.4 | Data extraction

Two of the authors (KCB, GA) independently reviewed full-text relevant retrieved articles and extracted key information into a Microsoft Word file for organization. To guide collection of the studies' characteristics, predetermined categories were created to design a standardized

data extraction form. These included authors and year of publication, purpose of the study, study setting (e.g., community, long-term care, assisted living, etc.), sample description (e.g., participants' N and age range, and whether they were PWDs, caregivers, or health-care professionals), stage of dementia (e.g., early, middle, or late stage, and how stage was measured); study design (e.g., qualitative, quantitative, etc.), constructs measured (e.g., distress, spiritual well-being, spiritual needs, etc.) along with measure used, measure validation information (e.g., psychometrics), key category of religion and spirituality according to the VSM-RS, and major relevant findings. Key R/S categories were selected and organized based on the VSM-RS¹⁵ R/S dimensions identified through empirical research measures: centrality of R/S, R/S resources, R/S coping, and spiritual well-being. The first author organized the data into categories, and co-authors examined and assisted in resolving any discrepancies among decisions.

2.5 | Methodological quality

Using three quality appraisal tools according to study design, the first author independently evaluated the methodological quality of all included studies while the second author assessed four randomly selected studies to ensure reliability in scoring. The Critical Appraisal Skills Programme (CASP) was used to evaluate qualitative and quantitative studies.²⁸ CASP offers different critical appraisal tools for different types of studies; for this review, we used the Cohort Study Checklist, Qualitative Checklist, Randomized Controlled Trial Checklist, and Case Control Study Checklist, with the checklists' number of questions ranging from 10 to 12. Criteria focus on research aim, methodology, research design, recruitment, data collection, bias, ethical considerations, data analysis, report of findings, and research value. The National Institute of Health's (NIH's) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies²⁹ was used for studies with cross-sectional designs, with 14 questions that provide the research aim, population, participation rate, participant recruitment, sample size, variable measurement, time frame, bias, and loss to follow-up. The Mixed Methods Appraisal Tool (MMAT) was used to evaluate mixed-methods studies;³⁰ the tool's five screening questions provide the study's design rationale, integration of components, interpretation of outcomes, consistencies between mixed methods, and design adherence to traditions of the methods.

We gave each study a percentage score for each quality appraisal tool (NIH, CASP, MMAT; see Table 1). This percentage was based on each study's fulfillment of the tools' criteria, with studies rated as good, fair, or poor. If ratings differed, the authors resolved any discrepancies through discussion. Percentages ranged from good, when a study met at least 80% of the tool's criteria, to fair, when a study met from 60% to 79% of the tool's criteria, to poor if the study met less than 60% of the criteria. Studies were not excluded on the basis of quality, owing to the limited number of studies identified after exclusion/inclusion criteria were applied. The three quality assessment tools helped to quantify potential bias in studies, identifying threats to internal and external validity.

3 | SUMMARY OF FINDINGS

The electronic database searches initially yielded 1395 publications (ATLA Religion, 5; CINAHL, 336; PsychInfo, 523; PubMed, 353; SocIndex, 178), after which 352 duplicates were removed (see Figure 2). After applying inclusion and exclusion criteria, 178 articles were found relevant and a subsequent hand search identified an additional three articles. After full-text screening, the final number of acceptable articles eligible for this integrative review was 14. The five databases were searched again on May 20, 2022, before publication using original search terms; no new articles fitting inclusion and exclusion criteria were found from publications between 2020 and 2022.

Of the 14 studies, most were quantitative (N = 12); two used mixed methods. One was an intervention study.³¹ The studies' locations varied greatly, with the most conducted in Europe (n = 7); others were conducted in the United States (n = 3), Taiwan (n = 1), Canada (n = 1), South Korea (n = 1), and Brazil (n = 1). Stage of cognitive impairment and dementia varied as well, with some studies including more than one stage (i.e., mild cognitive impairment [MCI] and mild dementia) and a majority reporting mild dementia (n = 8). Primary participants identified in the studies were PWDs (n = 14 studies), followed by family members/caregivers of PWDs (n = 3 studies). The studies' mean sample size was 100, with the majority reporting a higher percentage of female participants than male participants. The data extracted from the included studies were analyzed and organized into key categories from the VSM-RS:¹⁵ centrality of R/S, R/S resources, R/S coping, and spiritual well-being.

3.1 | Thematic domains

3.1.1 | Centrality of religion/spirituality

Centrality of R/S, representing religiosity, spirituality, and religiousness, was the most studied R/S dimension, in seven studies^{32–38} (see Table 1). More than one type of R/S centrality was examined in two of these studies.^{35,38} Of the four R/S centrality studies examining religiosity,^{35–38} two included participants with moderate dementia,^{35,36} four included those with mild dementia,^{33–36} and three studies did not specify dementia stage^{32,37,38} as some studies included one or more groups. Three of these studies specified participants with Alzheimer's disease (AD).^{35,37,38} Of the 4 R/S centrality studies that examined spirituality,^{32–35} all specified AD participants and three included participants with mild dementia,^{33–35} with Coin et al.³⁵ evaluating mild and moderate dementia; Jolley et al.³² did not specify dementia stage.

We identified 17 R/S measures in the 14 reviewed studies. The four studies that measured religiosity^{35–38} used three different instruments: a 3-item author-created scale,³⁶ the Duke University Religion Index (DUREL),³⁹ and the Behavioral Religiosity Scale (BRS).^{40,41} Nagpal et al.³⁶ developed one item for each of the organizational, nonorganizational, and personal aspects of religiosity and measured total religiosity based on frequency of religious attendance, frequency

TABLE 1 Key R/S and health outcome findings from final selection

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
Agli et al., 2017	To examine the psychometric properties of the French translation of the FACIT-Sp and associations between spirituality, QOL, and depression level in the cognitively impaired	France Nursing home residents N = 63 [Dementia stage unspecified] Control MMSE 24 and above, cognitively impaired MMSE 10-23 [no MMSE mean (SD) reported] Mean age (SD): 86.57 (7.07) [mean age (SD) not reported for each group] 69.84% female and 30.16% male	Cross-sectional, scale validation Questionnaire: In person 33% ^a (poor) ^d	Spiritual well-being: spirituality Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp12): French version	Meaning and peace were positively correlated with QOL and negatively correlated with depression Higher meaning scores had greater QOL ($r = 0.42, P < .01$) and less depression ($r = -0.61, P < .01$) Higher peace scores had greater QOL ($r = 0.50, P < .01$) and less depression ($r = -0.68, P < .01$)
Agli et al., 2018	To compare spiritual well-being between PWDs and non-PWDs, and to examine the relationship between spirituality and QOL and depression	France Nursing home residents N = 61 [Dementia stage unspecified; no MMSE range reported]; MMSE mean (SD): controls 27.23(1.81), dementia 19.48(4.77) Mean age (SD): controls 85.77 (7.50), dementia 88.65 (5.03) 77.05% female and 22.95% male	Cross-sectional Questionnaire: In person 55% ^a (poor) ^d	Spiritual well-being: spirituality/FACIT-Sp12 French version with 3 subscales (see above)	Spirituality or QOL was not significantly different between PWDs and healthy controls ($Z = -0.69, P = .488; Z = 0.33, P = .742$) PWDs had significantly different, lower self-esteem ($Z = -2.15, P < 0.031$) compared to healthy controls Meaning and overall spirituality were positively correlated with QOL ($r = 0.50, P < .05; r = 0.37, P < .05$) and negatively correlated with depression ($r = -0.36, P < 0.05$) in PWDs and also in healthy controls ($r = -0.64, P < .05; r = -0.70, P < .05$) Peace was positively correlated with sense of aesthetics ($r = 0.50$), self-esteem ($r = 0.53$), and positive emotions/humor ($r = 0.59$) in PWDs as well as healthy controls and positively correlated with QOL in healthy controls

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
Coin et al., 2010	To examine the relationships between religiosity, cognitive impairment, behavioral disorders, and caregiver stress	Italy Outpatients of AD assessment unit of geriatric clinic N = 64 Mild and moderate AD MMSE 15–24; MMSE mean (SD): High religiosity (HR) group 20.7(3.6), low religiosity (LR) group 20.56 (3.3) [no MMSE mean (SD) reported for control, MCI, mild groups] Mean age (SD): females 77.8 (6.2) and males 73.9 (4.8) [no mean (SD) reported for control, MCI, mild groups] Related caregivers also included (no demographics reported) 75% female and 25% male	12-month longitudinal study: measured at baseline and again at 12 months Questionnaire: in person 67% ^b (fair) ^d	Centrality of R/S: Religiosity & Spirituality Behavioral Religiosity Scale (BRS) for frequency of participation in religious activities of religious service attendance, praying, reading religious materials, and watching/listening to religious programs Divided into LR group and HR group based on BRS score Francis Short Scale (FSS)—short form of Francis Scale of Attitude toward Christianity for a person's internal attitude toward Christianity, reflecting long-term spirituality	LR was associated with significantly worse cognitive impairment conceptualized as 3-point decrease in MMSE score and behavioral expressions, whereas HR and spirituality were associated with slower cognitive decline and slower behavioral decline with significant reduction in caregiver burden BRS and FSS scores were significantly correlated with variations at 1-year follow-up in cognition ($r = 0.50$), behavioral expressions ($r = -0.51$), caregiver distress ($r = -0.55$), and caregiver burden ($r = -0.62$) Stress was higher among LR PWD caregivers
Despoina et al., 2018	To compare differences in religiosity among controls, those with MCI, and those with mild dementia	Greece AD adult day care center attendees N = 404 Control MMSE > 28; MCI MMSE 24–28, mild dementia MMSE < 24; MMSE mean (SD): control 29.1 (0.78), MCI 26.9 (1.80), mild dementia 22.3 (3.65) Mean age (SD): Control 68.11 (6.23), MCI 71.84 (7.11), mild dementia 74.39 (6.46) 71.8% female and 28.2% male	Cross-sectional Questionnaire: completed by patients or with assistance 55% ^a (poor) ^d	R/S Resources: Religiosity Systems of Belief Inventory (SBI-15R) Greek version, which has religious beliefs and practices and religious social support subscales.	Those with MCI ($M = 35.48, SD = 9.67$) demonstrated significantly higher levels of religiosity as R/S beliefs, practices, and support compared to the healthy control group ($M = 31.73, SD = 4.11, P < 0.002$); persons with mild dementia ($M = 35.13, SD = 9.09$) had increased religiosity scores versus control group ($M = 31.73, SD = 4.11, P < 0.010$) Total religiosity levels ($r = -0.221, P < .023$) and religious beliefs and practices ($r = -.260, P < .007$) were associated with lower depressive symptomatology in mild dementia group.

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
dos Santos et al., 2018	To examine the relationship between spirituality and self-esteem, life satisfaction, affect, hope, optimism, and perceived support networks between MCI, mild and moderate dementia, and healthy controls	Brazil Dementia clinic outpatients N = 128 CDR for severity: score of 0.5 = MCI, 1 = mild, 2 = moderate [no range or mean (SD) reported] Mean age (SD): Control 72.95 (7.63), MCI 73.27 (8.78), mild dementia 70.36 (7.39), moderate dementia 74.45 (7.67) 77% female and 23% male	Cross-sectional Questionnaire: unknown 55% ^a (poor) ^d	Spiritual Well-Being: spirituality (SSRS) Brazilian Portuguese Adaptation with three factors: peace, meaning, and faith for importance of spiritual domain and how individuals apply it in daily life	MCI and mild dementia groups had lower positive psychology constructs (social support, self-esteem, life satisfaction, positive affect, optimism, and hope scores), higher negative affect scores, and lower spiritual well-being ($M = 28; M = 31.28$) compared to healthy control ($M = 39.06; P < .001$) and moderate dementia groups ($M = 35.5$) Spiritual well-being and positive psychology constructs did not differ between moderate dementia ($M = 3.5.5$) and healthy control ($M = 39.06; P < .05$) group
Jolley et al., 2010	To examine the relationship between spirituality and dementia To examine any difference in spirituality profiles between PWDs and caregivers	UK Memory clinic outpatients N = 62 [Dementia stage unspecified] AD (75%); MMSE 12 and above; MMSE mean (SD): 24 (no SD reported) [No mean age (SD) reported for PWDs or caregivers] PWDs: 90% female and 10% male; Caregivers: 3% female and 97% male	Cross-sectional Questionnaire: unknown 30% ^a (poor) ^d	Centrality of R/S: spirituality (Royal Free Interview for Religious and Spiritual Beliefs for religious and spiritual beliefs)	No significant difference between religious and spiritual beliefs of PWDs and caregivers ($U = 240, P = .819$, two-tailed) Both PWDs and caregivers ranked presence and strength of belief and coping among most important components of spirituality
Jung et al., 2019	To examine the relationship between religious activity, intrinsic religiosity, and cognitive functions	South Korea Psychiatric clinic outpatients N = 325 [Dementia stage unspecified] AD GDS 5 or below; GDS mean (SD) = 4.01 (0.77) Mean age (SD) = 79.15 (6.47) 72.3% female and 27.7% male	Cross-sectional Questionnaire: unknown 63% ^a (fair) ^d	Centrality of R/S: religiosity (DUREL) Korean version for religiosity with three subscales: organizational religious activity (ORA) for frequency of religious attendance at meetings/activities, nonorganizational religious activity (NORA) for frequency of private religious activities, and intrinsic religiosity (IR) for subjective, importance of religious belief	Religiosity was positively associated with cognitive function, specifically: ORA was positively associated with memory ($r = 0.144, P = .010$), language ($r = 0.149, P = .007$), and constructional ability ($0 = 0.191, P = .001$) NORA and IR were positively associated with memory ($r = 0.115, P = .040; r = 0.140, P = 0.12$) and constructional ability ($r = 0.207, P = .000; r = 0.136, P = .015$)

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
Katsuno 2003	To describe spiritual experiences of PWDs and to examine the relationship between personal spirituality and QOL	United States Dementia daycare center and assisted living center residents N = 23 Probable & possible mild AD (78%); MMSE 18–28; MMSE mean (SD) = 20.8 (2.8) Mean age (SD) = 79 (6.2) 78% female and 22% male	Cross-sectional Mixed methods Semi-structured interview and questionnaire: in person 71% ^c (fair) ^d	R/S Resources; R/S resources SBI-15R adapted for AD, with religious beliefs and spiritual practices and religious social activity subscales <u>Spiritual Well-being: spirituality</u> Quality of Life Index (QOL) using psychological/spiritual subscale for satisfaction and importance of spirituality in one's life as perceived QOL	Spirituality as spiritual well-being was positively associated with total QOL (N = 21, r = 0.44, P < 0.05); total QOL was positively associated with beliefs and practices subscale (N = 21, r = 0.51, P < 0.05) but not social support (N = 21, r = 0.18, P = .42). Beliefs and practices were positively associated with health/functioning ($r = 0.48, P < 0.05$) and psychological/spiritual QOL ($r = 0.52, P < 0.05$). 83% of PWDs reported faith in God as very important One overall theme emerged from qualitative data, Faith in God, with six categories: beliefs, support from God, sense of meaning/purpose in life, private practice, public practice, changes due to dementia
Kaufman et al., 2007	To examine the relationship between spirituality, religiosity and examine effects of QOL and cognitive decline	Canada Neurology clinic outpatients N = 70 [No dementia stage specified] Probable AD MMSE > 10; MMSE mean (SD) = 23.66 (3.86) Mean age (SD) = 78.43 (8.64) 69% female and 31% male	Longitudinal study using retrospective and prospective data: mean follow-up time = 2.1 years and mean longitudinal follow-up time = 3.14 years Chart review and questionnaire: in-person 67% ^b (fair) ^d	<u>Centrality of R/S: Religiosity</u> DUREL for religiosity with three subscales: ORA for frequency of religious attendance at meetings/activities, NORA for frequency of private religious activities, and IR for subjective, importance of religious belief <u>Centrality of R/S: Religiosity and Spirituality</u> NIH/Fetzer Brief	Higher levels of spirituality and NORAs were associated with slower cognitive decline ($r = -0.315, P < 0.05; r = -0.374, P < 0.005$) and accounted for 17% of total variance [$F(11, 58) = 2.24, P < .05$]. Spirituality was not significantly associated with QOL ($r = 0.22, P < 0.09$) and QOL was not associated with cognitive decline ORA was not associated with rate of cognitive decline Older AD participants' religiosity and ORA were lower than in younger AD participants ($r = -0.26, P < 0.05; r = -0.20, P < 0.10$)

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
Lima et al., 2020	To examine the relationship between sociodemographic and psychological characteristics including spirituality, coping, mental health, and QOL	Portugal Patients from hospital neurology departments N = 158 Mild AD, MMSE ≤23; MoCA ≤26; MMSE mean (DP) = 19.69 (4.88); MoCA mean (DP) = 11.42 (4.85) Mean age (SD) = 75.94 (7.25) 67.1% female and 32.9% male	Cross-sectional Questionnaire: unknown 54% ^a (poor) ^d	Centrality of R/S: spirituality The Spiritual and Religious Attitudes in Dealing with Illness (SpREUK) Portuguese version with three subscales (Support, Trust, Reflection) and an overall score for spiritual attitudes on how individuals deal with chronic illness	Spirituality was negatively associated with QOL ($r = -0.234$, $P < .001$)
McGee et al., 2013	To examine the relationship between religious coping styles and resources and mental health outcomes	United States Memory centers and retirement community N = 28 Mild AD, MMSE 13–30; MMSE mean (SD): 24.33 (4.04) Mean age (SD): 77.88 (9.88) 57.1% female and 42.9% female	Cross-sectional Mixed methods Structured interview and questionnaire: in-person 57% ^c (poor) ^d	Religious coping: religious coping (1) Brief RCOPE-AD: AD adapted version of Brief RCOPE, includes positive or negative religious coping with (2) Religious Problem-Solving Scale-Short Version adapted for Alzheimer's (RPSS-AD): for degree to which an individual uses 3 types of religious problem-solving strategies—collaborative, deferring, and self-directed. R/S resources: R/S resources (1) Santa Clara Strength of Religious Faith (2) SCSRQFQ-AD for general role of faith in one's life (2) Brief Multidimensional Measure of Religiousness and Spirituality (BMMRS); using 4 subscales: (1) Daily Spiritual Experiences (DSE), (2) Values and Beliefs (VB), (3) Private Religious Practices (PRP), and (4) Religious Support (RS)	Negative religious coping was positively associated with anxiety [$r(16) = 0.52$, $P = .03$] and behavioral and psychological expression frequency [$r(10) = 0.78$, $P = .00$] and severity [$r(10) = 0.69$, $P = .01$] 90.4% practiced private prayer some or most days; 33% increased spiritual practice; and 53.6% decreased corporate/organized religious attendance since dementia diagnosis; 95.7% found relationship with the transcendent to be very important Three themes emerged from qualitative responses: (1) R/S beliefs were considered a guide for relating to self and the world, (2) importance of incorporating spirituality into daily life, (3) spirituality played a role in coming to terms with dementia diagnosis.

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: concept(s) measured	Findings
Nagpal et al., 2015	To examine the relationship between religiosity and QOL	United States Community residents N = 111 dyads [total N = 222] Mild and moderate dementia, MMSE 13–26, MMSE mean (SD) = 20.7 (3.8) PWDs: mean age (SD) = 76.8 (8.9); Caregivers: mean age (SD) = 61.2 (14); PWDs: 50% female and 50% male; Caregivers: 39% female and 61% male	Cross-sectional Interviews: in person 58% ^a (poor) ^d	Centrality of R/S: religiosity/Total Religiosity, with three individual items: (1) Organizational religiosity for frequency of religious service attendance; (2) non-organizational religiosity for frequency of prayer or meditation; (3) subjective religiosity for how religious or spiritual an individual identifies as being.	Higher levels of caregiver religiosity predicted higher self-reported PWD QOL ($B = 0.08, SE = .03, P < .05$) Religiosity for caregivers and PWDs was positively correlated with being African American ($r = 0.39, P < .01; r = 0.29, P < .05$) and negatively correlated with being a spouse ($r = -0.30, P < .05; r = -0.27, P < .05$) and having higher level of education ($r = -0.33, P < .01; r = -0.22, P < .10$) Total religiosity was not significantly different between caregivers and PWDs [$t(110) = 1.59, P = .12$] Caregivers' perceptions of PWDs' QOL differed significantly from PWDs' self-reported QOL [$t(109) = -5.83, P = .00$] Caregivers reported lower perceived PWD QOL ($M = 2.37, SD = 0.46$) than PWDs' self-reported QOL ($M = 2.66, SD = 0.43$)
Pereira et al., 2020	To validate the Portuguese version of SpREUK	Portugal Patients from hospitals N = 128 Probable mild AD; [no demographic data reported on MMSE and MoCA] Mean age (SD) = 76.05 (6.92) 66% female and 34% male	Cross-sectional, scale validation Questionnaire: unknown 55% ^a (poor) ^d	Centrality of R/S: spirituality SpREUK Portuguese version with 3 subscales (Support, Trust, Reflection) and an overall score for spiritual attitudes on how individuals deal with chronic illness Cognitive and Affective Mindfulness Scale-Revised (CAMS-R); Portuguese	QOL and mindfullness were negatively correlated with all three spirituality subscales: Search ($r = -0.23, P = .009; r = -0.20, P = 0.023$); Trust ($r = -0.24, P = .006; r = -0.23, P = .010$); Reflection ($r = -0.22, P = .013; r = -0.24, P = .006$) Longer duration of memory problems was positively associated with all three spirituality subscales: Search ($r = 0.264, P = .003$); Trust ($r = 0.217, P = .014$); Reflection ($r = 0.208, P = .018$)

(Continues)

TABLE 1 (Continued)

Authors & pub year	Purpose	Setting, sample, dementia stage	Study design & quality ratings	R/S category: Concept(s) measured	Findings
Wu & Koo, 2015	To assess the effect of spiritual reminiscence on hope, life satisfaction, spiritual well-being, and cognition	Taiwan Patients from geriatric department of a medical center N = 103 AD (99%); mild dementia, MMSE 21–24; moderate dementia, MMSE 13–20; MMSE mean (SD): Control = 22.9 (1.57), Intervention = 23.1 (1.31) Mean age (SD) = 73.6 (7.4) 68.9% female and 31.1% male	6-week RCT with intervention and pre- and posttest questionnaire: in person 58% ^b (poor) ^d	Spiritual Well-being: spiritual well-being	Females had significantly higher scores on all three spirituality subscales—Search ($M = 12.36$, SD 5.50); Trust ($M = 13.74$, SD 3.86); Reflection ($M = 8.24$, SD 4.75)—than did men ($M = 7.95$, SD 5.89, $M = 10.77$, SD 4.99; $M = 4.80$, SD 4.68; $P < .001$) Older AD participants reported higher levels of spirituality on the Trust subscale ($r = 0.179$, $P = .043$) Significant improvement in hope, life satisfaction, and spiritual well-being in the intervention group ($M = 37.4$, SD 7.4 pretest; $M = 40.1$, SD 8.0 posttest; $P < .001$) Significant improvement in cognitive impairment found in the intervention group ($M = 23.1$, SD 1.3 pretest; $M = 23.4$, SD 1.6 posttest; $P < .001$)

Abbreviations: AD, Alzheimer's disease; CDR, Clinical Dementia Rating scale; FACIT-Sp, Functional Assessment of Chronic Illness Therapy—Spiritual Well-being; GDS, Geriatric Depression Scale; MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination; MoCA, Montreal Cognitive Assessment; Pub, publication; PWDs, persons with dementia; QOL, quality of life; RCT, randomized controlled trial; R/S, religion/spirituality; SD, standard deviation; UK, United Kingdom.
^aNIH = National Institutes of Health.
^bCASP = Critical Appraisal Skills Programme.
^cMMAT = Mixed Method Analysis Tool.
^dGood ($\geq 80\%$), fair ($\geq 60\%$ and $< 80\%$), poor ($\leq 60\%$).

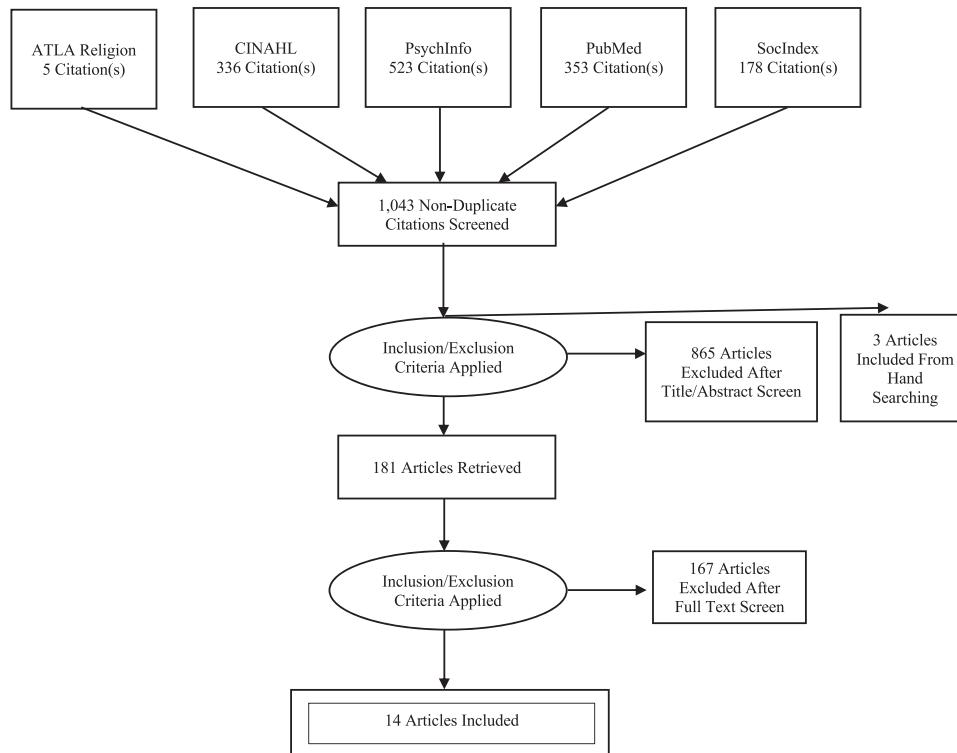


FIGURE 2 Preferred reporting items for systematic reviews and meta-analyses (PRISMA) selection of articles for review²⁶

of prayer or meditation, and subjective rating of how religious/spiritual the person is. Jung et al.³⁷ and Kaufman et al.³⁸ both used the DUREL, which another study adapted for the Korean population.⁴² The DUREL includes five items with three subscales: (1) organizational religious activity, which measures frequency of religious attendance at meetings and activities; (2) nonorganizational religious activity, which captures frequency of private religious activity such as prayer or meditation; and (3) intrinsic religiosity, which is a subjective assessment of the importance of religious belief one holds. Coin et al.³⁵ measured religiosity with the BRS,^{40,41} which examines frequency of religious participation in four activities: (1) religious service attendance, (2) praying, (3) reading religious material, and (4) watching/listening to religious programs on TV/radio. Using the BRS, Coin et al.³⁵ grouped participants as presenting either low or high religiosity.

Spirituality was measured using the Portuguese version of the Spiritual and Religious Attitudes in Dealing with Illness (SpREUK) questionnaire,^{34,43} the short Royal Free Interview for Religious and Spiritual Beliefs,^{44,45} and the Francis Short Scale (FSS).⁴⁶ Two studies^{33,34} used the Portuguese SpREUK. This questionnaire captures spiritual attitudes in how individuals deal with chronic conditions and illness; the instrument's 15 items are scored on a 5-point Likert scale, with higher scores indicating greater reliance and use of spirituality in coping with illness (the scale yields an overall score as well as three subscale scores for support, trust, and reflection). Pereira et al.³⁴ also used the Portuguese adaptation of the Cognitive and Affective Mindfulness Scale-Revised (CAMS-R),⁴⁷ a 9-item questionnaire assessing attention orientation regulation in the present without using judgement or

conditioning patterns; items are rated on a 4-point Likert scale, with higher scores indicating greater use of mindfulness strategies. Jolley et al.³² used the short Royal Free Interview for Religious and Spiritual Beliefs,^{44,45} a 6-item self-reported questionnaire that captures the strength of belief of individuals with illness using a 10-point Likert scale. Coin et al.³⁵ used the FSS, which is a short form of the adult version of the Francis Scale of Attitude toward Christianity,⁴⁶ to measure an individual's internal attitude toward Christianity as representing a reflection of long-term spirituality; the FSS is a 7-item instrument with items rated on a 5-point Likert scale; higher scores indicate a stronger positive attitude toward Christianity.

Centrality of R/S was assessed with one measure that combined religiousness with spirituality,³⁸ using the Overall Self-Ranking subscale from the NIH/Fetzer Brief Multidimensional Measurement of Religiousness/Spirituality subscales (BMMRS).⁴⁸ This subscale consists of two items rated on a 4-point Likert scale from 1 (low) to 4 (high; i.e., "To what extent do you see yourself as a spiritual or religious person?").

Although the reliability and validity of R/S scales were reported in these reviewed studies for populations with illnesses other than dementia, only two of the studies on religiosity and dementia^{37,38} reported calculated internal consistency for their respective instruments, with Cronbach's alpha at 0.80 in Jung et al.,³⁷ and separately in Nagpal et al.³⁶ for caregivers (0.71) and PWDs (0.66), revealing how closely related the set of items was as a group.³⁶ Nagpal et al.³⁶ reported associations among their instrument's three items as concurrent validity: in caregivers ($r = 0.61$, $r = 0.32$, $r = 0.39$, $P < .001$)

and in PWDs ($r = 0.62$, $P < .001$; $r = 0.30$ and $r = 0.28$, $P < .01$). Two studies did not report any reliability or validity in the dementia population,^{35,38} and no studies reported adapting the scale for dementia. Beyond these indications, no other validation psychometrics for R/S scales were reported. For reported psychometric properties of spirituality scales, one validation study examined an existing R/S measure in mild AD,³⁵ and the authors used this validated scale again in another study.³³ Reliability of this instrument was reported in both studies, with Cronbach's alpha ranging from 0.94 to 0.95 for the total scale, 0.92 to 0.93 for the support subscale, 0.84 to 0.89 for the trust subscale, and 0.84 to 0.90 for the reflection subscale. Findings from the Pereira et al. validation study³⁴ showed that the three SpREUK subscales were strongly correlated ($r > 0.70$), with acceptable model fit in factorial analysis (see Table 2). Acceptable internal consistency was reported for the CAMS-R mindfulness scale, with Cronbach's alpha of 0.83; this measure was reported to be validated in Portuguese in a previous thesis study but could not be verified as it was not available in English.⁴⁹ Jolley et al.³² used an R/S measure for the first time among dementia participants and reported that the measure was easy to use, but, like Coin et al.,³⁵ Jolley et al. did not report any psychometrics for the scale. Although the Overall Self-Ranking subscale from the BMMRS was reported valid and reliable in older adults in previous studies, it has not been validated in dementia specifically. Kaufman et al.³⁸ did not report adaptation or psychometrics.

Among persons with mild and moderate dementia, higher levels of religiosity were associated with slower cognitive decline in most of the studies' findings, and with decreased behavioral expressions and a significant reduction in caregiver burden³⁵ and in caregiver perception of lower levels of QOL for PWDs.³⁶ Two studies^{37,38} found an association between nonorganized religious activity (i.e., private religious activities) and slower cognitive decline; but only one of the two found a significant correlation between organized religious activity (i.e., religious attendance) and improved cognition,³⁸ reporting even higher cognitive benefits from organized religious activity with an additional subdomain, language. In this study, language was not associated with private religious practice, indicating that social and physical interactions in organized religious activities may be a protective factor for language engagement and strengthening for some. Interestingly, older AD participants had lower intrinsic religiosity and religious attendance than did younger AD participants.³⁸ Nagpal et al.³⁶ found that PWDs' self-perceptions of QOL were different from their caregivers' perceptions of PWDs' QOL, although total religiosity was similar between PWDs and caregivers. Higher levels of religiosity in caregivers predicted higher self-reported QOL among PWDs.

Higher levels of spirituality among persons with mild to moderate dementia were associated with slower cognitive decline, decreased frequency and severity of behavioral expressions, and decreased caregiver distress.³⁵ R/S beliefs were found to be similar between caregivers and PWDs with unspecified dementia stage, indicating that PWDs maintained spiritual awareness; both groups ranked beliefs as strong and reported R/S in coping with life stressors as very important.³² Two studies^{33,34} in the same population reported a nega-

tive relationship between spirituality and QOL, suggesting that in mild dementia, persons with lower QOL indicate greater use of spirituality. Similarly, in mild dementia, longer cognitive difficulties indicated greater use of spirituality.³⁴ In a longitudinal study, Kaufman et al.³⁸ found that higher levels of spirituality predicted slower cognitive decline in 20 participants, controlling for level of cognition, sex, education, and age. However, spirituality was not significantly associated with QOL. Religiosity was lower in older AD participants than in younger AD participants.

3.1.2 | Religious/spiritual resources

Three of the 14 studies examined R/S resources^{3,50,51} and identified participants with mild AD; one of the studies⁵¹ included mild dementia and MCI.

R/S resources include one's affiliation with religious communities, one's personal relationship or sense of unity with God, engagement in religious practices as a social resource, and personal beliefs and faith. The studies that examined R/S resources^{3,50,51} used three scales: the BMMRS,⁴⁸ the Santa Clara Strength of Religious Faith Questionnaire,⁵² and the Systems of Belief Inventory (SBI-15R).⁵³ Katsuno³ and Despoina et al.⁵¹ used the SBI-15R, a 15-item questionnaire with a 4-point scale to measure religious beliefs, practices, and social support, and Despoina et al.⁵¹ used the scale's Greek adaptation. Higher scores on the SBI-15R indicate stronger RS beliefs. McGee et al.⁵⁰ adapted the Santa Clara Questionnaire's 10 items using a 4-point Likert format to assess the role of faith in an individual's life. These authors also used 4 of the 12 BMMRS subscales: (1) daily spiritual experiences, with six items for frequency of connection with God (e.g., "I feel God's presence"); (2) values and beliefs, with four items for religious values and beliefs that an individual holds (e.g., "The events of my life unfold according to a divine plan"); (3) private religious practices, with five items measuring frequency of individual RS practices (e.g., Within your religious tradition, how often do you mediate?); and (4) religious support, with four items assessing the degree to which an individual believes that he or she has support from a religious community (e.g., "How often do the people in your congregation make too many demands on you?"). McGee et al.⁵⁰ adapted the items on these subscales to a 3-point Likert scale.

Katsuno³ and McGee et al.⁵⁰ adapted the scales that they used to measure R/S resources to accommodate dementia participants' ease of use and understanding. The scale items were provided in large bold type, with one question presented at a time verbally and visually. Based on feedback from a trial with three persons who had mild AD, McGee et al.⁵⁰ decreased answer choices to three options for consistency; the answer choices were coded in color; and participants indicated their answer choice for each question verbally and physically, with the procedure administered by a trained examiner. Katsuno³ presented answer choices in the same direction and order for ease (i.e., ascending order). Despoina et al.⁵¹ did not report dementia adaptation of their scale, only adaptation to the Greek language.⁵¹ As for psychometric properties, internal consistency was reported with Cronbach's alpha

TABLE 2 Reported psychometric findings from final selection

Authors, publication year	R/S category: concepts measured and scales	Psychometrics
Agli et al., 2017	<u>Spiritual well-being: spirituality</u> Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp12): French version with three subscales: Peace, Meaning, Faith, with 5-point Likert scale for each subscale and overall	This scale was validated in Agli et al. (2017) with the cognitively impaired Greater factorial validity in modified 3-factor model ($CFI = 0.952$, $TLI = 0.935$, $RMSEA = 0.067$) compared to modified 2-factor model ($CFI = 0.934$, $TLI = 0.916$, $RMSEA = 0.077$); modifications made to remove 1 item, totaling 11 items. Internal consistency reported with Cronbach's alpha: Faith (0.79), Peace (0.73), and Meaning (0.76); overall (0.84) No significant difference in factorial structure between participant groups
Agli et al., 2018	<u>Spiritual well-being: spirituality</u> FACIT-Sp12 French version with three subscales (see above) with 11 items; 5-point Likert scale for each subscale and overall	Validated in older adults with cognitive impairment—French version (see Agli, 2017 above) Internal consistency reported with Cronbach's alpha: Peace (0.66), Faith (0.77), Meaning (0.59); overall (0.81)
Coin et al., 2010	<u>Centrality of R/S: Religiosity & Spirituality</u> Behavioral Religiosity Scale (BRS) for frequency of participation in religious activities of religious service attendance, praying, reading religious materials, and watching/listening to religious programs, with 10-point Likert scale. Divided into two groups: LR group and HR group based on BRS score Francis Short Scale (FSS— short form of Francis Scale of Attitude toward Christianity, with seven items on a 5-point Likert scale for a person's internal attitude toward Christianity, reflecting long-term spirituality	These scales have not been validated with the ADRD population. FSS score was correlated with BRS score and with each BRS item. No psychometric data based on sample reported.
Despoina et al., 2018	<u>R/S Resources: Religiosity</u> Systems of Belief Inventory (SBI-15R) Greek version; 15-item 4-point scale for religious beliefs and practices and religious social support subscales.	The scale had not been previously validated with the ADRD population No psychometric data based on the sample reported
dos Santos et al., 2018	<u>Spiritual Well-Being: spirituality</u> Spirituality Self Rating Scale (SSRS) Brazilian Portuguese Adaptation with three factors: Peace, Meaning, and Faith, with six items for importance of spiritual domain and how individuals apply it to daily life	This scale has not been validated with the ADRD population No psychometric data based on sample reported
Jolley 2010	<u>Centrality of R/S: spirituality</u> Royal Free Interview for Religious and Spiritual Beliefs; 6-item self-report questionnaire with 10-point Likert scale for religious and spiritual beliefs.	This scale has not been validated with the ADRD population No psychometric data based on sample reported
Jung et al., 2019	<u>Centrality of R/S: religiosity</u> Duke University Religion Index (DUREL) Korean version for religiosity with five items on each of three subscales on a 6-point Likert scale: organizational religious activity (ORA) for frequency of religious attendance at meetings/activities, nonorganizational religious activity (NORA) for frequency of private religious activities, and intrinsic religiosity (IR) for subjective importance of religious belief	This scale has not been validated with the ADRD population Internal consistency reported with Cronbach's alpha (0.80)

(Continues)

TABLE 2 (Continued)

Authors, publication year	R/S category: concepts measured and scales	Psychometrics
Katsuno 2003	<u>R/S Resources: R/S resources</u> SBI-15R Alzheimer's adapted version; 15 item 4-point scale with religious beliefs and spiritual practices and religious social activity subscales. <u>Spiritual Well-being: spirituality</u> Quality of Life Index (QLI) using psychological/spiritual subscale for satisfaction and importance of spirituality in one's life as perceived QOL; 6-point Likert scale	Neither scale had been previously validated in the ADRD population (SBI-15R) Convergent validity was reported, with positive association between overall scale and overall QOL scale ($r = 0.44, P < .05$); Internal consistency reported with Cronbach's alpha: R/S beliefs and practices subscale (0.88), R/S social support (0.71); overall (.90) (QOL: psychological/spiritual subscale) overall scale concurrent validity reported for overall scale and single item, "life satisfaction" ($r = 0.45$); Internal consistency reported with Cronbach's alpha (0.87)
Kaufman et al., 2007	<u>Centrality of R/S: Religiosity</u> DUREL for religiosity, with five items on three subscales with a 6-point Likert scale: ORA for frequency of religious attendance at meetings/activities, NORA for frequency of private religious activities, and IR for subjective, importance of religious belief <u>Centrality of R/S: Religiosity and Spirituality</u> NIH/Fetzer Brief Multidimensional Measure of Religiousness/Spirituality (NIH/FB) using Overall Self-Ranking subscale, a 2-item 4-point Likert scale measuring religiosity and spirituality	These scales have not been validated with the ADRD population No psychometric data based on sample reported
Lima et al., 2020	<u>Centrality of R/S: spirituality</u> The Spiritual and Religious Attitudes in Dealing with Illness (SpREUK) Portuguese version; 15-item self-report with three subscales (Support, Trust, Reflection) and an overall score on a 5-point Likert scale for spiritual attitudes in how individuals deal with chronic illness	This scale was validated in the AD population in authors' previous study (see Pereira below) Internal consistency reported with Cronbach's alpha: Support (0.92) Trust (0.84), Reflection (0.84), overall (0.94)
McGee et al., 2013	<u>Religious coping: religious coping</u> (1) Brief RCOPE-AD: Alzheimer's adapted version of Brief RCOPE, with positive or negative religious coping; 14-item 3-point scale (2) Religious Problem-Solving Scale—Short Version adapted for Alzheimer's (RPSS-AD): 18-item self-report measure for degree to which an individual uses three types of religious problem-solving strategies: collaborative, deferring, self-directed. <u>R/S resources: R/S resources</u> (1) Santa Clara Strength of Religious Faith Questionnaire—Alzheimer's version (SCSRFQ-AD): 10-item self-report measure for general role of faith in one's life adapted to 3-point Likert scale (2) Brief Multidimensional Measure of Religiousness and Spirituality (BMMRS): Four subscales adapted to a 3-point Likert scale: (1) Daily Spiritual Experiences (DSE), six items; (2) Values and Beliefs (VB), four items; (3) Private Religious Practices (PRP), five items; (4) Religious Support (RS), four items.	None of these scales had been previously validated with ADRD population. Internal consistency reported with Cronbach's alpha: Brief RCOPE-AD positive religious coping (0.86), negative religious coping (0.71); RPSS-AD collaborative (0.91), deferring 90.88), and self-directed (0.86); SCSRQ-AD (0.93); BMMRS [none reported]

(Continues)

TABLE 2 (Continued)

Authors, publication year	R/S category: concepts measured and scales	Psychometrics
Nagpal et al., 2015	<u>Centrality of R/S: religiosity</u> Total Religiosity with three individual items: (1) Organizational religiosity for frequency of religious service attendance. (2) Nonorganizational religiosity for frequency of prayer or meditation, —both with 6-point Likert scale. (3) Subjective religiosity for how religious or spiritual an individual identifies as being —with 4-point Likert scale.	Concurrent validity reported between these three items in: PWDs: ($r = 0.62$ with $P < .001$; $r = 0.30$; $r = 0.28$ with $P < .01$) Caregivers: ($r = 0.61$; $r = 0.32$; $r = 0.39$ with $P < .001$) Internal consistency reported for total religiosity with Cronbach's alpha: PWDs (0.66) and caregivers (0.71)
Pereira et al., 2020	<u>Centrality of R/S: spirituality</u> SpREUK Portuguese version: 15-items self-report measure with three subscales (Support, Trust, Reflection) and an overall score; 5-point Likert scale for spiritual attitudes in how individuals deal with chronic illness Cognitive and Affective Mindfulness Scale-Revised (CAMS): Portuguese adaptation for Alzheimer's; nine items on 4-point Likert scale for openness, attention, and orientation to the present	SpREUK was validated in this study in the AD population 3-factor model revealed factorial validity of CFI = 0.961, TLI = 0.951, RMSEA = 0.075; convergent validity was reported by intercorrelation between subscales ($r > 0.70$); CAMS was reported to be validated in authors' previous study (Pereira et al., 2015) but could not be verified (English version unavailable) Internal consistency was reported with Cronbach's alpha. SpREUK subscales: Support (0.93), Trust (0.89), Reflection (0.90), overall (0.95); CAMS (0.83)
Wu & Koo, 2015	<u>Spiritual Well-being: spiritual well-being</u> Spirituality Index of Well-Being Chinese version; 12-item 5-point Likert scale for impact of spirituality on well-being, with two subscales: self-efficacy and life scheme	The scale had not been previously validated with the AD population No psychometric data based on the sample reported

Abbreviations: AD, Alzheimer's disease; ADRD, Alzheimer's disease and related dementias; CFI, comparative fit index; HR, high religiosity; LR, low religiosity; QOL, quality of life; RMSEA, root mean square error of approximation; R/S, religion/spirituality; TLI, Tucker-Lewis index.

for one scale, the Santa Clara measure (0.93). Neither reliability nor validity was reported for dementia in the other RS scales (BMMRS, SBI-15R).

For persons with mild dementia or AD dementia, the findings for R/S resources indicated a positive association between R/S beliefs and practices with QOL but not social support³ and a negative association with depressive symptoms.⁵¹ Those with cognitive impairment, specifically MCI and mild dementia, reported greater use of R/S practices, beliefs, and support than did a healthy control group.⁵¹ Among mild dementia participants, 90.4% reported practicing daily prayer or prayer on some days and since diagnosis, 53.6% reported decreased corporate/organized religious attendance and 33% reported an increase in RS practices like prayer.⁵⁰

3.1.3 | Religious/Spiritual coping

R/S coping was defined as religious or spiritual ways of understanding and viewing stressors or difficult life circumstances²² and how individuals deal with a crisis to overcome it, which can include behaviors and strategies. One study⁵⁰ examined this domain with two instruments: the Brief RCOPE⁵⁴ and the Religious Problem-Solving Scale—Short Version (RPSS).⁵⁵ The RCOPE consists of two subscales, positive and

negative religious coping, with 14 items on a 4-point Likert scale measuring the degree to which an individual uses positive or negative religious coping strategies to view and face stressors. The RPSS uses three subscales to measure self-reported (1) collaborative, (2) deferring, and (3) self-directed religious problem solving, with items scored on a 5-point Likert scale. These different styles of solving problems religiously consist of working in conjunction with God as an active participant or solving together (collaborative); remaining relatively inactive, placing the solving responsibility upon God (deferring); and sole responsibility, with the individual actively addressing a solution (self-directed).⁵⁵ McGee et al.⁵⁰ et al. adapted the R/S measures from the RPSS for older adults with AD. These measures have not been validated for those with dementia but have been validated in other populations. McGee et al.⁵⁰ reported reliability, specifically internal consistency, with Cronbach's alpha of 0.86 and 0.71 for the positive and negative Brief RCOPE and 0.91, 0.88, and 0.86, respectively, for the RPSS.

Positive religious coping was used more by participants with mild AD than negative religious coping⁵⁰ and negative religious coping, also known as spiritual struggle, was positively associated with anxiety and behavioral and psychological expression frequency and severity.⁵⁰ Collaborative religious coping was used the most for problem solving, followed by deferring and self-direction.⁵⁰

3.1.4 | Spiritual well-being

This domain refers to a sense of well-being based on satisfaction or dissatisfaction with a particular aspect of life that is important to a person;²³ it may include aspects of faith, peace, and meaning.²⁴ Three studies focused on mild dementia, two on moderate dementia, one on MCI, one on cognitively impaired older adults with no specified dementia, and one on dementia with no stage specified.

Five studies^{3,32,56–58} examined spiritual well-being using four scales: the Spirituality Self-Rating Scale (SSRS), Brazilian Portuguese Adaptation;⁵⁹ the Spirituality Index of Well-Being⁶⁰ translated into Chinese; the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp12)⁶¹ in French; and the Quality of Life Index (QLI)²³ psychological/spiritual subscale. dos Santos et al.⁵⁸ used the SSRS to measure spiritual orientation to life, representing the importance of this spiritual domain to well-being and how one may apply it in one's life. Based on three concepts—faith, peace, and meaning—the SSRS consists of six items rated on a 5-point Likert-type scale, with higher scores indicating a higher level of spirituality.⁵⁹ Wu and Koo³¹ used the Spirituality Index of Well-Being, a 12-item instrument measuring the effect of spirituality on subjective well-being, divided into two subscales for (1) self-efficacy and (2) life scheme. Two studies^{56,57} used the French version of the FACIT-Sp12, with three subscales for faith, meaning, and peace; items are rated on a 5-point scale with total scores for the instrument's 11 items representing overall spirituality. Higher scores represent greater spirituality. Katsuno³ used the QLI psychological/spiritual subscale to measure importance and satisfaction in psychological/spiritual aspects of an individual's life. Satisfaction responses are adjusted according to the importance indicated and are rated on a 6-point Likert-style scale, with higher scores indicating greater QOL.

The majority of the five studies that examined spiritual well-being reported internal consistency with Cronbach's alpha.^{3,56,57} Agli et al.⁵⁶ tested the psychometric properties of a 3-factor French model of the 2-factor FACIT-Sp12⁶¹ to determine which one reported stronger validity in cognitively impaired older adults and a control group. Internal consistency measured with Cronbach's alpha was satisfactory (faith = 0.79, peace = 0.73, meaning = 0.84), and confirmatory factor analysis supported the 3-factor version with acceptable model fit (see Table 2). The model's results were not significantly different between the cognitively impaired group and control group, supporting validity in the cognitively impaired group similarly. Agli et al.⁵⁷ used the same measure in a later study and reported internal consistency with Cronbach's alpha for faith (0.77), peace (0.66), meaning (0.59), and overall (0.81), indicating limiting to adequate reliability. One study³ adapted its R/S scale to the dementia population by using large bold type for questions, with answer choices presented in the same order (i.e., ascending) and direction for ease and deliberately shown while reading one question at a time, but no other studies reported adapting scales. Two studies did not report reliability or validity in this population for instrument use.^{31,58} In Katsuno,³ internal consistency for the QLI psychological/spiritual subdomain was reported with Cronbach's alpha at 0.87. Concurrent validity of the QLI was reported ($r = 0.45$) for the over-

all scale, not specifically for the psychological/spiritual subdomain by itself.

There were no differences in spiritual well-being for moderate and general dementia groups^{57,58} compared to healthy control groups in the spiritual well-being dimension; Agli et al.⁵⁷ also found no differences in QOL. Agli et al.^{56,57} found a significant difference in self-esteem between dementia and healthy controls. In Wu and Koo,³¹ those with MCI and mild dementia reported lower spiritual well-being, social support, life satisfaction, positive affect, optimism, and hope, and higher negative affect, than did healthy controls; and in mild and moderate dementia, there was a significant increase in spiritual well-being, cognitive function, hope, and life satisfaction after a spiritual reminiscence intervention. Among those with cognitive impairment and dementia with unspecified stage, positive associations were reported between meaning and QOL;^{56,57} between peace and QOL;⁵⁶ and between peace and self-esteem, sense of aesthetics, and positive emotions/humor⁵⁷—but no association between faith and QOL.⁵⁶ Negative associations were reported between meaning and depression.^{56,57} Findings for importance and satisfaction in the spiritual domain included 90% of those with mild, probable AD dementia reporting faith in God to be very important; 95%, very or moderately satisfied with their faith in God; and 90% agreeing that religion was important in everyday life, with 62% strongly agreeing.³

4 | DISCUSSION

The studies in this review provide an understanding of R/S for PWDs and demonstrate a need for greater attention to R/S in this population and further development of validated measures. The studies' quality varied, with the majority rated as poor ($n = 10$) and some fair ($n = 4$) due to study design limitations (Table 1). Most studies were cross-sectional ($n = 8$), with one of them rated fair; two of the three longitudinal or randomized controlled trial (RCT) studies were rated fair; and one mixed-methods study was fair. Only one study indicated effect size or power needed to detect a true effect in its sample, and most studies collected data at one point in time. Only a few studies controlled for covariates in statistical analyses.

Two scales were validated for use with PWDs, six scales were adapted for use with PWDs, and most studies reported only scales' reliability, using Cronbach's alpha. The studies suggest that R/S has positive associations with cognitive and mental health and more rigorous studies are needed to examine associations over time to evaluate potential for improving health outcomes. Increased interest in and attention to the importance of R/S is warranted in future research in those with cognitive impairment and dementia to promote coping, finding meaning, and positive psychological strengths.

4.1 | Measurement assessment

Overall, data were collected in person in eight studies, and five studies did not specify how questionnaires were completed. Only two studies

reported adapting R/S scales originally designed for the general population to accommodate PWDs, and five studies used validated measures for the dementia population. These validated measures covered only two of the five R/S categories in the VSM-RS framework, leaving a gap for more measures to be validated for R/S resources, R/S coping, and spiritual needs. Future studies should consider Mini-Mental State Examination (MMSE) scores and stage of dementia in accommodating measures. Development and validation of R/S measures for PWDs should be prioritized.

The reviewed articles used both different and overlapping R/S measures. Several were adapted to a different language ($n = 8$) and several were used without any modifications ($n = 7$). Five scales were adjusted to accommodate PWDs in various ways: by decreasing answer choices, with questions asked both verbally and visually with larger bold type and one question per page; by providing ample time for answering; and by providing a short break during interviews. But there was a lack of R/S scales validated in the dementia population. Only two measures, the FACIT-Sp12 and SpREUK, were validated for assessing spiritual well-being and R/S attitudes in dealing with illness in cognitively impaired older adults.^{33,34,56,57} No measures assessed spiritual needs.

4.2 | Conceptual and operational definitions of religion/spirituality

In research, the definitions of R/S and the measures used to assess them vary. An appropriate measure to accurately capture the specific R/S construct is needed. Careful examination of the wording of such scales is warranted to support their purpose and to facilitate comparison across studies.¹⁵ Some of the studies reported general religiosity or spirituality as a measured concept when the scale actually measured spiritual well-being. For example, in two of the studies, spirituality was reported as a construct representing faith, meaning, and peace, identified by the FACIT-Sp12⁵⁷ and the SSRS.⁵⁸ However, developers of the FACIT-Sp12 have indicated that it represents aspects of religious faith and spirituality that contribute to QOL in chronic illness, indicating spiritual well-being,⁶¹ which is more of an outcome¹⁵ than a fundamental element as in other R/S research.^{5,62} The concept of spirituality is abstract, and a clear definition with a clear model of R/S dimensions could further scientific understanding of the connection between spirituality and health and inform effective interventions. This has been articulated by Steinhauer et al.²⁷ in reporting on the state of science in R/S research and emphasizing the need for models with clear boundaries in future R/S studies.

4.3 | Religion/Spirituality and health

Research with PWDs in the reviewed studies showed that R/S was important to them and that they continued to engage in R/S activities, including prayer and religious attendance. However, as PWDs age and their capacity and functionality decline, they may not self-

initiate R/S practices and therefore may need R/S assessment and support so that they can still connect with these activities that may remain important. Supporting this idea, religious attendance was found to be lower among older adults with dementia than among younger adults with dementia,³⁸ and 53% of persons with mild dementia reported a decrease in organizational religious involvement since their diagnosis.⁵⁰ At the same time, Despoina et al.⁵¹ reported that individuals with MCI and mild dementia had higher levels of religious practices, beliefs, and support (R/S resource use) than did non-dementia controls (see Table 1). Agli et al.⁵⁷ reported that levels of spiritual well-being were similar between PWDs and controls, yet dos Santos et al.⁵⁸ found lower spiritual well-being among those with MCI and those with mild dementia compared to controls. Two studies^{3,51} suggested that individuals facing uncertainty or terminal illness such as dementia may use religion as a coping source. dos Santos et al.'s findings⁵⁸ highlight the struggle of uncertainty as individuals with MCI and mild dementia work through their peace, meaning, and faith, whereas Despoina et al.'s study⁵¹ suggest that they may use religiosity to find some control or schema to work through these struggles—possibly working through ways of spiritually coping. Jolley et al.³² found that PWDs were not losing their spirituality and that it was important to them in everyday experiences, and supportive as they worked through life stressors. Perhaps dos Santos et al.⁵⁸ captured attributes of individuals' expectations about progressing toward unfavorable, incapacitating states in dementia that are overwhelming.⁶³ This aligns with Ismail et al.'s⁶⁴ findings on the prevalence of depression in those with MCI.

The findings between R/S and cognitive function support a positive association, but more studies are needed. Higher levels of spirituality, private religious practices, and higher religiosity^{35,38} were associated with slower cognitive decline³⁸ but results varied on organized religious attendance, which appears to decrease with age. Longer duration of memory problems was associated with spirituality, suggesting that the longer duration of cognitive struggle may prompt greater spirituality.³⁵ It is possible that organizational religiosity may provide greater cognitive benefits than non-organizational and intrinsic religiosity by prompting PWDs to use language to interact with others socially, but more studies are needed to further examine these differences. Persons with mild dementia (97%) reported no changes in their spiritual practices, with 33% increasing private practices such as prayer, which is more accessible to older adults with dementia who often depend on others for spiritual support. Indeed, spiritual reminiscence³¹ improved spiritual well-being, hope, life satisfaction, and cognitive function in mild and moderate dementia, suggesting R/S may serve as a protective factor. Spiritual reminiscence may help PWDs find meaning in life and transcendence as they reconnect to their past, finding hope for the future.⁶⁵ These findings also align with Kaufman et al.,³⁸ reporting spirituality was associated with slower cognitive decline.

In the studies in this review, meaning was associated with QOL in cognitively impaired individuals. Kaufman et al.³⁸ found no significant correlation between spirituality and QOL, whereas Lima et al.³³ and Pereira et al.³⁴ reported that individuals with dementia and lower QOL used greater levels of spirituality. More studies are needed to further

examine this association in this vulnerable population; increasing QOL in those who suffer from dementia is a worthy health-care goal.

In studies focusing on psychological and behavioral health, R/S has been associated with decreased levels of depression and psychological stress.^{66,67} In the reviewed studies, religiosity and religious beliefs and practices⁵¹ and meaning and peace⁵⁷ were associated with less depressive symptoms in those with dementia; similar literature on this topic suggests religiosity may help facilitate mental health and successful aging, reducing the risk of depression in adults with mental disorders.⁶⁸ Negative religious coping, also known as spiritual struggle, was associated with anxiety and increased severe behavioral and psychological expressions in AD.^{50,35} Religiosity and spirituality were found to be associated with decreased behavioral and psychological expression frequency and severity in AD, which were also found to be highly associated with negative religious coping. These findings suggest that R/S is associated with mental health, specifically neuropsychiatric symptoms. The studies' findings support the need for additional research on spiritual support in this population to evaluate behavioral health outcomes over time, which are common in dementia and can increase caregiver burden and depression.⁶⁹ Because dementia caregivers are twice as likely to experience emotional, physical, and financial difficulties as other caregivers, and because PWDs have twice as many hospital visits yearly as do older adults without dementia, creating and testing R/S interventions with the potential to improve QOL is warranted. Dementia is one of the costliest health conditions for society, so interventions with the potential to decrease financial burden and unnecessary health-care use⁷⁰ are greatly needed.

In the reviewed studies, no significant difference in religiosity was found between PWDs (mild to moderate) and caregivers.³⁶ It is possible for individuals co-residing to share similar behaviors and as caregivers engage in R/S activities themselves, some may include PWDs in those activities. This was supported by reports that caregivers' religiosity was associated with PWDs' self-reported QOL. No significant differences were found for R/S beliefs³² and QOL⁵⁷ between PWDs (mild to moderate) and caregivers or controls. For persons with greater cognitive impairment, it is possible that anosognosia, which can include an optimism with responses becoming more positive as dementia progresses, may suppress the disease's impact on R/S.⁵⁸ It is also possible that spirituality and spiritual well-being are simply strong in persons with dementia as Bell and Troxel⁷¹ and Berry⁷² have found in persons with moderate dementia. In Jolley et al.,³² PWDs with a mean score of 21 on the MMSE reported strong beliefs, with practices supporting their beliefs very important, spirituality evident in everyday experiences, and spirituality as a support in facing disease stressors.

Of the R/S categories in the VSM-RS, an association was identified only between individual R/S resources on the beliefs and practices subscale of the SBI-15R and spiritual well-being on the QLI psychological/spiritual subscale for QOL.³ No other R/S categories were examined for associations in our findings for this review. Exactly how R/S dimensions are associated with each other and how they influence health and well-being should be examined in future research.

5 | NURSING IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

The findings of this review indicate that PWDs or those with MCI may have lower spiritual well-being as they face a poor prognosis with an uncertain future, yet that some PWDs have the same levels of R/S as do those without dementia. The studies' ratings indicate a need for more high-quality research, with longitudinal designs to collect data at more than one time point, exploration of R/S mediators and moderators between stress and health outcomes in dementia, the use of blinding when two groups are involved, power analyses with effect sizes, control for confounders, and RCTs when possible. More research is needed to explore R/S mediators and moderators between stress in dementia and health. Perhaps religious coping or R/S resources could impact that relationship. A PWDs spirituality may change throughout the course from MCI to mild and then moderate disease. The findings of the studies reviewed here reveal the need for further examination of associations over time. Supporting the R/S of PWDs throughout the stages of their disease needs additional evaluation on QOL, well-being, behavioral and psychological expressions, and for coping.

PWDs may use R/S as a way to cope and work through their suffering to find faith, hope, life satisfaction, and meaning in their suffering, yet PWDs may be more dependent on others to support their R/S practices. Thus, nurses can assist by determining the religious and spiritual needs of persons with dementia. Nurses must reflect on their own spiritual understanding to be able to attend to others' spiritual needs. Referral to spiritual care experts (i.e., chaplains) can be used for those who have R/S needs beyond the compassion of a nurse's care and presence. Nurses could incorporate spiritual histories within social histories to identify PWDs who may have R/S preferences.⁷³

This review has revealed a need for further exploration of the intersection of religion, spirituality, and dementia using rigorous research methods. Future research should include prospective and longitudinal studies, as well as more RCTs of persons throughout the stages of disease, especially at end of life. Studying the progression of the disease and changes in religion and spirituality over time could be very useful for exploring spiritual care support in the future. There is a lack of spiritual interventions for this population, which faces distress and uncertainty. Research must develop, test, and apply reliable, valid instruments to measure the various constructs of religion and spirituality in PWDs, which include religiosity, spirituality, R/S coping, R/S resources, R/S needs, R/S preferences, and spiritual well-being. Studies should report religious beliefs and affiliations of samples for comparison of findings and transparency. Because racial and ethnic minorities find religion and spirituality important⁷⁴ and have a significantly higher incidence of dementia,⁷⁵ it should be a priority to use diverse samples when studying these constructs to increase our understanding of the roles of race, ethnicity, and culture among PWDs.

In this review, no studies were identified that measured spiritual needs or spiritual distress of PWDs, both of which may drive individuals to find meaning, purpose, and value in their lives,⁷⁶ and no studies were identified that recorded R/S preferences. Very few scales for measuring R/S in this population have been validated. More R/S measures

need to be created and validated for dementia and used in longitudinal studies to assess R/S constructs with greater precision, because PWDs report R/S as being important in their lives for dealing with their disease. Future measures will contribute greater knowledge of PWDs' R/S needs, practices, beliefs, and activities to inform future interventions to examine their impact on QOL and well-being in this vulnerable population.

6 | LIMITATIONS

In this review, the quality of the included studies was evaluated and found to be fair to good. However, only one study was a RCT. The multiple definitions of the R/S constructs call for a standard definition because studies with similar terms yet different definitions make the interpretation and comparison of findings difficult. Also, R/S may differ across ethnicities and cultures, which limits generalizability. The evidence available is overwhelmingly dependent on the ability of PWDs to communicate with research teams.⁷⁷

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CONFLICTS OF INTEREST

The authors declare no competing interests in relation to this submission. Author disclosures are available in the [supporting information](#).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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