

Perceived Stigma in Caregivers of Persons with Dementia and its Impact on Depressive Symptoms

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Abstract

Objective: To examine the relationship between perceived stigma and depressive symptoms among caregivers of persons with dementia (PwD).

Methods: A descriptive longitudinal study of 51 caregivers of persons with dementia and 47 PwD, recruited from memory disorders and diagnostic centers and the VA Healthcare system. Modified Labeling Theory served as the organizing framework. Data were collected at baseline, 6, 12 and 18 months to assess changes in perceived stigma and depressive symptoms over the early-mid disease stages as part of a multisite study. Caregivers provided information on ethnic background, geographic location (rural/urban), knowledge of dementia, perceived stigma, depressive symptoms, and the PwD's behavioral symptoms and their reactions to the behaviors. PwD were assessed on their mental ability and disease stage. Inclusion criteria for PwD included a physician-confirmed dementia diagnosis within the last 12-18 months, a Mini Mental State Examination score >15 (to target early-mid disease stage participants), and residence in the community or assisted living facility. Caregivers were non-paid primary caregivers who had ≥ 3 contacts weekly with the PwD, and were ≥21 years old. A linear mixed model analysis was used to determine the relationship between variables, and to examine missing data.

Results: Caregivers' perceptions of stigma were significantly associated with depressive symptoms both at baseline ($r=0.36$, $p=0.017$) and over 18 months ($p=0.004$). Results also indicated that caregivers of PwD felt more depressed when they perceived more stigma ($p=0.016$), despite differences in ethnicity/race, geographic location as well as different levels of cognitive impairment of the person with dementia, and caregiver reactions in response to PwD memory and behavior problems. We also found that perceived stigma minimally mediated the effect between caregivers' reaction toward PwD's memory and behavior problems and depressive symptoms (13.7% decrease in the coefficient).

Conclusions: Caregivers of persons with dementia felt more depressed when they perceived more stigma after adjusting for other covariates in the model. Perceived stigma minimally mediated the effect between caregivers' reactions toward the PwD's memory and behavior symptoms and depressive symptoms. Results underscore the effects of stigma in relation to caregiver depressive symptoms. Effective interventions to combat caregiver perceived stigma are needed to enhance caregiver psychological well-being and to increase positive responses to PwD behaviors.

Keywords: Perceived stigma, caregivers, depressive symptoms, dementia, mediated effects, Modified Labeling theory, Descriptive longitudinal study

Introduction

In 2013, 44.4 million persons worldwide were living with dementia. The number is expected to increase to 75.6 million in 2030, and by the year 2050 worldwide prevalence will reach 135.5 million [1]. Family members often assume an unpaid caregiving role for persons with dementia (PwD). The caregiver role can be stressful. Studies indicate that caregivers of PwD are more stressed compared to caregivers of persons with other chronic conditions, both physically and psychologically [2,3]. Moreover, the strain of caring for a PwD often results in psychiatric morbidity including depression [4-6].

Despite the growing population of PwD and their caregivers, as well as the adverse consequences associated with being a caregiver, the topic of stigma has received little attention. Defined as the labeling behaviors of others which brings about an internalization process and results in negative consequences [7], perceived stigma impacts not only affected individuals but their families as well [8]. Caregivers of people with mental illness report feeling stigmatized, and that perceived stigma is associated with depressive symptoms [9,10]. Similarly, caregivers of persons with dementia also report feeling stigmatized [11]. However, little is known about the effects of perceived stigma on fostering depressive symptoms among caregivers of PwD.

Therefore, the purpose of this descriptive, longitudinal, multi-site study was to examine the relationship between perceived stigma and

depressive symptoms among caregivers of persons with dementia in the early stages of the disease.

Review of the Literature

Caregiver Depression

Reports of the incidence and severity of caregiver burden and depression are often based on different characteristics of the PwD (e.g., frequency of problem behaviors; level of functional impairment) and their caregivers (e.g., female gender, familism) [12,13], as well as environmental conditions (e.g. co-location, social support) [14]. Although the literature supports numerous factors that predict caregiver depression [4,15,16], many of these variables are not changeable. On the other hand, perceived stigma is a potentially changeable and understudied condition that may be associated with caregiver depression.

Stigma

Stigma was first conceptualized by Goffman [17] more than 50 years ago as a deeply discrediting attribute that can reduce a whole person to "a tainted, discounted one" (p. 3). Persons with dementia are stigmatized due to their progressive impairments such as decline in cognitive function, personality change, disruptive behaviors, poor self-care and incontinence. The magnitude of stigmatization is comparable to or greater than other populations of persons with chronic illness [18-20]. Stigma not only affects the individual but also may spread to those closest to him/her [17], which Goffman termed "courtesy stigma" (p. 30). Thus, family members, including caregivers, may experience stigma through their association with persons with mental illness or dementia, and society may treat them alike [17]. For example, when people avoid social interactions with persons with dementia (a common occurrence), their family caregivers may be inadvertently excluded as well. Goffman argues that these individuals may be discredited along with the stigmatized person [17].

Research on Stigma in Caregivers of Persons with Dementia

Little research has been conducted on courtesy stigma among family members of persons with dementia. MacRae [21] investigated the phenomena and found that both primary caregivers and other family members caring for PwD experienced stigma including shame, fear, and embarrassment. Liu and colleagues [22] qualitatively examined the relationship between stigma and dementia among Chinese and Vietnamese family caregivers. They found two sources of stigma: one that resembled the stigma of mental illness, and another that reflected the stereotypes of aging in the Chinese and Vietnamese cultures. However, these findings may be unique to the cultures examined.

The most recent and highest quality research has been conducted by Werner and colleagues. Werner and Heinik [23] interviewed Israeli caregivers of PwD and examined courtesy stigma. Caregivers themselves perceived minimal stigma but reported high levels of stigma regarding persons with dementia. These researchers also found high levels of structural discrimination, especially regarding the delivery of services. Later, Werner and colleagues explored the subjective experience of family stigma as reported by the adult children caregivers of PwD [24]. They found that stigma was experienced in multiple domains including caregiver stigma, stigma of the lay public and structural stigma. More recently Werner and

associates examined the effects of family stigma on caregiver burden and demonstrated that caregiver stress is increased by stigma associated with dementia [25].

Theoretical Framework

The Modified Labeling Theory (MLT) served as the organizing framework for this study. Based on this theory, the mechanisms of perceived stigma were conceptualized by Fife and Wright [26] to include four dimensions: social rejection (e.g., friends, family, colleagues abandoning PwD), financial insecurity (e.g., financial impact of stigma), internalized shame (e.g., feelings of embarrassment about PwD's diagnosis), and social isolation (e.g., limiting social contact due to abandonment, fear of PwD's cognitive deficits being obvious). Support for these four dimensions of perceived stigma was found through testing the relationships of stigma and a variety of demographic variables on persons with HIV/AIDS, cancer, Alzheimer's dementia, and Parkinson's disease [11-27]. Variables that may lead to stigmatizing responses of others and perceived stigma in caregivers of PwD include personal and environmental factors such as: gender, living situation, disease stage, mental ability, setting (e.g. urban or rural), ethnic background, and caregiver knowledge of Alzheimer's disease [27].

We examined the above variables in our study to determine if they impacted the relationship between perceived stigma and depressive symptoms among caregivers of persons with dementia in the early to mid-stages of the disease. Prior studies on the association between social rejection, internalized shame, social isolation and depressive symptoms also provided evidence to support further investigation of the association between perceived stigma and depressive symptoms among caregivers of PwD [28-32]. Thus, our study also examined how dimensions of perceived stigma might mediate the effects of dementia caregiving. The following questions guided our research:

What is the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease?

Does the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease change over 18 months?

Are depressive symptoms affected by perceived stigma as well as personal (disease stage, cognitive impairment, behavior symptoms and caregiver reactions to those behaviors, caregivers' knowledge of dementia, demographic information), environmental (different geographic location: rural and urban) and ethnic background variables?

Does perceived stigma among caregivers of PwD mediate the effect of dementia caregiving (including personal, environmental and ethnic background variables) on caregiver depressive symptoms?

Methods

This was a multi-site, descriptive longitudinal study. Data were collected, as part of a larger NIH-funded project, over a period of 18 months at six month intervals: baseline, six months, 12 months, and 18 months. Inclusion criteria for PwD included a physician-confirmed and documented diagnosis (using nationally accepted standard diagnostic criteria) of Alzheimer's disease or related dementias within the last 12-18 months, a Mini Mental State Examination (MMSE) score ≥ 15 (to better target persons in the early-mid disease stages), and residence in the community or assisted living

facility. Family caregivers (spouse, adult child and other kin) who were enrolled were non-paid family caregivers, who had a minimum of three contacts weekly with PwD, and who were at least 21 years old. Primary caregivers were identified by the care-receiver (PwD) as the family member most responsible for providing their care. Caregivers did not need to reside with the PwD. Subjects in Illinois, Iowa, and North Carolina were selected from Institutional Review Board (IRB) approved diagnostic centers, community centers, the Veterans Affairs system, and assisted living facilities. Recruitment efforts targeted underrepresented minority and rural participants in particular [27].

Measures

Caregiver characteristics were assessed using a demographic data sheet that included: age, gender, education, length of time the person with dementia had been diagnosed with dementia, relationship to the person with dementia, living arrangement, ethnic origin, and geographic location.

The Mini-Mental State Examination (MMSE) was used to screen for cognitive ability in the person with dementia. The score is the sum of correct responses and ranges from 0 to 30. Scores below 24 indicate global cognitive impairment and below this, scores can indicate severe (≤ 9 points), moderate (10-20 points) or mild cognitive impairment (21-24 points). The MMSE has a test-retest reliability of .83 and convergent validity demonstrated by positive correlations on the verbal ($r=.78$) and performance ($r=.66$) sections of the Wechsler Adult Intelligence Scale [33].

The Clinical Dementia Rating Scale (CDR) measured PwD's stage of disease. It accurately assesses six categories including memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care, with good inter-rater reliability [34]. Each of the six CDR categories is scored based on the following scale: 0 = Healthy; 0.5 = Questionable Dementia; 1 = Mild Dementia; 2 = Moderate Dementia; and 3 = Severe Dementia. The rater scores participants in each of the six categories and an overall score is determined [34].

The Knowledge of Alzheimer's Test Family Version (FKAT) was used to assess caregivers' knowledge of Alzheimer's disease [35]. The scale consists of 22 items that are rated as either true or false. The score is the sum of correct responses and ranges from 0 to 22 with higher scores indicating better caregiver knowledge of dementia. Content validity was established from a review of the literature and by a panel of gerontological nurse-experts in the care of AD patients. Previous studies evaluating psychometric properties of the FKAT have found adequate internal consistency and the scale was able to distinguish between family members with different levels of education [35].

The Revised Memory and Behavior Problems Checklist (RMBPC) were used to measure behavioral symptoms found more commonly in the early disease stages. The scale consists of 24 items that are rated on a 0-4-point Likert-type scale. There are two sets of scores ranging from 0 to 96 with higher scores representing more frequent or more types of behavior symptoms (RMBPCF) and how bothered or upset the caregivers were when the behavioral symptoms occurred (RMBPCR). Internal consistency (Cronbach's alpha) is .83 for the scale for behaviors of PwD and .88 for the scale assessing caregivers' reaction to the behaviors. Validity is supported through comparing scores on the RMBPC with MMSE and a memory-related problems subscale ($r=-.48$) and diagnosis of major depression and depression subscale ($r=.36$) [36].

Given the need for appropriate measures of experienced stigma, Burgener and Berger [11] adapted the Stigma Impact Scale (SIS) for persons with dementia and their family caregivers from the original SIS scale developed and tested by Fife and Wright [26] for persons with HIV/AIDS and cancer. The adapted SIS scale was then tested to assess perceived stigma in populations of PwD and their caregivers [11].

We used the adapted SIS to measure caregiver perceived stigma in this study. It comprises four subscales: social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items). The instrument consists of 24 items in total with scores that are rated on a 0-4-point Likert-type scale. Scores range from 0 to 96 with higher scores indicating higher perceived stigma. Internal consistency (Cronbach's alpha) is .92 for the scale [11].

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure caregiver depression. The CES-D consists of 20 items with scores that are rated on a 0-3-point Likert-type scale [37]. Scores were summed, with higher scores indicating greater depression and a score of 16 or higher indicative of depressive symptoms. Internal consistency (Cronbach's alpha) was .84 for the CES-D in this study.

Procedure

Per IRB requirements, participants were asked about their willingness to participate when they contacted the research team after being provided a description of the study through recruitment brochures, posters and information from health care providers. During the initial contact, members of the research team also verified that all study criteria were met. When concern about the diagnosis of dementia arose, participants were asked to obtain further diagnostic information from their health care provider. Every six months we reexamined the status of participants. If any changes in diagnosis or cognitive ability had occurred, such as an altered MMSE score, further information was obtained to determine if study criteria were still met.

Whenever possible, two research assistants conducted the data collection interviews, one with the caregiver and one with the person with dementia. This allowed for increased privacy, more candid responses and occupation of the person with dementia while the caregiver completed the study instruments.

Analysis

To determine whether there was a significant relationship between perceived stigma and depressive scores among caregivers of PwD at baseline, a Pearson product-moment correlation (PPMC) was conducted. PPMC were also used to evaluate the relationship between scores on the RMBPCR and RMBPCF, measuring the association between PwD behaviors and caregiver reaction to those behaviors. To examine the relationship between perceived stigma and depressive symptoms over an 18-month period, after adjusting for personal, environmental, and ethnic background covariates, a linear mixed model (LMM) was used. After first considering possible covariance structures to model the variances at each measurement, a first-order autoregressive (AR (1)) structure was chosen based on the Akaike (AIC) measure. Covariates were included in the model based on significance. The final model included the following covariates: RMBPCR scores and caregiver ethnicity/race. A LMM was also used to test whether perceived stigma among caregivers of PwD mediated the effect of dementia caregiving on caregiver depressive symptoms over 18 months. A percentage of change in the coefficient was calculated

after adding perceived stigma in the model to determine the degree of mediation effect. Missing data was analyzed using LMM, which can handle incompletely observed subjects by using likelihood estimation methods, and which provided valid estimates and tests under the assumption that the data were missing at random.

Results

Sample characteristics

A total of 47 persons with dementia and 51 family caregivers were included in the analysis. The unmatched numbers of PwD and their family caregivers were due to recruitment difficulties, and death or institutionalization of the person with dementia. Attrition over the entire study neared 40%, with 31 participant pairs remaining at the 18 month assessment.

Variable	n	PwD Mean ± SD	n	Caregiver of PwD Mean ± SD
Age (years)	47	78.04 ± 8.45	51	64.31 ± 12.55
Education (years)	47	13.16 ± 4.01	51	14.92 ± 2.55
Length of AD(months)	47	12.6 ± 11.67		
	n	%	n	%
Gender				
Male	21	44.68	13	26
Female	26	55.32	37	74
Ethnicity/race				
African American	19	40.43	18	35.29
Caucasian	28	59.57	33	64.71
Marital Status				
Married	26	55.32		
Single (divorced)	3	6.38		
Single (never married)	3	6.38		
Widowed	15	31.91		
Geographic location				
Urban	25	49.02		
Rural	26	50.98		
Abbreviations: PwD: persons with dementia; AD: Alzheimer's disease. a Marital status between PwD and their caregivers.				

Table 1: Characteristics of the study participants

The majority of attrition was due to disease progression, resulting in a move to live closer to family or into a long-term care facility. Deaths of the person with dementia participant (n=5, 10% of sample) were due to co-morbid conditions and not progression in dementia.

A comparison of participants who remained in the study for 18 months and with those who dropped out did not reveal significant differences between these groups at baseline with respect to perceived stigma and cognitive function.

The sample represented both a racially mixed urban population (in Chicago and North Carolina) and a rural mostly Caucasian population (in Iowa and Central Illinois). As seen in Table 1, the study sample had an almost equal distribution between geographic location and PwD gender; however, most caregivers of PwD were female (74%), consistent with other studies and national data. Just over half of the PwD and their caregivers were married. Despite targeted recruitment efforts to increase participant diversity across geographic locations, the study sample had more Caucasian participants than African Americans. All but one of the participant dyads were of the same ethnicity/race. Mean years of education (p=0.01) and age (p<0.00) were both significantly different between PwD and caregivers. Lastly, the mean length of time with a diagnosis of dementia was 12.6 months for PwD (SD=11.67), in keeping with the study purpose to examine persons with dementia in the early-mid stages of the disease.

Findings by Research Questions

Caregivers' perceptions of stigma were moderately positively associated with depressive symptoms at baseline (r=0.36, p=0.017). The bivariate relationship between perceived stigma and depressive symptoms over 18 months was significant (p=0.004). As seen in Table 2, caregivers' perceptions of stigma were significantly associated with depressive symptoms after adjusting for the other covariates in the model (p=0.016); caregivers became increasingly depressed when they perceived more stigma associated with dementia. However, caregivers' depressive symptoms did not change significantly over time (p=0.43).

Among the covariates included in the model, scores on the Revised Memory and Behavior Problem Checklist (RMBPCR) were positively associated with depressive symptoms (p=0.006). As caregivers' reactions in response to the person with dementia's

Variable	Estimate	Standard Error	Confidence Interval	p-value
Time^a				0.4262
1	-1.04	1.24	(-3.50, 1.43)	0.4057
2	-0.32	1.21	(-2.72, 2.07)	0.7886
3	-1.78	1.22	(-4.20, 0.63)	0.1459
SIS	0.13	0.05	(0.02, 0.23)	0.0166 ^b
RMBPCR	0.13	0.05	(0.04, 0.23)	0.0056 ^b
Caregiver Ethnicity/Race^a				
African American	-1.76	1.91	(-5.55, 2.04)	0.3614
Abbreviations: SIS: Stigma Impact Scale; RMBPCR: Revised Memory and Behavior Problems Checklist Ratings. ^a Reference categories are 4 for Time, Caucasian/White for Ethnicity ^b p<0.05				

Table 2: Result of liner mixed model on the relationship between perceived stigma and depressive symptoms as well as included covariates

memory and behavior symptoms increased, their level of depression also increased, given that all other covariates remained the same.

Scores on the RMBPCR subscale (measuring caregiver upset or bother in response to behaviors) was the only predictor variable significantly ($p=0.001$) associated with depressive symptoms among caregivers in this sample.

RMBPCR scores were also significantly associated with caregivers' perceived stigma (mediator variable) ($p=0.03$). Together with the significant relationship between caregivers' perceived stigma and their depressive symptoms ($p=0.004$), caregivers' perceived stigma was verified to mediate the relationship between scores on the RMBPCR and depressive symptoms among caregivers of PwD.

Perceived stigma minimally mediated the effect between RMBPCR and depressive symptoms (13.7% decrease in the coefficient) (Table 3). Reduction in the coefficient indicated that the effect of caregivers' reaction in response to the PwD's memory and behavior symptoms on depressive symptoms may have been slightly mediated through perceived stigma.

Variable s	Depression Without Mediation Effect	Depression With Mediation Effect	
	Estimate	Estimate	Percent Change
RMBPCR	0.1553 ^a	0.1341 ^a	13.70%
Abbreviation: RMBPCR; Revised Memory and Behavior Problems Checklist Ratings. ^a $p<0.05$			

Table 3: Result of linear mixed model of caregiver depressive symptoms and evaluation of potential mediating effect of perceived stigma

That is, those caregivers feeling more bothered or upset by the PwD's memory and behavioral problems had more perceived stigma, which in turn was associated with more depressive symptoms.

Discussion

This study confirms previous findings of a positive relationship between depressive symptoms and caregivers' reaction in response to the person with dementia's memory and behavior symptoms [38-41]. However, inconsistent with other studies, we did not find an association between caregivers' ethnicity/race and depressive symptoms, given all other variables examined in the model. Many studies have reported African American caregivers are less depressed and experience higher levels of well-being than their Caucasian counterparts, suggesting African American caregivers respond differently to the burden of caregiving, especially when using depression as an outcome measure [39,42-45]. Our findings regarding ethnicity and depressive symptoms among caregivers may be due to small sample size and insufficient diversity in our study sample.

Our study demonstrated significant relationships between perceived stigma and depressive symptoms, both at baseline and over the 18 month study period. Moreover, findings indicated that perceived stigma minimally mediated the effect between caregiver response to behaviors of the PwD (i.e. scores on the RMBPCR subscale) and depressive symptoms. Caregiver reactions to the PwD's

memory and behavior symptoms had both direct and indirect effects on their depressive symptoms, but the direct effect was stronger.

Behavioral and psychological symptoms associated with dementia (BPSD) typically follow a curvilinear path, increasing in the early and middle stages and decreasing as the disease progresses to the end stage. Common symptoms include forgetfulness, loss of language, emotional outbursts, including anger and aggression, and violation of social norms regarding appropriate conduct. Some PwD may act in odd and unpredictable ways depending on their individual disease trajectory. Consequently, these difficult to manage and potentially burdensome BPSD may directly increase caregivers' depressive symptoms or indirectly cause caregivers of PwD to feel ashamed, embarrassed and/or stigmatized, thereby increasing their depressive symptoms.

Results of our study suggest that education and individualized interventions should be directed toward modifying both the caregivers' reactions to behavioral manifestations in the person with dementia, as well as the PwD's behavioral and psychological symptoms in the early-mid stages of dementia in order to reduce caregivers' depressive symptoms, increase their psychological well-being or indirectly decrease caregivers' level of perceived stigma. (See O'Conner and colleagues for a systematic review of studies on relevant psychosocial interventions [46].

Given the significant relationship between caregivers' perceived stigma and depressive symptoms found in our study, it is important for health care providers to assess for and understand the potential impact of stigma for family caregivers. Providers should also assist caregivers of persons with dementia to better manage the perception of stigma. Although there are few well validated interventions to decrease stigma in this population, multifaceted approaches may be borrowed from the mental illness literature, and then rigorously evaluated among persons with dementia and their caregivers.

Contact and education appear to be effective in changing attitudes and behaviors in both the lay public and across health care disciplines [47,48]. Thus, curricular content for healthcare professionals should include more information on stigma, as well as how to manage BPSD. This would enable providers to be more aware of both stigma and depression among caregivers, and also encourage them to routinely assess for and provide referrals, for example to support groups offered by the Alzheimer's Association, or to mental health specialists for treatment of depressive symptoms. Finally, in 2012 the National Alzheimer's Association Early Stage Advisory group developed guidelines for persons with dementia to combat stigma. These guidelines and other practical strategies should be adapted for use by caregivers as well.

Limitations

There are several limitations to this study. First, we are not able to make causal inferences about the effects of perceived stigma among caregivers of PwD on depressive symptoms due to the study's descriptive design. Second, although the sample was geographically diverse, the sample was limited to only Caucasian and African-American caregivers. Together with the small sample size and the relatively homogeneous characteristics of participants, it is not possible to generalize our findings. In particular, future research needs to include participants from other ethnic groups, especially Hispanic and Asian caregivers.

Recruitment challenges may be explained in part by the stigma associated with dementia [49]. On the other hand, persons willing to participate in this study may have had lower levels of perceived stigma. Finally, there was a potential for response bias (more positive) on the part of caregivers rating their perceived stigma on the Stigma Impact Scale.

Future Research

As noted above, a larger and more diverse sample is needed to further examine the longitudinal relationship between caregivers' perceived stigma and depressive symptoms, and to investigate the relationship into later stages of the disease. Replication of this study using caregivers' perceived stigma as a mediator is recommended. If a greater coefficient change is found specific interventions to lower caregivers' perceived stigma and to enhance their psychological well-being can be developed and tested. Future studies should also consider, both theoretically and analytically, the relationships between BPSD, stigma, depression and burden among caregivers of persons with dementia. Although this study focused on the relationship between caregiver depression and stigma, future research should include examination of and adjustment for other aspects of caregiver psychological status that could affect depression and burden.

Conclusions

This study provided insight into the relationship between perceived stigma and depressive symptoms among caregivers of PwD in the early stages of the disease and over an 18 month course. Given the dearth of research on perceived stigma among caregivers of PwD, this study provides beginning evidence in support of developing and testing interventions that focus on caregiver-perceived stigma with an emphasis on caregiver reactions to the PwD's memory and behavioral problems as a means to reduce depressive symptoms.

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