

Communication, coping behavior outcomes, and Alzheimer's caregiver stress

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"A DIAGNOSIS
OF CANCER
AND EVERYONE
RUSHES TO
HELP...
DEMENCIA
AND EVERYONE
DISAPPEARS."

Ita Buttrose AD OBE
Alzheimer's Australia National Ambassador



Every 66 seconds someone in the U.S. develops Alzheimer's disease. There are more than 15 million unpaid U.S. Alzheimer's caregivers (AA, 2017).

Abstract

Family members are taking more ownership in the caregiving process for the more than 5.4 million people in the U.S. who are living with Alzheimer's disease (CDC, 2016; AA, 2017). However, many are not trained or prepared for the impending challenges. Alzheimer's is an irreversible, progressive disease (NIA, 2017). As symptoms worsen, the patient's self-care needs and behavior problems increase. Identifying and strengthening resources and finding ways to bridge healthcare provider knowledge is imperative for lay caregivers to address the challenges of Alzheimer's disease care (Roth et al., 2005). Examining Alzheimer's disease (AD) caregivers ($N = 160$) from the Caregiving in the U.S. 2015 data set from the National Alliance for Caregiving and AARP (2015) unveiled variables for a multivariate quantitative examination of caregiver stress. Findings indicate that current healthcare provider communication practices and coping strategies used by caregivers are significantly associated with increased levels of stress and burden. Results could be used to help create new AD caregiver stress interventions.

Introduction

As the number of AD patients increases, a lack of care facilities emerges, and costs grow beyond individual resources; family members and spouses are taking more ownership in the caregiving process. However, many are not trained or prepared for the challenges they will face. Caregiving is described as the act of providing physical, emotional, psychological, and social support to another individual (Teper & Hughes, 2010). Often, a caregiver can be an unpaid spouse, family member, or friend. These lay caregivers, provide unpaid care estimated at 18.2 billion hours in the U.S. (AA, 2017). Lay caregiving can carry many advantages for families and patients including social and economic benefits. However, it also can negatively impact caregivers resulting in emotional stress, social withdrawal, physical strain, and psychological issues. Negative outcomes of caregiving are associated with the physical and psychological demands of giving care, and difficulty of balancing identities and roles (Miller, et al., 2008). Demands of AD caregivers are not only handling self-care needs (bathing, continence, feeding) but also patient behavior problems (agitation, wandering). Self-care needs impose physical demands on the caregiver, but can often be managed. Behavioral problems, however, create greater stress for the caregiver since they are less predictable and harder to control (Goode, et al., 1998).

Purpose

Caregiver stress theory (Tsai, 2003), ways of coping (Lazarus and Folkman 1984), and the role of caregiver social support (Goode, et al., 1998) were selected to theoretically inform this inquiry. In addition to examining the effect of chronic caregiving, this investigation explores the impact of communication, care strategies, social support, and coping on caregiver stress.

- **RQ1:** What is the relationship between the length of time caregiving and caregiver stress?
- **RQ2a:** How does a healthcare professional asking what the caregiver needs to take care of his/herself influence the level of emotional stress?
- **RQ2b:** How does the use of respite service influence level of burden?
- **RQ2c:** How does having plans in place for the caregiver's own future care influence level of emotional stress?
- **RQ2d:** How does acknowledging a need for more information or help to manage challenging behaviors influence level of burden?
- **RQ2e:** How does the caregiver acknowledging a need for more help or information to manage his/her own emotional and physical stress influence caregiver stress?



Procedure and Measures

Data were collected from a larger quantitative online cross-sectional research study conducted in 2014 with 1,248 participants. AD and dementia caregivers ($N = 160$) were selected from the 2015 *Caregiving in the U.S.* data set from the National Alliance for Caregiving and AARP.

Analysis of the data revealed a multivariate framework for evaluating the caregiver issues. One dependent variable, *caregiver stress*, was measured in level of physical strain and emotional stress. Thus, Physical Strain + Emotional Stress = Caregiver Stress ($\alpha = .77, M = 2.99, SD = 1.08$). Another dependent variable is *burden*. The dependent variables were operationalized using the following Likert-type single item questions. The level of *physical strain* in caring for the patient was contextualized in a measure of (1) not a strain at all, to (5) very much of a strain ($M = 2.62, SD = 1.19$). *Emotional stress* was measured as (1) not at all stressful, to (5) very stressful ($M = 3.38, SD = 1.21$). *Burden* was measured both on scale of (1) low to (5) high ($M = 3.11, SD = 1.50$).

The independent variables to examine are *length of time giving care* and the use of *coping strategies*. Length of time was assessed by an ordinal level scale measure with range options. Problem and emotion-focused coping strategies were identified in the study with single item questions addressing interpersonal support and intrapersonal coping.

Measures

The first measure of coping was whether or not (yes, no) a healthcare professional had asked what the caregiver needs to take care of his/herself (yes, $n = 36, 22.5\%$). Secondly, coping was measured by whether or not the caregiver ever used respite services (no, $n = 112, 70\%$). Third, coping was operationalized in intrapersonal techniques: an acknowledgement (yes, no) of need for more help or information to manage: a) challenging behaviors, such as wandering (yes, $n = 69, 43.1\%$), and b) the caregiver's own emotional and physical stress (yes, $n = 67, 41.9\%$). Finally, coping was also measured as (yes, no) having plans in place for the caregiver's own future care (yes, $n = 88, 55\%$).

Results RQ1 – RQ2c

The relationship between length of time providing care (an ordinal categorical measure) and caregiver stress (as measure by the caregiver stress scale) was investigated using Spearman's rho to answer RQ1. Although the findings were not statistically significant, there was a small positive correlation between length of time providing care and caregiver stress [$\rho (n = 155) = .118, p > .05$].

Table 1. Pearson's Product Moment Correlations for Study Variables ($n = 154$)

	M	SD	1	2	3	4
Caregiver Stress (1)	3.00	1.08				
Burden (2)	3.09	1.50	.25**			
Physical Strain (3)	2.62	1.20	.90**	.32**		
Emotional Stress (4)	3.38	1.21	.90**	.14*	.63**	
Length of Time Providing Care (5)	3.91	1.01	.12	-.02	-.04	-.17*

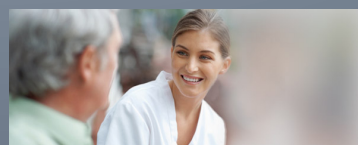
*Correlation is significant at the .05 level (1-tailed). **Correlation is significant at the .001 level (1-tailed).

Independent-samples t-tests were conducted to answer the remaining RQs. Each RQ addressed yes/no question responses and DVs.

RQ2a: If healthcare professionals asked what the caregiver needs' (yes/no), this influenced the level of emotional stress [$t (152) = 2.15, p = .03, d = .41$]. There was a significant difference between individuals that reported a healthcare professional asking them what they needed ($M = 3.77, SD = 1.22$) and those that reported not being asked what they need for self care ($M = 3.28, SD = 1.19$). Although statistically significant, the magnitude of the difference was small.

RQ2b: Use of respite service (yes/no) did not influence level of burden [$t (152) = .823, p > .05$]. There was not a significant difference between individuals that reported using a respite service ($M = 3.28, SD = 1.55$) and those that reported not using a respite service ($M = 3.06, SD = 1.47$).

RQ2c: Caregivers having plans in place for their own future care (yes/no) did not influence the level of emotional stress [$t (151) = -1.765, p = .08$]. There was not a significant difference between individuals that reported having plans in place for their own future care ($M = 3.23, SD = 1.15$) and those not having plans in place ($M = 3.58, SD = 1.27$).



Results RQ2d – RQ2e

RQ2d: Caregivers acknowledging a need for help to manage challenging patient behavior (yes/no) did influence the level of emotional stress [$t (152) = 4.44, p < .0001, d = .73$]. There was a significant difference between individuals that reported a need for help to manage challenging patient behavior ($M = 3.69, SD = 1.36$) and those that reported not needing help to manage challenging patient behavior ($M = 2.67, SD = 1.45$). The magnitude of the difference was medium.

RQ2e: Caregivers acknowledging a need (yes/no) for more help to manage their own emotional/physical stress influenced caregiver stress, as measured by the caregiver stress scale [$t (151) = 5.58, p < .0001, d = .90$]. There was a significant difference between individuals that reported asking for help to manage their own emotional and physical stress ($M = 3.51, SD = 1.05$) and those that reported not asking for help ($M = 2.62, SD = .95$). The magnitude of this difference was large.

Discussion

Healthcare professionals asking what caregivers need for self care resulted in significantly more emotional stress. Regardless of whether the caregivers reported using a respite service, this did not significantly influence level of burden. Whether or not the caregivers reported having plans in place for their own future care did not significantly influence level of emotional stress. Caregivers who reported acknowledging a need for help to manage challenging patient behavior resulted in significantly greater levels of burden. Caregivers who reported acknowledging a need for help to manage their own emotional and physical stress resulted in significantly greater caregiver stress.

Conclusion

Results indicate that current healthcare provider communication practices and coping strategies used by caregivers are significantly associated with increased levels of stress and burden. These findings could be used to help create new AD caregiver stress interventions. This group of AD caregivers overwhelmingly felt unprepared for the task of caregiving. Health communication scholarship should examine ways that preparedness training could be developed and implemented in a feasible manner for lay caregivers. Findings can also inform future studies of AD lay caregiver stress. Future research can include measures such as Cohen's Perceived Stress Scale (1988). Practical implications of this examination of communication practices can help inform healthcare professionals and AD organizations in understanding ways to better meet the needs of patients and their family member lay caregivers.

References

- Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. Retrieved from <http://www.alz.org/factsandfigures.asp>
- Alzheimer's Australia. (2017). Images/Photographs. Retrieved from <https://www.alzheimersaustralia.org.au>
- Centers for Disease Control and Prevention. (2016). At a glance, 2016: Alzheimer's disease. Retrieved from <https://www.cdc.gov/nchs/data/infodiv/infodiv2016/alzheimers.pdf>
- Cohen, S. & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In Spector, S. and Oskamp, S. (Eds.), *The social psychology of health*. Newbury Park, CA: Sage.
- Goode, K. T., Haley, W. E., Roth, D. L., & Fort, G. R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17*(2), 196-199. doi:10.1037/0278-6133.17.2.199
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Miller, J. L., Shoemaker, M. M., Willard, J., & Addison, P. (2008). Providing care for elderly parents: A structural approach to family caregiver identity. *Journal of Family Communication, 8*(1), 19-43. doi:10.1080/15257290701604940
- National Alliance for Caregiving & AARP (2015). *Caregiving in the U.S. 2015*. Retrieved from <http://www.caregiving.org/researchreports/data/>
- National Institute on Aging. (2010). *Alzheimer's disease: Alzheimer's basics*. Retrieved from <http://www.nia.nih.gov/health/publications/alzheimers-basics>
- Roth, D., Malsman, M., Cho, O., Meador, A., Haley, W., & Zucko, Rose T. (2005). Changes in social support as mediators of the effect of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging, 20*(4), 634-644.
- Teper, E. L., & Hughes, J. C. (2010). Critical and ethical issues in palliative care and dementia - An overview. *European Neurological Review, 5*(2), 29-33. doi:10.11925/ENR.2010.05.02.29
- Ten, P. (2003). A middle-range theory of caregiver stress. *Nursing Science Quarterly, 16*(2), 137-145.