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Research Article

Purpose in Life Among Family Care Partners Managing Dementia: Links to Caregiving Gains

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Abstract

Background and Objectives: Purpose in life is associated with better health and has been found to minimize caregiving stress. Greater purpose may also promote caregiving gains (i.e., rewards or uplifts from providing care), yet the implications of purpose for positive aspects of the care role are largely unknown. The present study determined how perceptions of purpose in life among persons with dementia (PWDs) and their family caregivers are linked to caregiving gains.

Research Design and Methods: This cross-sectional study examined 153 co-resident family caregivers drawn from the 2011 National Health and Aging Trends Study and National Study of Caregiving. Linear regressions were estimated to evaluate associations between caregivers' and PWDs' reports of their own purpose in life and caregivers' perceived caregiving gains, along with whether these associations vary by caregiver gender. Models controlled for caregivers' sociodemographic characteristics, relationship to the PWD, care tasks, role overload, negative caregiving relationship quality, and both care partners' chronic health conditions.

Results: Caregivers' higher purpose in life was significantly linked to greater caregiving gains. Beyond this association, PWDs' higher purpose in life was significantly associated with greater caregiving gains for women but not for men.

Discussion and Implications: Purpose in life is a psychological resource that contributes to positive caregiving outcomes. Interventions to improve caregiver well-being could benefit from strategies that strengthen and maintain feelings of purpose among caregivers and PWDs.

Keywords: Caregiving-informal, Caregiver rewards, Caregiver uplifts, Dementia, Family issues

Perceptions of purpose in life (e.g., the belief that one's life has direction and meaning) have been prospectively associated with better sleep quality (Kim, Hershner, & Strecher, 2015), lower incidence of depression (Wood & Joseph, 2010), cognitive decline (Wilson et al., 2013), disability (Boyle, Buchman, & Bennett, 2010), and mortality (Boyle,

Barnes, Buchman, & Bennett, 2009). Along with these protective health effects, a strong sense of purpose may mitigate the stress of caring for an older relative who is ill or disabled (Chow & Ho, 2012, 2015; Okamoto & Harasawa, 2009; Polenick, Kales, & Birditt, 2018). Greater purpose may also promote caregiving gains (i.e., rewards or uplifts

from the care role), perhaps especially in challenging situations such as caring for a person with dementia (PWD); but little is known about links between purpose in life and positive caregiving outcomes. Guided by Pearlin's stress process model and interdependence theory, this study draws from a nationally representative U.S. sample to examine how views of purpose in life among PWDs and family caregivers are linked to caregiving gains. We also considered whether these links vary by caregiver gender.

Purpose in Life and Caregiving Gains in the Dementia Care Context

The stress process model developed by Pearlin and colleagues holds that care-related stressors (e.g., PWDs' neuropsychiatric symptoms) and secondary strains (e.g., activity restrictions) can diminish caregiver well-being, even after accounting for background characteristics including age, educational attainment, and health conditions (Pearlin, Mullan, Semple, & Skaff, 1990; Pinquart & Sörensen, 2003). At the same time, caregivers commonly report gains that include fulfilling family commitments, mastering new skills, and overcoming challenges (Cohen, Colantonio, & Vernich, 2002; Lawton, Moss, Kleban, Glickman, & Rovine, 1991; Mackenzie & Greenwood, 2012; Pearlin et al., 1990; Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015). Beyond care-related stressors, caregiving gains have implications for the well-being of both care partners (i.e., caregiver and PWD) such as reduced caregiver burden and depression (Cohen et al., 2002; Mackenzie & Greenwood, 2012), higher caregiving relationship quality (Sánchez-Izquierdo et al., 2015), and lower likelihood of the PWD's institutionalization (Mausbach et al., 2004). Perceived gains are also linked to positive well-being indicators (e.g., life satisfaction) and may offset caregiving stress (Lawton, 1991; Mackenzie & Greenwood, 2012; Pinquart & Sörensen, 2003). The rapidly increasing number of PWDs in the United States and worldwide (Alzheimer's Association, 2017) signals the urgency to understand factors that contribute to gains among their family caregivers.

According to Pearlin's stress process model, psychological resources (e.g., personal mastery) buffer caregiving stress and improve caregiver well-being (Pearlin et al., 1990). Purpose in life is an understudied psychological resource that may promote caregiving gains in several ways. First, higher purpose could sustain one's motivation to provide care. People who perceive greater purpose are more able to persevere despite obstacles, which keeps them centered on valued goals such as supporting a loved one with dementia (Frankl, 1959; McKnight & Kashdan, 2009). Second, purpose aids psychological flexibility in adapting to the shifting demands of dementia care (McKnight & Kashdan, 2009). Perceptions of purpose are linked to proactive and flexible coping strategies that could make caregivers more resilient (Bonanno, Papa, Lalande, Zhang, & Noll, 2005; Souglers & Ranzijn, 2011). Third, purpose in

life fosters efficient resource allocation during stressful circumstances (McKnight & Kashdan, 2009). Higher purpose may support caregivers in regulating emotional and physiological responses to stress (Ishida & Okawa, 2006; Polenick et al., 2018). Similarly, caregivers with greater purpose may engage more frequently in self-care activities (e.g., exercise, regular check-ups) that maintain their health and ability to provide care (Hooker & Masters, 2016; Kim, Strecher, & Ryff, 2014). Taken together, previous work indicates that caregivers' perceived purpose may play a powerful part in shaping their long-term well-being.

Interdependence theory asserts that relational partners influence one another's thoughts, feelings, and behaviors (Rusbult & Van Lange, 2008). Thus, PWDs' reports of their purpose in life may also be consequential for caregivers' perceived caregiving gains. Although few studies consider PWDs' perspectives, they can reliably express their values and components of personal meaning such as feeling useful (e.g., Whitlatch, Feinberg, & Tucke, 2005; Whitlatch, Piiparinen, & Feinberg, 2009). Moreover, caregivers view meaningful activity as fundamental to preserving the PWD's personhood (Han & Radel, 2016; Roland & Chappell, 2015), which implies that purpose among PWDs may be a distinct resource for caregivers in addition to their own purpose. Bolstering this point, care recipients' psychological resources including confidence (Lyons et al., 2015), self-efficacy (Kershaw et al., 2015), and self-esteem (Chung, Bakas, Plue, & Williams, 2016) are associated with their caregiver's better mental and physical health, over and above caregivers' psychological resources. PWDs' sense of purpose may therefore be associated with caregiving gains beyond caregivers' perceptions of their own life purpose.

Potential gender differences

Pearlin's stress process model poses that caregiver gender is a key background characteristic that shapes caregiving experiences (Pearlin et al., 1990; Pinquart & Sörensen, 2006). We posit that the links between each care partner's perceived purpose and caregiving gains may be stronger for women than for men. Relative to men, women provide more hours of care, assist with a higher number of tasks, and report greater secondary strains (e.g., financial problems), burden, and depression (Pinquart & Sörensen, 2006; Polenick & DePasquale, 2018; Swinkels et al., 2017). Women are also more attuned and responsive to people's emotions in general (Christov-Moore et al., 2014) and within caregiving relationships (Calasanti, 2010). Collectively, prior research questions whether women's more intense care situations and heightened susceptibility to their own and the PWD's distress render each care partner's reported purpose more vital to caregiving gains. Supporting this possibility, higher purpose in life has been associated with fewer emotional caregiving difficulties among wives but not husbands (Polenick et al., 2018). To deliver tailored care, it is important to determine gender

variations in how PWDs' and caregivers' perceptions of purpose are linked to caregiving gains.

The Present Study

This study extends the literature by evaluating how caregivers' and PWDs' perceptions of purpose in life are associated with caregivers' reported caregiving gains. We examined co-resident family care partners from a nationally representative U.S. sample. We hypothesized that caregivers' and PWDs' higher purpose in life would be significantly linked to greater caregiving gains, controlling for caregivers' sociodemographic characteristics, relationship to the PWD, care tasks, role overload, negative caregiving relationship quality, and each care partner's chronic health conditions. We further predicted that these links would be significantly stronger for caregiving women than for caregiving men.

Design and Methods

Sample and Procedures

The sample included 153 informal caregivers of PWDs from the 2011 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC). Participants were eligible for NHATS if they were Medicare enrollees aged 65 and older, lived in the contiguous United States, and received health-related assistance in the past month with mobility, personal care, and/or household chores. Participants were recruited from a Medicare enrollment database using a stratified three-stage sampling design. Of the 12,411 contacted enrollees, 8,245 (71%) were interviewed.

NHATS participants were eligible for NSOC if they had at least one family or unpaid nonfamily helper who provided health-related assistance with mobility, self-care, household chores, and/or medical care activities. The 2,423 eligible NHATS participants had 4,935 eligible caregivers. Of the 3,362 (68.1%) caregivers for whom contact information was obtained, 2,007 (59.7%) completed a 30-min telephone interview.

Of the 2,007 participating caregivers, 739 cared for a person with probable dementia, which was determined in NHATS using the following (Kasper, Freedman, & Spillman, 2013a): (a) a reported diagnosis by the participant or a proxy; (b) meeting criteria for diagnosis based on the AD8, a frequently used and validated dementia screening interview (Galvin, Roe, Xiong, & Morris, 2006); or (c) scoring at least 1.5 standard deviations below the mean in two or more domains of cognitive testing including memory, executive function, and orientation. We selected 368 who lived with the PWD in the community because co-resident caregivers have greater exposure to the care situation than nonresident caregivers. To examine both caregivers' and PWDs' perceived purpose, we removed 210 caregivers whose PWD had a proxy respondent for health reasons (e.g., cognitive impairment). Five of the remaining

158 caregivers had missing data, resulting in an analytic sample of 153 caregivers. Most were the sole participating caregiver (74.5%), while others lived in households with two (23.5%) or three (2.0%) caregivers.

Measures

Purpose in life

Purpose in life was measured with an item derived from the widely used Ryff Scales of Psychological Well-Being (Ryff, 1989; Ryff & Keyes, 1995). Caregivers and PWDs reported the degree to which they agreed with the statement, "My life has meaning and purpose." Responses for caregivers ranged from 1 (*disagree strongly*) to 4 (*agree strongly*), and responses for PWDs ranged from 1 (*agree not at all*) to 3 (*agree a lot*). Prior research demonstrates that this item has construct validity and is associated with care-related outcomes (Polenick et al., 2018). Likewise, the subscale from which the item is adapted has shown high construct validity and test-retest reliability, with strong correlations between shortened and full versions (Cooke, Melchert, & Connor, 2016; Ryff, 1989; Ryff & Keyes, 1995).

Caregiving gains

On a scale from 1 (*not so much*) to 4 (*very much*), caregivers reported the extent to which caregiving has: (a) made them more confident about their abilities; (b) taught them to deal with difficult situations; (c) brought them closer to the PWD; and (d) given them satisfaction that the PWD receives good care. Mean scores were determined ($\alpha = .66$).

Caregiver gender

Caregiver gender was coded as 1 = *female* and 0 = *male*.

Covariates

We controlled for four caregiver background characteristics: age, educational attainment (1 = *no schooling completed* to 9 = *masters, professional, or doctoral degree*), relationship to the PWD (1 = *spouse*, 0 = *non-spouse*), and chronic health conditions. Caregivers reported whether they had been diagnosed with arthritis, cancer, diabetes, heart disease, hypertension, lung disease, and osteoporosis. Summed scores were calculated.

We also controlled for objective and subjective care-related stressors. Caregivers reported on their assistance with the PWD's activities of daily living (ADLs), instrumental activities of daily living (IADLs), and medical care activities. ADLs included bathing, dressing, eating, toileting, getting in/out of bed, and mobility inside/outside the house. IADLs included laundry, shopping, preparing meals, banking, and managing money. Medical care activities included keeping track of medications, giving shots/injections, managing medical tasks (e.g., ostomy care, IVs, testing blood), assisting with exercises, helping with a special diet, skin wound/sore care, teeth/denture care, foot

care (e.g., clipping nails), ordering medication, scheduling appointments, speaking to providers, helping to change/add a health insurance or drug plan, and other medical insurance matters. Summed scores were created for ADL/IADL assistance and medical care activities. PWDs or their proxies reported whether they had been diagnosed with arthritis, cancer, diabetes, heart disease, hypertension, lung disease, osteoporosis, and stroke. Summed scores were calculated.

Role overload was measured with three items assessing how much caregivers feel they (a) are exhausted when they go to bed at night; (b) have more things to do than they can handle; and (c) do not have time for themselves (1 = *very much*, 2 = *somewhat*, 3 = *not so much*). Items were reverse coded and averaged ($\alpha = .79$). Negative caregiving relationship quality was ascertained from caregivers' reports of how much the PWD (a) argues with them; and (b) gets on their nerves from 1 (*a lot*) to 4 (*not at all*). Items were reverse coded and averaged, and the Spearman-Brown coefficient (recommended for two-item scales) was .63.

Statistical Analysis

We conducted hierarchical linear regressions to allow for examination of the variance in caregiving gains that is explained with each model step. Although reports of purpose from both caregivers and PWDs were used as predictors, the outcome was caregivers' reported caregiving gains. The caregiver was the unit of analysis instead of the care dyad, and so the assumption of independence of observations was not violated (Kenny & Cook, 1999). In the first step, we entered the covariates. Caregivers' and PWDs' reports of purpose in life were added in the second step to evaluate their independent associations with caregiving gains. Two interaction terms (Caregivers' purpose \times Caregiver gender; PWDs' purpose \times Caregiver gender) were included in the third step to determine whether these links differed by caregiver gender. We explored the pattern of significant interactions by estimating simple slopes for caregiving women and men. Continuous predictors and covariates were mean centered. Models were estimated in SAS version 9.4 (SAS Institute, Inc., Cary, NC) with the NSOC analytic weight and statistical procedures to account for clustering and stratification in the complex survey design (Kasper, Freedman, & Spillman, 2013b).

Results

Table 1 presents caregiver background characteristics and scores on major variables. Gender differences were tested in preliminary analyses using independent *t*-tests and Pearson chi-square tests. Relative to caregiving men, caregiving women provided significantly greater ADL/IADL assistance [$t(151) = 2.43, p = .02$] and more medical care activities [$t(151) = 2.53, p = .01$]. Caregiving men were significantly more likely to care for a female PWD

Table 1. Background Characteristics and Scores on Major Variables for Family Caregivers

Variable	Caregiving women ($n = 96$)		Caregiving men ($n = 57$)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
CG age in years	63.75	15.60	67.33	16.72
CG chronic health conditions	1.85	1.37	1.65	1.48
CG ADL/IADL assistance	5.21*	2.65	4.11	2.81
CG medical care activities	6.01**	2.91	4.75	3.06
CG role overload	1.71	0.68	1.54	0.56
CG negative caregiving RQ	2.26	0.79	2.13	0.75
CG purpose in life	3.77	0.47	3.68	0.78
CG caregiving gains	3.62	0.41	3.71	0.38
PWD chronic health conditions	2.76	1.28	2.81	1.45
PWD purpose in life	2.55	0.65	2.60	0.62
	<i>n</i>	%	<i>n</i>	%
CG relationship to PWD				
Spouse	36	37.5	26	45.6
Adult child	47	49.0	20	35.1
Child-in-law	1	1.0	7	12.3
Grandchild	6	6.3	2	3.5
Sibling	3	3.1	0	0.0
Other relative	3	3.1	2	3.5
CG educational attainment				
High school graduate	29	30.2	15	26.3
Some college	15	15.6	14	24.6
College graduate	18	18.8	5	8.8
Post graduate	4	4.2	3	5.3
PWD gender (female)	52***	54.2	53	93.0

Note: $N = 153$ family caregivers. ADL/IADL = activities of daily living and independent activities of daily living; CG = caregiver; PWD = person with dementia; RQ = relationship quality.

*Significant difference between caregiving women and men at $p \leq .05$. **Significant difference between caregiving women and men at $p \leq .01$. ***Significant difference between caregiving women and men at $p \leq .001$.

$[\chi^2(1, N = 153) = 25.03, p < .001]$. Caregivers' and PWDs' reports of purpose were not significantly correlated.

Hierarchical regressions are shown in Table 2. Unstandardized coefficients, standardized betas, confidence intervals, and accounted variance are presented from each step of the model.

Associations Between Purpose in Life Among Care Partners and Caregiving Gains

Table 2 shows that caregivers' higher purpose in life was significantly associated with greater caregiving gains ($B = 0.09, \beta = .14, p = .01, 95\%$ confidence interval [CI] = [0.02, 0.15]). This association was not moderated by caregiver gender.

The association between PWDs' perceived purpose and caregivers' caregiving gains was moderated by caregiver gender ($B = 0.23, \beta = .30, p = .01, 95\%$ CI = [0.06, 0.41]). PWDs' higher purpose in life was significantly linked to

Table 2. Associations Between Perceptions of Purpose in Life Among Care Partners and Caregivers' Reported Caregiving Gains

Predictor	Caregivers' caregiving gains					ΔR^2
	<i>B</i>	<i>SE</i>	β	95% CI		
Step 1						
Intercept	3.66***	.07	—	3.52, 3.80		.10
CG gender (female)	-0.14	.09	-.17	-0.31, 0.03		
CG age in years	-0.002	.002	-.09	-0.01, 0.003		
CG educational attainment	-0.03	.02	-.13	-0.07, 0.02		
CG relationship to PWD (spouse)	0.13	.12	.16	-0.11, 0.37		
CG chronic health conditions	-0.02	.03	-.05	-0.08, 0.05		
CG ADL/IADL assistance	-0.004	.01	-.03	-0.03, 0.02		
CG medical care activities	0.03**	.01	.24	0.01, 0.05		
CG role overload	-0.07	.06	-.11	-0.19, 0.05		
CG negative caregiving RQ	-0.03	.05	-.05	-0.13, 0.07		
PWD chronic health conditions	-0.01	.03	-.03	-0.07, 0.05		
Step 2						
CG purpose in life	0.09**	.03	.14	0.02, 0.15		.04
PWD purpose in life	0.09	.05	.14	-0.02, 0.20		
Step 3						
CG purpose in life × CG gender	0.07	.09	.07	-0.11, 0.25		.04
PWD purpose in life × CG gender	0.23**	.09	.30	0.06, 0.41		
Total R^2	.18					

Note: $N = 153$ family caregivers. Estimates are presented from each step of the model. ADL/IADL = activities of daily living and independent activities of daily living; CG = caregiver; CI = confidence interval; PWD = person with dementia; RQ = relationship quality.

** $p \leq .01$. *** $p \leq .001$.

greater caregiving gains for women ($B = 0.17$, $\beta = .27$, $p = .01$, 95% CI = [0.05, 0.29]) but not for men ($B = -0.06$, $\beta = -.10$, $p = .39$, 95% CI = [-0.21, 0.08]).

Post Hoc Tests

To ascertain whether caregivers' perceived purpose is linked to caregiving gains across a fuller spectrum of impairment among PWDs, we estimated the models using a sample of 355 co-resident caregivers (including those caring for PWDs who had proxy respondents) with complete data. Consistent with the main analysis, caregivers' higher purpose was significantly associated with greater caregiving gains ($B = 0.10$, $\beta = .13$, $p = .01$, 95% CI = [0.03, 0.17]), and this association did not vary by caregiver gender.

Using the sample from the main analysis, we evaluated whether the association between caregivers' purpose and caregiving gains varied by PWDs' reported purpose. We entered an interaction term (Caregivers' purpose × PWDs' purpose) in the third step of the model. We then added a three-way interaction term (Caregivers' purpose × PWDs' purpose × Caregiver gender) in a separate step to examine differences by caregiver gender, including all two-way interactions within the three-way interaction. Neither interaction was significant, implying that caregivers' and PWDs' views of purpose are independently linked to caregiving gains.

Finally, we examined whether caregivers' relationship to the PWD moderated the links between each care partner's perceived purpose and caregiving gains with a model including two interaction terms (Caregivers' purpose × Relationship; PWDs' purpose × Relationship) in the third step. Next, three-way interaction terms (Caregivers' purpose × Relationship × Caregiver gender; PWDs' purpose × Relationship × Caregiver gender) to evaluate caregiver gender differences were tested in a separate step that included all two-way interactions within the three-way interactions. The interactions were not significant, showing that the pattern of findings does not differ between spouse and nonspouse caregivers.

Discussion and Implications

This study demonstrates that perceptions of purpose in life among PWDs and family caregivers are consequential for caregiving gains. Caregivers own higher purpose was linked to greater gains from the care role. PWDs' reports of purpose in life were positively associated with gains specifically among caregiving women. Notably, these associations were found after accounting for caregivers' sociodemographic characteristics, health conditions, and an array of care-related stressors, revealing that caregivers' and PWDs' feelings of purpose may be an understudied source of caregiving gains. Considering the rising number

of PWDs and adverse health effects of dementia caregiving that may be mitigated by psychological resources (Harmell, Chattillion, Roepke, & Mausbach, 2011), these findings have critical implications for clinicians and policymakers invested in preserving caregiver well-being. Based on theory highlighting the pivotal role of purpose in life during stressful circumstances (Frankl, 1959), both caregivers' and PWDs' views of their own purpose may empower caregivers to thrive in the midst of mounting and often uncontrollable challenges related to dementia caregiving. This study expands Pearlin's stress process model of caregiving by identifying caregivers' and PWDs' perceived purpose in life as important psychological resources in the context of informal dementia care.

Caregivers' sense of purpose in life appears to be a psychological resource among both men and women. Whereas a study of spousal caregivers found that greater purpose was associated with fewer emotional caregiving difficulties for wives but not for husbands (Polenick et al., 2018), the current findings reveal no significant gender differences in the link between purpose and caregiving gains. Men and women, therefore, may benefit equally from higher purpose in promoting positive aspects of caregiving. Post hoc tests showed that this association was found in the larger co-resident caregiver sample including PWDs with proxy respondents, indicating that caregivers' purpose is a psychological resource even when PWDs can no longer articulate their own life purpose. Higher purpose may help caregivers appraise caregiving more positively, cope more effectively, and uphold their self-care (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Folkman, 2007). As a consequence, caregivers' perceived purpose could be a key target for interventions to sustain their well-being.

PWDs' reports of purpose in life predicted caregiving gains for women but not for men. Caregiving women may be comparatively more aware of and influenced by the PWD's beliefs about purpose (Calasanti, 2010). PWDs with higher purpose also tend to seek goal-oriented activities of interest (Mak, 2011) that reduce passivity and increase positive affect (Han, Radel, McDowd, & Sabata, 2016a), potentially leading to behavioral and mood enhancements that are more salient to women's caregiving gains. Consequently, in line with interdependence theory, greater purpose reported by PWDs may encourage positive sentiments about caregiving for women that are independent of their own perceived purpose in life. The findings remained when controlling for PWDs' gender (analysis not shown), demonstrating their stability. Hence, while women's heightened awareness of the PWD's feelings renders them more vulnerable to distress over care-related stressors including behavioral and psychological symptoms of dementia (Bédard et al., 2005), this study implies that there may be concurrent advantages such as greater sensitivity to caregiving gains.

Future Directions

This study lends support to the notion that purpose in life has broad-based benefits which spill over into various domains including caregiving (McKnight & Kashdan, 2009). Future research should explore how caregivers integrate the care situation into their sense of purpose in ways that magnify gains. When caregiving is aligned with caregivers' wider conception of purpose in life, they may be more likely to gain from providing care than those who perceive this role as hindering their purpose. The link between purpose in life and caregiving gains may also be bidirectional in that care provision becomes an increasingly potent source of purpose. Disentangling these dynamic mechanisms would inform interventions to improve caregiver well-being. Connecting the care role to established components of purpose such as close family ties, for instance, may make caregiving more meaningful and rewarding (Motenko, 1989; Wadham, Simpson, Rust, & Murray, 2016). Caregivers could also reap rewards from the enactment of caregiving as a higher-order goal that augments their life purpose (Farran et al., 1991; Folkman, 2007). Furthermore, caregivers' and PWDs' perceived purpose may influence caregiving gains indirectly through their enjoyable social interactions (Mak & Sörensen, 2018).

Given the link between PWDs' higher purpose in life and greater gains among caregiving women in the present study, another important area for future work is to explore how PWDs' perceived purpose informs person-centered dementia care and may lead to additional positive outcomes for both care partners. Research has typically measured the PWD's interests and preferred activities from caregiver or other proxy reports, which may not reflect the PWD's own views of purpose (Han et al., 2016a, Han, Radel, McDowd, & Sabata, 2016b). As such, PWDs' perspectives should be assessed and incorporated into their care. A complementary line of inquiry is to understand what factors drive purpose in life among PWDs, along with how this is impacted by the progression of cognitive impairment. Meaningful activity, for example, has been identified by PWDs as a primary goal of dementia care (Jennings et al., 2017), suggesting that proactive strategies to stay involved with valued social roles and leisure pursuits may be instrumental in sustaining purpose. As dementia progresses, however, adaptations in activities are generally needed (Han et al., 2016b). For instance, when a PWD who finds purpose in painting is unable to do so independently, she could continue by changing to a simpler medium or with help from her caregiver. Alternatively, other activities such as household tasks or volunteering for dementia-related research might become more central sources of purpose (Han et al., 2016b). Caregivers report difficulty with motivating PWDs to participate in activities as their functioning worsens (Han et al., 2016b; Roland & Chappell, 2015), and so guidance in maximizing purposeful engagement at each stage of dementia may be warranted.

Future studies should also examine how purpose in life and caregiving gains change and covary between caregivers and PWDs. Purpose in life among PWDs and caregivers may be a lasting resource; but the level and quality of purpose could ebb and flow. Dementia eventually leads to severe cognitive impairment restricting the ability to realize one's purpose (McKnight & Kashdan, 2009). Once this occurs, caregivers' perspectives on whether the PWD retains purpose may be crucial to their well-being. Similarly, caregivers' own purpose could become more essential to care-related gains throughout the dementia trajectory. One or both care partners may also encounter shifts in purpose (e.g., from an individual focus to a joint focus) that amplify or deplete caregiving gains. Elucidating knowledge of these dyadic processes would identify critical periods for intervention.

The current findings contribute to growing recognition of the need for a dyadic approach to clinical care and intervention that could build on caregivers' and PWDs' feelings of purpose. Assisting caregivers in planning meaningful activities with the PWD such as reminiscing about shared memories or preparing a favorite meal together could reinforce each care partner's sense of personhood and strengthen the caregiving relationship (Han & Radel, 2016; Han et al., 2016b). Social and leisure activities external to the care dyad may also cultivate purpose. In a study of a person-centered social program for PWDs, for example, spousal caregivers reported mutual gains including the PWD's enjoyment, time for each partner to partake in meaningful activities outside the caregiving relationship, and positive interactions with new people (Han & Radel, 2016). Caregivers and PWDs might not always agree on what brings purpose to their lives, however, which underscores the importance of obtaining both care partners' reports (Han & Radel, 2016; Han et al., 2016b). Guiding caregivers and PWDs in their negotiation of differing perspectives may help to ensure that each party's values and preferences are honored (Whitlatch et al., 2005, 2009, 2017).

We acknowledge several limitations. First, causal associations cannot be determined in cross-sectional studies. Second, on average, high levels of purpose in life and caregiving gains were reported. The findings may therefore not generalize to more distressed samples. Third, reliability coefficients for the caregiving gains, role overload, and negative relationship quality measures were moderate. Fourth, purpose in life was measured with a single item, limiting reliability and validity. Last, the effect sizes were relatively small; but even small effects may have a substantial clinical and public health impact (Rutledge & Loh, 2004). Overall, this study generates valuable insights and lays the foundation to advance understanding of how perceptions of purpose in life among PWDs and family caregivers are linked to caregiving gains.

Conclusions

In sum, this study indicates that perceived purpose in life among PWDs and their family caregivers may contribute

to favorable caregiving outcomes. Enhancing perceptions of purpose among caregivers and PWDs could boost caregiving gains with broader implications for the health and well-being of both individuals. Routine clinical care, interventions, and policies to serve informal caregivers should recognize and support the enduring need of each care partner to preserve a satisfying life purpose.

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Conflict of Interest

None reported.

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