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‘The Filter is Kind of Broken’: Family Caregivers’ Attributions About Behavioral and Psychological Symptoms of Dementia

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Abstract

Objectives: Behavioral and psychological symptoms of dementia (BPSD) are common, often challenging to manage, and may erode caregivers’ well-being. Few studies have explored caregivers’ perspectives of what causes these behaviors; but such attributions may be important, particularly if they negatively impact the care dyad. This study examined causal attributions about BPSD among individuals caring for a family member with dementia.

Design: In-depth qualitative data were obtained from family caregivers of older adults with dementia.

Setting: As part of a larger study (NINR R01NR014200), four focus groups were conducted with caregivers by an experienced facilitator.

Participants: A total of 26 family caregivers participated in the four focus groups.

Measurements: Caregivers reported their own attributions about the causes of their care recipient’s BPSD. Sessions were audio-recorded. Data were transcribed, coded to determine relevant concepts, and reduced to identify major categories.

Results: Five categories were determined. Caregivers attributed BPSD to: (1) neurobiological disease factors; (2) physical symptoms or comorbid health conditions; (3) psychological reactions to dementia; (4) shifting social roles and relationships following dementia onset; and (5) environmental changes such as lack of routine and medical transitions (e.g., hospitalization).

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Despite this seemingly multifactorial attribution to BPSD etiology, a number of respondents also indicated that BPSD were at least partly within the care recipient's control.

Conclusion: Family caregivers attribute BPSD to a range of care recipient and environmental factors. Caregivers' own causal beliefs about BPSD may reflect unmet educational needs that should be considered in the development of targeted interventions to minimize caregiving stress.

Keywords

informal caregiving; neuropsychiatric symptoms of dementia; focus group; qualitative data analysis

Objective

Caring for a family member with dementia can be highly stressful, placing caregivers at risk of mental and physical health problems.¹⁻³ Behavioral and psychological symptoms of dementia (BPSD) are pervasive and pose a substantial threat to both care partners' well-being.^{2,4} Indeed, BPSD such as psychomotor agitation, psychosis, and sleep disturbances are associated with heightened caregiver burden and depression, excess care recipient morbidity and mortality, and earlier nursing home placement.² Multiple factors in addition to neurodegeneration may trigger BPSD including characteristics of the care recipient (e.g., medical conditions), the caregiver (e.g., ineffective coping mechanisms), and the environment (e.g., lack of routine).² Despite the salience of BPSD in caregivers' lives along with research showing that their conceptions of dementia include a mix of biomedical and folk beliefs,⁵⁻⁸ few studies have considered caregivers' views of what triggers these behaviors. A greater understanding of caregivers' causal beliefs about BPSD may generate key insights for targeted interventions to reduce caregiving stress. This study utilized focus group data to explore family caregivers' attributions about the causes of BPSD.

According to attribution theory, caregivers form attributions about the care recipient's behavioral changes to explain their occurrence.^{9,10} These attributions can involve internal (e.g., biological or psychological factors) or external (e.g., environmental factors) causes.^{11,12} They also vary regarding the degree to which behaviors are viewed as within the control of the care recipient and/or caregiver.^{12,13-16} Caregiver attributions are formed in part by knowledge or expectations of the care recipient's physical and mental capacities. Prior work has found, for example, that adult daughters caring for a parent with dementia are not critical of problematic behaviors with a clear biological cause (e.g., incontinence) but criticize BPSD such as aggression or repetition.¹⁷ This may stem from caregivers' tendency to perceive BPSD as intentional, controllable, or reflective of the care recipient's personality rather than the disease.^{13,14,16-18}

Caregivers' causal attributions are important to evaluate for at least three reasons. First, recognizing triggers of BPSD may help caregivers anticipate future patterns and potentially avoid some disruptions. Caregivers may express uncertainty about the accuracy of their attributions, however, and be ill equipped to discern which behaviors are related to dementia and which are influenced by other factors (e.g., personality).¹⁹ Such ambiguity could diminish caregivers' confidence in managing BPSD.¹⁹ Second, caregivers' attributions about

BPSD could affect how they interact with the care recipient. Caregivers may respond negatively to difficult behaviors, particularly when they believe the care recipient is responsible.^{13,16,19,20} Negative communication patterns can in turn amplify BPSD and expose care recipients to poor quality of care.^{2,13} Third, caregivers' attributions have implications for their well-being. Caregivers report higher care-related burden, for instance, when they attribute the care recipient's behaviors to personal characteristics (e.g., laziness, lack of discipline) or malicious intent.^{15,16} Similarly, perceiving BPSD as willful or manipulative is linked to elevated depression and resentment toward the care recipient.^{21,22}

The present study builds upon the literature by using focus group data to consider family caregivers' perspectives of what triggers their care recipient's BPSD. We examined: (1) what caregivers believe to be the causes of these behaviors; and (2) language indicating caregivers' perceptions of BPSD as controllable or uncontrollable.

Methods

Four focus groups were conducted with a total of 26 caregivers. These groups were part of an NIH-funded project (NINR R01NR014200) to design a web-based caregiver tool for assessing and managing BPSD,²³ which received human subjects approval in accord with the University of Michigan's policies. Caregivers were recruited by: (1) responding to fliers at local senior resource centers; and (2) referral from center staff. Participants were eligible if they served as primary caregivers of a family member with dementia. Before the group meeting, caregivers provided written informed consent and completed a brief survey assessing their sociodemographics, caregiving characteristics, and technology familiarity.

An experienced facilitator led each 90-min focus group. Three groups included 5 caregivers and one group had 11 caregivers. An interview guide developed by the research team with 17 questions and 12 probes assessed caregivers' views, understanding, and communication related to BPSD (see Supplemental Table 1). Specific to this study, caregivers were asked: "What do you think causes the behavior changes your family member experiences as part of their dementia?" Sessions were audio-recorded, and were later transcribed and verified for accuracy.

Content analysis was used to identify attribution categories. Data from the four focus groups were coded in succession by six study team members (C.A.P., L.M.S., B.S., M.T., B.B., and H.C.K.) who worked together during one in-person meeting. An all-inclusive data table technique in Microsoft Excel was used to code and analyze the data, which involved separate spreadsheets of data from the transcripts for each focus group with seven columns: transcript number, outline section, question asked, participant response, notes, code, and category.²⁴⁻²⁶ The coding was led by B.S., who has had extensive training and experience in this technique. A procedure called rigorous and accelerated data reduction (RADaR) was applied to efficiently generate results.²⁴⁻²⁶ Open coding identified concepts specific to caregivers' attributions about BPSD. The first author then reduced the coded data to determine categories that summarized all attributions. All co-authors separately gave feedback on the categories, and minor differences of opinion were discussed and resolved as a group.

Results

Table 1 shows background characteristics for the 26 caregivers. Most cared for a parent, had provided care for 2 years or longer, and gave over 10 hours of care per week. The majority were women, married, White, and had a college degree or higher.

Five attribution categories were determined (Table 2): (1) neurobiological disease factors; (2) physical symptoms and comorbid health conditions; (3) psychological reactions to dementia; (4) shifting social roles and relationships; and (5) environmental changes. In total, 50% of the caregivers provided attributions from two or more categories.

Caregivers' Causal Attributions

Neurobiological disease factors.—Many caregivers identified neurobiological changes as a cause of BPSD. Some used technical language:

“Oh synapses, brain functioning. So if his behavior changes and he’s no longer sweet, which could happen, it’s only because some sort of more central amygdala level of the brain has become involved instead of, you know, another part of the brain.”

(Participant 1, Group 3)

Others used less specialized language:

“The disease is causing wiring problems in the brain and it’s changed, and that’s where the problem’s coming from is up here.”

(Participant 2, Group 2)

“...I began to realize it was not what was being said at that moment. It was something that had been said a little bit before that now just came out. Because the filter is kind of broken. There isn’t that thing where you can kind of figure it out in your head and go, ‘Well, yeah that kind of made me angry that (De-identified name) said that, but you know I’ll let it go.’”

(Participant 4, Group 1)

The care recipient’s difficulties with processing and responding to environmental stimuli were also described as causal factors:

“I know my husband is constantly saying, ‘Wow, there’s so much more traffic than there used to be,’ things are going so much faster and as your brain is not functioning as well, information processing is slowing down.”

(Participant 1, Group 3)

“He got glacial with the dementia. You just had to, like, be able to wait five minutes for a response but then it would come.”

(Participant 2, Group 3)

Physical symptoms or comorbid health problems.—In some cases, BPSD were attributed to physical symptoms such as fatigue:

“So, like, if she was sitting here at this table [banging on the table], she would be trying to take everything off the table or [banging table] starting to get agitated. Usually it happens when she is tired...”

(Participant 5, Group 4)

Caregivers also mentioned the contributions of chronic medical conditions:

“My mother, some of it is, I think, my mother is hard of hearing, so that is certainly something that she resents, being left out of conversations, and that’s kind of a hard problem to take care of sometimes with hearing aids.”

(Participant 5, Group 1)

“Not only that, but so my dad had macular degeneration, had glaucoma, was hard of hearing. So all of a sudden not only are we dealing with whatever place he is with the disease but it is being further exacerbated by other co-existing conditions that just make it all that much more pronounced, as well as in attempting to correct these things people are putting them on medications which might make the whole situation 10 times worse...”

(Participant 4, Group 2)

Psychological reactions to dementia.—A number of caregivers considered the care recipient’s negative psychological reactions to dementia, such as fear, as a cause of BPSD:

“It’s fear within the patient, yeah, reaction. The uncertainty and the beginning awareness that things ain’t right, you know, that’s pretty terrifying and fear often brings out anger.”

(Participant 4, Group 1)

“I think of emotional reasons because my parents are not clinically diagnosed, either one of them and they’re in various stages of dementia.... There are many indications that there is dementia there, and primarily I think the emotion that they are feeling and the reason for some of their reactions to things is fear.”

(Participant 3, Group 2)

The care recipient’s feelings of anger or frustration over diminished communication abilities were also viewed as triggers:

“He’s not capable of saying I don’t remember and so anger is the way that these come out, and I think with a lot of aggressive behaviors, I think that’s what it is.”

(Participant 11, Group 3)

“I think it’s just the frustration because she can’t remember and she can’t express why.”

(Participant 1, Group 4)

Several caregivers perceived the care recipient’s loss of personal control or independence as a cause of BPSD:

“She also, I think a lot of it comes out of just the general loss of control as far as getting angry or some, she’s not real aggressive but some sort of aggressiveness is like you’re making me get out of bed, you’re making me change out of my nightgown, you’re making me take my pills.”

(Participant 5, Group 1)

“It seems like when she was losing her independence with the ability to do things were some of the triggers into her behaviors and stuff. Like you said, they kind of know. They know this is going on and it’s very frustrating to them.”

(Participant 2, Group 4)

Shifting social roles and relationships.—The adverse social consequences of dementia were voiced as contributors to BPSD, including social isolation:

“Otherwise my mother was, I think she policed herself a lot. She was so uneasy about what she had that she didn’t get into, you know, she dropped out of a lot of social situations early on. She just was so afraid she’d forget someone’s name or she’d forget something that they told her or something like that.”

(Participant 5, Group 1)

The care recipient’s feelings of social exclusion within their families and in wider society were mentioned as well:

“I think the biggest thing is she gets the sense of being left out. You know, she got very agitated, you know, my daughter and daughter-in-law were fixing dinner when they were all here and, you know, it really wasn’t something that she could keep track of.”

(Participant 2, Group 1)

“My feeling is that the cause is what the disease has done to them that affects their fitting into society. The socially acceptable stuff the rest of us do like eating with knife, fork, and spoon, for example. Eventually (De-identified name) reached a point where she didn’t know what a fork was for. So she’s using her fingers and she’s trying to eat ice cream with her fingers, and people would look at her and say, ‘What is wrong with that?’”

(Participant 1, Group 1)

Loss of meaningful social roles was cited as an additional trigger:

“My wife had to quit work because of this condition, and she wants to work....She just, today she was complaining that everybody, I get to do things, other people get to do things, but she can’t do anything and she really feels that. I try to find things for her to do, but it just doesn’t work.”

(Participant 1, Group 2)

Environmental changes.—Caregivers noted changes in routine as a cause of BPSD:

“I think when there’s a routine and a ritual things are calm. When something kind of comes out of, you know, left field, I think some of the behavior kicks in.”

(Participant 4, Group 4)

Medical transitions were also described as triggers:

“Every trip to the emergency room, because the surroundings are not familiar, is a shock to their system and was a major setback.”

(Participant 2, Group 2)

“Where I saw it was when he came from the hospital to the rehab place and he just latched on to my mom, and my father has never been a real demonstrative individual. I’ll tell you what that night it was, and just like you said, just terror. You know, what is going to happen next, you know?”

(Participant 4, Group 2)

Perceptions of Controllability

We then considered caregivers’ views of BPSD as within or outside the care recipient’s control. Several caregivers used language indicating their views of BPSD as uncontrollable:

“It’s not that they know better and want to do these things.”

(Participant 2, Group 2)

“He had no control over how fast they moved or what they said, and those were the times that these hostile behaviors would emerge. He was never trying to hit somebody, he was trying to get his space clear either with his hands or feet or, you know, whatever, however he could.”

(Participant 2, Group 3)

Language indicating that BPSD is partly controllable was also used. Pre-existing personality characteristics were referenced:

“If he had an ounce of energy in him, he would try to smile and say something like, ‘You look nice,’ or ‘I’m so glad to see you,’ to anybody who he met. But if people were trying to get him to shower or change clothes or, you know, were in his physical space, he was a very deliberate man to begin with.”

(Participant 2, Group 3)

Assumptions of the care recipient’s deliberate or malicious intent were also apparent:

“A con artist at hiding stuff to the point of when I finally got to the stage where we had pill reminders and I had to put her medication for every day or whatever it is. Then she’d figure it out that when I would come once or twice a week that I would notice if things weren’t taken....She would learn to not leave pills, okay. She didn’t know that she hadn’t taken them but she knew they shouldn’t be there, and so she’d put them in a bottle and hide them.”

(Participant 5, Group 4)

Finally, a number of caregivers remarked that the care recipient voluntarily displays BPSD around certain family members:

“That’s where a lot of her being pretty negative or being for her aggressive, and it’s usually towards me because she, you know, because she still knows I’m her daughter so she can get away with more.”

(Participant 5, Group 1)

“... I think on some level she remembered these are grandkids and had a softer approach. But when it came to her kids, they got the brunt of the aggression.”

(Participant 4, Group 3)

Discussion

This study demonstrates that family caregivers perceive a variety of causes for BPSD. In line with qualitative research using individual interviews,^{11,12} caregivers attributed these behaviors to a combination of internal and external factors. Also similar to previous qualitative studies,⁵ many caregivers made multifactorial attributions from two or more categories. We build upon prior work by using a focus group approach, which generates candid and spontaneous responses that allow participants to “piggyback” on each other’s thoughts and observations. Consequently, the findings provide unique insights on the varied experiences that shape how caregivers develop attributions about BPSD, yielding crucial information for clinicians working with families facing the multifaceted challenges of dementia.

Consistent with previous research,^{11,12} caregivers partly attributed BPSD to comorbid conditions. People with dementia commonly have physical comorbidities and symptoms (e.g., pain) that are linked to BPSD such as agitation and delusions.² Drug side effects or drug-drug interactions can also contribute to these behaviors.² Furthermore, health system interactions (e.g., making appointments) are associated with greater emotional caregiving difficulties, perhaps from the stress of coordinating care with multiple providers.²⁷ In turn, caregivers’ distress may negatively impact interactions within the care dyad, possibly intensifying BPSD.^{2,13} The present findings pinpoint the urgency for a fuller understanding of this interplay of factors as well as caregiver techniques to prevent or mitigate these processes.

Caregivers’ beliefs that BPSD are caused by the care recipient’s psychological reactions to dementia indicate perceptions of emotional suffering. Regardless of whether these attributions are accurate, they potentially raise concern for caregivers’ well-being. Exposure to the care recipient’s emotional suffering is associated with higher depressive symptoms among dementia caregivers, over and above factors including functional impairment and disruptive behaviors.²⁸ As such, these attributions could mirror an overlooked source of caregiver distress. During the early stages of dementia, dyadic interventions that engage both care partners in discussing their emotions and worries may alleviate uncertainty and distress for each individual.^{29,30}

Similarly, several caregivers perceived that BPSD arise from the adverse social ramifications of dementia, underscoring caregivers' recognition that people with dementia retain their desire for belonging and a purposeful role in society.³¹ Providing opportunities for care recipients to socialize in a way that fosters their sense of community and social acceptance while adapting to current functioning could help combat these detrimental effects.³² Maintaining the care recipient's engagement in meaningful or productive activities (e.g., intergenerational volunteer work) may also be beneficial for both care partners.^{33,34}

Caregivers' views that environmental changes contribute to BPSD point to the value of a daily routine for each care partner. Additionally, following sudden and upsetting events (e.g., hospitalizations), caregivers may require support in managing BPSD as well as their own and their care recipient's distress.

Although many caregivers acknowledged that BPSD are influenced by brain disease factors, their language also indicated perceptions of these behaviors as somewhat under the care recipient's control. This is in accord with prior research,^{11,12,15,19,21} and highlights the significance of guiding caregivers in differentiating willful behaviors from involuntary behaviors. Assisting caregivers in problem solving to determine modifiable factors that could aggravate BPSD has proven effective in reducing their frequency and intensity.² The present study and previous work imply the additional need to assess caregivers' beliefs that the care recipient is volitionally creating behaviors.

Interestingly, none of the caregivers discussed their own potential role in BPSD. Yet caregiver factors (e.g., ineffective communication, mismatched expectations with illness stage) could inadvertently worsen problem behaviors.^{2,13} BPSD may also strain the caregiving relationship, especially when care recipients are held responsible.^{13,22,35} An overdeveloped sense of "blame" on the caregiver for BPSD may be unhealthy as well; caregivers who blame themselves or their care recipient for difficult behaviors report higher caregiver burden and depression^{15,21,36} and often exhibit maladaptive caregiving behaviors such as overinvolvement or criticism.^{13,16,19,20,36} In both cases, educating caregivers about the neurodegeneration underlying BPSD and common patient/caregiver/environmental triggers is often helpful. Future work should devise strategies to assist caregivers in navigating these complicated issues, with the awareness that caregiving emerges from a broader family context that can obscure understanding of BPSD.³ Caregivers with a negative pre-caregiving relationship, for instance, may have trouble disentangling behaviors caused by dementia from longstanding interaction patterns.

Several limitations warrant comment. First, caregivers were homogeneous in their sociodemographics and care situations, limiting generalizability. The sample was highly educated and likely to be more socialized to the biomedical model of dementia than caregivers with lower education who may show different attribution patterns. Caregivers were also mostly women and adult children caring for a parent, consistent with current reports of dementia caregiving;³⁷ however future studies should examine attributions from more diverse caregivers. Second, the sample was relatively small and self-selected, introducing potential bias. Third, we assessed retrospective appraisals, which may differ from real-time perceptions. Fourth, it appears that some attributions were about root causes

of BPSD (e.g., fear) and others pertained to what exacerbates symptoms (e.g., fatigue), suggesting the need for future research to distinguish between these two types of attributions during interviews. Nevertheless, the present study forms the basis for subsequent work to gain more nuanced knowledge of caregivers' views of BPSD and their implications for the care dyad.

In sum, this study reveals the complex ways that family caregivers make sense of BPSD. Findings shed light on potentially unmet educational needs that inform comprehensive geriatric care and interventions to sustain caregivers' health and ability to provide quality care. Routine clinical care may benefit from proactive education on the involuntary nature of BPSD and guidance in avoiding or minimizing possible triggers to promote both care partners' well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Background Characteristics of Family Caregivers (N = 26)

Characteristic		N (%)
Relationship to care recipient	Adult child	15 (57.7%)
	Spouse	6 (23.1%)
	Other relative	5 (19.2%)
Mean age	52 (range = 24–76)	
Gender	Female	21 (80.8%)
	Male	5 (19.2%)
Race	White	25 (96.2%)
	African American	1 (3.8%)
Marital status	Married	18 (69.2%)
	Divorced	5 (19.2%)
	Never married	2 (7.7%)
	Widowed	1 (3.8%)
Education	High school or less	1 (3.8%)
	Some college/Associate's degree	5 (19.2%)
	Bachelor's degree	11 (42.3%)
	Graduate degree	9 (34.6%)
Time providing care	1 year or less	3 (11.5%)
	2–3 years	9 (34.6%)
	4–5 years	7 (26.9%)
	>5 years	7 (26.9%)
Care hours per week	<5	1 (3.8%)
	5–10	(19.2%)
	11–15	8 (30.8%)
	16–20	1 (3.8%)
	>20	11 (42.3%)
Mean age of care recipient	82 (range = 61–96)	

Table 2.

Major Categories of Caregivers' Attributions About Behavioral and Psychological Symptoms of Dementia

Category	Example
1. Neurobiological disease factors	"The disease is causing wiring problems in the brain and it's changed, and that's where the problem's coming from is up here."
2. Physical symptoms or comorbid health conditions	"My mother, some of it is, I think, my mother is hard of hearing, so that is certainly something that she resents, being left out of conversations, and that's kind of a hard problem to take care of sometimes with hearing aids."
3. Psychological reactions to dementia	"It's fear within the patient, yeah, reaction. The uncertainty and the beginning awareness that things ain't right, you know, that's pretty terrifying and fear often brings out anger."
4. Shifting social roles and relationships	"I think the biggest thing is she gets the sense of being left out. You know, she got very agitated, you know, my daughter and daughter-in-law were fixing dinner when they were all here and, you know, it really wasn't something that she could keep track of."
5. Environmental changes	"I think when there's a routine and a ritual things are calm. When something kind of comes out of, you know, left field, I think some of the behavior kicks in."