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Finding fault: Criticism as a care management strategy and its impact on outcomes for dementia caregivers

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Abstract

Background: Despite a large literature on the stress process, little attention has focused on how caregivers for persons living with dementia (PLWDs) provide care and how this may impact care outcomes. Criticism is a management strategy caregivers may use to respond to behavioral symptoms. We consider whether criticism is associated with caregivers' mental health and service utilization.

Methods: Data are drawn from the Advancing Caregiver Training intervention study including 256 informal caregivers living with a PLWD. In multiple linear regressions controlling for caregivers' demographics and PLWDs' clinical factors, we consider criticism (criticism subscale of the Dementia Management Strategies scale) as a predictor of caregiver burden, depressive symptoms, desire to institutionalize the PLWD, level of frustration with care and the number of home-based, social, and health services utilized.

Results: On average, 15% of the sample sometimes reported using criticism as a management strategy to manage the challenges of care. Greater use of criticism was associated with significantly more caregiver burden ($\beta=.26, p<.001$) and frustration with caregiving ($\beta=.66, p<.001$), but not depressive symptoms or a desire to institutionalize the PLWD. Criticism was also associated with significantly greater utilization of home-based ($\beta=.14, p<.05$) and social services ($\beta=.15, p<.05$), but not health care services.

Conclusion: Criticism appears to be used by more burdened and frustrated caregivers. The association of criticism with social and home-based services potentially reflects a need for greater support among this group of caregivers. Behavioral interventions that can help caregivers manage behavioral symptoms with positive, empirically validated strategies may be helpful.

Keywords

criticism; caregiving; care management; dementia

Conflict of Interest: The authors have no conflicts of interest to disclose.

More than 15 million Americans serve in a dementia care role with the care they provide estimated at a total of 18.1 billion hours per year.¹ The ability of the caregiver to manage the symptoms and changing demands of dementia can impact the well-being and adjustment of the caregiver and the person living with dementia (PLWD), and whether the PLWD can be cared for in the home. Yet despite a large literature on the stress process associated with caregiving for PLWDs, considerably less attention has focused on how caregivers actually manage and provide care, and how the strategies they use may impact their own well-being and care outcomes. Criticism is one form of management caregivers may use either in response to the stresses of care and/or as a strategy to address challenging behaviors. The use of criticism may stem from the incorrect belief that symptoms of dementia are volitional and within the control of the PLWD.² Regardless of motivation or underlying reason for using criticism, this strategy is typically ineffective, and therefore may have negative consequences both for the caregiver and the PLWD. In the current study, we examine two main questions: whether criticism as a care management strategy is associated with a 1) caregiver's well-being and 2) the caregiver and PLWD's service utilization.

Stress, Coping, and Criticism.

Research on stress and coping suggests that certain coping strategies are more effective than others. For example, studies generally show poorer adjustment among caregivers using emotion-focused coping strategies such as avoidance, as opposed to problem-focused coping which utilizes more practical ways of managing the stressor.³ Criticism, as a specific coping or management strategy, has received notable attention within social science research broadly and the caregiving literature specifically. For example, in his seminal work on marriage and divorce, Gottman coined criticism expressed toward a spousal partner as one of the "four horsemen of the apocalypse" in predicting divorce.⁴ In another line of research with family members of individuals with schizophrenia, a literature on expressed emotion (involving criticism, hostility, and emotional over-involvement) has shown that family member' expressed emotion can negatively impact patient outcomes.⁵ In applying this theory to caregivers for PLWDs, it has been found that in contrast with the literature on other mental disorders such as schizophrenia, while expressed emotion may have little effect on the course of dementia (e.g. cognitive and functional decline), it may be significantly associated with more behavioral and psychological problems displayed by the individual with dementia over time as well as impacting outcomes for caregivers themselves.⁶⁻⁹

Most research concerning how caregivers provide and manage care has examined general coping strategies and personality characteristics of the caregiver and their associations with caregiving outcomes however, as opposed to more situationally specific strategies utilized to manage the unique challenges caregivers confront in managing challenging behaviors. Criticism is one specific management strategy which may be utilized by caregivers for PLWDs. Utilizing pilot interviews with PLWDs and their family members as well as existing clinical literature, The Dementia Management Strategies Scale (DMSS) was developed which included such constructs as coercion and conflict avoidance.¹⁰ Later work developed three subscales through factor analytic techniques which included criticism, encouragement and active management.^{10,11} A subscale of the criticism items, including the constructs of coercion and authoritarianism, is used as the key measure in the current study.

Criticism and Caregiver Well-Being.

Prior research has found that negative-type management strategies such as criticism, anger, and lower encouragement are associated with caregiver burden, a desire to institutionalize the PLWD, and less experienced positive aspects of caregiving (e.g. fulfillment).^{2,10,12–15} These associations tend to persist across cultural contexts (ex. Singapore) and do not appear to occur based on the severity of the dementia, level of functional impairment, cognitive decline, or presence of behavioral and psychological symptoms, as well as characteristics of the caregiver. Furthermore, criticism has been associated with more general, negative coping strategies such as venting, blaming oneself, and self-distraction and may reflect disengagement from the objective stressor.²

Criticism and Services Utilization.

Use of criticism may also be associated with potentially inappropriate service use. For example, Gitlin and colleagues¹⁶ found that the use of positive dementia-management strategies such as facilitating a safer environment and diverting the attention of persons with dementia (items drawn from a subscale of the DMSS¹⁰) when they were upset were associated with the use of more adaptive behavioral strategies (such as taking rest breaks from activity or using pictures to identify objects in a room; drawn from the Task Management Strategies Index¹⁶), whereas criticism was not associated with the use of these positive behavioral strategies. Additionally, recent work found that caregivers reporting high levels of distress or burden utilized more acute care services such as emergency department visits as well as other social and health services for both themselves and the PLWD.^{17–20} Martindale-Adams, Nichols, Zuber, Burns, Graney²¹ found that compared with non-service users, caregivers utilizing health and social services for themselves had significantly more burden, depression, upset with behavioral symptoms, and a stronger desire to institutionalize the PLWD.

Further, recent work has shown the criticism management strategy utilized by family caregivers to be associated with the frequency and severity of behavioral and psychological symptoms of dementia in individuals with Alzheimer's disease suggesting that criticism may relate to the severity of symptoms and need for services.²² However, the strategies that caregivers are using in their home to manage the PLWD have not been considered as correlates of services utilized. Further, unlike caregiving for other chronic medical conditions, caregivers for PLWDs may play a particularly active role in determining services utilized for themselves as well as the PLWD due to the declining cognitive and functional capacity of the PLWD. Ultimately, caregiver management strategies, such as criticism, may be modifiable and through intervention, prevent increased caregiver distress and unnecessary service utilization.

In the current study, we consider criticism as a care management strategy that may be associated with 1) a caregiver's mental health and well-being (burden, depressive symptoms, expressed frustration, and desire to institutionalize the PLWD) and 2) service utilization in three categories: home, social, and health services. We hypothesize that criticism is

associated with a) reduced well-being for the caregiver and b) greater utilization of supportive services of both the caregiver and PLWD.

Methods

Data are drawn from the baseline (pre-intervention) survey from the Advancing Caregiver Training (Project ACT) intervention study, a study designed to test a non-pharmacological approach to help caregivers manage behavioral symptoms they identify as most challenging to them. The analytic sample included 256 of the 272 informal caregivers in the trial (16 participants were deleted from models due to a missing score on the MMSE) living with an individual with diagnosed dementia or a Mini-Mental Status Examination score of less than 24, and who reported experiencing “upset” related to management of behavioral problems. Caregivers were managing care for persons at the moderate stage of dementia and had expressed challenges in managing behavioral symptoms. The study was approved by the Johns Hopkins University Institutional Review Board and informed consent was obtained from all participants.

Measures.

Demographics: Age, gender, race (white, black, other), spousal caregiver (versus non-spousal caregiver), and level of education (less than high school, high school, greater than high school) were included as demographic controls in all models.

Caregiver specific covariate: Caregiver’s upset with behavioral symptoms was a sum of caregiver’s rated upset (0= no upset to 10= extreme upset) for up to 23 PLWD’ behavioral problems drawn from standardized scales (possible range 0 to 230).^{23–25}

Person living with dementia specific covariates: The Mini-Mental State Examination (MMSE), a 30-point scale assessing cognitive abilities (memory, orientation and arithmetic), was used as a measure of care receiver cognitive function with a lower score indicating greater cognitive impairment.²⁶ Activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were assessed with the Caregiver Assessment of Function and Upset scale.²⁷ ADLs (e.g. dressing) was a count of 7 possible functional care tasks a PLWD needed support with and IADLs (e.g. food preparation) was a count of 8 possible tasks.

Criticism: Criticism was measured as a mean score on a four item subscale (I criticized or scolded my CR to try to prompt better behavior from him/her, I threatened by CR with undesirable consequences if he/she did not cooperate, I withdrew from my CR, I yelled or acted enraged; it was often the only way to get my way with him/her) drawn from the Dementia Management Strategies Scale.¹⁰ Items were on a five-point scale from never to always (range: 1–5) with a higher score indicating greater expressed criticism toward the PLWD ($\alpha=0.72$).

Outcomes related to caregiver and person living with dementia well-being: We examine the desire of caregivers to institutionalize their PLWD with six yes/no items concerning the last six months (e.g. in the past six months, have you felt your care receiver

would be better off in a nursing home?) ($\alpha=0.67$). Scores range from zero to six with a higher score indicating a greater desire to institutionalize.²⁸ We examined three outcomes concerning caregivers: their level of frustration with caregiving, depressive symptoms, and burden. Frustration was measured as a mean score with the Frustrations of Caregiving scale which is an eight item measure from the REACH II battery questioning caregivers about how often in the past six months they felt like using harsh measures such as hitting or confining the PLWD ($\alpha=0.74$). Items were on a five-point scale from one (never) to five (always) with a higher score indicating greater frustration (range: 1–5).²¹ For depressive symptoms, we used a ten-item short form of the Center for Epidemiological Studies-Depression Scale (CES-D).²⁹ Participants responded on a four point scale of zero (rarely or none of the time) to three (most or almost all of the time) with a higher score indicating greater depressive symptoms (range: 0–30). The scale showed strong reliability ($\alpha=0.81$). The twelve item Zarit Burden Inventory ($\alpha=0.88$) was used to assess caregiver burden on a five-point scale from zero (never) to four (always) with a higher score (range: 0–48) indicating greater burden (e.g. “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?”).³⁰

Service utilization outcomes: Caregivers were also asked about the formal care and support services they utilized for themselves or their care receiver in support of their care provision for the PLWD. These included a count of five home services (e.g. home health aide, meal service, visiting nurse, disruptive behavior manager, homemaker-helps with meals, shopping, cleaning etc.), five social services (e.g. adult day care, support groups, transportation, senior day health program, overnight respite), and seven past-month health services (e.g. hospital admission, rehabilitation facility, physician visits, nurse or physician’s assistant, counselor/psychiatrist, lab tests, private medical services).

Statistical Analysis.

Descriptive statistics were run for all variables. To address our research question regarding whether the caregiver strategy of using criticism was associated with caregiver well-being (burden, depressive symptoms, desire to institutionalize the PLWD, and level of frustration with care), we ran multiple linear regressions controlling for caregivers’ demographics and PLWDs’ functional and cognitive impairment with expressed criticism as the key predictor. Additionally, we considered whether criticism was associated with the number of services utilized in three categories: home-based, social, and health services, accounting for the same controls. SPSS 24.0 was used for all analyses.

Results

Caregivers on average were 66.8 years old ($SD=12.5$; range=33–95), approximately 27% ($n=68$) were African American, and half were caring for a spouse ($n=131$). Out of a possible 23 behavioral problems that a PLWD may exhibit, caregivers reported an average of 9.4 ($SD=3.8$; range 2–19). Upset over these problems was moderate with an average score of 52.9 ($SD= 30.2$; range 7–153). On average, 15% ($n=37$) of the sample used criticism as a management strategy “sometimes” or more frequently. Overall, caregivers had moderate burden ($M=21.2$; $SD=9.4$; range=1–46; a mean item score of 1.8 indicating caregivers

reported feeling burdened “sometimes” on average) and depressive symptoms ($M=9.6$; $SD=5.8$; $range=0-25$) yet relatively low frustration ($M=2.0$; $SD=0.5$; $range=1-4.5$) and desire to place the PLWD ($M=1.1$; $SD=1.3$; $range=0-6$). On average, caregivers used one home service ($SD=0.9$; $range=0-4$) and social service ($SD=1.1$; $range=0-4$) and two health services ($SD=1.3$; $range=0-6$) for themselves or the PLWD in support of their care provision. Full sample characteristics can be found in Table 1.

Relationship of criticism to caregiver well-being

In regards to our first research question, controlling for demographic characteristics, behavioral symptom upset, and disability of the PLWD, greater use of criticism was associated with significantly more caregiver burden ($\beta=.22$, $p<.001$) and frustration levels ($\beta=.62$, $p<.001$), but not with depressive symptoms or a desire to institutionalize the PLWD (see Table 2 for full results).

Relationship of criticism to service utilization

We next considered whether criticism as a management strategy was associated with greater services utilization. Controlling for demographics and level of cognitive and functional disability and behavioral upset, criticism was associated with significantly greater utilization of home-based ($\beta=.15$, $p<.05$) services and was the only predictor significantly associated with social services ($\beta=.19$, $p<.01$), however was not significantly associated with the use of health services (see Table 3 for full results).

Discussion

The specific management strategies used by family caregivers in dementia care are understudied, and their impact on critical outcomes for the well-being of both PLWDs and caregivers are not well understood. In this study we found that among caregivers providing care to individuals at the moderate stage of the disease and expressing challenges regarding behavioral problems in the PLWD, a small percent (15%) used criticism as an active management strategy. Use of criticism was associated with more burden and frustration in caregivers and had significant implications for service utilization even controlling for behavioral problem upset, as well as the functional and cognitive impairment of the PLWD.

Criticism and Quality of Life.

Though relatively few caregivers in our sample expressed criticism towards the PLWD, it's utilization may relate to stigma or the belief that behavioral symptoms of dementia are volitional. Weisman de Mamani, Weintraub, Maura, Martinez de Andino, Brown³¹ found that caregivers who reported greater perceived stigma relating to their care recipient's illness tended to have higher expressed emotion, and expressed emotion was associated with worse quality of life for caregivers. As criticism and hostility are facets of expressed emotion, it may be that stigma is associated with the use of criticism as a management strategy as well. Indeed, in the current study, criticism was associated with greater subjective appraisals of burden and frustration in care, though unassociated with more objective measures of desire to place the PLWD in a nursing home or caregiver depression. Practically, efforts to reduce stigma and help caregivers normalize behavioral problems and attribute them to dementia,

and not the PWDs character, may help to reduce the expressed criticism and improve quality of life.

Criticism and Service Use.

If criticism is a reflection of frustration related to care or a strategy utilized due to a lack of other more adaptive management strategies, it may follow that a caregiver would feel more burdened and seek more services to assist in care provision. Indeed, caregivers in the current study who displayed greater criticism were more likely to use more social and home-based services, potentially reflecting a need for greater support among this group of caregivers. It may be that caregivers using care strategies other than criticism were better able to adapt and manage without the use of supportive services. However supportive home and social based services such as respite care and meal services, are positive supports for overloaded or burdened caregivers. For example, services such as respite care have shown powerful positive effects, even biologically, on the health and well-being of both caregivers and PLWDs.^{32,33} Therefore, increased service utilization among caregivers using criticism as a management strategy may be viewed as a positive outcome, and it may be posited that service use may decrease expressed criticism over time, a point for future study.

Of note, caregivers' upset over behavioral symptoms was consistently associated with caregiver' quality of life outcomes, but negatively associated with social services utilization. Social services measured in the current study largely include respite care services, and prior work has shown that services such as adult day care lower care-related stressor exposure.³⁴ Thus we similarly see here less upset among caregivers using more social services. Further, in spite of our inclusion of demographic characteristics and PLWD clinical factors (ex. cognitive impairment, functional impairment), our models explained little of the variance in services use. While criticism was associated with home-based and social services, none of our covariates (caregiver demographics, PLWD cognitive and functional status, and caregiver upset over behavioral symptoms), predicted health services utilization. As our services measures incorporated services used by both the caregiver and care receiver, this variability may have complicated the model, and service utilization was already low in our sample. Further other health related need variables (e.g. multimorbidity), not included in the current models, may have explained greater variance.

Limitations.

We examined criticism and its associations in a sample of caregivers for persons in the moderate stage of dementia with reported behavioral problems. Thus, we don't know if criticism is used in equal measures among caregivers for individuals at other disease stages, whether criticism is an enduring management strategy, or if it arises with increased behavioral disturbances; these questions would be fruitful for future study. As analyses are not causal, it is unclear whether caregivers utilizing greater criticism may develop more burden and frustration, or whether burden and frustration led to the use of criticism, and future work should consider this question. We also could not determine whether the critical management strategy preceded service use. Likewise, it is unclear whether management strategies such as criticism are stable over time or whether change in strategy may impact outcomes such as utilization. The criticism subscale and frustrations of caregiving (use of

harsh measures in care) were significantly correlated and it is possible that they may make up a broader factor or style of caregiving such as an “authoritarian” or “disciplinarian” caregiving style (similar to the theories of parenting research); future studies may consider the classification of management strategies into broader caregiving styles. Given the nature of our services measure, we also could not distinguish between potentially preventable services utilization and necessary services utilization. Rates of depressive symptoms and other outcomes were relatively low suggesting that these findings may only generalize to a relatively well adapted group of caregivers.

In conclusion, in this sample of caregivers of persons at the moderate disease stage in which hands-on care management increases, we found that 15 percent of caregivers used criticism as a strategy to manage the behaviors of a PLWD and criticism was associated with caregiver’ well-being and services utilization. Therefore, the strategies a caregiver uses to handle the unique context of dementia care are important to consider in addition to the more objective care context of dementia symptoms and decline. As depression, anger, and stress in caregivers has been associated with potentially harmful behavior toward PLWDs, it may be fruitful for researchers to consider whether criticism in and of itself has a harmful impact on PLWDs and when intervention may be indicated.^{35,36} Ultimately, as criticism is not likely to have an adaptive influence on PWDs and is associated with negative outcomes for caregivers, behavioral interventions that can help burdened caregivers learn how to manage behavioral symptoms and other stressful aspects of care with positive, empirically validated strategies may be helpful.

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Key points:

- Among caregivers of persons at the moderate stage of dementia in which hands-on care management increases, we found that one in ten caregivers used criticism as a strategy to manage the behaviors of a person living with dementia.
- Criticism was associated with caregiver burden and frustration, as well as social and home-based services utilization, independent of the functional, cognitive, and behavioral status of the person living with dementia.

Table 1.

Sample characteristics for persons with dementia and their caregivers

	M or %	SD	Range/Scale Range
<i>Care receiver characteristics</i>			
MMSE	12.74	8.14	0-29/0-30
ADLs	4.54	2.28	0-7/0-7
IADLs	7.59	0.92	2-8/0-8
<i>Caregiver characteristics</i>			
Age	66.76	12.52	35-95
Male	18.40%		
Race			
Black	26.60%		
White	71.10%		
Other	2.30%		
Non-Spouse	48.80%		
Education			
Less than high school	9.80%		
High school	25.00%		
Greater than high school	65.20%		
Upset over behavioral symptoms ¹	52.89	30.23	7-153/0-230
Criticism	2.10	0.72	1-5/1-5
Burden	21.25	9.40	1-46/0-48
CESD Score	9.61	5.79	0-25/0-30
Desire to place person living with dementia	1.07	1.27	0-5/0-6
Care frustration	1.95	0.51	1-4.5/1-5
Home services utilization	0.92	1.02	0-4/0-5
Social services utilization	1.03	1.11	0-4/0-5
Health services utilization	2.30	1.31	0-6/0-7

Notes. n=256;

¹Upset based on an average of 9.36 (SD= 3.80) behavioral problems

Predictors of burden, depressive symptoms, desire to institutionalize and caregiver frustration among caregivers for a person living with dementia.

Table 2.

	Burden			Depressive Symptoms			Desire to Institutionalize			Caregiver Frustration		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
Age	-0.12	0.06	-0.16*	-0.02	0.04	-0.03	0.01	0.01	0.09	0.00	0.00	0.03
Male	-1.82	1.34	-0.08	-2.82	0.90	-0.19**	0.10	0.21	0.03	-0.05	0.06	-0.04
Black	-0.52	3.31	-0.02	-2.79	2.24	-0.21	-0.08	0.53	-0.03	-0.10	0.15	-0.09
White	4.69	3.24	0.21	-2.30	2.19	-0.18	0.48	0.52	0.17	-0.16	0.15	-0.09
Non-Spouse	1.16	1.31	0.06	0.10	0.89	0.01	0.22	0.21	0.09	-0.10	0.06	-0.10
Education	0.58	0.74	0.04	-2.08	0.50	-0.24***	0.18	0.12	0.10	-0.08	0.03	-0.11*
MMSE	0.06	0.07	0.05	-0.01	0.05	-0.01	0.01	0.01	0.05	-0.00	0.00	-0.04
ADLs	-0.04	0.28	-0.01	0.01	0.19	0.00	-0.00	0.05	-0.00	-0.01	0.01	-0.03
IADLs	0.73	0.64	0.07	0.02	0.43	0.00	0.05	0.10	0.04	0.01	0.03	0.03
Upset over behavioral symptoms	0.11	0.02	0.34***	0.07	0.01	0.35***	0.01	0.00	0.25***	0.00	0.00	0.23***
Criticism	2.83	0.71	0.22***	0.10	0.48	0.01	0.15	0.11	0.08	0.44	0.03	0.62***
<i>F</i>	12.91***			6.98***			3.21***			27.26***		

Notes. n=256;

* $p < .05$,

** $p < .01$,

*** $p < .001$

Table 3. Predictors of home, social, and health services among caregivers for persons living with dementia

	Home Services Utilization			Social Services Utilization			Health Services Utilization		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Age	0.02	0.01	0.26**	-0.01	0.01	-0.07	-0.01	0.01	-0.05
Male	0.08	0.17	0.03	-0.35	0.19	-0.12	0.16	0.23	0.05
Black	0.40	0.42	0.18	0.74	0.47	0.29	0.18	0.57	0.06
White	0.35	0.41	0.16	0.60	0.46	0.24	0.48	0.55	0.17
Non-Spouse	0.48	0.17	0.24**	-0.12	0.18	-0.05	0.15	0.22	0.06
Education	-0.05	0.09	-0.03	0.13	0.10	0.08	0.19	0.13	0.10
MMSE	-0.01	0.01	-0.04	-0.01	0.01	-0.07	0.02	0.01	0.14
ADLs	0.10	0.04	0.23**	0.03	0.04	0.05	-0.02	0.05	-0.03
IADLs	-0.02	0.08	-0.02	0.11	0.09	0.09	0.11	0.11	0.08
Upset over behavioral symptoms	-0.00	0.00	-0.03	-0.01	0.00	-0.18**	-0.00	0.00	-0.03
Criticism	0.21	0.09	0.15*	0.28	0.10	0.19**	0.09	0.12	0.05
<i>F</i>		3.69***			2.69**			1.12	

Notes. n=256;

* $p < .05$,

** $p < .01$,

*** $p < .001$