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Predeath Grief, Resourcefulness, and Perceived Stress Among Caregivers of Partners with Young-Onset Dementia

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Abstract

More than 200,000 Americans are currently diagnosed with young-onset dementia (YOD). YOD is dementia diagnosed prior to the age of 65. Most persons of YOD are cared for by their partners. Using the theoretical framework of Resilience Theory, this cross-sectional, correlational study examined the moderating effects of personal and social resourcefulness on the relationship between predeath grief and perceived stress among 104 YOD caregiving partners (life partners/spouses) using an online survey platform. Results indicated a large positive correlation between predeath grief and caregiver perceived stress ($r = .65$; $p < .001$). Together predeath

grief, personal resourcefulness and social resourcefulness explained 51.5% of the variance in perceived stress. Personal resourcefulness did not moderate the relationship. Social resourcefulness did positively moderate this relationship between predeath grief and perceived stress. These findings allow for a better understanding of the caregiving experience for a partner with YOD and creates opportunities for future research studies.

Keywords

[caregiver stress](#), [partner](#), [predeath grief](#), [resourcefulness](#), [young-onset dementia](#)

Introduction

Currently, more than 200,000 Americans are diagnosed with young-onset dementia (YOD). YOD is any form of dementia, including Alzheimer's disease that occurs prior to the age of 65 years ([Alzheimer's Association, 2018](#)). This number is thought to underrepresent the actual incidence of YOD due to a delay in diagnosis, which frequently results from an initial misdiagnosis by primary care health professionals ([Alzheimer's Association, 2018](#)). Also, in many circumstances, there is a delay in seeking a diagnosis due to a perceived stigma by patients and families ([Alzheimer's Association, 2018](#)). YOD has been used interchangeably with the terms "early-onset dementia" and "early-onset alzheimer's disease" ([Alzheimer's Association, 2006](#)). Practitioners prefer the term YOD to avoid confusion between the staging of dementia as "early dementia" or "early Alzheimer's disease" versus diagnosis prior to the age of 65 ([Alzheimer's Association, 2018](#)). YOD has occurred as early as people in their 20s and 30s but is more commonly seen in people in their 40s and 50s ([Alzheimer's Association, 2018](#)). Caregiving for a partner with YOD creates challenges resulting from changes in relationships and household dynamics ([Alzheimer's Association, 2006](#); [Flynn & Mulcahy, 2013](#)).

YOD and Caregiving Partners

Caregiving for a partner (life partner/spouse) diagnosed with YOD has unique challenges including multiple losses resulting from the functional, cognitive, and behavioral declines which can be demanding and stressful for the caregiver ([Alzheimer's Association, 2006](#); [Flynn & Mulcahy, 2013](#); [Romero, Ott, & Kelber, 2014](#); [van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010](#)). These losses experienced by the caregiver of a partner diagnosed with YOD may result in predeath grief (PDG). PDG may contribute to high levels of burden and stress that are often reported by caregivers of partners with YOD. High levels of stress have resulted in increased incidence of depression, anxiety, hopelessness, as well as development or exacerbation of chronic illness such as cardiovascular disease along with increased mortality for these caregivers ([Alzheimer's Association, 2006](#); [Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016](#)).

PDG exposes family members to the risk of maladaptation and depression as they watched the social and intellectual death of their loved one due to dementia ([Marwit & Meuser, 2005](#)). [Lindauer and Harvath \(2014\)](#) defined the concept of PDG in caregivers of persons diagnosed with dementia as the "emotional and physical response to the perceived loss in a valued care recipient" (p. 2203). Caregivers of partners with YOD experienced PDG in the loss of the reciprocal relationship ([Lindauer & Harvath, 2014](#); [Marwit & Meuser, 2005](#)) which has been associated with sadness, loneliness, and frustration ([Flynn & Mulcahy, 2013](#)). This differs from anticipatory grief since with PDG there is a disruption in the relationship and in the communication with the partner, resulting in a loss of personhood ([Lindauer & Harvath, 2014](#); [Marwit & Meuser, 2005](#)). The care partner may be experiencing a loss of the partner "who used to be" even when the partner is still present in a physical sense.

Caregiving partners of a person diagnosed with YOD also experience PDG with the losses associated with job loss, financial loss, companionship loss, social loss, and other personal loss. These other personal losses include loss of personal freedom, recreation opportunities, personal identity, and personal health ([Svanberg, Spector, & Stott, 2011](#); [Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017](#)). In addition, there is ambiguous loss that occurs when the life partner is physically present but not able to be part of the dynamic psychosocial

relationship between the couple ([Frank, 2007](#); [Svanberg et al., 2011](#)). The partner also faces the loss of future hopes and dreams which includes the loss of all the plans the couple may have made prior to the YOD diagnosis ([Wawrziczny et al., 2017](#)).

For caregivers of persons with YOD, PDG also results from a continual loss that occurs because of the disease trajectory with new losses occurring as the dementia progresses ([Lindauer & Harvath, 2014](#)). With the progressive deterioration in functioning experienced with a YOD diagnosis, losses continue to cascade as the care recipient moves from the inability to work outside the home to inability to help around the house to inability to care for self ([Alzheimer's Association, 2006](#); [Meuser, Marwit, & Sanders, 2004](#)). In addition, the care recipient slowly loses the ability to actively engage in social settings and in the reciprocal relationship with the caregiving partner ([Alzheimer's Association, 2006](#); [Lindauer & Harvath, 2014](#); [Marwit & Meuser, 2005](#); [Millenaar et al., 2016](#); [Warchol-Biedermann et al., 2014](#)). This downward spiral of losses compounds PDG as the caregiving partner grieves for their previous life together ([Alzheimer's Association, 2006](#); [Meuser et al., 2004](#); [Millenaar et al., 2016](#); [Warchol-Biedermann et al., 2014](#)).

Resourcefulness skills have been found to be a protective factor for caregivers of persons with dementias diagnosed after the age of 65 ([Bekhet, 2013](#); [Zauszniewski, Lau, & Tithiphontumrong, 2006](#)). Resourcefulness was originally defined as behaviors and skills that allow for adjustment against disruption ([Rosenbaum, 1990](#)). More recent definitions of resourcefulness include two complimentary parts known as personal resourcefulness and social resourcefulness ([Zauszniewski et al., 2006](#)). Personal resourcefulness is the ability to function and maintain daily independence often referred to as "self-help" ([Bekhet, 2013](#); [Zauszniewski et al., 2006](#)). Whereas, social resourcefulness (help seeking) is the ability to seek out, find, and ask for help when needed ([Bekhet, 2013](#); [Zauszniewski et al., 2006](#)). Social resourcefulness is an external process of seeking assistance from other individuals or agencies when one is no longer able to successfully manage on one's own ([Zauszniewski et al., 2006](#)). The ability to self-help and seek-help are behaviors that are important for managing stressful situations and cope with adverse events ([Zauszniewski et al., 2006](#)). Both personal and social resourcefulness skills are important for optimizing well-being, health promotion, and health maintenance.

Caregiver perceived stress (PS) is the result of how unpredictable, uncontrolled, and overloaded an individual finds life events which is a frequent experience of caregivers of partners with YOD ([Cohen, Kamarck, & Mermelstein, 1983](#)). In 2004, the Alzheimer's Association and National Alliance on Caregiving concluded that caregivers for persons with dementia carry a uniquely heavy caregiving burden due to the physically and emotionally demanding caregiving role of persons with dementia resulting in high levels of stress and taking a heavy toll on family life ([Wilks & Croom, 2008](#)). [Allen and colleagues \(2017\)](#) concluded, in a systematic review examining the psychobiological burden of caregiving for persons with dementia, the chronic stress of dementia caregiving results in sustained elevated cortisol level and altered immune functioning associated with depression and the development or exacerbation of chronic illness. This physical stress of YOD caregiving can exacerbate existing conditions specifically high blood pressure and diabetes ([Alzheimer's Association, 2018](#)). Also, caregivers of partners diagnosed with YOD reported the development of depression secondary to their caregiving experience ([van Vliet et al., 2010](#)).

Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress" ([American Psychological Association, 2014](#), p. 4). Resilience theory proposes resilience as a dynamic process of balancing risk and protective factors in the face of adversity. Protective factors can enhance resilience by balancing out risk factors which allow for greater opportunity for positive adaptation ([Rutter, 1985](#)). Resilience in caregivers of partners diagnosed with YOD is important for enhancing overall well-being for both the caregiver and the partner diagnosed with YOD during this devastating illness ([Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013](#); [Flynn & Mulcahy, 2013](#)).

Purpose

The purpose of this study was to investigate the moderating effects of both personal resourcefulness and social resourcefulness on the relationship between PDG and PS of caregivers of partners diagnosed with YOD using the theoretical framework of Resilience Theory.

Hypotheses

Hypothesis 1 (H1): Caregiver PDG has a positive association with PS in caregivers of a partner with YOD.

Hypothesis 2 (H2): Personal resourcefulness moderates the relationship between PDG and PS in caregivers of a partner with YOD.

Hypothesis 3 (H3): Social resourcefulness moderates the relationship between PDG and PS in caregivers of a partner with YOD.

Method

Design

The study used a cross-sectional, correlational design to assess the moderating effects of personal and social resourcefulness on the relationship of PDG and PS of YOD caregiving partners through the online survey platform of Qualtrics. Institutional review board (IRB) approval was obtained from Marquette University prior to the initiation of the study, recruitment of caregivers of YOD, or collection of data.

Recruitment Strategy

A convenience sample was obtained by recruiting potential subjects via IRB preapproved fliers emailed to Alzheimer's Associations throughout Wisconsin and the United States, Departments of Aging and Disability in the State of Wisconsin, University of Kansas Alzheimer's Disease Center, Dominantly Inherited Alzheimer's Network (DIAN) Project Expanded Registry and word of mouth until the desired sample size is reached. Fliers contained a link to the survey. Participants then accessed the study at their convenience.

Sample

The study included a convenience sample of 104 caregivers of partners (life partner/spouse) diagnosed with YOD who were 18 years or older and able to read and understand the English language, operate computers, and navigate the Internet. Sample size of 100 ($N = 100$) was determined using G*Power ([Faul, Erdfelder, Lang, & Buchner, 2007](#)) with an $\alpha = .05$, $\beta = .8$, and $f^2 = .1$ for a small to medium effect size.

Data Collection Procedure

The initial screen of the survey provided participants with background information for the study, resources for participants if needed, and an agreement for their informed consent to participate or opt out of survey. Participants were informed that their participation in the study was voluntary, Internet protocol (IP) addresses would not be identified, and they could withdraw at any time without penalty. Contact information for the Alzheimer's Association, Wisconsin Family Caregiver Support Program, and State of Wisconsin resources was provided prior to participate in the study. Participants who declined the study were not identified and the data were not collected. If participants clicked yes on the informed consent screen, the survey began with measures for the construct of PDG, followed by PS and then personal and social resourcefulness. The final screen of the survey included demographic information asking participants gender, age, education, income, and self-rated health questions. Participants were able to opt out of the survey at any time. At the completion of the surveys, participants were thanked for their participation and linked to a US\$20.00 gift card. Data were collected for 104 surveys via the online survey platform of Qualtrics from fall 2017 through spring 2018.

Instruments

The independent variable: PDG

PDG was measured using the Marwit Meuser Caregiver Grief Inventory Short Form, which has acceptable interitem correlation as demonstrated by a Cronbach's alpha of .96 ([Marwit & Meuser, 2005](#)). This 18-item instrument uses 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Scores can be

determined by summing the points associated with the chosen Likert-type responses with total scores ranging from 18 to 90. Higher scores indicate greater grief ([Marwit & Meuser, 2002](#)). Examples of items include “I’ve had to give up a great deal to be a caregiver” (Personal Sacrifice Burden), “I have this empty, sick feeling knowing that my loved one is gone” (Heartfelt Sadness and Longing), and “The people closest to me do not understand what I’m going through” (Worry and Felt Isolation) ([Marwit & Meuser, 2005](#), p. 199).

The moderating variable: Resourcefulness

Resourcefulness was measured using the Resourcefulness Scale ([Zauszniewski et al., 2006](#)). The 28-item Resourcefulness Scale has two different subscales; personal resourcefulness (16 items) and social resourcefulness (12 items). The Resourcefulness Scale uses 6-point Likert-type scale ranging from 0 (not at all like me) to 5 (very much like me). The 28 item Resourcefulness Scale scores range from 0 to 140 with higher scores indicating greater resourcefulness. Cronbach’s alpha for the full scale, the Social Resourcefulness subscale, and the Personal Resourcefulness subscale were .85, .79, and .83, respectively. The personal resourcefulness subscale has 16 items with scores ranging from 0 to 80 and higher scores indicative of greater personal resourcefulness skills. An example of a personal resourcefulness item includes “When I am faced with a number of things to do, I usually plan my work” ([Zauszniewski et al., 2006](#)). The social resourcefulness subscale has 12 items with scores ranging from 0 to 60 and higher scores indicative of greater social resourcefulness skills. An example of a social resourcefulness item includes “When I am feeling sad, it helps to talk to other people” ([Zauszniewski et al., 2006](#)). For this study Personal Resourcefulness subscale scores and Social Resourcefulness subscale scores were examined independently.

The dependent variable: Caregiver stress

PS for caregivers of YOD was measured using the 14-item Perceived Stress Scale. The Cronbach’s alpha for the Perceived Stress Scale ranged from .84 to .86 ([Cohen et al., 1983](#)). This 14-item Perceived Stress Scale uses a 5-point Likert-type scale ranging from 0 (never) to 4 (very often). Respondents are asked to respond, “fairly quickly” in a global sense about their feelings to statements such as “In the last month, how often have you been upset because of something that happened unexpected?” ([Cohen et al., 1983](#), p. 394). Results are obtained by using the mean across items. Seven items need to be reverse scored ([Cohen et al., 1983](#)). Higher scores indicate higher PS ([Cohen et al., 1983](#)).

Data Analysis

Data analysis was performed using R ([R Core Team, 2018](#)) with the packages lavaan ([Rosseel, 2012](#)) and semTools ([semTools Contributors, 2018](#)). The reliability was evaluated with the maximal reliability (MR) coefficient, which measures reliability of a scale, unlike Cronbach’s alpha which estimates interitem correlation ([Raykov, 2012](#)). Mean scores for all instruments were used for statistical analysis. The initial relation between PDG and PS was set as a linear correlation to answer H1. To answer H2 and H3, regression models were used. To evaluate the moderating effect of personal resourcefulness and social resourcefulness on the regression of PDG on PS, interactions between PDG and the resourcefulness scores were calculated (PDG × Personal Resourcefulness, and PDG × Social Resourcefulness) are added as predictors of PS. The relevance of the interactions was tested by the p value of the interaction regressions and the change in R² when the interactions are included, and finally by plotting and probing the interaction effects ([Darlington & Hayes, 2017](#)). Plotting and probing the interaction estimates the intercept and slope for the regression of interest (PDG → PS) conditional on the moderating variables, allowing for the evaluation of how personal resourcefulness and/or social resourcefulness change the regression. These regressions were evaluated in the framework of Structural Equation Modeling with path analysis ([Kline, 2016](#)). Missing data were handled with Full Information Maximum Likelihood.

Results

Descriptive Statistics

The sample consisted of 104 caregivers of partners diagnosed with YOD. The participants age ranged from 27 years old to 80 years old with a mean age of 58.27 (SD = 11.21). The participants had been caregiving for their partner in a range from 1 to 20 years with a mean of 5.93 (SD = 3.36). The majority of participants indicated that they were White (94.74%), female (65.26%), with a college or higher education (82.11%), and an annual household income between US\$50,000 and US\$100,000 (50.53%). The remaining participants indicated that they were Asian (2.11%), Hispanic (2.11%) or African American (1.05%). The majority of participants indicated that they had not received professional counseling, which was defined as a fee for service with a person licensed in therapy, related to their caregiving experience (58.95%) with most rating their health in the previous month as fair or better (92.63%). The remaining participants rated their health in the past month as poor (6.32%) or terrible (1.05%).

Data Analysis Results

The total score for scales of interest were created by averaging the item scores. The mean and standard deviations for the total scale scores are presented in [Table 1](#) along with the MR coefficient ([Raykov, 2012](#)). The MR coefficient showed that the scales have high reliability, indicating proper precision of measurement.

Table 1. Summary of Instruments, Descriptive and Reliabilities (N = 104).

| Variables/Concepts | Measures | Number of Items | M (SD) | Possible Range | Actual Scores | Reliability Reported in This Study MR |
|----------------------------|-----------------------------------------------------------------|-----------------|-------------|----------------|---------------|---------------------------------------|
| Independent predeath grief | Marwit Meuser Caregiver Grief Inventory–Short Form ^a | 18 | 3.54 (0.78) | 18-90 | 18-90 | .938 |
| Dependent Perceived stress | Perceived Stress Scale 14 ^b | 14 | 2.13 (0.75) | 0-56 | 0-53 | .939 |
| Moderating resourcefulness | Resourcefulness Scale ^c | 28 | | 0-140 | 38-113 | |
| Subscale | Social resourcefulness | 12 | 2.24 (0.91) | 0-60 | 2-60 | .919 |
| Subscale | Personal resourcefulness | 16 | 3.18 (0.82) | 0-80 | 0-74 | .885 |

Note. MR = maximal reliability.

a. Marwit and Meuser (2005).

b. Cohen, Kamarck, and Mermelstein (1983).

c. Zauszniewski, Lau, and Tithiphontumrong (2006).

H1: Caregiver PDG has a positive association with caregiver PS in caregivers of a partner with YOD.

[Table 2](#) demonstrates the correlation between scales. The relationship between PDG and PS (H1), demonstrated a large positive correlation ($r = 0.649, p < .001$). This led to an $R^2 = 0.42$.

Table 2. Correlations Between Scales (N = 104).

| | PDGa | PSb | PRc | SRc |
|------|--------|--------|-------|-----|
| PDGa | 1 | | | |
| PSb | .649* | 1 | | |
| PRc | .070 | -.177 | 1 | |
| SRc | -.198* | -.327* | -.041 | 1 |

Note. PDG = predeath grief; PS = perceived stress; PR = personal resourcefulness; SR = social resourcefulness.

- a. PDG as measured by Marwit Meuser Caregiver Greif Inventory—Short Form.
 - b. PS as measured by Perceived Stress Scale 14.
 - c. PR and SR as measured by the Resourcefulness Scale.
- * $p < .05$

H2: Personal resourcefulness moderates the relationship between PDG and caregiver PS in caregivers of a partner with YOD.

H3: Social resourcefulness moderates the relationship between PDG and caregiver PS in caregivers of a partner with YOD.

To answer H2 and H3, two regression models were estimated. The first is the main effects model where PS is predicted by PDG, social resourcefulness, and personal resourcefulness. The second model included the same predictors and added the interactions PDG \times Social Resourcefulness and PDG \times Personal Resourcefulness and tested for moderation of the relationship between PDG and PS (Figure 1).

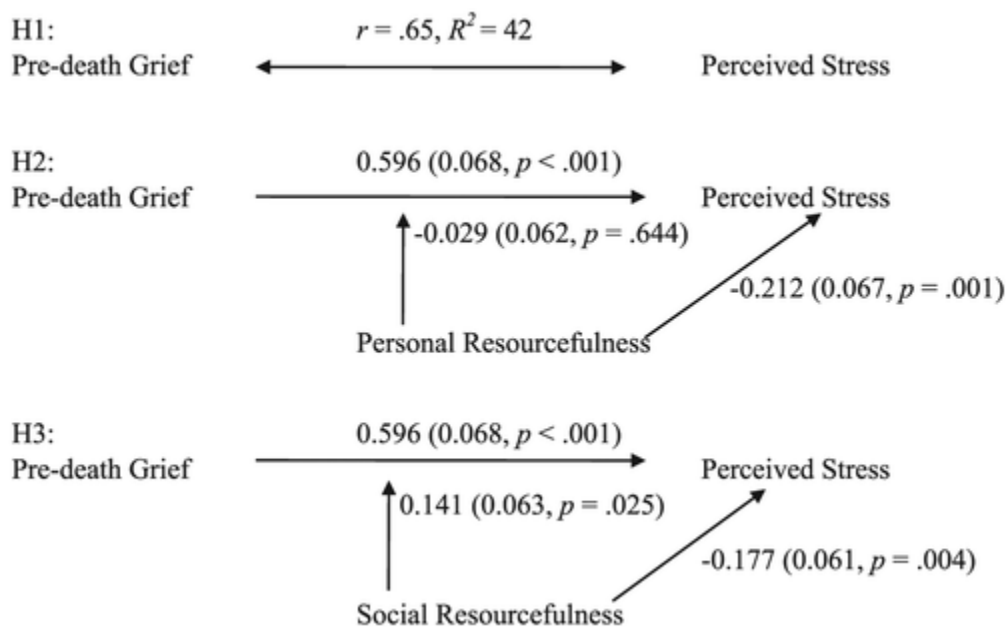


Figure 1. Path analysis (N = 104).

In the main effects model, PDG, personal resourcefulness, and social resourcefulness explained 51.5% of the variance in PS. When PDG, social resourcefulness, and personal resourcefulness are set to 0, the expected PS scores is 1.097 (SE = 0.362, $p = .002$). For the slopes, when PDG increases by 1 unit, PS increases by 0.596 units (SE = 0.596, $p < .001$). As social resourcefulness increases by 1 unit PS decreases, by 0.177 units (SE = 0.061, $p = .004$). Finally, as personal resourcefulness increases by 1 unit, PS decreases by 0.212 (SE = 0.067, $p = .001$). These are the conditional effects, while keeping every other predictor constant.

When interactions are added to the regression, the R^2 increases by .04. Looking at the slopes for the interactions, the null hypothesis is rejected being equal to 0 only for the interaction between PDG \times Social Resourcefulness, indicating that the relation between PDG \rightarrow PS is only moderated by social resourcefulness levels. Moderation testing continued for social resourcefulness only since this was the only relevant interaction effect. Simple intercepts and slopes were tested to determine regression PDG \rightarrow PS at different levels of social resourcefulness. Medium social resourcefulness was set as the average social resourcefulness for the sample, low was set as the $M - 1$ SD, and high was set as the $M + 1$ SD. At all three levels the social resourcefulness slope was different from 0 ($p < .05$). As social resourcefulness increased the intercept decreased while the regression

slope increased with a low social resourcefulness slope of 0.536 (SE = 0.235, $p = .023$), medium resourcefulness slope of 0.664 (SE = 0.235 $p = .001$), and high resourcefulness slope of 0.793 (SE = 0.180, $p = <.001$). Finally, PDG → PS was evaluated at continuous values of social resourcefulness. The intercept and slope were tested at social resourcefulness values ranging from 0 to 5 in 0.1 increments at 51 possible social resourcefulness values. For the intercept, as social resourcefulness increased the intercept decreased, ranging from 2.099 to -1.178. For the slope (PDG → PS) only when social resourcefulness was higher than 1, the null hypothesis of being equal to 0 ($p < .05$) was rejected. As social resourcefulness increased the slope PDG → PS increased ranging from 0.503 to 1.052. This demonstrates that caregivers of partners with YOD with higher social resourcefulness skills also had stronger relation between PDG and PS.

Discussion

To date, this is the first study that investigated the possible moderating effect of personal and social resourcefulness on the relationship between PDG and PS among YOD caregivers. The results of the current study indicated that there was a high positive correlation between PDG and PS. This in fact is similar, in part, to the results of previous research that showed that caregiver well-being is negatively impacted by PDG as the ever-increasing caregiving demands place these caregivers at risk for long term mental and physical health consequences including possible premature death ([Paun et al., 2015](#)).

In this study, PDG accounted for 42% shared variance of caregiver stress. Caregivers of YOD report high levels of caregiver stress ([Ducharme et al., 2013](#)). Much of this stress can be accounted for with the multiple losses caregivers of partners diagnosed with YOD face. The multiple losses of PDG affecting finances and social and personal relationships combined with the loss of personhood of the partner diagnosed with YOD ([Frank, 2007](#); [Svanberg et al., 2011](#); [Wawrziczny et al., 2017](#)) contribute to the heavy burden and stress of caregiving partners of YOD ([Allen et al., 2017](#); [Alzheimer's Association, 2018](#)). Programs, interventions, and resources that address the specific losses faced by caregiver of partners with YOD may decrease part of the caregiver stress.

Personal resourcefulness, self-help, was not found to moderate the relationship of PDG and PS in this study. The scale items indicators of personal resourcefulness address coping skills such as visualization and time management ([Zauszniewski et al., 2006](#)) that may or may not have been learned and would have been derived after social resourcefulness or help seeking has occurred. In fact, YOD consists of a series of continual, compounded losses. Similar to a tsunami, waves of loss continue to roll in never quite allowing the caregiver to completely adjust to the previous loss. This continual disease progression may not allow the caregiver to fully develop necessary personal resourcefulness skills as they function from one crisis to the next.

The positive moderation of social resourcefulness, help seeking, on the relationship of PDG and PS in caregivers of partners with YOD means that as social resourcefulness increased, the relationship between PDG and PS increased. Although H3 predicted social resourcefulness would moderate the relationship, the a priori thought was for a negative moderation. The scale item indicators of social resourcefulness indicate that the assistance one is receiving from seeking help from others is helpful ([Zauszniewski et al., 2006](#)). It is possible that caregivers of partners with YOD are not experiencing positive support from seeking help from others. Another possible explanation may be related to the age of caregivers reported in this study; with a mean age of 58 years old, the majority of caregivers in this study were of working age prior to retirement. These caregivers may have been searching for age appropriate resources and experienced increased stress as they reached out to find resources and found none. This thought is in alignment with [Carter, Oyeboode, and Koopmans's \(2018\)](#) report that resources and services for both people with and caregivers of persons with YOD are "largely lacking" (p. 470). Also, [Wawrziczny and colleagues \(2017\)](#) found that caregivers of YOD experience frustration in their abilities to navigate the system to locate resources and services for their partner and for themselves. In a systematic review, [Millenaar and colleagues \(2016\)](#) found six themes that support the difficulty of YOD caregivers in which two themes speak directly to the YOD caregiver's frustrations with accessing services and with finding appropriate services. YOD caregivers with high social resourcefulness as they search for and reach out for

resources and services to meet their needs may experience high levels of frustration which add to and increase their PDG and stress.

Previous research has shown positive outcomes on psychological well-being for traditional dementia caregivers who are resilient ([Gibson, Andersen, & Acocks, 2014](#)). Resourcefulness has been shown to be a protective factor thereby enhancing resilience in caregivers ([Bekhet, 2013](#); [Zauszniewski et al., 2006](#)). In fact, the ability to self-help and seek-help are behaviors that are important for managing stressful situations and coping with adverse events ([Zauszniewski et al., 2006](#)). [Zauszniewski, Lekhak, Au, Yolpant, and Morris \(2015\)](#) found in a sample size of 126 female caregivers that 75% had scores that indicated a moderate to high need for resourcefulness training. In addition, [Zauszniewski's et al. \(2015\)](#) results indicated that caregivers of persons with dementia could benefit from resourcefulness skill training to decrease caregiver stress. In a descriptive, cross-sectional study with 73 dementia caregivers, [Bekhet \(2015\)](#) found that caregivers with greater social resourcefulness had scores indicating greater psychological well-being. Resourcefulness skill building was associated with a decrease in caregiver burden and stress in these studies. In sum, previous research with traditional dementia caregivers showed that resourcefulness skills are a protective factor and can enhance adaptation and well-being ([Zauszniewski et al., 2006](#)). Therefore, it is important to better understand the lived experience of being a caregiver of someone with YOD and the resources needed as well as quality of the social resourcefulness. For example, caregivers with high social resourcefulness might seek help from others (one of the items on the Social Resourcefulness Scale) but find that the support is not available or that others do not understand their needs as a caregiver, making their PDG and stress even higher. Although caregiving for someone with dementia is a challenge at any age, rather than having help of adult children, caregivers of partners with YOD may also be parenting children still in the home. Unlike those with traditional dementia, friends and families may still expect caregivers of partners with YOD to be reciprocally providing interest and support for family and community social interactions.

As the detrimental effects of caregiver stress has been well documented, an assessment of variables that can be protective and enhance resilience in the face of risk will lead to intervention studies that have the potential to decrease PS and enhance caregiver well-being. One risk factor that may contribute to caregiver stress is PDG. Developing resources and services that address YOD caregiver PDG may be one path to decrease caregiver stress. Researchers agree that the mediator variable addresses how or why events occur while the moderator variable addresses when events will hold ([Baron & Kenny, 1986](#); [Bennett, 2000](#)). Therefore, future research might look at possible mediator effects of personal resourcefulness in relation to PDG and PS. More research is needed to properly identify needed resources and services for this population. Using methodological triangulation, that is, across methods design to combine both quantitative and qualitative data would be beneficial in providing more comprehensive data that would enhance understanding of the studied phenomena ([Bekhet & Zauszniewski, 2012](#)). Therefore, further studies that incorporate methodological triangulation are recommended.

Caregivers of partners with YOD are searching for meaningful support and resources to address their needs ([Ducharme et al., 2013](#); [Flynn & Mulcahy, 2013](#); [Gibson et al., 2014](#)). Development of proper programming, interventions, resources, and support systems, is predicted to decrease caregiver stress along with an overall increase in caregiver well-being ([Deist & Greeff, 2015](#)). It is recommended that health care professionals consider the needs of the caregiving partner as well as the person diagnosed with YOD. Referrals to specialty services or programming related to loss along with education on loss and PDG may be helpful.

Limitations to this study include the use of convenience sample that was recruited by and responded using an online platform. Participants in this study needed to have access to and working knowledge of computers and the Internet. Therefore, the results of the study will be generalizable only to those who are using the Internet. There are potential covariants that were not addressed in this initial study such as the stage of the disease the person with dementia is in, the length of time the partner has been caregiving, current access and use of

resources, and use of a support system for caregiving. Additional limitation includes the cross-sectional design format as this takes into account a person's responses at one moment in time. Dementia caregiving is a lengthy experience with fluctuations expected in a person's responses which may be dependent on occurring events at the time. Future studies may include longitudinal studies that evaluate these variables and how they may change over time. In addition, future studies may identify the different characteristics of stress related to PDG in YOD caregiving partners.

Declaration of Conflicting Interests

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References

- Allen, A. P., Curran, E. A., Duggan, A., Cryan, J. F., Chorcocain, A. N., Dinan, T. G., . . . Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive biological markers of stress. *Neuroscience & Biobehavioral Reviews*, 73, 123-164. doi:10.1016/j.neubiorev.2016.12.006
- Alzheimer's Association . (2006). Early onset dementia: A national challenge, a future crisis. Retrieved from https://www.alz.org/national/documents/report_earlyonset_full.pdf
- Alzheimer's Association . (2018). 2018 Alzheimer's disease facts and figures. Retrieved from <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- Alzheimer's Association and National Alliance for Caregiving . (2004). Families care: Alzheimer's caregiving in the United States. Retrieved from https://www.alz.org/national/documents/report_familiescare.pdf
- American Psychological Association . (2014). The road to resilience. Retrieved from <http://www.apa.org/helpcenter/road-resilience.aspx>
- Baron, R. M., Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- Bekhet, A. K. (2013). Effects of positive cognitions and resourcefulness on caregiver burden among caregivers of persons with dementia. *International Journal of Mental Health Nursing*, 2, 340-346. doi:10.1111/j.1447-0349.2012.00877.x
- Bekhet, A. K. (2015). Resourcefulness in African American and Caucasian American caregivers of persons with dementia: Associations with perceived burden, depression, anxiety, positive cognitions, and psychological well-being. *Perspectives in Psychiatric Care*, 51, 285-294. doi:10.1111/ppc.12095
- Bekhet, A. K., Zauszniewski, J. (2012). Methodological triangulation: An approach to understanding data. *Nurse Researcher*, 20, 40-43. doi:10.7748/nr2012.11.20.2.40.c9442
- Bennett, J. A. (2000). Focus on research methods: Mediator and moderator variables in nursing research. *Research in Nursing & Health*, 23, 415-420.
- Carter, J. E., Oyebode, J. R., Koopmans, R. T. C. M. (2018). Young-onset dementia and the need for specialist care: A national and international perspective. *Aging & Mental Health*, 22, 468-473. doi:10.1080/13607863.2016.1257563
- Cohen, S., Kamarck, T., Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385-396.
- Darlington, R. B., Hayes, A. F. (2017). *Regression analysis and linear models: Concepts, applications, and implementation*. New York, NY: Guilford Press.
- Deist, M., Greeff, A. P. (2015). Resilience in families caring for a family member diagnosed with dementia. *Educational Gerontology*, 41, 93-105. doi:10.1080/03601277.2014.942146

- Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F., Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *The American Journal of Alzheimer's Disease & Other Dementias*, 28, 634-641. doi:10.1177/1533317513494443
- Faul, F., Erdfelder, E., Lang, A.-G., Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191. doi:10.3758/BF0319346
- Flynn, R., Mulcahy, H. (2013). Early onset dementia: The impact on family care-givers. *British Journal of Community Nursing*, 18, 598-606. doi:10.1177/1471301216661427
- Frank, J. B. (2007). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 516-527. doi:10.1177/1533317507307787
- Gibson, A. K., Andersen, K. A., Acocks, S. (2014). Exploring the service and support needs of families with early-onset alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, 29, 596-600. doi:10.1177/1533317514558160
- Kline, R. B. (2016). *Principles and practice of structural equation modeling* (4th ed.). New York, NY: Guilford Press.
- Lindauer, A., Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70, 2196-2207. doi:10.1111/jan.12411
- Marwit, S. J., Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42, 751-765.
- Marwit, S. J., Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29, 191-205. doi:10.1080/07481180590916335
- Meuser, T., Marwit, S., Sanders, S. (2004). Assessing grief in family caregivers. In Doka, K. J. (Ed.), *Living with Grief: Alzheimer's disease* (pp. 169-198). Washington DC: Hospice Foundation of America. doi:10.1177/533317509333902.
- Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A., de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry*, 31, 1261-1276. doi:10.1002/gps.4502
- Paun, O., Farran, C. J., Fogg, L., Loukissa, D., Thomas, P. E., Hoyem, R. (2015). A chronic grief intervention for dementia family caregivers in long-term care. *Western Journal of Nursing Research*, 37, 6-27. doi:10.1177/0193945914521040
- Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W., Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 14, 238-273. doi:10.11124/JBISRIR-2016-002555
- Raykov, T. (2012). Scale construction and development using structural equation modeling. In Hoyle, R. H. (Ed.). *Handbook of structural equation modeling* (pp. 472-494). New York, NY: Guilford Press.
- R Core Team . (2018). R: A language and environment for statistical computing. Vienna, Austria: R Foundation for Statistical Computing. Available from <https://www.R-project.org/>
- Romero, M. M., Ott, C. H., Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. *Death Studies*, 38, 395-403. doi:10.1080/07481187.2013.809031
- Rosenbaum, M. (1990). *Learned resourcefulness on coping skills, self-control, and adaptive behavior*. New York, NY: Springer.
- Rosseel, Y. (2012). lavaan: An R package for structural equation modeling. *Journal of Statistical Software*, 48(2), 1-36.
- Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry*, 147, 598-611. doi:10.1192/bjp.147.6.598
- semTools Contributors . (2018). semTools: Useful tools for structural equation modeling (R Package Version 0.4-15.918). Retrieved from <https://CRAN.R-project.org/package=semTools>

- Svanberg, E., Spector, A., Stott, J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics*, 23, 356-371. doi:10.1017/S1041610210001353
- van Vliet, D., de Vugt, M., Bakker, C., Koopmans, R., Verhey, F. (2010). Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry*, 25, 1091-1100. doi:10.1002/gps.2439
- Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., Madeda, A. (2014). What causes grief in dementia caregivers? *Archives of Gerontology and Geriatrics*, 59, 462-467. doi:10.1016/j.achger.2014.05.013
- Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M., Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics*, 17, 282-291. doi:10.1111/psyg.12234
- Wilks, S. E., Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging & Mental Health*, 12, 357-365. doi:10.1080/13607860801933323
- Zauszniewski, J. A., Lau, C. Y., Tithiphontumrong, S. (2006). Development and testing of a resourcefulness scale for older adults. *Journal of Nursing Measurement*, 14, 57-68.
- Zauszniewski, J. A., Lekhak, N., Au, T. Y., Yolpant, W., Morris, D. L. (2015). Need for resourcefulness training for women caregivers of elders with dementia. *Issues in Mental Health Nursing*, 36, 1007-1012. doi:10.3109/01612840.2015.1075236