

Spiritual Well-Being in Appalachian Family Caregivers

Ubolrat Piamjariyakul, PhD, RN^{1*}

Stephanie Young, PhD, MSN, RN²

Saima Shafique, PhD, MPH³

Nathaniel Palmer⁴

Kesheng Wang, PhD⁵

¹ Associate Dean of Research, Office of Research and Scholarly Activities and Associate Professor, School of Nursing, West Virginia University, ubolrat.piamjariyakul@hsc.wvu.edu

² Clinical Assistant Professor, School of Nursing, West Virginia University, SAYERS1@hsc.wvu.edu

³ Research Specialist, School of Nursing, West Virginia University, ss0093@hsc.wvu.edu

⁴ Undergraduate Student, School of Public Health, West Virginia University, njp0022@mix.wvu.edu

⁵ Professor, School of Nursing, West Virginia University, kesheng.wang@hsc.wvu.edu

*Correspondence: Ubolrat Piamjariyakul

Abstract

Introduction: Dementia and heart failure (HF) are the most common co-existing end-of-life conditions among rural older adults requiring extensive caregiving. Studies conducted in Appalachia have found that caregivers report a lack of information about palliative care and managing complex care at home. They also indicate the need for spiritual support.

Purpose: This study aimed to assess the factors contributing to the spiritual well-being of caregivers in the rural Appalachian region.

Methods: This descriptive correlational design allowed the collection of surveys from caregivers (N= 20) of loved ones with the diagnosis of HF and dementia. A multiple regression analysis was performed on caregivers' spiritual well-being scores as the dependent variable. Factors impacting caregiving (i.e., measures of caregivers' preparedness for HF and dementia home care and patients' physical, emotional, and palliative care scale needs) were the independent variables.

Findings: The average age of these family caregivers was 64.95 years ($SD = 12.42$). These caregivers had a high median score on the spiritual well-being scale (32.5 out of 45). In the regression analysis, a large amount (53%) of variance in spiritual well-being was explained by caregivers' greater preparedness for HF and dementia home care ($p < .01$) and by informational communications about caregivers' practical care concerns ($p < .05$). These caregivers age, number of years of caregiving, and patients physical and emotional status did not statistically contribute to caregiver spiritual well-being.

Conclusion: The rural Appalachian population values spiritual well-being. There is a need for nurse-led interventions specific to HF and dementia home care to support caregivers' spiritual well-being and provide information about managing in-home care practical concerns. Nurses may also support caregivers' spiritual well-being by holding supportive caregiver discussion groups and setting up home visits and telephone contacts with their spiritual advocates.

Keywords: spiritual well-being, rural Appalachia, home caregiving, preparedness, communication, palliative care

Spiritual Well-Being in Appalachian Family Caregivers

This study was conducted within the rural Appalachian region among older adult family caregivers of Heart Failure (HF) and dementia. (Appalachian Regional Commission, n.d.). This region has the third largest population of adults aged 65 years and older in the United States (U.S.

Census Bureau, n.d.) who have high heart failure (HF) and dementia-related death rates (Centers for Disease Control and Prevention, n.d.; USAFACTS, n.d.). Appalachia is a mountainous rural region with limited access to healthcare services and few internet and cellular services (Callaghan et al., 2023). Thus, family caregivers report a lack of access to healthcare services and information (Vipperman et al., 2023). Previous studies described the Appalachians as independent-minded, family and spiritually oriented, and not trusting outsiders (Roberto et al., 2022).

Little has been published on rural family caregiving for older adults with HF and dementia, the most common co-existing end-of-life diseases of aging (Lalani et al., 2018; Lovell et al., 2019). Our previous studies with these caregivers found that a lack of specific information on the disease and palliative home care management were major concerns (Piamjariyakul et al., 2013; Piamjariyakul et al., 2015; Piamjariyakul et al., 2019; Young et al., 2023). Notably, these caregivers universally reported being unprepared by health professionals for managing HF, dementia, and palliative home care (Waligora et al., 2019).

Annually, about 53 million caregivers provide support and in-home care for family members with chronic illnesses and disabilities, and 24% of them care for Alzheimer's disease or dementia (Alzheimer's Association, 2023; National Alliance for Caregiving & AARP, 2020). Caregivers assist with patients' activities of daily living (i.e., dressing, bathing), perform essential day-to-day household chores (i.e., preparing meals, shopping), and coordinate care among different healthcare providers (Family Caregiver Alliance, n.d.). Evidence suggests that thorough communication with caregivers and spiritual support professionals can improve caregivers' readiness for complex and end-of-life home care (Hebert, Dang, et al., 2006; McDonagh et al., 2004).

Spiritual well-being is defined as feeling at peace and recognizing meaning in life, and for many includes having faith (Phenwan et al., 2019; Saffari et al., 2018). Spiritual well-being may

or may not include a specific ideology, religion, or spiritual practices (Goyarrola et al., 2023). However, it has been established that older adults, rural dwellers, Appalachian families, and those providing palliative care value faith and church memberships (Mixer et al., 2023). Notably, many philosophers, social-psychologists, and religious leaders write about spiritual well-being based on prayer or positive thoughts. This often aligns with religious beliefs such as ‘care for your neighbors.’ Caregiving with limited spiritual support and without the know-how to manage a specific chronic illness can compromise the patient’s and caregiver’s overall health and spiritual well-being (Holm et al., 2015; Schulz & Beach, 1999).

Spiritual well-being has been found to mediate the effects of caregiver burden on caregivers’ health and can help the caregiver manage the patients’ healthcare demands (Saffari et al., 2018). In addition, spiritual well-being sustains family caregivers during times when their loved ones are experiencing deterioration, entering palliative care, and facing death (Lalani et al., 2018; O’Callaghan et al., 2020). Unfortunately, few studies have been conducted on caregivers’ spiritual well-being, including during palliative care (Ødbehr et al., 2017; Tirgari et al., 2022; Tobin et al., 2022). These Appalachian caregivers also expressed the need to maintain their spiritual well-being (Young et al., 2023). Thus, this follow-up study was undertaken to fill in the gaps in information needed to sustain caregivers’ spiritual well-being while managing home HF and dementia care.

Preparedness is defined as caregivers' readiness to assume and sustain the role of caregiving (Hebert, Schulz, et al., 2009). A significant component of preparedness is communication between caregivers and healthcare providers (Hagedoorn et al., 2020). It is well known that end-of-life communications with healthcare providers are among the most important but often neglected aspects of palliative care (Holm et al., 2015). Notably, higher preparedness scores have been associated with caregivers’ positive health outcomes, lower depression, anxiety, and burden, and

greater caregiver hope and quality of life among caregivers (Petruzzo et al., 2019). Caregivers report the need for information to manage many unanticipated behaviors of those patients with dementia (Werner et al., 2017). Moreover, when dementia is complicated with HF, home care becomes much more complex (Bressan et al., 2020).

As with other life-limiting illnesses, HF home care includes demanding medication and treatment schedules and daily patient monitoring and symptom reporting requirements (Lovell et al., 2019; Nicastri et al., 2021). Therefore, it is essential to determine any relationships of preparedness and communication with healthcare providers that could improve spiritual well-being among caregivers. This is a follow-up study based on caregiver's description of their spiritual well-being as necessary to home care management for patients with end-of-life HF disease, dementia, and palliative care needs (Piamjariyakul et al., 2016; Piamjariyakul et al., 2019; Young et al., 2023).

Purpose

The purpose of this study was to determine the factors impacting the spiritual well-being of caregivers providing in-home care for patients with HF and dementia. The research question was: What are the independent variable measures (i.e., caregivers' demographics, preparedness for HF and dementia home care, and patient's physical, emotional, communication and practical care aspects) that explain significant variance in caregivers' spiritual well-being?

Theoretical Framework Guiding the Study

This study was guided by the theoretical framework of caregivers' preparedness developed by Hebert, Prigerson, and colleagues (2006). Preparedness was defined as the readiness of the caregivers for home care, which should include conversations about the patient's prognosis, advance care planning, anticipatory grief, and spiritual needs (Hebert, Schulz, et al., 2009; Holm

et al., 2015). The model verified that better communication from healthcare providers to caregivers about care demands enhanced caregivers' spiritual well-being (Hebert, Prigerson et al., 2006). The underlying components of preparedness for in-home caregiving included meeting caregivers' psychological, spiritual, and practical home care informational needs (Hebert, Prigerson et al., 2006; Petruzzo et al., 2019). The model also recommended that preparedness communication should accommodate the caregivers' own health and concerns, particularly regarding disease-specific and palliative home caregiving (Hagedoorn et al., 2020; Hebert, Prigerson et al., 2006).

Methods

Design, Sample, and Setting

This study used a descriptive correlational design. The study was conducted in rural Appalachia from September 2020 through December 2022. Inclusion criteria were adult family caregivers (age 18 and older), who were designated as the non-paid primary family members providing home care for patients with HF and dementia. The patients were 55 years and older, with the diagnosis of HF marked by limitation of physical activity but comfort at rest (NYHA II & III, or Stages B & C; Tsao et al., 2023) and mild to moderate vascular dementia (stage 1 to 5 on the Functional Assessment Staging; Alzheimer's Association, 2023). Exclusion criteria were family caregivers with a disability that precluded their ability to complete the survey. Both patients and family caregivers signed consent forms to participate. A research assistant nurse was trained to enroll participants. All participants signed the IRB-approved consent form to participate.

Data Collection

Family caregivers completed the following questionnaires that included caregivers' demographic characteristics, caregivers' rating on the Integrated Palliative Care Outcome Scale (IPOS) of the patient's symptoms and care needs, caregivers' preparedness for HF and dementia

home care scale, and the caregiver spiritual well-being questionnaire the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp-12). These questionnaires were combined into one short survey administered by a trained research assistant who did not provide direct clinical care to the patients or family caregivers. The survey took 20-30 minutes to complete. The survey answers were entered into a secured Qualtrics database and exported to SPSS for data analysis.

Ethical Consideration

The University Institution Review Board (IRB) approved the study (IRB No. 2006024614). The privacy and confidentiality of the study participants were protected. Participants' names were replaced with assigned study numbers that were anonymous. Data were stored on an encrypted firewall-protected server. All research staff completed the NIH-approved Human Subjects Protection Certification through the Collaborative Institutional Training Initiative and abided by the Health Sciences Center human subject's protection policy.

Measures

Dependent Variable

Caregivers' Spiritual well-being was measured by the FACIT-Sp-12 questionnaire. This measure has been validated in caregiving studies of patients with various chronic illnesses, including HF, dementia, and palliative care (Canada et al., 2008; Rogers et al., 2017; Santana-Berlanga et al., 2020). The 12-item FACIT-Sp-12 is the most used spiritual well-being scale, comprising two subscales measuring 8-item concepts of peace/meaning in life and the 4-item faith subscale (Canada et al., 2008). A sample question for peace was "I feel peaceful," a sample item for meaning was "I have a reason for living," and a sample item for faith was "I find comfort in my faith or spiritual beliefs." The 4-point Likert response options ranged from not at all (score =

0) to very much (score = 4). Total scores from the 12 items were calculated; a higher total score indicated better spiritual well-being. The Cronbach's alpha (α) was .91 for the total scale; $\alpha = .87$ for peace/meaning in life, and $\alpha = .91$ for faith subscales.

Independent Variables

The IPOS is a valid and reliable measure to assess the patients' physical, psychological, emotional, and spiritual well-being and the provision of information and support. (Murtagh et al., 2019). The IPOS is a 17-item, 5-point Likert scale with three subscales (Schildmann et al., 2016). This scale is valid for use in various clinical populations such as dementia (Collins et al., 2015), and other palliative care studies (Murtagh et al., 2019; Oriani et al., 2019). The 10-item patient physical items (i.e., pain, weakness, mobility, etc.) were rated by symptom impact or severity, with scores ranging from 0 (not at all) to 4 (overwhelming/severe). The 4-item emotional ratings include patient anxiety, depression, feeling at peace, and caregiver anxiety. In addition, there are two items to measure communication issues (caregiver sharing feelings, information needs) rated by frequencies ranging from 0 (not at all) to 4 (always). The last item on the Likert scale is a question of whether the practical problems related to the patient's illness have been addressed, which is rated from 0 (no problems) to 4 (problems not addressed). The higher scores of each IPOS subscale represent severe symptoms, poorer communication, and worse practical care concerns. The Cronbach's alpha (α) was .84 for the total IPOS scale; $\alpha = .80$ for physical (IPOS1), $\alpha = .78$ for emotional (IPOS2), and $\alpha = <.70$ for communication/practical concern subscale. In addition, there is the open-ended question on the IPOS questionnaire for the participants to describe their most important problems or concerns (other than those listed in the IPOS home care ratings items).

Preparedness for managing heart failure and dementia in-home caregiving is another independent variable in this study. Preparedness was measured by a 2-item, 5-point Likert scale

for each condition of HF and dementia (Prep_HF_Dementia). Family caregivers were asked: “How well prepared do you think you are to manage the daily home caregiving for (a) heart failure and (b) dementia?” Response options range from not at all (0) to very well prepared (4); a higher score indicated more preparedness (Smith et al., 2010). Overall, preparedness was defined as caregivers' readiness to assume and sustain the role of caregiving in palliative care (Hebert et al., 2009). Family caregivers' preparedness was linked to improved patient symptoms and mental health (Hagedoorn et al., 2020; Henriksson & Årestedt, 2013). In addition, caregivers completed demographic questions including their age, gender, race/ethnicity, level of education, employment, health insurance, and years of home caregiving for HF and dementia care.

Data Analyses

Descriptive statistical analysis was used for demographic variables, scales, and subscales. The initial correlations among the demographics, independent, and dependent variables (FACIT-Sp-12 scale and three subscales) were calculated. Independent variables significantly associated with dependent variables ($p < .05$) were selected and entered into the multiple regression model for the dependent variable (Spiritual well-being total score; Kutner et al., 2004). In the regression analyses, the adjusted R^2 identifies the proportion of variance of the dependent variable explained by the independent variables. The beta weight (β) indicates each independent variable's positive or negative relationship with the dependent variable. A significant F ratio and $p < .05$ in the analysis can be established to indicate a good fit of the data in the regression model. All the analyses were conducted using SPSS version 28 (IBM, Corp, 2021). In addition, the responses to the IPOS open-ended question asking caregivers about their most important caregiving problems or concerns were summarized.

Results

Demographic and Descriptive Analyses

Of 20 family caregivers, the majority were white ($n = 19$, 95%), and female ($n = 16$, 80%). Eight (40%) were spouses, nine (45%) were daughters/sons, and three (15%) were siblings or significant others. The average age of family caregivers was 64.95 ($SD = 12.42$), ranging from 40 to 80 (an outlier). The average length of home caregiving for HF was 6 years ($SD = 4.97$) and 4.29 years ($SD = 4.82$) for dementia, including one caregiver reported 20 years of caregiving for HF and dementia (an outlier). The majority of these caregivers in this study are in the early years of caregiving on average for HF (3.5 years) and dementia (2.5 years), with HF occurring prior to vascular dementia. Five caregivers (25%) were currently employed, and 15 (75%) were either retired or disabled. Six (30%) completed high school, seven (35%) had some college, and another seven (35%) completed college or higher. Family caregivers had Medicare (40%), private health insurance (35%), Medicaid (15%), and Military or other (10%) insurance coverage. Of 20 family caregivers, 7 (35%) reported their family income adequacy as unable to make ends meet or have just enough, no more. (See Table 1).

Table 1

Demographic Variables of Family Caregivers (N=20)

| Variables | Frequency (n, %) |
|-----------------------|------------------|
| Gender | |
| Female | 16 (80.0) |
| Male | 4 (20.0) |
| Ethnicity* | |
| Non-Hispanic | 18 (100%) |
| Hispanic | 0 |
| Race (n, %) | |
| White | 19 (95.0) |
| Black | 1 (5.0) |
| Marital status (n, %) | |

| | |
|---|---|
| Married | 14 (70.0) |
| Widowed, Divorced, Never married (2 each) | 6 (30.0) |
| Relationship with patient | |
| Spouse (husband/wife) | 8 (40) |
| Daughter/Son | 9 (45) |
| Sibling or significant other | 3 (15) |
| Education level (n, %) | |
| ≤High school | 6 (30.0) |
| Vocational/some college | 7 (35.0) |
| Completed college or more | 7 (35.0) |
| Employed (Yes, No) | |
| Yes | 5 (25.0) |
| No (Retired, n=8; Retired & disabled, n=6; Disabled, n=1) | 15 (75.0) |
| Health insurance | |
| Medicare | 8 (40.0) |
| Private | 7 (35.0) |
| Medicaid | 3 (15.0) |
| Others (i.e. Military) | 2 (10.0) |
| Income adequacy** | |
| I can't make ends meet (1) | 2 (10.0) |
| I have just enough; no more (2) | 5 (25.0) |
| I have enough, a little extra sometimes (3) | 6 (30.0) |
| I always have money left over (4) | 7 (35.0) |
| Number of people in the household (Median) | 2.00 (range 2 – 4) |
| Caregivers' age in years | 64.95 (12.42) Range 40-80, Median = 68.5 |
| HF caregiving in years | 6.00 (4.97) Range 1-20, *** Median = 3.5 |
| Dementia caregiving in years | 4.29 (4.82) Range 0.5 – 20, *** Median = 2.5 |

*Missing data (n=2)

**Scores were categorized into binary variables (score 1 to 2 = 1, score 3 to 4 = 2) for income adequacy

*** One caregiver reported provision of HF and dementia care for 20 years (an outlier)

Three caregivers wrote about the patient's anxiety when asked to name their most important caregiving problem. One caregiver reported being overwhelmed by the patient's agitation, anger, easy upsets, and inability to find the right words. There were three comments on various aches and pains their patients experienced. Also, sleep deprivation was a continuing problem, including one

patient's sleep apnea that was associated with their HF decline. Descriptive statistics of independent and dependent variable scores are shown in Table 2.

Table 2

Mean, Standard Deviation of Dependent (Spiritual Well-Being) and Independent Variables

| Variables | <i>M (SD)</i> | Possible Range | Median |
|--|----------------------|-----------------------|---------------|
| FACIT-Sp-12 Scale (Spiritual Well-being) | 30.78 (10.63) | 11-45 | 32.5 |
| Prep-HF-Dementia | 4.47 (1.31) | 2-7 | 4 |
| IPOS1_Physical | 10.33 (5.72) | 2-21 | 9.5 |
| IPOS2_Emotional | 5.83 (3.63) | 0-16 | 5.83 |
| IPOS3_Communication/practical | 4.06 (2.21) | 0-8 | 4.03 |

Multiple Regression Analysis Results

In the initial binary analysis, no significant associations existed between the caregiver's demographic variables and the dependent variable of spiritual well-being. Thus, no demographic variables were included in the multiple regression analysis. Four independent variables (preparedness for HF and dementia home caregiving, IPOS1-physical symptoms, IPOS2-emotional symptoms, and IPOS3-communication/practical issues having significant association with spiritual well-being were entered into the final multiple regression analysis.

Overall, 53% of the variance in spiritual well-being was explained by higher preparedness scores for HF and dementia home care ($\beta = .53, p < .01$) and lower scores for IPOS3-communications/practical problems ($\beta = -.70, p < .05$). The regression F ratio was ($F(4,15) = 4.16, p < .05$) indicating a good fit of the significant independent variables to the dependent spiritual well-being variable. Patients' physical (IPOS1) and emotional (IPOS2) symptom ratings from the

IPOS scale did not contribute variance to caregivers' spiritual well-being. See Table 3. The average caregiver spiritual well-being score was 30.78 ($SD = 10.63$), with a high median score of 32.5 out of the top score of 45.

Table 3

Multiple Regression Analyses for Spiritual Well-Being among Family Caregivers (N=20).

| Independent Variables | Unstandardized Coefficients <i>B</i> | Standard Error <i>SE</i> | Standardized Coefficients <i>Beta β</i> | Sig |
|---|--|-----------------------------|---|--------|
| Preparedness for HF & Dementia Caregiving | 4.28 | 1.45 | .53 | <.01** |
| IPOS1-Physical | -.38 | .35 | -.20 | .30 |
| IPOS2-Emotional | 1.56 | .83 | .53 | .08 |
| IPOS3-Communication/Practical | -3.36 | 1.36 | -.70 | <.05* |
| R^2 | | .53 | | |
| F | | 4.16* | | |

* $p < .05$; ** $p < .01$

Discussion

Our findings from this multiple regression analysis indicated that caregivers' preparedness and better communication were largely ($R^2 = .53$) related to the spiritual well-being of family caregivers providing in-home care for patients with HF and dementia. Specifically, communicating with caregivers and providing information on in-home management of patient's medical care regimens was related to their spiritual well-being. Providing complete and specific information to these caregivers over time and preparing them for the inevitable problems of decline and loss could help maintain their spiritual well-being. When caregivers are prepared, they possibly have greater peace of mind, a component of spiritual well-being. These results demonstrate components in the

study framework of meeting caregivers' health, informational, and practical needs for caregiving preparedness, which relates to their spiritual well-being.

Our results were consistent with a recent study showing that communication and collaboration with nurses and other healthcare providers increased family caregivers' preparedness to provide specific home care (Hagedoorn et al., 2020). Further, better preparedness had a positive association with caregivers' health outcomes, including lower depression and anxiety, lesser home caregiving burden, and greater quality of life (Petruzzo et al., 2019). Systematic reviews showed that higher spiritual well-being helps caregivers to handle psychological distress, physical symptoms, and other caregiving challenges (Balboni, et al., 2022; Ferrell, et al., 2013). Spiritual well-being can help improve caregivers' overall health and reduce their burden and anxiety while managing end-of-life multiple chronic illnesses (Monteiro et al., 2018; Petruzzo et al., 2019; Tirgari et al., 2022).

Studies report that finding meaning in life by helping others (McLennon et al., 2011), and maintaining engagement with others were related to improved spiritual well-being (Strange et al., 2023). One study showed that caregivers with lower preparedness scores displayed lower spiritual growth scores (Dionne-Odom et al., 2016). Previous studies have shown a link between caregivers' preparedness and psychosocial well-being (Wang et al., 2013; Wu et al., 2022).

Caregivers in this study had high median scores on spiritual well-being (32.5 out of 45), reflecting the prevailing sense of value for spiritual well-being in rural Appalachia, where these caregivers lived (Strange et al., 2023). Spiritual concerns can be addressed by seeking out social support from faith community groups and providing supportive caregiver groups per caregivers' needs (Lentz, 2018). However, caregivers attending such groups might require leaving the patient alone. Thus, providing spiritual support using home visits by a caregiver's advisor or clergy of

choice might be another option (Ross & Miles, 2020). Also, spiritual radio or television programs can be beneficial to caregivers managing serious illnesses, and these activities would not require leaving the home (Soroka, et al., 2019). Other strategies, specifically in rural areas may include home communication interventions such as a visiting neighbor program, supportive caregiver discussion groups, or telephone contact lists for spiritual advocates (Piamjariyakul et al., 2019; Piamjariyakul et al., 2023)

In palliative home care, the research indicates preparedness should include helping caregivers realize the seriousness of the situation, guiding their palliative home management skills, and helping caregivers anticipate future challenges (Holm et al., 2015). Nurse-led interventions in palliative care are regarded as essential for preparing caregivers for in-home care (Kavalieratos et al., 2017; Piamjariyakul, et al., 2016). Repeated clear communication between caregivers and healthcare providers results in greater caregiver preparedness. Preparedness and communication improve psychological adjustments, necessary for caregivers to be ready for the patient's palliative care needs and patients' death (Hauser, 2017).

Notably, in the current study, the patients' physical and emotional health scores were not significant in explaining caregivers' spiritual well-being. It is possible since these families were in the early years of HF and dementia care, the patient's symptoms were manageable (Kavalieratos et al., 2017). Also, it may be the high spiritual well-being of these caregivers gave them strength to manage regardless of the patient's health status. Further, these caregivers listed patients' sleep disturbance, anxiety, aches, and pain required constant challenging caregiving, which may impact caregivers' health. Nurses can assist with any issues regarding caregivers' health and improve their psychological status (Suksatan et al., 2022; Zhang et al., 2023).

Considering the escalating populations of older adults with co-existing HF and dementia, Appalachian family caregivers will continue to need preparedness and communication about home care (Hauser, 2017). Rural families are often isolated from specialty services and palliative care (Fernando et al., 2014). The rural distance from specialist providers and healthcare services might have influenced the caregivers' greater need for communication and home care information (Vipperman et al., 2023). Thus, it behooves healthcare professionals to better communicate and prepare rural-dwelling caregivers of family members with complex diseases and about palliative care needs. Only a few studies have examined the relationships between preparedness and spiritual well-being.

Limitations

This study's small sample size is a limitation to statistical and clinical significance. A longitudinal study with a larger sample is warranted to confirm significant measures associated with caregivers' spiritual well-being. Another limitation is that the sample was predominantly White females. These limitations preclude the generalizability of these findings. This small sample of rural Appalachian caregivers has high median spiritual well-being score. Thus, in practice, nurses can continue developing clinically safe home care interventions for supporting spiritual well-being in this population.

Implications for Nursing Practice

Heart failure and dementia patients make up a large population needing complex disease-specific information, palliative care, and support for their caregivers' spiritual well-being (Ross & Miles, 2020). Gaining an understanding of the factors associated with these caregivers' spiritual well-being can lead to nursing interventions that support in-home caregiving. For example, nursing interventions can include spiritual guidance by volunteer faith-based nurses in rural areas or

referral to spiritual advocates of the family's choice (Lentz, 2018; Ross & Miles, 2020). Nurses should also address questions about persons spirituality in their early assessments by not only asking if they have a religious preference but if they would want to have any of their beliefs considered in their nursing care.

Another recommendation from this study was to provide caregivers with specific home care information on the patients' illnesses and any identified caregiving concerns. Hebert and colleagues (2009) recommended that to better prepare family caregivers for palliative care, nurses must provide them with specific information tailored to their home care needs and continue communication for caregivers to seek and process the information. Also, integrating spiritual well-being support is a culturally appropriate intervention to help these patients and family caregivers in rural Appalachia manage health challenges (Mixer et al., 2023; Smothers et al., 2023).

Conclusion

A large (53%) amount of variance in these caregivers' spiritual well-being was explained by their preparedness, better communication, and practical information about home care. Thus, to enhance caregivers' spiritual well-being, nurses need interventions to increase their specific disease home care preparedness and communication about practical problems. Integrating spiritual well-being support for these caregivers is imperative. This small study addressed rural nursing care research, a larger longitudinal study is recommended to examine relationships between spiritual well-being and preparedness in caregivers.

Conflicts of Interest

These authors declare no conflicts of interest.

References

- Alzheimer's Association. (2023). 2023 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 19(4), 1598-1695. <https://doi.org/10.1002/alz.13016>
- Appalachian Regional Commission. (n.d.). *About the Appalachian region*. <https://www.arc.gov/about-the-appalachian-region/>
- Balboni, T. A., VanderWeele, T. J., Doan-Soares, S. D., Long, K. N. G., Ferrell, B. R., Fitchett, G., Koenig, H. G., Bain, P. A., Puchalski, C., Steinhauser, K. E., Sulmasy, D. P., & Koh, H. K. (2022). Spirituality in serious illness and health. *Journal of the American Medical Association*, 328(2), 184–197. <https://doi.org/10.1001/jama.2022.11086>
- Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, 28(6), 1942-1960. <https://doi.org/10.1111/hsc.13048>
- Callaghan, T., Kassabian, M., Johnson, N., Shrestha, A., Helduser, J., Horel, S., Bolin, J. N., & Ferdinand, A. O. (2023). Rural healthy people 2030: New decade, new challenges. *Preventive Medicine Reports*, 33, Article 102176. <https://doi.org/10.1016/j.pmedr.2023.102176>
- Canada, A. L., Murphy, P. E., Fitchett, G., Peterman, A. H., & Schover, L. R. (2008). A 3-factor model for the FACIT-Sp. *Psycho-Oncology*, 17(9), 908-916. <https://doi.org/10.1002/pon.1307>
- Centers for Disease Control and Prevention. (n.d.). *About underlying cause of death, 1999-2020*. <http://wonder.cdc.gov/ucd-icd10.html>
- Collins, E. S., Witt, J., Bausewein, C., Daveson, B. A., Higginson, I. J., & Murtagh, F. E. M. (2015). A systematic review of the use of the palliative care outcome scale and the support
- Online Journal of Rural Nursing and Health Care*, 24(1) <https://doi.org/10.14574/ojrnhc.v24i1.757>

team assessment schedule in palliative Care. *Journal of Pain and Symptom Management*, 50(6), 842–853. <https://doi.org/10.1016/j.jpainsymman.2015.07.015>

Dionne-Odom, J. N., Demark-Wahnefried, W., Taylor, R. A., Rocque, G. B., Azuero, A., Acemgil, A., Martin, M. Y., Astin, M., Ejem, D., Kvale, E. A., Heaton, K., Pisu, M., Partridge, E. E., & Bakitas, M. (2016). Differences in self-care behaviors by varying levels of caregiving intensity, performance, and well-being among family caregivers of patients with high-mortality cancer. *Journal of Clinical Oncology*, 34(26_suppl), 239-239. https://doi.org/10.1200/jco.2016.34.26_suppl.239

Family Caregiver Alliance. (n.d.). *Alzheimer's disease and caregiving*. <https://www.caregiver.org/alzheimers-disease-caregiving>

Fernando, J., Percy, J., Davidson, L., & Allan, S. (2014). The challenge of providing palliative care to a rural population with cardiovascular disease. *Current Opinion in Supportive and Palliative Care*, 8(1), 9-14. <https://doi.org/10.1097/SPC.0000000000000023>

Ferrell, B., Otis-Green, S., & Economou, D. (2013). Spirituality in cancer care at the end of life. *Cancer journal (Sudbury, Mass.)*, 19(5), 431–437. <https://doi.org/10.1097/PPO.0b013e3182a5baa5>

Goyarrola, R., Lipsanen, J., Saarelainen, S. M., Suviranta, R., Rahko, E., Lamminmäki, A., Klaavuniemi, T., Ahtiluoto, S., Ohvanainen, A., Metso, P., & Pöyhiä, R. (2023). Spiritual well-being correlates with quality of life of both cancer and non-cancer patients in palliative care - further validation of EORTC QLQ-SWB32 in Finnish. *BMC Palliative Care*, 22, Article 33. <https://doi.org/10.1186/s12904-023-01153-0>

Hagedoorn, E. I., Keers, J. C., Jaarsma, T., van der Schans, C. P., Luttik, M. L. A., & Paans, W. (2020). The association of collaboration between family caregivers and nurses in the hospital

and their preparedness for caregiving at home. *Geriatric Nursing*, 41(4), 373-380.
<https://doi.org/10.1016/j.gerinurse.2019.02.004>

Hauser J. (2017). Communication in heart failure and palliative care. *Heart Failure Reviews*, 22(5), 535-542. <https://doi.org/10.1007/s10741-017-9643-2>

Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine*, 9(3), 683-693. <https://doi.org/10.1089/jpm.2006.9.683>

Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, 9(5), 1164-1171. <https://doi.org/10.1089/jpm.2006.9.1164>

Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management*, 37(1), 3-12. <https://doi.org/10.1016/j.jpainsymman.2007.12.010>

Henriksson, A., & Årestedt, K. (2013). Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine*, 27(7), 639-646.
<https://doi.org/10.1177/0269216313486954>

Holm, M., Henriksson, A., Carlander, I., Wengström, Y., & Öhlen, J. (2015). Preparing for family caregiving in specialized palliative home care: An ongoing process. *Palliative & Supportive Care*, 13(3), 767-775. <https://doi.org/10.1017/S1478951514000558>

IBM Corp. (2021). *IBM SPSS statistics for windows (Version 28.0)* [Computer software]. Armonk, NY: IBM Corp.

- Kavalieratos, D., Gelfman, L. P., Tycon, L. E., Riegel, B., Bekelman, D. B., Ikejiani, D. Z., Goldstein, N., Kimmel, S. E., Bakitas, M. A., & Arnold, R. M. (2017). Palliative care in heart failure: Rationale, evidence, and future priorities. *Journal of the American College of Cardiology*, 70(15), 1919-1930. <https://doi.org/10.1016/j.jacc.2017.08.036>
- Kutner, M. H., Nachtsheim, C. J. & Neter, J. (2004) *Applied linear regression models* [4th Ed.]. McGraw-Hill/Irwin.
- Lalani, N., Duggleby, W., & Olson, J. (2018). Spirituality among family caregivers in palliative care: An integrative literature review. *International Journal of Palliative Nursing*, 24(2), 80-91. <https://doi.org/10.12968/ijpn.2018.24.2.80>
- Lentz J. C. (2018). An innovative role for faith community nursing: Palliative care ministry. *Journal of Christian Nursing*, 35(2), 112-119. <https://doi.org/10.1097/CNJ.0000000000000478>
- Lovell, J., Pham, T., Noaman, S. Q., Davis, M-C., Johnson, M., & Ibrahim, J. E. (2019). Self-management of heart failure in dementia and cognitive impairment: A systematic review. *BMC Cardiovascular Disorders*, 19, Article 99. <https://doi.org/10.1186/s12872-019-1077-4>
- McDonagh, J. R., Elliott, T. B., Engelberg, R. A., Treece, P. D., Shannon, S. E., Rubenfeld, G. D., Patrick, D. L., & Curtis, J. R. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*, 32(7), 1484-1488. <https://doi.org/10.1097/01.ccm.0000127262.16690.65>
- McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15(4), 522-530. <https://doi.org/10.1080/13607863.2010.543656>

- Mixer, S. J., Smith, J. L., Brown, M. L., & Lindley, L. C. (2023). Community-academic partnership: Intervention to prepare community members for the end-of-life journey. *Journal of Hospice and Palliative Nursing* 26(1), 41-48. <https://doi.org/10.1097/NJH.0000000000000995>
- Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer disease: A systematic review. *Trends in Psychiatry and Psychotherapy*, 40(3), 258-268. <https://doi.org/10.1590/2237-6089-2017-0065>
- Murtagh, F. E., Ramsenthaler, C., Firth, A., Groeneveld, E. I., Lovell, N., Simon, S. T., Denzel, J., Guo, P., Bernhardt, F., Schildmann, E., van Oorschot, B., Hodiament, F., Streitwieser, S., Higginson, I. J., & Bausewein, C. (2019). A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliative Medicine*, 33(8), 1045-1057. <https://doi.org/10.1177/0269216319854264>
- National Alliance for Caregiving & American Association of Retired Persons. (2020). *Caregiving in the U.S. 2020*. <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- Nicastri, C., Hensley, J., & Lane, S. (2021). Managing the forgetful patient: Best practice for cognitive impairment. *Medical Clinics of North America*, 105(1), 75-91. <https://doi.org/10.1016/j.mcna.2020.09.001>
- O'Callaghan, C., Seah, D., Clayton, J. M., Welz, M., Kissane, D., Georgousopoulou, E. N., & Michael, N. (2020). Palliative caregivers' spirituality, views about spiritual care, and

associations with spiritual well-being: A mixed methods study. *American Journal of Hospice and Palliative Medicine*, 37(4), 305-313. <https://doi.org/10.1177/1049909119877351>

Ødbehr, L. S., Hauge, S., Danbolt, L. J., & Kvigne, K. (2017). Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: A meta-synthesis. *Dementia*, 16(7), 911-929. <https://doi.org/10.1177/1471301215625013>

Oriani, A., Guo, P., Gadoud, A., Dunleavy, L., Kane, P., & Murtagh, F. E. M. (2019). What are the main symptoms and concerns reported by patients with advanced chronic heart failure?- A secondary analysis of the Palliative care Outcome Scale (POS) and Integrated Palliative care Outcome Scale (IPOS). *Annals of Palliative Medicine*, 8(5), 775-780. <https://doi.org/10.21037/apm.2019.08.10>

Petruzzo, A., Biagioli, V., Durante, A., Emberti Gialloreti, L., D'Agostino, F., Alvaro, R., & Vellone, E. (2019). Influence of preparedness on anxiety, depression, and quality of life in caregivers of heart failure patients: Testing a model of path analysis. *Patient Education and Counseling*, 102(5), 1021-1028. <https://doi.org/10.1016/j.pec.2018.12.027>

Phenwan, T., Peerawong, T., & Tulathamkij, K. (2019). The meaning of spirituality and spiritual well-being among Thai breast cancer patients: A qualitative study. *Indian Journal of Palliative Care*, 25(1), 119-123. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6388600/pdf/IJPC-25-119.pdf>

Piamjariyakul, U., McKenrick, S., R., Smothers, A., Giolzetti, A., Melnick, H., Beaver, M., Shafique, S., Wang, K., WVU Advisory Committee Members (2023, October 5-6). A study protocol and feasibility report: A visiting neighbors program in rural West Virginia. [Poster Presentation]. Appalachian Translational Research Network, Morgantown, WV, United States. <https://appalachianresearchnetwork.org/page-1075481>

- Piamjariyakul, U., Petite, T., Smothers, A., Wen, S., Morrissey, E., Young, S., Sokos, G., Moss, A. H., & Smith, C. E. (2019). Study protocol of coaching end-of-life palliative care for advanced heart failure patients and their family caregivers in rural Appalachia: A randomized controlled trial. *BMC palliative care*, 18(1), Article 119. <https://doi.org/10.1186/s12904-019-0500-z>
- Piamjariyakul, U., Smith, C. E., Russell, C., Werkowitch, M., & Elyachar, A. (2013). The feasibility of a telephone coaching program on heart failure home management for family caregivers. *Heart & Lung*, 42(1), 32–39. <https://doi.org/10.1016/j.hrtlng.2012.08.004>
- Piamjariyakul, U., Smith, C. E., Werkowitch, M., Thompson, N., Fox, M., Williamson, K. P., & Olson, L. (2016). Designing and testing an end-of-life discussion intervention for African American patients with heart failure and their families. *Journal of Hospice and Palliative Nursing*, 18(6), 528–535. <https://doi.org/10.1097/NJH.0000000000000290>
- Piamjariyakul, U., Werkowitch, M., Wick, J., Russell, C., Vacek, J. L., & Smith, C. E. (2015). Caregiver coaching program effect: Reducing heart failure patient rehospitalizations and improving caregiver outcomes among African Americans. *Heart & Lung*, 44(6), 466–473. <https://doi.org/10.1016/j.hrtlng.2015.07.007>
- Roberto, K. A., Savla, J., McCann, B. R., Blieszner, R., & Knight, A. L. (2022). Dementia family caregiving in rural Appalachia: A sociocultural model of care decisions and service use. *Gerontology Series B, Psychological Sciences and Social Sciences*, 77(6), 1094–1104. <https://doi.org/10.1093/geronb/gbab236>
- Rogers, J. G., Patel, C. B., Mentz, R. J., Granger, B. B., Steinhauser, K. E., Fiuzat, M., Adams, P. A., Speck, A., Johnson, K. S., Krishnamoorthy, A., Yang, H., Anstrom, K. J., Dodson, G. C., Taylor, D. H., Jr, Kirchner, J. L., Mark, D. B., O'Connor, C. M., & Tulsky, J. A. (2017).

Palliative care in heart failure: The PAL-HF randomized, controlled clinical trial. *Journal of the American College of Cardiology*, 70(3), 331-341. <https://doi.org/10.1016/j.jacc.2017.05.030>

Ross, L., & Miles, J. (2020). Spirituality in heart failure: A review of the literature from 2014 to 2019 to identify spiritual care needs and spiritual interventions. *Current Opinion in Supportive and Palliative Care*, 14(1), 9-18. <https://doi.org/10.1097/SPC.0000000000000475>

Saffari, M., Koenig, H. G., O'Garro, K. N., & Pakpour, A. H. (2018). Mediating effect of spiritual coping strategies and family stigma stress on caregiving burden and mental health in caregivers of persons with dementia. *Dementia*, 0(0), 1-18. <https://doi.org/10.1177/1471301218798082>

Santana-Berlanga, N. D. R., Porcel-Gálvez, A. M., Botello-Hermosa, A., & Barrientos-Trigo, S. (2020). Instruments to measure quality of life in institutionalised older adults: Systematic review. *Geriatric Nursing*, 41(4), 445-462. <https://doi.org/10.1016/j.gerinurse.2020.01.018>

Schildmann, E. K., Groeneveld, E. I., Denzel, J., Brown, A., Bernhardt, F., Bailey, K., Guo, P., Ramsenthaler, C., Lovell, N., Higginson, I. J., Bausewein, C., & Murtagh, F. E. (2016). Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the integrated palliative care outcome scale. *Palliative Medicine*, 30(6), 599-610. <https://doi.org/10.1177/0269216315608348>

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215-2219. <https://doi.org/10.1001/jama.282.23.2215>

Smith, C. E., Piamjariyakul, U., Yadrich, D. M., Ross, V. M., Gajewski, B., & Williams, A. R. (2010). Complex home care: Part III-economic impact on family caregiver quality of life and

patients' clinical outcomes. *Nursing Economic\$,* 28(6), 393-414. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3075108/>

Smothers, A., Morrissey, E., Melnick, H., Beaver, M., Wang, K., & Piamjariyakul, U. (2023). COVID-19 caregiving strategies, quality of life, and stress among faith community nurses and faith leaders in Appalachia. *Journal of Christian Nursing,* 40(1), 36-41. <https://doi.org/10.1097/CNJ.0000000000001017>

Soroka, J. T., Collins, L. A., Creech, G., Kutcher, G. R., Menne, K. R., & Petzel, B. L. (2019). Spiritual care at the end of life: Does educational intervention focused on a broad definition of spirituality increase utilization of chaplain spiritual support in hospice? *Journal of Palliative Medicine,* 22(8), 939–944. <https://doi.org/10.1089/jpm.2018.0579>

Strange, K. E., Troutman-Jordan, M., & Mixer, S. J. (2023). Influence of spiritual engagement on Appalachian older adults' health: A systematic review. *Journal of Psychosocial Nursing and Mental Health Services,* 61(5), 45-52. <https://doi.org/10.3928/02793695-20221026-02>

Suksatan, W., Tankumpuan, T., & Davidson, P. M. (2022). Heart failure caregiver burden and outcomes: A systematic review. *Journal of Primary Care & Community Health,* 13, 1-19. <https://doi.org/10.1177/21501319221112584>

Tirgari, B., Khaksari, M., Soltani, Z., Mirzaee, M., Saberi, S., & Bashiri, H. (2022). Spiritual well-being in patients with chronic diseases: A systematic review and meta-analysis. *Journal of Religion and Health,* 61, 3969-3987. <https://doi.org/10.1007/s10943-022-01595-5>

Tobin, R. S., Cosiano, M. F., O'Connor, C. M., Fiuzat, M., Granger, B. B., Rogers, J. G., Tulskey, J. A., Steinhauer, K. E., & Mentz, R. J. (2022). Spirituality in patients with heart failure. *JACC. Heart Failure,* 10(4), 217-226. <https://doi.org/10.1016/j.jchf.2022.01.014>

- Tsao, C. W., Aday, A. W., Almarzooq, Z. I., Anderson, C. A. M., Arora, P., Avery, C. L., Baker-Smith, C. M., Beaton, A. Z., Boehme, A. K., Buxton, A. E., Commodore-Mensah, Y., Elkind, M. S. V., Evenson, K. R., Eze-Nliam, C., Fugar, S., Generoso, G., Heard, D. G., Hiremath, S., Ho, J. E., Kalani, R., ... American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee (2023). Heart disease and stroke statistics-2023 update: A report from the American Heart Association. *Circulation*, 147(8), e93-e621. <https://doi.org/10.1161/CIR.0000000000001123>
- United States Census Bureau. (n.d.). *Population Estimates*. <https://www.census.gov/quickfacts/fact/table/>
- USAFACTS. (n.d.). *Health in America. How has the death rate changed in the US?* <https://usafacts.org/topics/health#how-has-the-death-rate-changed-in-the-us>
- Vipperman, A., Savla, J., Roberto, K. A., & Burns, D. (2023). Correction: Barriers to service use among dementia family caregivers in rural Appalachia: Implications for reducing caregiver overload. *Prevention Science*, 24(5), 961. <https://doi.org/10.1007/s11121-023-01528-y>
- Waligora, K. J., Bahouth, M. N., & Han, H-R. (2019). The self-care needs and behaviors of dementia informal caregivers: A systematic review. *The Gerontologist*, 59(5), e565-e583. <https://doi.org/10.1093/geront/gny076>
- Wang, Y-N., Shyu, Y. I. L., Tsai, W-C., Yang, P-S., & Yao, G. (2013). Exploring conflict between caregiving and work for caregivers of elders with dementia: A cross-sectional, correlational study. *Journal of Advanced Nursing*, 69(5), 1051-1062. <https://doi.org/10.1111/j.1365-2648.2012.06092.x>
- Werner, N. E., Stanislawski, B., Marx, K. A., Watkins, D. C., Kobayashi, M., Kales, H., & Gitlin, L. N. (2017). Getting what they need when they need it: Identifying barriers to information

needs of family caregivers to manage dementia-related behavioral symptoms. *Applied Clinical Informatics*, 8(1), 191-205. <https://doi.org/10.4338/ACI-2016-07-RA-0122>

Wu, Q., Yamaguchi, Y., & Greiner, C. (2022). Factors associated with the well-being of family caregivers of people with dementia. *Psychogeriatrics*, 22(2), 218-226. <https://doi.org/10.1111/psyg.12805>

Young, S., Smith, M., Shafique, S., & Piamjariyakul, U. (2023). You're not who you used to be: A case report of a family living with heart failure and vascular dementia. *Home Healthcare Now*, 41(3), 140–148. <https://doi.org/10.1097/NHH.0000000000001165>

Zhang, J., Wang, J., Liu, H., & Wu, C. (2023). Association of dementia comorbidities with caregivers' physical, psychological, social, and financial burden. *BMC Geriatrics*, 23(1), Article 60. <https://doi.org/10.1186/s12877-023-03774-9>