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Karie R. Kobiske
Marquette University

Abir K. Bekhet
Marquette University, abir.bekhet@marquette.edu

Marquette University

e-Publications@Marquette

Nursing Faculty Research and Publications/College of Nursing

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Resilience in Caregivers of Partners With Young Onset Dementia: A Concept Analysis

Karie R. Kobiske

College of Nursing, Marquette University, Milwaukee, WI

Abir K. Bekhet

College of Nursing, Marquette University, Milwaukee, WI

ABSTRACT

Introduction: Over 200,000 Americans diagnosed with young onset dementia (YOD), dementia diagnosed prior to age 65, are cared for by family members. This can be costly to caregivers' physical and psychological health. Some adapt well to the caregiver role and are said to be resilient. **Aim/Question:** This paper builds on current understanding of the concept of resilience and applies this to caregivers of partners diagnosed with YOD. **Method:** Concept analysis. **Results:** Resilient caregivers exhibit attributes including determination, flexibility, positive thinking, self-efficacy, resourcefulness, social support and spirituality. **Discussion:** YOD affects caregiver's health. Much research has been done on interventions for dementia caregivers. These interventions do not necessarily meet the needs of YOD caregivers as they do not account for dynamics in the family. By recognizing what is resiliency in YOD caregivers, interventions can be developed that focus on characteristics that build these attributes. **Implications for Practice:** Understanding the concept of resilience related to caregiving for a partner diagnosed with YOD allows for future development, measurement, and evaluation of

nursing interventions. Nursing staff are in a strategic position to provide effective interventions to enhance resilience among caregivers of YOD.

Resilience is defined as “the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress.” (American Psychology Association, [2014](#), p. 4). The concept of resilience **exemplifies** why some individuals maintain or adapt well in response to adversity and others do not (Cabanyes Truffino, [2010](#)). The goal of a concept analysis is to improve understanding through synthesis and integration of attributes that differentiate the concept from **other concepts** (Fawcett, [1999](#)). To fully appreciate a concept, essential attributes must be identified. These attributes then are the foundation of a theoretical concept as it relates to a specific population (Rodgers & Knafl, [2000](#)). The purpose of this paper is to build on current understanding of the concept of resilience and apply this understanding to the specific population of caregivers of a partner diagnosed with young onset dementia (YOD), dementia diagnosed prior to age 65, using Walker and Avant's method of concept analysis. Caregivers of YOD are at high risk for physical and psychosocial complications resulting from financial, social, and role changes imposed by the YOD caregiving role (van Vliet, de Vugt, Bakker, Koopmans, & Verhey, [2010](#)). **Increased understanding of the specific needs of YOD caregivers may lead to the development of interventions that positively impact YOD caregiver well-being.**

Background/ significance

Dementia refers to a decline in cognitive function that significantly impacts a person's ability to function daily (Alzheimer's Association, [2017](#); American Psychiatric Association, [2013](#)). In the United States, approximately 5.3 million Americans are living with a diagnosis of dementia (Alzheimer's Association, [2017](#)). Over 200,000 of these Americans are diagnosed with YOD, which is the diagnosis of dementia prior to the age of 65 (Brookmeyer et al., [2011](#)). These **numbers** are considered to under-represent the actual number of people affected with YOD since there is often a delay in diagnoses or early misdiagnosis (Brookmeyer et al., [2011](#); Crimmins, Kim, Langa, & Weir, [2011](#)).

Aim

The aim of this concept analysis is to explore and understand resilience as it relates to caregivers of a partner diagnosed with YOD.

Phenomena of interest

Caregivers of a partner with YOD

The diagnosis of YOD occurs ^{Table 1} prior to the age of 65, which is often **before** retirement.

Family **commonly** assumes the role of informal caregiver with the partner most frequently becoming the primary caregiver (Aria, Matsumoto, Ikeda, & Aria, [2007](#)). As a partner of the individual diagnosed with YOD undertakes the caregiver role, changes occur in family and household dynamics (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, [2014](#); Gibson, Andersen, & Acocks, [2014](#)). The effects of these changes are described as caregiver stress. **The** negative effects of caregiver stress on the physical and emotional health of YOD caregivers has been well **documented** (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, [2013](#); Kaiser & Panegyress, [2007](#)). The University of Michigan Institute of Research found that in the United States, an estimated 59% caregivers of family members with dementia rate their stress as high or very high, 56% report high financial strain, and 40% of caregivers suffer from depression (Alzheimer's Association, [2006](#); Mausbach, Chattillion, Roepke, Patterson, & Grant, [2013](#); Plassman et al., [2007](#)). The chronic stress of caregiving for a family member with dementia can result in depression, cardiovascular **disease**, and exacerbations of existing chronic inflammatory conditions, all of which increase morbidity and mortality (Mausbach et al., [2013](#), ,

[Scholar](#)]; MetLife Mature Market Institute, [2006](#); National Alliance for Caregiving and AARP, [2009](#); von Kanel et al., [2006](#)).

Caregivers of YOD report high levels of caregiver stress (Kaiser & Panegyress, [2007](#)) due to the ever-increasing caregiving demands placing these caregivers at risk for long term mental and physical detrimental health consequences including **premature** death (Paun et al., [2015](#); Schulz et al., [2004](#)). **Caregiving for a partner diagnosed with YOD has been found to be different from caregiving for other forms of dementias since the younger family development stage has a distinct set of needs** (Cabote, Bramble, & McCann, [2015](#); van Vliet et al., [2010](#); Werner, Stein-Shvachman, & Korczyn, [2009](#)). The clinical manifestation of YOD often involve more behavior symptomology which has been associated with high levels of caregiver stress (Aria et al., [2007](#); Cabote et al., [2015](#)). Additionally, caregiver stress related to the diagnosis of YOD is linked **with** the financial impact that severely destabilizes the family's financial security due to income loss and an increase in health care costs (Werner et al., [2009](#)). YOD affects the family with role shifts **related to** child rearing, household tasks, and relationship changes with lifelong partner and with friends. A model of care for people diagnosed with YOD should **include** of the needs of the partner (Flynn & Mulcahy, [2013](#)).

Resilience

Resilience is a concept that has been used in various disciplines to describe a property or characteristic. In physics, engineering, and physical sciences, resilience is conceptualized as material strength and the ability of the material to return to its original shape after physical strain (Gillespie, Chaboyer, & Wallis, [2007](#)). In ecology, resilience describes nature's ability to rebound and regenerate after environmental insult. In microbiology, resilience is conceptualized as the ability of an organism to regenerate on a cellular level (Cabanyes Truffino, [2010](#); Earvolino-Ramirez, [2007](#)). Resilience is also applied in business with corporate trends, money, production, and the stock market with their ability to recover from economic or market downturns (Earvolino-Ramirez, [2007](#)). The concept of resilience was introduced in the field of psychology to describe children who **succeeded** as adults despite adverse childhood conditions (Earvolino-Ramirez, [2007](#); Herrman et al., [2011](#); Wald, et al., [2006](#)). Educators use the term resilience when describing student achievement in overcoming barriers (Cabanyes Truffino, [2010](#)). In the social sciences, such as psychology, social work, and nursing, research has shifted from examining negative or risk factors to examining positive factors or individual strength that contribute to healthy development and positive outcomes (Fletcher & Sarkar, [2013](#); Windle, [2011](#)).

A round table of interdisciplinary behavioral science experts concluded that the definition of resilience is determined by the context of study (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, [2014](#)). The common denominator in all areas is the ability to achieve or regain homeostasis or ‘bounce back’ from adversity/adverse experience (Earvolino-Ramirez, [2007](#); Wald, Taylor, & Asmundson, [2006](#)). Table 1 contains examples of definitions of resilience in social science and nursing literature. Advancing the ability to be resilient in caregivers of partner diagnosed with YOD could be important for not only decreasing **caregiver stress but also** for enhancing overall wellbeing of both the caregiver and the partner diagnosed with YOD (Earvolino-Ramirez, [2007](#); Herrman et al., [2011](#)).

Table 1. Definitions of resilience.

Author	Year	Definition
Rutter	1985	Ability to bounce back or cope successfully despite substantial adversity.
Dyer & Minton McGuiness	1996	“Global term describing a dynamic process whereby people bounce back from adversity and go on with their lives” (p. 277).
Luthar, Cicchetti & Becker	2000	Dynamic process of positive adaptation in the context of significant adversity.

Wald, Taylor, & Asmundson	2006	Positive adaptation or ability to maintain or regain mental health, despite experiencing adversity.
Gillespie, Chaboyer, & Wallis	2007	Capacity to transcend adversity and transform it into an opportunity for growth.
Bonanno, Westphal, & Mancini	2011	"A stable trajectory of healthy functioning after a highly adverse event" (in Southwick et al., 2014 , p. 2).
Garcia-Dia, DiNapoli, & Garcia-Ona, Jakubowski, & O'Flaherty	2013	"...one's ability to bounce back or recover from adversity. It is a dynamic process that can be influenced by the environment, external factors, and/or the individual and the outcome." (p.267).

Previous research in the [Figure 1](#) social and behavioral sciences has treated resilience as a personality trait, a process, and an outcome. Currently, resilience is viewed not as a static state but as a dynamic one, with current definitions supporting resilience as a process. Resilience is best described on a continuum that changes in response to an individual's perception of stressors, which supports this current understanding of resilience as a process (Herrman et al., [2011](#); Southwick et al., [2014](#)).

Definition of resilience in caregivers of partner/spouses diagnosed with YOD

Resilience is a dynamic process that results in positive adaptation after adversity. **Adversity involves an undesirable life situation (Luther & Cicchetti, 2000) which is consistent with the experience of caring for an individual with YOD.** Positive adaptation is maintaining or optimizing wellbeing of the caregiver, the care recipient, and the household (O'Rourke et al., [2010](#)). A resilient caregiver of a partner diagnosed with YOD can positively adapt following adversity. Indicators of resilience include attributes of flexibility, positive thinking, self-efficacy, resourcefulness, social support, and spirituality.

Method

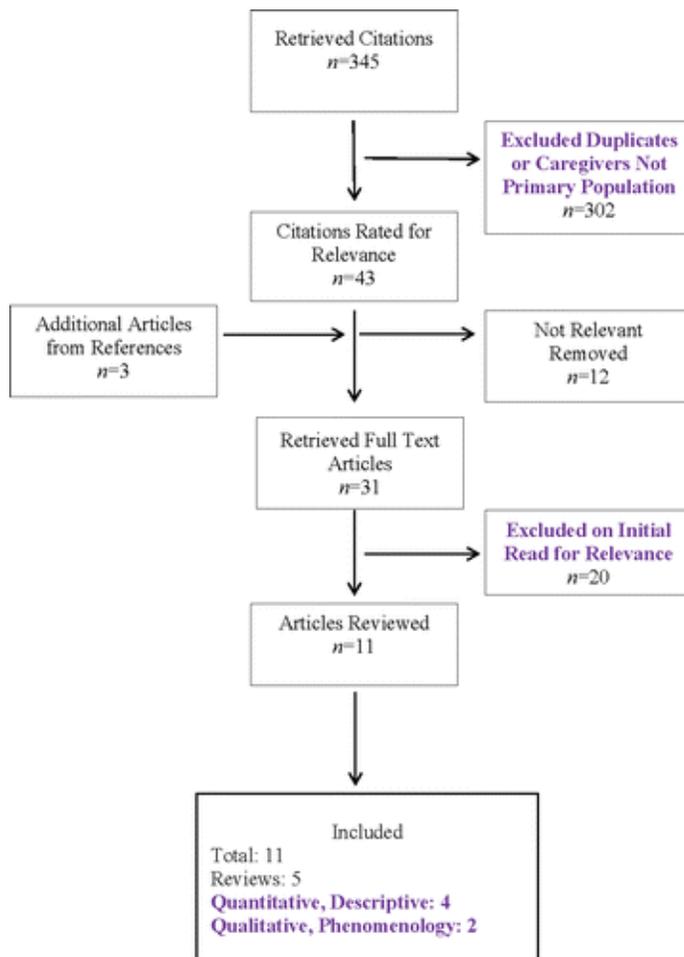
Walker and Avant's method for concept analysis provides a means to understand resilience in caregivers of a partner diagnosed with YOD, which is needed for the future development of clinical interventions **that enhance** attributes of resilience. This method was chosen for differentiating relevant attributes to distinguish resilience as it relates to the population of YOD caregivers (Walker & Avant, [2010](#)).

A systematic review of data bases was conducted using the Cumulative Index of Nursing and Allied Health (CINAHL), PsychInfo, PubMed, Web of Science, and Google Scholar. Data bases were chosen **which** offer articles specific to nursing, caregiving, and health sciences. Initial search dates were limited to 2005 to 2015 to evaluate the most current **literature as YOD** research has only begun to gain recognition **in recent years** (Alzheimer's Association, [2006](#)). Key terms used were 'resilience', 'young onset dementia', 'early onset Alzheimer's disease', 'caregiver', and 'spouse'. Resilience was combined with the other key terms through advanced searches using 'and'. Searches were limited to **peer reviewed, professional journal articles in English.**

From all databases, **345 articles** were assessed through ^{Table 2} review of the abstracts. Criterion used for identifying articles for review include major themes of caregiving, partner relationship, a diagnosis of YOD, and resilience. Of these articles, 302 were discarded due to duplication or to not having caregiving as a major theme. The remaining 43 articles were read and reviewed. An additional three articles were located through references. Of these 46 articles, 12 were discarded due to lack of relevance related to resilience. The remaining 31 articles were reviewed thoroughly in full text. Twenty articles were then discarded due to lack of relevance for not specifically correlating to YOD caregiving and resilience. The remaining 11 articles were reread and **used synthesis of themes to identify** positive caregiving of YOD.

The population focus for all 11 articles was exclusively caregivers for YOD. Five of the articles were literature reviews of YOD caregiving. Four articles were quantitative surveys that offered a descriptive research on YOD caregiving. Two were qualitative semi-structured interviews that examined the phenomenological experience of caregiving for a partner/spouse diagnosed with YOD. [Figure 1](#) demonstrates the article retrieval process for inclusion criteria of listed search terms, search dates for previous 10 years, English language, **peer-reviewed, professional journals, and relevance to topic.**

Figure 1. Article relevance flow chart.



Analysis

Attributes were identified through multiple iterations of review of the articles using a thematic analysis approach. This undertaking consists of **exploring context for meaning based on identifying relevant characteristics of resilience.** The goal of these iterations of analysis is to find meaning of the resilience concept as it relates to partner carers of YOD (Rodgers & Knaf, [2000](#)).

Attributes

Attributes are the vital characteristics that differentiate a concept from other concepts (Walker & Avant, [2010](#)). Caregivers of a partner diagnosed with YOD face many challenges related to reported high levels of caregiving stress (Aria et al., [2007](#); Ducharme et al., [2013](#); Kaiser & Panegyress, [2007](#)). This high level of stress is compounded by the unique set of unmet needs that accompany YOD (Ducharme et al., [2014](#); Flynn & Mulcahy, [2013](#)). **These unmet needs are different from other dementias as caregivers of partners diagnosed**

with YOD often have children still residing in the home and need to juggle both partner roles in the household and employment outside the home, along with the caregiving role (Ducharme et al., 2013; Ducharme et al., 2014; Flynn & Mulcahy, 2013; van Vliet et al., 2010). Flexibility, positive thinking, self-efficacy, resourcefulness, social support, and spirituality were the defining attributes of resilience in caregivers of partners diagnosed with YOD. These attributes were distinguished through thematic discovery during iterative readings and data synthesis of the articles. Table 2 lists each attribute and its definition.

Table 2. Definition of attributes of resilience.

Attribute	Definition	Example	Differentiation
Flexibility	Adaptability to unexpected changes and challenges (Earvolino-Ramirez, 2007).	Caregiver is planning to go to the store to buy groceries for dinner with partner diagnosed with YOD. Partner suddenly starts having angry outburst, so caregiver changes plans to find a soothing activity for partner while planning on leftovers for dinner.	Ability to roll with the changes (things did not go as planned – let's try something else).
Positive Thinking	Positive thinking is optimism by reframing adversity in a hopeful manner (Bekhet, 2013).	Person with YOD is angry and breaks a vase. Caregiver reframes stating the vase was ugly and he/she was thinking of getting rid of it. Caregiver also states he/she is glad no one got hurt.	Ability to look on the bright side.
Self-efficacy	A self-esteem and confidence in ability to accomplish a goal (Gillespie, Chaboyer, & Wallis, 2007).	Caregiver believes that he/she is competent and able to successfully accomplish caregiving tasks.	Belief that “I can do this!”
Resourcefulness	Ability to attain, maintain or promote health through help-seeking or self-help skills (Zauszniewski et al., 2016).	Caregiver looks for adult day programming so he/she can go to work (help-seeking). Caregiver figures out how to manage morning routine for partner and him/herself to accomplish all morning tasks prior to leaving for work (self-help).	Ability to accomplish whatever needs to be done.
Social Support	Meaningful relationships with family and/or friends that offer support and communication (Gillespie, Chaboyer, & Wallis, 2007; Tusaie & Dyer, 2004).	Caregiver calls his/her best friend to vent about the caregiving challenges. Caregiver's friends or family give caregiver a day of respite and friends spend day with YOD partner.	A network of people that listen to, care for, and help and support each other.
Spirituality	Belief that there is a purpose to events, challenges and life which may involve a belief in a higher power (Deist & Greeff, 2015; Selby et al., 2016).	Caregiver belief that even though he/she does not understand why this happened that there is a reason for this challenge.	Ability to believe in a greater good and a purpose even when the purpose is not readily evident.

Flexibility

Flexibility is the ability to adapt to an ever-changing environment (Earvolino-Ramirez, 2007). A resilient caregiver of a partner with YOD can be flexible in thoughts and actions to adapt to the challenges of the day when caring for their partner (Cabanyes Truffino, 2010; McAllister & McKinnon, 2009; Windle, 2011). Caregivers need to be able to find a new “normal” in day-to-day life while living with and caring for their partner as the YOD progresses. (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski, & O'Flaherty, 2013). Adaptation to this ever changing

new “normal” is necessary to optimize both caregiver and care recipient well-being (Earvolino-Ramirez, [2007](#); Garcia-Dia et al., [2013](#)). Caregivers of a partner diagnosed with YOD face challenges including loss of income from their partner's employment (Werner et al., [2009](#)), assumption of their partner's parenting role (Gibson, Andersen, & Acocks, [2014](#)), and additional role demands of caregiving for their partner/spouse (Ducharme et al., [2013](#)). The ability to adapt and adjust to the ever-changing challenges of caregiving were found to decrease burden (Lockeridge Simpson, [2013](#))

Positive thinking

Positive thinking is thoughtful consideration of benefits and affirmations even during challenging situations (Bekhet, [2013](#)). Positive thinking allows for maintaining optimistic attitude for the caregiver by reframing adversity in a hopeful manner (Bekhet, [2013](#); Deist & Greeff, [2015](#)). **This positive outlook** does not diminish the pain of the psychosocial loss one experiences when a partner is diagnosed with YOD. However, the caregiver can view challenges as opportunities for growth (Cabanyes-Truffino, [2010](#); Deist & Greeff, [2015](#)). In a study conducted by Bekhet ([2013](#)), positive thinking mediated the relationship between caregiver burden and resourcefulness in dementia caregivers. Caregivers that reframe challenges as growth opportunities demonstrated less burden (Bekhet, [2013](#)). Deist and Greeff ([2015](#)), found that positive thinking was key to overcoming stress in families caring for a member with dementia.

Self-efficacy

Self-efficacy is the belief that the **caregiver has in his or her own ability to care for his or her partner/spouse**. Earvolino-Ramirez ([2007](#)) states this belief that one can accomplish a goal is important for resilience. Belief in one's own caregiving ability allows the caregiver to remain strong during the struggles of caregiving (Garcia-Dia et al., [2013](#)). In a study conducted by Semiatin and O'Connor ([2012](#)), self-efficacy was found to significantly support positive aspects of caregiving for people diagnosed with dementia.

Resourcefulness

Resourcefulness is the ability to solve problems and overcome challenges (Zauszniewski, [2012](#)). Resourcefulness includes the ability to maintain independence, known as personal resourcefulness (Rosenbaum, [1990](#); Zauszniewski, [2012](#)), and to seek help from others when needed, known as social resourcefulness (Zauszniewski, [2012](#)). Gaugler, Kane, and Newcomer ([2007](#)), found that caregivers that accessed and utilized community resources had higher levels of resilience than caregivers that did not access and use resources. Hendrick and Young ([2013](#)) found that the availability of community resources for caregivers to access, decreased caregiver vulnerability and thereby increased resilience potential. Deist and Greeff ([2015](#)) found that caregivers of family members adapted and managed symptoms of the illness better when they accessed resources and information regarding the illness. Cherry, Salmon, Dickson, Powell, and Sikdar ([2013](#)) found that when available services are used by caregivers, burden is decreased and resilience is increased. Zauszniewski, Lekhak, Burant, Variath, and Morris ([2016](#)) found that **female** caregivers of people with dementia who received the resourcefulness training intervention experienced lower stress, fewer depressive cognitions and less negative emotions. **Resourcefulness both social and personal increase resilience in caregivers.**

Social support

A support system with meaningful relationships has been identified as essential to resilience and positive adaptation to the new caregiving role (Earvolino-Ramirez, [2007](#); Flach, [1997](#); Richardson, [2002](#); Tusaie & Dyer, [2004](#); Wilks, [2008](#)). Wilks and Croom ([2008](#)) found a social support network correlated strongly with resilience. The caregiver utilizes the social support system for respite but even more importantly as a confidant(s) with whom the caregiver can confide (Ross, Holliman, & Dixon, [2008](#)). Caregivers who perceive

more social support demonstrate higher resilience (Wilks, [2009](#)). Deist and Greeff ([2015](#)), found that caregivers who received support from family, friends, and community demonstrated better integration into the community and better adaptation to the stress of caregiving. Nichols et al. ([2013](#)) found partaking in social support groups, whether in person or online, was a positive experience for caregivers of dementia.

Spirituality

Spirituality is individualized for each person (Selby, Seccaraccia, Huth, Kurrpa, & Fitch, [2016](#)). Spirituality usually involves faith in a higher power that often incorporates activities such as prayer and meditation with a key focus on finding meaning in life events (Deist & Greeff, [2015](#); Selby et al., [2016](#)). Faith in a higher power often provides comfort and belief in one's capacity to handle challenges of caregiving (Deist & Greeff, [2015](#)). The belief that meaning exists in the caregiving role increases resilience (Deist & Greeff, [2015](#); Southwick et al., [2014](#)). **Spirituality does not mean caregivers** believe everything will turn out well, but that caregivers believe this role has a higher purpose (Gillespie, Chaboyer, & Wallis, [2007](#); Southwick et al., [2014](#)). In a study conducted by Deist and Greeff ([2015](#)), caregivers **who** acknowledged spirituality as an integral component in their life were better able to adapt positively to trials and difficulties.

Antecedents

Antecedents precede the occurrence of a concept (Walker & Avant, [2010](#)). Adversity is necessary for resilience to occur (Earvolino-Ramirez, [2007](#)). The adversity or antecedent necessary for resilience in caregivers of partner with YOD is the diagnosis of YOD.

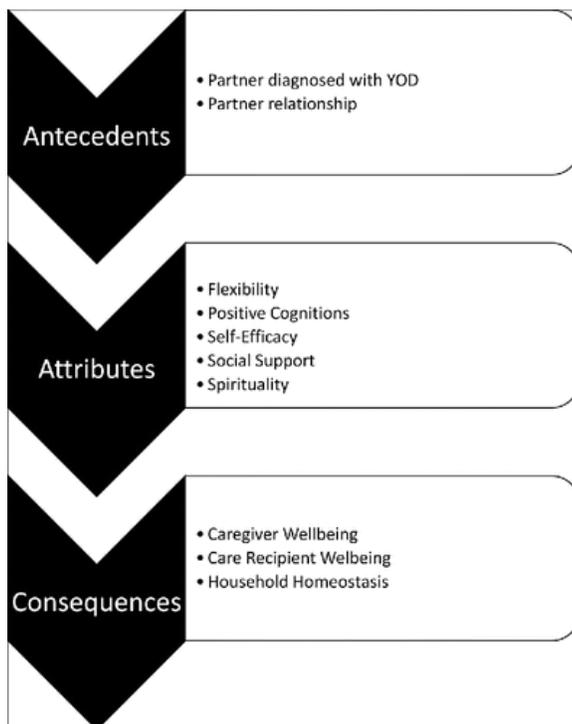
The relationship between the partner is also an antecedent for resilience of caregiving (Garcia-Dia et al., [2013](#)). **A** relationship, whether compatible or hostile, **must exist** between the partner prior to the diagnosis of YOD (Garcia-Dia et al., [2013](#)). This relationship is the foundation of the couple experience that has and will continue to influence couple interactions (Dyer & Minton McGuinness, [1996](#); Garcia-Dia et al., [2013](#); Gillespie, Chaboyer, & Wallis, [2007](#); Lindauer and Harvath, [2014](#)).

Consequences

Consequences are the outcomes that occur as a result of a concept (Walker & Avant, [2010](#)). The consequence of resilience when caring for a partner with YOD is positive adaptation as evidenced by caregiver wellbeing, care recipient wellbeing, and household homeostasis (Herrman et al., [2011](#); Southwick et al., [2014](#); Windle, [2011](#)). Wellbeing incorporates physical status, emotional status, and cognitive status (Earvolino-Ramirez, [2007](#)).

Household homeostasis is the integration of the new normal. This refers to the members of the household functioning and cohabiting in an overall level of harmony. The healthy partner becomes the main caregiver, which may be a role change and affect family dynamics (Werner et al., [2009](#)). **With YOD, a change occurs** in employment and **finances** due to the diagnosis occurring prior to the age of 65 when retirement benefits often begin (Paun et al., [2015](#); Werner et al., [2009](#),). The household may have children still living at home. One parent is experiencing a decline in functional status with possible alterations in personality and behavior due to the diagnosis, while the other parent is experiencing changes in role function. These changes will affect the family and the household management (Ducharme et al., [2013](#); Flynn & Mulcahy, 201; Paun et al., [2015](#)). The other factors of finances, employment, children, and household roles are influenced by the relationship of the partners. Resilience is not just managing one chaotic or traumatic moment to the next; resilience allows the reestablishment of a household homeostasis and well-being of household members. [Figure 2](#) gives an illustration between the antecedents, attributes, and consequences of YOD caregiver resilience.

Figure 2. Relationship of antecedents, attributes and consequences of resilience of caregivers for partners diagnosed with YOD.



Empirical referents

Empirical referents represent operational definitions of concept variables (Bekhet & Zauszniewski, [2008](#)). These are the phenomena that allow the concept to occur and can therefore be measured (Walker & Avant, [2010](#)). Windle ([2011](#)), found there are 19 resilience measures commonly used. The following scales could be used to measure resilience in YOD caregivers: The Connor-Davidson Resilience Scale, The Resilience Scale for Adults, The Resiliency Attitudes and Skills Profile, The Brief Resilience Scale, **and** The Resilience Scale (Windle, [2011](#)). The instruments appropriate for this population are the Connor-Davidson Resilience Scale, the Resilience Scale for Adults, and the Brief Resilience Scale **since these have the best psychometric ratings when used with adults** (Garcia-Dia et al., [2013](#); Windle, [2011](#)).

Connor-davidson resilience scale

The Connor-Davidson Resilience Scale is a self-report 25-item instrument used with adults to measure stress and coping ability through five domains: personal competence, trust/tolerance/ strengthening effect of stress, acceptance of change and secure relationships, control, and spiritual influences (Garcia-Dia et al., [2013](#)). The five domains of this scale theoretically incorporate attributes of resilience, **however**, the overall scale has been used primarily to measure stress and coping **with** caregiving (Windle, [2011](#)).

As caregiving stress is a consequence of the diagnoses of a partner with YOD, this scale may have merit when measuring **the** resilience of these caregivers. The Connor-Davidson Resilience scale was originally developed from work with people diagnosed with posttraumatic stress disorder and has since been used with a variety of populations, including caregivers of persons with dementia (Connor & Davidson, [2003](#)). This scale has been used with both clinical and community populations (Garcia-Dia et al., [2013](#)), which would support measuring resilience in caregivers of partner diagnosed with YOD especially when performing **intervention-based** studies.

The resilience scale

The Resilience Scale for Adults is a **37-item** self-report scale for adults to measure intrapersonal and interpersonal protective factors (Windle, [2011](#)). Personal competence, social competence, family cohesion,

social support, and personal structure are the five domains of the intrapersonal and interpersonal protective factors measured. (Garcia-Dia et al., [2013](#); Windle, [2011](#)). Garcia-Dia et al. ([2013](#)) state that the Resilience Scale for Adults, with Cronbach's α ranging from .73 to .91, is used to measure resilience in adults more frequently than other resilience measures. This scale is based on Resiliency Theory and measures focus on the protective factors that promote adaptation (Windle, [2011](#)).

The brief resilience scale

The Brief Resilience Scale measures resilience as recovery from stress using a **four-item** self-report survey for adults. This scale measures recovery from stress through coping ability (Garcia-Dia et al., [2013](#)). It is brief instrument that measures and individual's ability to bounce back and recover from stress specifically health related stressors (Garcia-Dia et al., [2013](#); Windle, [2011](#)).

Case studies

Case studies are part of a concept analysis that allow for clarification of the attributes through exemplars incorporating essential features. Case studies are a venue that allow the concepts to be viewed in a social and practical context (Rodgers & Knafel, [2000](#)). These case studies help clarify the concept of resilience in caregivers of partners diagnosed with YOD.

Model case

A model case contains all necessary attributes of a concept (Walker & Avant, [2010](#)). Mabel and Harold have been married 31 years after meeting in college. They are both 52 years old. Mabel is determined to care for her husband in their home and to find resources and services that optimize his well-being. She understands that this situation is difficult, and she will need to use different types of services and resources to provide her husband with optimal care. She is able to be **flexible** in her daily schedule. This flexibility in the schedule and in expectations allows for shifting of plans **to adapt to Harold's needs**. She is able to see humor in life as she is able to laugh at things that **do not** go as planned. Even though this diagnosis was not in the couple's life plans, Mabel believes she will manage everything successfully and finds joy and purpose in life. She has high **self-efficacy**. Mabel has hope that she can make a difference for Harold and her children. A rotation of friends come by her house daily to talk, to give Mabel an hour or more of respite, and to provide overall help as needed. She has two close friends that she can confide in regularly as they talk in person or on the phone multiple times during a week.

Positive adaptation is a consequence of resilience and Mabel is adapting well to this unexpected change in the family life plans. Harold is safe, clean, fed, **and physically healthy**. Mabel plans activities to try and keep him cognitively active and to optimize his wellbeing. She has someone to spend time with Harold four times a week so she can go to the YMCA and exercise. Healthy eating habits are incorporated for both caregiver and care recipient's health and wellbeing. Mabel has rearranged the tasks of the household amongst herself and her children and built a list of resources for tasks she or her children cannot manage. She maintains that though not perfect her household has achieved a homeostatic equilibrium; this new normal has been integrated into the **family's daily life**. Her resilience has come from her **resourcefulness** to locate and use services to care for herself and her husband and her ability to be **flexible** in her schedule. Mabel is able to use **positive thinking** to reframe situations to be viewed positively. She believes she can care for her husband. Mabel has an active **social support** network. **She believes in a higher power and a higher purpose for her current challenges. It is this spirituality that strengthens her.**

Borderline case

A borderline case is an example of the concept containing some but not all of the attributes of the concept (Walker & Avant, [2010](#)). Mabel is determined to make the best of this situation; however, she often finds herself angry with God and life. She reaches out to her friends and receives support from them. She is determined to provide the best care to her husband. **At** times, she becomes overwhelmed and depressed. Mabel is trying to keep the household functioning, **but she has days when she** wants to “give it all up”. This is a borderline case since there is inconsistency in Mabel's ability to positively adapt to caregiving for husband with YOD.

Contrary case

A contrary case is an example of a concept in which none of the attributes are present (Walker & Avant, [2010](#)). Mabel has become overwhelmed with **caregiving** and **with** the disruption in the household. She continues to allow him to drive even though the doctor has said he is no longer safe. **Mabel** complains to anyone who will listen about how unfair life is and how hard her life has become. She often questions why this is happening to her. She no longer talks with her friends. **Mabel** blames God for her misery. **She has increased her alcohol intake and has started to drink a bottle of wine every night.** Mabel is not able to demonstrate positive adaptation to caregiving for her husband with YOD.

Discussion/Conclusion

YOD is diagnosed prior to the age of 65 and can occur as early as 30 years of age, (Alzheimer's Association, [2017](#)) which creates caregiver challenges different from other those experienced by caregivers when dementia onset occurs after age 65. The challenges can include changes in financial status with loss of income and changes in child rearing and household roles. The response of the caregiver to these challenges has implications for the wellbeing of the caregiver, care recipient, and household. Positive adaptation, as evidenced by caregiver wellbeing, care recipient wellbeing, and household homeostasis, is the result of resilience exemplified in the attributes of flexibility, positive thinking, self-efficacy, resourcefulness, social support, and spirituality.

Recent systematic reviews by Petriwskyj, Parker, O'Dwyer, Moyle, and Nucifora ([2016](#)) and Richardson et al. ([2016](#)), **support the need for interventional studies that address caregiver resources.** Understanding resilience as it appears in carers of YOD is important in building interventional studies. Through the identification of essential attributes, interventions can be designed that enhance and support attributes and may increase well-being for both caregiver and care recipient. Maximizing caregiver resilience has significant potential clinical implications.

Limitations

A search of literature, while extensive, is not exhaustive. The literature review included only articles in English and articles that were in **peer-reviewed, professional journals**. Critical articles may have been missed that were not available in English. Similarly, popular literature that was not included could have offered insight into the caregiver role from a caregiver perspective.

Future considerations

More research is needed to better support caregivers of a partner diagnosed with YOD as their circumstances are different from other dementia caregivers. Empirical research is necessary to measure the interventions thought to enhance attributes of resilience. Future research should also include differentiating resources needed by caregivers related to stage of disease.

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