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Psychosocial Predictors of Dementia Caregiver Desire to Institutionalize: Caregiver, Care Recipient, and Family Relationship Factors

Mary Beth Spitznagel, Ph.D.[1,2], **Geoffrey Tremont, Ph.D.**[1,2], **Jennifer Duncan Davis, Ph.D.**[1,2], and **Suzanne M. Foster, B.A.**[2]

1*Brown Medical School, Providence, RI*

2*Rhode Island Hospital, Providence, RI*

Abstract

Several factors influence dementia caregiver desire to institutionalize; however, little is known about differences in caregivers who desire institutionalization versus those who do not. The current study compares predictors of desire to institutionalize in dementia caregivers. Seventy-two caregivers completed the Desire to Institutionalize Scale (DIS) and several psychosocial measures, including burden, dementia knowledge, self-efficacy, depression, health, care recipient daily functioning and memory/behavior problems, family functioning and social support. Based upon DIS responses, caregivers were divided into No DI versus DI groups. DI caregivers had significantly higher burden, greater dementia knowledge, more family dysfunction, and decreased social support compared to No DI caregivers. Findings emphasize the importance of caregiver and family relationship variables in DIS, suggesting potentially modifiable targets for caregiver interventions. Dementia knowledge was associated with higher DIS, suggesting educational programs alone may not be helpful to delay institutionalization.

Introduction

Institutionalization of individuals with dementia within the first five years of diagnosis occurs at a rate of 10% per year (Smith et al., 2001). Research in the past two decades indicates numerous variables are associated with increased risk of institutionalization, including both demographic factors (e.g., caregiver employment, financial resources, and older care recipient age; Colerick & George, 1986; Montgomery & Kosloski, 1994) as well as psychosocial and care recipient factors (e.g., caregiver burden, care recipient problem behaviors; Brodaty et al., 1993; Cohen et al., 1993). Although demographic factors are clearly significant predictors, they may be less amenable to change than psychosocial variables. In recent years, several caregiver interventions targeting psychosocial factors that predict nursing home placement have shown success in delaying institutionalization of dementia care recipients (e.g., Mittelman et al., 1993; reviewed by Tremont et al., 2004).

Psychosocial predictors of nursing home placement appear to be related to characteristics of the caregiver, care recipient features, and also to the quality of family relationships. Caregiver burden, negative reaction to the care recipient's behavior problems, and poorer caregiver physical or mental health are linked with greater likelihood of care recipient institutionalization (Brodaty et al., 1993; Cohen et al., 1993; Cohen et al., 1994; Colerick & George, 1986; Mittelman et al., 1993; Montgomery & Kosloski, 1994; Yaffe et al., 2002). Patient

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Address correspondence to Geoffrey Tremont, Ph.D., Rhode Island Hospital Neuropsychology Program, 593 Eddy Street, Providence, RI 02903, e-mail: gtremont@lifespan.org.

characteristics associated with greater risk for institutionalization include increased dependence in activities of daily living, severity of cognitive impairment, and difficult behaviors (Brodaty et al., 1993; Cohen et al., 1993; Mittelman et al., 1993; Montgomery & Kosloski, 1994; Pruchno et al., 1990; Smith et al., 2000; Yaffe et al., 2002). Though less well investigated, family relationship characteristics such as decreased level of affection in the caregiver/care recipient relationship also predict institutionalization (Montgomery & Kosloski, 1994).

In addition to the factors described above, there is an increased likelihood of institutionalization when caregivers report that they have taken steps toward placing their care recipient in a structured living facility. Specifically, the Desire to Institutionalize Scale (DIS; Morycz, 1985) is predictive of later institutionalization of care recipients (Pruchno et al., 1990). Instruments such as the DIS may be especially important in early identification of caregivers considering nursing home placement, allowing prevention or reduction of escalating risk factors (e.g., burden) that may otherwise lead to care recipient institutionalization. Little research has been conducted examining predictors of caregiver desire to institutionalize, though existing evidence indicates impact of caregiver and care recipient factors similar to those predicting actual institutionalization (Hamel et al., 1990). In addition, caregivers desiring institutionalization were more likely to be non-spousal caregivers, though quality of the dyadic or family relationships was not examined.

The current study sought to better understand psychosocial caregiver and care recipient predictors, as well as explore the impact of quality of family relationships underlying caregiver consideration of nursing home placement. Caregivers completed several psychosocial measures and the DIS. The hypotheses were that caregiver, care recipient, and family relationship variables would significantly contribute to caregiver desire to institutionalize.

Methods

Participants

Participants were 72 caregivers of dementia patients who completed baseline assessment measures as part of a caregiver intervention study. Participants were recruited from outpatient memory disorder clinics and from the community through advertisements. All caregivers resided with the care recipient and were providing a minimum of 4 hours of daily care for at least 6 months. Etiology of dementia in the care recipients included probable Alzheimer’s disease (n=43), vascular dementia (n=4), mixed dementia (n=4), frontotemporal dementia (n=5), diffuse lewy-body disease (n=4), Parkinson’s dementia (n=3), hydrocephalus (n=2), progressive supranuclear palsy (n=1), dementia NOS (n=5), and 5 patients’ diagnoses were unknown. Dementia severity was determined by total sum of boxes (i.e., summation of category ratings) of the Clinical Dementia Rating scale (CDR; Morris et al., 1993). See Table 1 for further description of sample characteristics.

Instruments and Procedures

Desire to Institutionalize Scale (Morycz, 1985): The DIS is a seven-item self-report inventory that quantifies stages in considering nursing home placement, ranging from discussion with family or friends about care recipient placement to actually applying for placement. An overall desire to institutionalize score can be calculated based on caregiver responses (e.g., a caregiver who has never discussed or obtained information about care recipient placement would yield a score of 0; one who has completed a nursing home application might obtain the highest score of 7). In light of a positively skewed distribution of responses on the DIS, caregivers were divided into two groups based upon a median split of the distribution of DIS responses: those reporting they had never taken any steps toward placement (i.e., DIS=0) were grouped into the

"No Desire to Institutionalize" group (No DI); those reporting they had at least spoken with a friend or family, had obtained information about placement, or had visited a nursing home (i.e., DIS>/=1) were grouped into the "Desire to Institutionalize" group (DI).

Other Measures: Geriatric Depression Scale (GDS; Yesavage et al., 1983); Zarit Burden Interview (ZBI; Zarit et al., 1980); Alzheimer's Disease Knowledge Test (ADKT; Dieckmann et al., 1988); SF 36 General Health (SF-36; Ware, 1988); Self Efficacy Scale (SES; Fortinsky et al., 2002); Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992); Frontal Systems Behavior Scale (FrSBe; Grace & Malloy, 2001); Activities of Daily Living (ADLs; Lawton & Brody, 1969); Family Assessment Device (FAD; Epstein et al., 1983); Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988); Burns Relationship Satisfaction Scale (BRSS; Burns, 1983).

Statistical Analyses

Independent sample t-tests were utilized to examine between-group differences on demographic variables. Multivariate analyses of variance (MANOVAs) were used to examine between-group differences for each of three groups of variables: caregiver (i.e., burden, dementia knowledge, self-efficacy, depression, health, and reaction to care recipient memory/behavior problems), care recipient (i.e., activities of daily living, memory/behavior problems, and dementia severity), and family relationship factors (family functioning, spousal social support, family social support, and premorbid relationship quality). When meaningful, multivariate analysis of covariance was used to control for group differences that emerged in demographic variables. False Discovery Rate corrected post-tests were used to clarify significant omnibus tests. Given the paucity of previous research on predictors of desire to institutionalize, we followed up on omnibus test trends using exploratory oneway analyses of variance (ANOVAs) with corrections, to ensure that factors unrelated to desire to institutionalize did not obscure factors that were. In addition, the same analyses were conducted within a subsample of the total sample to address a potential confound raised by a between-group difference in one demographic variable.

Results

Sample Description

Twenty-nine caregivers were included in the No DI group and forty-three in the DI group. Adult children reported significantly higher desire to institutionalize than spouses, $t(70)=2.65$, ($p=.01$). No other significant between group differences emerged. See Table 1. *Caregiver, Care Recipient, and Family Relationship Differences between DI and No DI*

Multivariate tests showed differences in caregiver characteristics between DI and No DI, $\Lambda(6, 65)=3.04$, $p=.01$, with DI caregivers reporting higher burden, $F(1,70)=9.46$, $p<.01$ and greater dementia knowledge, $F(1,70)=6.47$, $p<.05$. Level of depression, reaction to care recipient memory/behavior problems, self-efficacy, and general health did not significantly differ after correction. The omnibus multivariate test for care recipient variables approached but did not reach significance, $\Lambda(4, 67)=2.31$, $p=.07$. Exploratory analyses showed trends toward greater frontal systems behavior problems, $F(1,70)=5.79$, $p<.05$ and decreased independence in activities of daily living, $F(1,70)=5.98$, $p<.05$, though these were not significant after correction. No differences in frequency of memory/behavior problems or dementia severity were found. Within family relationship variables, the omnibus multivariate test again approached but did not reach significance, $\Lambda(4, 61)=2.47$, $p=.05$. Exploratory analyses revealed better family functioning, $F(1,70)=6.42$, $p<.05$ and perceived family social support, $F(1,70)=6.51$, $p<.05$ in the No DI group. In contrast, quality of the spousal relationship and significant other social support were not significantly different after correction. See Table 2.

In light of the between-group difference in caregiver type (i.e., spouse versus adult children), the same analyses were run in DI versus No DI spouses to examine robustness of the findings and ensure that the results presented above are not driven solely by caregiver type. Although the reduced sample size of these groups did not allow adequate power (observed power <65%), to detect the differences seen in the total group, trends toward a difference in caregiver variables $\Lambda(6, 37)=1.99$, $p=.09$ and relationship variables $\Lambda(4, 34)=.2.38$, $p=.07$ emerged. Exploratory examination of the univariate analyses revealed a significant difference in caregiver dementia knowledge $F(1, 43)=6.93$, $p<.05$ and a trend toward significance of caregiver depression level $F(1,43)=3.54$, $p=.07$. Other univariate analyses within the caregiver and relationship variables were not significant. The omnibus multivariate test for care recipient variables was not significant, $\Lambda(4, 39)=.77$, p=ns.

Discussion

The current findings emphasize the importance of caregiver and family relationship variables in desire to institutionalize. Consistent with previous research examining predictors of insitutionalization (e.g., Brodaty et al., 1993; Cohen et al., 1994; Colerick & George, 1986; Yaffe et al., 2002) and findings of Hamel and colleagues (1990), group differences were found in burden, with higher levels of burden seen in those desiring institutionalization relative to those intending to maintain their care recipient at home. The current study also found greater caregiver knowledge about dementia in those desiring to institutionalize, and this appears to be the first report of this finding in the literature. Greater dementia knowledge in caregivers desiring to place their care recipient may be initially counterintuitive; however, it is possible that caregivers who are more informed about dementia more fully appreciate the eventuality of severe cognitive decline or behavior problems. As such, this group may be more willing to consider placement of their care recipient. These findings highlight the importance of creating caregiver interventions that include components aimed at reducing burden, as these may be more effective at delaying institutionalization than educational programs alone.

Family relationship variables emerged as important factors through exploratory analyses, with better family functioning and perceived family social support protecting against desire to institutionalize. It is noteworthy that in the current study, family factors predicting desire to institutionalize were those related to overall family functioning and support, which differs from previous findings of relationship variables that examined the exclusive caregiver/care recipient relationship (e.g., Montgomery & Kosloski, 1994). The current study is the first to show that the quality of family relationships and social support impact desire to institutionalize. These findings suggest that additional modifiable targets for intervention include improving family functioning and family social support.

In addition to caregiver and family relationship differences, exploratory analyses showed trends toward greater frontal systems behavior problems and decreased independence in activities of daily living in care recipients of caregivers desiring institutionalization, consistent with findings of several previous studies (e.g., Cohen et al., 1993; Mittelman et al., 1993; Montgomery & Kosloski, 1994; Yaffe et al., 2002). The less robust care recipient findings suggest that these variables may be weaker predictors of institutionalization than the caregiver and family relationship variables. This finding is in some ways encouraging, as burden and family functioning/social support may be more amenable to change through caregiver interventions than declining functional abilities or behavior problems associated with cognitive decline.

In contrast to much of the previous literature investigating predictors of institutionalization, the present study did not find evidence for increased desire to institutionalize associated with caregiver mental health (specifically depression) (e.g., Brodaty et al., 1993), negative reaction to care recipient behavior problems (e.g., Cohen et al., 1993; 1994), general health (e.g., Cohen et al., 1994), or severity of the care recipient's dementia (e.g., Pruchno et al., 1990).

Though not the focus of the current study, these results confirm previous demographic findings that there is greater likelihood of younger caregivers and non-spousal caregivers to institutionalize or desire institutionalization of their dementia care recipient (Colerick & George, 1986; Mittelman et al., 1993). This finding also supports the notion that the nature of the caregiver/care recipient relationship (i.e., spouse versus other) is a risk factor for increased desire to institutionalize (Hamel et al., 1990). However, it may also present a potential confound in these results, as spouse versus child differences may impact some of the variables examined in the current study. Although the analyses were insufficiently powered (less than 65%) to appropriately test if the caregiver, relationship, and care recipient differences noted in the two caregiver groups within the total sample, trends toward the differences in caregiver and relationship variables emerged within the smaller subsample of spouses. This pattern suggests the observed findings are not simply a result of the greater number of adult children caregivers among those desiring institutionalization. In contrast, there was no difference for the care recipient variables within the spousal subsample, which may suggest that care recipient variables are a more important factor in desire to institutionalize for adult children caregivers than in spousal caregivers. Future research is needed to clarify this possibility, particularly in larger samples with equal numbers of spouse and adult children caregivers.

The present study may have been limited by the use of data obtained through baseline assessment of caregivers living with their care recipients who were involved in an intervention study. These caregivers may thus be more inclined to keep their care recipient in the home, and may not be fully representative of the general caregiver population. In addition, given the exploratory nature of the current findings, results should be cautiously interpreted, and need to be replicated. Future investigations of desire to institutionalize may benefit from random selection of caregivers and a larger sample allowing examination of different caregiver groups, including differences between child versus spouse caregivers, and male versus female caregivers. Also, given that nursing home placement may be a negative outcome for some caregivers, but a positive one for others (e.g., Gold et al., 1995; Lieberman & Fisher, 2001), it may be useful to investigate how the caregiver, care recipient, and relationship variables examined in the current study might impact these caregiver groups after institutionalization does eventually occur. In general, longitudinal investigation of how changes in predictors of desire to institutionalize may influence actual nursing home placement may reveal further potential areas to target interventions.

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Table 1

Demographic Data for the Sample

	No DI		**DI**	
	n = 29		**n=43**	
	M	**SD**	**M**	**SD**
Months of Caregiving	33.89	37.76	43.44	33.99
Months Since Diagnosis	33.72	32.08	44.05	38.24
Caregiver Age	68.62	12.82	61.49	9.96
Care Recipient Age	74.76	8.61	78.81	9.76

		% of No DI Group	**% of DI Group**
Caregiver Gender	Female	69%	84%
	Male	31%	16%
Relationship[**]	Spouse	83%	17%
	Child	47%	53%
Race	Caucasian	93%	98%
	African Am	0%	2%
	Native Am	3%	0%
	Latin Am	3%	0%

[**] Note. denotes DI different from No DI, significance $p<.01$.

Table 2.

Caregiver, Care Recipient, and Family Relationship Differences in DI and No DI groups

	No DI		**DI**	
	n = 29		**n=43**	
	M	**SD**	**M**	**SD**
Caregiver Variables				
GDS	6.83	5.84	8.58	6.63
ZBI[**]	27.79	15.71	39.51	15.95
ADKT[*]	11.59	3.85	13.84	3.57
SF 36 General Health	52.59	12.44	49.30	10.83
SES	42.59	13.05	38.60	13.28
RMBPC: Reaction	18.69	14.95	20.91	13.29
Care Recipient Variables				
RMBPC: Frequency	28.79	13.01	34.21	15.81
FrSBe[†]	130.86	28.27	146.19	25.25
ADLs[†]	15.03	5.78	11.44	6.34
CDR Sum of Boxes	6.38	2.67	7.57	2.94
Family RelationshipVariables				
FAD: General Functioning[*]	1.79	0.40	2.09	0.54
MSPSS: Family[*]	2.09	1.70	3.16	1.64
MSPSS: Significant Other	2.31	1.62	2.91	1.88
BRSS	36.69	9.92	33.12	9.61

[**] Note. denotes DI different from No DI, significance p<.01;

[*] denotes DI different from No DI, significance p<.05.;

[†] denotes DI different from No DI, significance at p<.05; did not withstand correction; GDS=Geriatric Depression Scale; ZBI=Zarit Burden Interview; ADKT=Alzheimer’s Disease Knowledge Test; SES=Self Efficacy Scale; RMBPC=Revised Memory and Behavior Problem Checklist; FrSBe=Frontal Systems Behavior Scale; ADLs=Activities of Daily Living; CDR=Clinical Dementia Rating scale; FAD=Family Assessment Device; MSPSS=Multidimensional Scale of Perceived Social Support; BRSS=Burns Relationship Satisfaction Scale