Journal of Aging Studies 40 (2017) 57–63

Contents lists available at ScienceDirect

Journal of Aging Studies

journal homepage: www.elsevier.com/locate/jaging

‘In this together’ or ‘Going it alone’: Spousal dyad approaches to Alzheimer's

Ryan T. Daley [a], Maureen K. O'Connor [a], Steven D. Shirk [a], Renée L. Beard [b,*]

[a] Edith Nourse Rogers Memorial Bedford VAMC, Bedford, MA 01730, USA
[b] College of the Holy Cross, Worcester, MA 01610, USA

ARTICLE INFO

Article history:
Received 9 September 2016
Received in revised form 11 January 2017
Accepted 19 January 2017
Available online 10 February 2017

Keywords:
Dyadic interviews
Relationship closeness
Alzheimer's disease
Positive aspects of caregiving

ABSTRACT

Spouses provide the majority of care for individuals with Alzheimer's disease (AD). The qualitative literature suggests that couples adopt one of two perspectives in their accounts of AD: a We/Us approach where couples describe experiences as a composite whole or an I/Me approach where couples describe themselves as experiencing the impact of AD separately. Little is known about how these perspectives relate to the individual characteristics of either affected party. This study investigated the experiences of dyads taking both approaches. Eleven spousal dyads were divided into I/Me ($n = 5$) and We/Us ($n = 6$) groupings based on qualitative analyses completed as part of a larger project. Diagnosed individuals were given measures of cognitive and functional ability and caregivers completed anxiety, depression, burden, relationship satisfaction, and positive aspects of caregiving measures. We found no significant differences between groups on patient cognitive or functional ability, or caregiver anxiety, depression, burden, or relationship satisfaction. However, We/Us caregivers expressed more positive aspects of caregiving than I/Me caregivers. These findings suggest the I/Me approach is not associated with differences in variables of patient cognitive status or functional ability or caregiver emotional health, perceived burden, or relationship satisfaction. Caregivers taking a We/Us approach, however, were able to identify more positive aspects of caregiving. This may be related to mutual compassion, a characteristic of the We/Us approach, which may be protective.

Introduction

The population is aging, and with this trend has come considerable increases in the prevalence of Alzheimer's disease (AD). Currently, an estimated 43 million people over the age of 65 reside in the United States (Ortman, Velkoff, & Hogan, 2014). This group is expected to increase to a staggering 83.7 million by 2050, making up 20% of the U.S. population. Projections claim that more than 5.1 million people over the age of 65 have a diagnosis of AD in America alone (Alzheimer's Association, 2015). Given these demographic predictions, over the next 25 years the number of AD diagnoses is expected to dramatically increase. While the scientific community searches for a cure, research on the psychosocial impact of AD is necessary in order to design interventions for people and their families currently living with the condition.

The vast majority of individuals diagnosed with AD are cared for by family members (Alzheimer's Association, 2015). In fact, approximately 70% of informal, or unpaid, caregivers are married to the person for whom they provide care (Bouldin & Andresen, 2014). As cognitive and functional abilities decrease, the demands on informal caregivers increase and often have detrimental psychosocial consequences. Increases in spousal caregiver depression, anxiety, and burden are associated with decreases in care recipient cognitive and functional abilities (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Mahoney, Regan, Katona, & Livingston, 2005; Razani et al., 2007; Shua-Haim, Haim, Shi, Kuo, & Smith, 2001). Also, relationship satisfaction has been found to have important health implications for older adults in general (Ablitt, Jones, & Muers, 2009; Dykstra & Fokkema, 2007; Margelisch, Schneewind, Violette, & Perrig-Chiello, 2015; Walker & Luszcz, 2009; Whisman & Uebelacker, 2006) and a negative correlation with dementia caregiver burden (Braun et al., 2009; Simonelli et al., 2008). That is, as burden increases, relationship satisfaction decreases for dementia caregivers.

The potential benefits to informal AD caregivers have been far less studied despite potential positive aspects being established long ago (Kinney & Stephens, 1989). Since then, a growing body of literature has begun to examine the positive aspects of informal dementia caregiving (Carbonneau, Caron, & Desrosiers, 2010; Roff et al., 2004; Tarlow et al., 2004). Outcomes such as meaning making (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Farran, Miller, Kaufman, Donner, & Fogg, 1999), companionship/sustaining

---

* Corresponding author.
E-mail addresses: Daleyrb@bc.edu (R.T. Daley), Maureen.OConnor@va.gov (M.K. O'Connor), Steven.Shirk@va.gov (S.D. Shirk), rbeard@holycross.edu (R.L. Beard).

http://dx.doi.org/10.1016/j.jaging.2017.01.003
0890-4065/

Table 1
Demographics.

Variables	We/Us ($n = 6$)		I/Me ($n = 5$)	
	AD	Caregivers	AD	Caregivers
Gender				
Male	4	2	5	0
Female	2	4	0	5
Age	81.6 (7.63)	80.8 (6.61)	82.6 (4.61)	77.6 (9.39)
Years of education	15.3 (2.07)	15.0 (3.28)	15.4 (1.95)	17.4 (1.94)
Years married	47.5 (19.69)		49.8 (10.28)	
Residence				
Single family home	6		3	
Senior living community	0		2	

“couplehood” (Hellström, Nolan, & Lundh, 2007), and fulfillment (Cohen, Colantonio, & Vernich, 2002) have been identified as positive aspects associated with the caregiving experience. Also, caregiver perceived self-efficacy is associated with increased positive aspects of caregiving (Crellin, Orrell, McDermott, & Charlesworth, 2014; Hilgeman, Allen, DeCoster, & Burgio, 2007; Semiatin & O'Connor, 2012). Importantly, rewarding appraisals of and satisfaction with caregiving may reduce stress and improve emotional outcomes that can be associated with caring for a family member diagnosed with AD (Kinney & Stephens, 1989; Roff et al., 2004). This suggests that caregiver perceptions may impact appraisals of caregiving experiences. However, due to the relative neglect of this topic, it is unclear what other variables contribute to informal caregiver ratings of positive aspects of caregiving.

One unexplored variable that may contribute to informal caregiver ratings of positive aspects of providing care is the spousal dyads' relationship closeness. Kaplan (2001) seeks to understand the varying degrees of spousal dyad approaches to life stressors by establishing a “couplehood typology,” with “We (Til death do us part)” and “I (Unmarried marrieds)” acting as opposite poles. This study utilizes semi-structured dyad interviews to examine spousal appraisals of couplehood, in light of AD. While providing the groundwork for the operationalization of couplehood, Kaplan (2001) identifies what is now widely considered an overly medicalized understanding of AD experiences reflected in and reinforced by a literature base that neglects the voices of the spouses diagnosed with AD (Beard, Sahktah, Imse, & Galvin, 2012; Clare & Shakespeare, 2004; Davies, 2011; Hellström, Nolan, & Lundh, 2005). It is well established that individuals diagnosed with AD have the ability to communicate and maintain personhood in the early and middle stages of the disease process (Beard, 2004, 2016; Beard & Fox, 2008; Kitwood & Bredin, 1992). In light of this fact, when examining experiences of AD, both voices must be heard because they each play a part in defining the other through “interactive personal experience” (Perry & O'Connor, 2002). Thus, it is crucial to consult individuals diagnosed with AD alongside their spousal caregivers when attempting to understand AD experiences. The couple-based studies reported above establish that dyadic interview data are able to offer a richer understanding of couplehood than studies that only examine the experiences of the spousal caregiver (Braun et al., 2009). As Beard and O'Connor (2015) suggest, marital status alone may not afford the benefits experienced by some spousal dyads. Rather, it may be that the quality of the bond, or perceived relationship closeness, has a larger effect on experiences. Therefore, having a sense of connectedness that promotes a joint approach to the adversities of AD may be a better predictor of positive perceptions of living with the condition. It is possible, therefore, that spousal caregiver appraisals of positive aspects of caregiving may be associated with specific approaches within the couplehood typology.

What the biomedical studies do not address and the extensive socio-behavioral research on experiences of AD have reported but failed to explain is the discrepancy between subjective complaints of memory loss, “caregiver burden,” and objective impairment or scores on psychometric tests for either party. The current study seeks to examine the relationship between spousal dyad approaches to AD, perceived marital closeness, and positive aspects of caregiving. Several studies have used qualitative methods (i.e. semi-structured interviews and focus groups) to understand the lived experiences of spousal dyads in the context of AD (Hellström et al., 2007, 2005; Hydén & Nilsson, 2015). The current study employs a mixed methods research design to expand upon the findings of Kaplan (2001). By employing both quantitative questionnaires and qualitative semi-structured interviews, the current study hopes to further engage the couplehood typology.

Methods

Participants

Data were collected from 11 spousal dyads ($n = 22$), where one individual had a diagnosis of AD and their non-affected spouse self-identified as an informal caregiver. Participants were recruited from flyers posted in local senior centers and other public spaces. The sampling procedures involved a non-probability strategy, including convenience and snowball sampling. AD participants were eligible if they had a diagnosis of AD based upon NINCDS-ADRDA criteria (McKhann et al., 1984). To be included, AD participants and their spousal caregivers had to reside together. All of the spousal dyads were community dwelling, nine residing in private homes and two in retirement communities. Dyads were excluded if either party had a history of a psychotic disorder, such as schizophrenia or bipolar disorder, or active drug or alcohol abuse. Dyads were also excluded if the AD participant had a comorbid diagnosis of a neurological disorder other than AD. All participants were heterosexual Caucasian couples.

Measures

Questionnaires were administered to provide quantitative support for the semi-structured interviews. As AD cognitive and functional abilities can have negative impacts on caregiver mental health and relationship satisfaction, the Montreal Cognitive Assessment (MoCA) was administered to determine AD participant cognitive ability at the time of interview. MoCA is generally considered to be more sensitive to mild memory loss than, say, the Mini-Mental State Examination (MMSE), so was deemed the most apt measure for our purposes. MoCA has been found to discriminate very well between normal cognition and mild impairment or dementia. Spousal caregivers completed the Activities of Daily Living and Instrumental Activities of Daily Living scale (ADL/IADL) to report on AD participant functional ability. The following scales were also administered because caregiver depression and anxiety are associated with caregiver burden and relationship satisfaction: Beck Anxiety Inventory (BAI), Center for Epidemiological Studies Depression Scale (CES-D), Burns Relationship Satisfaction Survey (BRSS), and Zarit Burden Interview (ZBI). Finally, the Positive Aspects of Caregiving scale (PAC) was administered to capture how positive aspects of the caregiving experience might relate to caregiver mental and emotional health.

Table 2
Questionnaire means, standard deviations and range by spousal dyad approach.

Variable	We/Us		I/Me	
	M	*SD* (range)	*M*	*SD* (range)
MoCA	17.1	8.01 (6–26)	13.8	6.94 (6–25)
ADL/IADL	20.8	4.31 (16–26)	17.4	3.13 (14–22)
BAI	2.0	2.45 (0–6)	5.0	5.7 (0–14)
CES-D	4.3	4.08 (0 − 12)	11.4	13.69 (0–34)
BRSS	36.3	7.81 (21–42)	25.8	14.15 (13–42)
ZBI	24.3	12.53 (2–36)	31.2	11.14 (17–44)
PAC	37.3	6.12 (29–45)	26.4	8.96 (17–40)