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# Cognitive dysfunction in patients with brain metastases: influences on caregiver resilience and coping

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## Abstract

**Purpose** Neurologic deficits that may be manifested as cognitive impairment contribute to the challenges faced by caregivers of patients with brain metastases. To better address their needs, we examined how caregivers respond to these challenges and explore the relationship between the patient's cognitive impairment and caregiver resilience and coping.

**Methods** We conducted a descriptive, cross-sectional study using self-reported data from 56 caregivers of patients with brain metastases. Study participants from a comprehensive cancer center were asked to complete a series of instruments that measured their perception of the patient's cognitive dysfunction (revised memory and behavior problems checklist, RMBC), their own personal resilience (Resilience Scale, RS), and their utilization of a broad range of coping responses (COPE inventory and Emotional-Approach Coping scale).

**Results** Caregivers reported that memory-related problems occurred more frequently in the patients they cared for compared to depression and disruptive behavior (mean scores 3.52 vs 2.34 vs. 1.32, respectively). Coping strategies most frequently used by caregivers were acceptance (3.28), planning (3.08), and positive reinterpretation and growth (2.95). Most caregivers scored moderate to high on the RS (77%). The coping strategy *acceptance* correlated significantly with the memory and disruptive behavior subscales of the RMBC.

**Conclusions** Given the protective effect of problem-focused coping and the high rate of caregivers utilizing less effective coping strategies in instances of worsening cognitive dysfunction, healthcare professionals need to systematically assess the coping strategies of caregivers and deliver a more personalized approach to enhance effective coping among caregivers of patients with brain metastases.

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**Keywords** Brain metastases · Caregiver burden · Cognitive dysfunction · Coping · Resilience

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## Introduction

The number of people of all ages in the USA who have cancer is projected to grow to 18.1 million in 2020, a 30% increase from 2010 [1]. The rise in the prevalence of cancer consequently increases the population at risk for developing brain metastases, with the reported annual incidence estimated between 98,000 and 170,000 [2–4]. Brain metastases can lead to rapid deterioration in quality of life (QOL) brought on by progressive neurologic deficits which can be a daunting challenge for family caregivers [5]. Neurologic deficits that may be manifested as cognitive impairment may contribute to the challenges faced by caregivers of patients with brain metastases. It is therefore important to examine how caregivers

respond to these challenges and explore the relationship between the patient's cognitive impairment and caregiver resilience and coping.

It has been reported that family caregivers provide greater than 80% of the care needed by patients with cancer during initial treatment phases and close to 60% during the last year of life [6]. While family caregiving can be regarded as rewarding and positive, studies have shown the negative emotional (e.g., depression and anxiety) and physical (e.g., altered immune function, hypertension, poor overall physical health) consequences of caregiving on the caregiver [7]. Furthermore, studies have documented a reduction in caregiver QOL with increased responsibilities [8].

### Cognitive impairment

While there is a wealth of literature on caregiver burden in cancer, more information is needed on a variety of predictors of caregiver burden, including situational and personal factors, (e.g., patients' cognitive functioning and caregivers' coping and resilience). In patients with primary brain tumors, cognitive impairment has been identified as a leading cause of disability and the single greatest cause of patient distress [9] that potentially contributes to increased caregiver burden. In a study of patients with high-grade gliomas, alterations in cognitive function were shown to reflect the severity of the underlying disease, which was not always apparent in measurements of functional or performance status such as the Karnofsky or Barthel scores [10]. Assessment of patients' cognitive functioning can help determine the differential contributions of the neurocognitive effects of brain metastases on caregiver burden [11]. However, assessment and interpretation of neurocognitive function in brain metastases can be challenging, as assessment is confounded by multiple variables that include neurotoxic effects of previous anti-cancer therapies and supportive care agents and the presence of mood disorders.

What makes the experience of caregivers of patients with brain metastases unique is that caregivers are forced to deal not only with the emotional sequelae of a metastatic cancer diagnosis [12] but also with the physical and cognitive consequences that accompany the brain metastases [13]. The relationship between the patients' cognitive function and caregiver burden in patients with intracranial tumors, including brain metastases, warrants further investigation because literature in this area is scant. We have learned from studies done in other populations that variables associated with burden in caregivers of patients with cognitive impairment, include resilience, an inherent personality characteristic that can be developed throughout the caregiving trajectory, and coping, the caregivers' response to burden [14–16].

### Caregiver resilience and coping

Resilience, a personality trait that allows individuals to withstand stress and adapt to adversity, has been defined both as a preexisting trait and a dynamic, modifiable process [17, 18]. Resilience may affect variability in caregiver burden by decreasing the likelihood of distress from caring for an impaired individual or increasing the benefits derived from social support. It is a variable that can influence the perception of caregiver burden and have a protective effect on various health outcomes in cancer caregivers. While numerous papers have been written about resilience in caregivers of neurocognitively impaired individuals [19–25], few studies examined resilience in caregivers of patients with cancer.

Coping, described as voluntary internal psychological processes to address the demands created by stressful events, is recognized as a mediator of stress-related mental and physical health outcomes that carries a significant intervention potential [26]. Interventions aimed at improving the coping skills of caregivers can easily be tailored to fit the needs of individual caregivers and have been shown to be effective in moderating the burden associated with the caregiving experience [27]. Coping can be considered effective to the extent that caregiver burden is reduced.

The purpose of this study was to examine the impact of the patients' cognitive impairment on caregiver resilience and caregiver coping strategies. The study was guided by the following research questions:

1. What is the level of observed cognitive impairment among patients with brain metastasis?
2. Which coping styles are most frequently used by caregivers?
3. What is the extent of the caregiver's perceived resilience?
4. Is cognitive impairment negatively associated with caregiver resilience?
5. Is caregiver-perceived cognitive impairment associated with specific, caregiver coping strategies?

## Methods

### Conceptual framework

The Comprehensive Health-Seeking and Coping Paradigm (CHSCP) was the conceptual framework used in our caregiver research [28]. While caregiver research is driven by multiple disciplinary perspectives and theoretical orientations [29], one of the most common approaches used to guide caregiving research is from the perspective of the stress process. CHSCP proposes that a number of factors impact health outcomes. It describes antecedents and variables that influence

long-range consequences and is guided by the nursing perspective on health seeking and coping [28, 30, 31].

The CHSCP is a complex, multi-dimensional framework that depicts a highly interactive relationship among variables [28, 32–35]. In this study, *situational factors* that might be relevant to predictors of caregiver burden was represented by the patients' cognitive impairment, *personal factors* that describe individual characteristics and traits was measured using resilience, and *health seeking* and *coping behavior* was represented by caregivers' coping strategies.

## Design

We initiated the study using a cross-sectional analysis of self-reported data among caregivers of patients with brain metastases. Data were obtained using a survey instrument that had undergone pilot testing using a small group of cancer caregivers [36]. Given that all but the demographics section of the survey were already tested for validity and reliability, pilot testing of the survey instrument was conducted to appraise possible trends in missing data, determine clarity of instructions, seek feedback on the formatting and organization of the instruments, estimate time to completion, and desirability and ease of use. This study was approved by the Institutional Review Boards (IRB) of the academic and healthcare campuses that have oversight of the research staff and participants.

## Sample

The sample for the study consisted of family caregivers of patients with brain metastases from any solid tumor. A waiver of informed consent was granted by the IRB for the patients with brain metastases who were acknowledged as secondary subjects based on Title 45 Code of Federal Regulations Part 46. Convenience sampling was used to enroll eligible caregivers at a comprehensive cancer center in Southern California. Inclusion criteria were (a) age  $\geq 18$  years; (b) self-identified primary caregiver of patients diagnosed with brain metastasis; (c) able to speak, read, and understand English; (d) willing to participate in completion of surveys; (e) co-resided with the patient with brain metastasis; and (f) provided a minimum of 4 h of direct care for at least 3 days per week. Inclusion criteria were not limited by the type of relationship such as spouse, parent, child, sibling, and friend, or by the duration of caregiving role or the level of dependency.

## Procedure

Recruitment of subjects involved the use of informational flyers that described the study and included the criteria for enrollment and contact information of the research team. The flyers were placed in strategic locations and made available to patients,

caregivers, providers, and staff in three departments (multispecialty cancer clinic, infusion center, and radiation oncology clinic) in a comprehensive cancer center. Participants who agreed to be contacted by the study team were approached and were offered more information about the study.

Eligible subjects who agreed to participate in the study and signed the consent form were given the option to mail or hand-deliver the completed survey. All the participants received a survey packet that included a cover letter with information on the study and a copy of the consent. A self-addressed, stamped envelope for returning the documents were also included in the packet. Participants who agreed to participate were provided with a \$5.00 gift card as a small token of appreciation.

## Instruments

**Caregiver data form** A data collection form was developed from the relevant literature to collect socio-demographic data, employment and financial status, educational status, and health condition. In addition, the caregivers were asked to recall the history of the patient's present illness, including the date of initial diagnosis of the primary cancer, date of diagnosis of the brain metastasis, cancer treatment modalities received, and other comorbidities.

**Cognitive dysfunction** The caregiver's perception of the patient's cognitive dysfunction was measured using a modified version of the Revised Memory and Behavior Problems Checklist (RMBC), a brief, conceptually, and psychometrically sound instrument for assessing behavioral problems [37, 38]. The RMBC has demonstrated concurrent and discriminant validity and a Cronbach's alpha of 0.67–0.90. The modified RMBC (mRMBC) uses the same 24 stimulus phrases as the original instrument. It provides one global score and three subscale scores for memory, depression, and disruptive behavior. The modification was a change from Likert-type scale responses indicating frequency of each problem (0 = never and 4 = daily or more often) to "yes" or "no" indicating occurrence of the observable behavioral problem during the past week [37]. Behaviors that have occurred in the past week were then scored on caregiver reaction using a five-point Likert scale where 0 = not at all bothersome or upsetting to 4 = extremely bothersome or upsetting. Cronbach's alpha for the mRMBC ranged from 0.55 to 0.78 for the number of problem subscales and 0.73 to 0.87 for the total reaction subscales. Spearman rank-order correlation between the mRMBC scores and the Center for Epidemiological Studies Depression (CES-D) scale revealed moderate positive correlations [37].

**Resilience** Caregiver resilience was measured using the Resilience scale (RS-25) developed by Wagnild and Young [39]. Caregivers were asked to state the degree to which they

agreed or disagreed with each of the 25 items on this scale that were scored on a 7-point scale, with 1 = disagree and 7 = agree. Possible scores ranged from 25 to 175 with higher scores reflecting higher resilience. The reported internal consistency was high with a coefficient alpha of 0.91, and item-to-total correlations ranged from 0.37 to 0.75, with the majority falling between 0.50 and 0.70 ( $p \leq 0.001$ ).

**Coping** The coping responses of the caregiver were measured by the COPE Inventory [40] and the Emotional-Approach Coping (EAC) scale [41]. The COPE Inventory is a 60-item questionnaire that was developed to assess a broad range of coping responses, specifically to assess the different ways people respond to stress. The scale assessed 15 conceptually distinct methods of coping, and respondents were asked to rate the frequency with which they utilized each strategy based on a Likert-type scale, ranging from 1 (“I usually don’t do this at all”) to 4 (“I usually do this a lot”). Scores on each subscale range from 4 to 16, with higher scores indicating greater use of that coping strategy. Cronbach’s alpha reliability coefficients for the majority of scales ranged from  $\alpha = 0.45$  to 0.92 with one scale falling below 0.6.

The EAC scales, which are typically embedded in the COPE Inventory, has also undergone psychometric testing that revealed high internal consistency, test-retest reliability, and convergent and discriminant validity. The EAC includes two subscales (emotional processing and emotional expression) of eight items for each. Use of emotional processing is an active attempt to acknowledge and understand emotions, while use of emotional expression is said to assist in regulating the individual’s social environment [41]. Similar to the COPE Inventory, respondents were asked to rate each item on a four-point scale. Subsequent tests supported the predictive validity of the scales with regard to adjustment to stressful encounters [41]. Cronbach’s alpha for the eight-item scales ranged from 0.72 to 0.94, with correlations for test-retest reliabilities ranging from 0.63 to 0.89 [41].

### Data analysis

IBM SPSS 21.0 software (SPSS Inc., Chicago, IL, USA) was used for statistical analysis. Descriptive data, including frequencies and percentages of demographic variables, were used to describe the sample. Occurrence scores for memory-related problems, affective distress, and disruptive behaviors were determined by adding the scores on items that occurred during the past week while reaction scores for the subscales were determined by adding the score for each of the items on the subscale.

The occurrence of behavioral problems, the caregiver reaction to memory and behavioral problems of patients, and the utilization of coping strategies of caregivers were summarized as means and standard deviations. The scores for caregiver

resilience were summed and categorized into six categories ranging from “very low” to “high” as recommended in instrument scoring instructions [39] and summarized as frequencies and percentages. In scoring instruments, missing items were imputed as the average of non-missing items in the subscale, assuming that data were missing at random. Spearman’s rho was used to examine correlations between the patients’ cognitive impairment and caregivers’ coping and resilience. Statistical significance was set at  $p < 0.05$ .

## Results

The study team received 56 completed surveys from 104 caregivers who responded to the flyers and were sent a survey packet, yielding a response rate of 53.8%. The response rate was within the range for mail-in surveys but lower when compared to similar cancer caregiving studies [42, 43]. Since demographic or identifying data were not collected during the screening and consenting process, we were not able to distinguish between responders and non-responders.

### Description of the sample population

The characteristics of the caregivers are presented in Table 1. Most caregivers were women (69.6%,  $n = 39$ ) and white (71.4%,  $n = 40$ ) with a mean age of 56.3 years. Caregivers were most often the spouses or partners of care recipients (67.9%,  $n = 38$ ), and a subset of caregivers reported they were also the primary caregiver for at least one other individual in addition to the care recipient with brain metastasis (26.8%,  $n = 15$ ). Table 2 presents data from caregivers who responded to questions about the clinical characteristics of the patients with brain metastases.

### What is the level of observed cognitive impairment among patients with brain metastasis?

The sample means for the number of problem behaviors for each of the mRMBC occurrence subscales were  $3.52 \pm 2.42$  for memory,  $2.34 \pm 2.12$  for depression, and  $1.32 \pm 1.63$  for disruptive behavior, with a global mean of  $2.39 \pm 2.26$ . Caregivers reported that memory-related problems occurred more frequently compared to depression and disruptive behavior. The mRMBC reaction subscale means were  $4.50 \pm 5.63$ ,  $4.59 \pm 5.74$ ,  $2.14 \pm 3.57$ , and  $3.74 \pm 5.18$  for memory, depression, disruptive behavior, and global reaction, respectively. Table 3 includes the minimum and maximum reported problems for each of the subscales.

**Table 1** Demographics of caregivers of patients with brain metastasis ( $N = 56$ )

Characteristics	Mean $\pm$ SD or $n$ (%)
Age (years)	56.3 $\pm$ 14.9
Gender	
Female	39 (69.6%)
Male	17 (30.4%)
Education	
Graduate degree	16 (28.6)
College grad	19 (33.9)
Some college	18 (32.1)
High School	1 (1.8%)
Grade school	1 (1.8%)
Missing data	1 (1.8%)
Ethnicity	
Not Hispanic or Latino	24 (42.8)
Hispanic or Latino	9 (16.1)
Missing data	23 (41.1)
Race	
Asian	9 (16.1)
Black/African-American	2 (3.5)
White/Caucasian	40 (71.4)
Missing data	5 (8.9)
Marital Status	
With spouse or partner	48 (85.7)
Without spouse or partner	6 (10.7)
Missing data	2 (3.6)
Income	
>\$75,000	30 (53.6)
\$40,001 to \$75,000	10 (17.9)
\$20,001 to \$40,000	5 (8.9)
<\$20,000	6 (10.7)
Missing data	5 (8.9)
Covered by health insurance	
Yes	53 (94.6)
No	3 (5.4)
Self-assessment of health	
Excellent	19 (33.9)
Good	29 (51.8)
Fair	7 (12.5)
Poor	1 (1.8)
Self-assessed health status compared to 6 months ago	
Better	3 (5.4)
Same	45 (80.3)
Worse	8 (14.3)
Relationship	
Spouse/significant other	38 (67.9)
Son/daughter	9 (16.1)
Parent	3 (5.3)
Brother/sister	2 (3.6)
Son-in-law/daughter-in-law	1 (1.8)

**Table 1** (continued)

Characteristics	Mean $\pm$ SD or $n$ (%)
Missing data	3 (5.3)
Length of time caring for patient	
>24 months	24 (42.8)
13–23 months	10 (17.9)
7–12 months	7 (12.5)
<6 months	14 (25.0)
Missing data	1 (1.8)
Primary caregiver for others	
Yes	15 (26.8)

Note. Values are mean  $\pm$  SD or  $n$  (%)

### Which coping styles were most frequently used by caregivers?

The most frequently used coping strategies included acceptance, planning, positive reinterpretation and growth, active coping, and suppression of competing activities. The least frequently used strategies included substance use, denial, and behavioral disengagement. For the EAC scale, mean score for emotional processing was  $2.61 \pm 0.68$  and the mean score for expression was  $2.47 \pm 0.69$  (Table 4).

### What is the extent of the caregiver's resilience?

For resilience, the caregivers scored an overall mean of  $146.36 \pm 17.02$  (range 25–175) on the RS-25. Most caregivers scored moderate to high on the scale ( $n = 43$ , 77%) (Table 5).

### Is cognitive impairment associated with specific, caregiver coping strategies?

In our sample, the coping strategy *acceptance* correlated significantly with the *memory* and *disruptive behavior* subscales of the mRMBC, both for occurrence and strength of reaction (Table 6).

### Is cognitive impairment associated with caregiver resilience?

In our sample, only the occurrence of memory problems measured by the mRMBC had a significant negative correlation with caregiver resilience. There was no correlation between caregiver resilience and the mRMBC subscales for disruptive behavior and depressive symptoms (Table 6).

**Table 2** Clinical characteristics of patients with brain metastases based on caregiver recall

Characteristics	n (%)
Primary Tumor Site	
Breast	4 (7.1)
Lung	12 (21.4)
Melanoma	6 (10.7)
Other (bladder, cervical, colon, gastric, kidney, ovarian, renal)	8 (14.4)
Missing data	26 (46.4)
Number of metastatic lesions	
1	12 (21.4)
2–3	9 (16.1)
≥4	11 (19.6)
Missing data	24 (42.9)
Surgical treatment of brain metastasis	
Yes	23 (41.1)
No	19 (33.9)
Not sure	2 (3.6)
Missing data	12 (21.4)
Chemotherapy for brain metastasis	
Yes	22 (39.3)
No	13 (23.2)
Not sure	4 (7.1)
Missing data	17 (30.4)
Stereotactic surgery for brain metastasis	
Yes	14 (25.0)
No	17 (30.4)
Not sure	6 (10.7)
Missing data	19 (33.9)
Whole brain radiation for brain metastasis	
Yes	15 (26.8)
No	14 (25.0)
Not sure	5 (8.9)
Missing data	22 (39.3)

## Discussion

### Cognitive impairment among patients with brain metastasis

In this study, the mRMBC was used for caregivers to indicate the occurrence of behavioral problems of patients with brain

metastases. In our sample, memory problems were most frequently reported (mean = 3.52, SD = 2.42). A study measuring neurocognitive function in patients with brain metastases found that despite a high functional status, 76 and 70% of the patients demonstrated impairment with Hopkins Verbal Learning Tests recall and delayed recall, respectively [44]. While our results were consistent with findings from a previous research study

**Table 3** Scores for the modified version of the revised memory and behavior problem checklist

mRMBC subscales	Behavior occurrence Mean ± SD	No. of problem behaviors reported		Caregiver reaction Mean ± SD
		Min	Max	
Memory	3.52 ± 2.42	0	7	4.50 ± 5.63
Depression	2.34 ± 2.12	0	9	4.59 ± 5.74
Disruptive behavior	1.32 ± 1.63	0	8	2.14 ± 3.57
Total Score	2.39 ± 2.26	0	24	3.74 ± 5.18

**Table 4** Distinct aspects of coping using the COPE Inventory and the Emotional Approach Coping scales ( $N = 56$ )

	Mean $\pm$ SD
COPE Inventory	
Acceptance	3.28 $\pm$ 0.60
Planning <sup>a</sup>	3.08 $\pm$ 0.68
Positive reinterpretation and growth	2.95 $\pm$ 0.81
Active coping <sup>a</sup>	2.88 $\pm$ 0.61
Suppression of competing activities <sup>a</sup>	2.76 $\pm$ 0.72
Religious coping	2.69 $\pm$ 1.17
Use of emotional social support	2.57 $\pm$ 0.75
Use of instrumental social support <sup>a</sup>	2.45 $\pm$ 0.82
Restraint <sup>a</sup>	2.38 $\pm$ 0.52
Focus on and venting of emotion	2.29 $\pm$ 0.69
Mental disengagement	2.19 $\pm$ 0.48
Humor	1.83 $\pm$ 0.90
Behavioral disengagement	1.59 $\pm$ 0.58
Denial	1.45 $\pm$ 0.71
Substance use	1.31 $\pm$ 0.59
Emotional Approach Coping	
Emotional processing	2.61 $\pm$ 0.68
Emotional expression	2.47 $\pm$ 0.69

Note: scores range from 1 = "I usually do not do this at all" to 4 "I usually do this a lot"

<sup>a</sup> Problem-focused coping strategies

using mRMBC in patients with dementia showing that memory problems were most frequently reported by caregivers (mean = 5.08, SD 1.55), we found that depression was the problem that most bothered the caregivers in our study [37]. A similar study conducted among caregivers of patients with Alzheimer's disease revealed that memory problems were most frequently reported, but disruptive behaviors elicited the most negative reactions [45].

Cognitive deficits create care demands for the caregivers and increase the number of tasks with which the caregiver must render assistance. In patients with primary brain tumors, cognitive dysfunction has been consistently linked to increased caregiver demands [46] and when compared with

**Table 5** Resilience ( $N = 56$ )

Resilience category	Possible range	$N$ (%)
Very low	25–100	0 (0)
Low	101–115	3 (5.36)
On the low end	116–130	10 (17.86)
Moderate	131–145	8 (14.29)
Moderately high	146–160	24 (42.86)
High	161–175	11 (19.64)

functional status, cognitive status was found to be a much stronger predictor of caregiver burden [47].

In addition to the impact of cognitive impairment on caregiver burden, in patients with intracranial tumors, cognitive function has now become an important marker to determine whether a positive neuroimaging response truly translates into a clinical benefit for the patient [48].

### Coping among caregivers of patients with brain metastasis

Coping strategies used by caregivers are important variables to consider within the context of this study. Coping is conceptualized as an effort made by the caregiver to manage the burden of caregiving regardless of the outcome.

Our results revealed that the most frequently used coping strategies included acceptance, planning, positive reinterpretation/growth, active coping, and suppression of competing activities. The least frequently used strategies included substance use, denial, and behavioral disengagement. Interestingly, these clusters of coping strategies, made up of what theoretically can be classified as adaptive (frequently used strategies) and questionable (less frequently used strategies) coping strategies, have been found to be correlated, albeit weakly [40]. Acceptance is a functional coping response that is particularly important in situations wherein the stressor is interminable (e.g., providing care at the end-of-life) in contrast to a stressor that can be managed by active coping skills.

Planning and active coping are problem-focused coping strategies that involve outlining and executing direct action, and suppression of competing activities relates to eliminating distraction to allow focus on the task at hand [40]. For the EAC scale, emotional processing and expression were reported at similar levels.

### Resilience in caregivers of patients with brain metastasis

Our sample's mean RS-25 scale score were within the average range of RS-25 scores in multiple studies involving a variety of individuals of different ages, socioeconomic, and educational backgrounds (range 140–148) [49]. Previously published studies have reported a positive correlation between higher resilience scores and positive factors, i.e., coping effectiveness and optimism, and an inverse relationship between resilience and perceived burden and depression [50].

### Cognitive impairment and caregiver coping strategies

In our sample, the caregiver coping strategy acceptance was found to be significantly correlated with patients' memory problems and disruptive behavior. Acceptance is an active coping strategy in situations where the stressor is not likely to change [40].



**Table 6** Spearman's rho correlation for mRMBC and coping/EAC (reporting only coping subscales with statistically significant results) and RS

mRMBC		Positive re-interpretation or Growth	Mental dis-engagement	Active coping	Denial	Religious coping	Acceptance	Resilience
Memory	Occurrence	-0.07	0.13	0.08	-0.18	0.00	0.31*	-0.30*
	Reaction	-0.15	0.28*	0.07	-0.20	-0.25	0.28*	-0.24
Disruptive behavior	Occurrence	0.28*	0.11	0.20	-0.24	0.28*	0.42**	0.005
	Reaction	0.12	0.08	0.15	-0.14	0.03	0.33*	0.03
Depression	Occurrence	0.01	-0.01	0.27*	0.07	-0.14	-0.04	-0.21
	Reaction	-0.09	0.05	0.26	0.27*	-0.21	-0.08	-0.11

\* $p < 0.05$ ; \*\* $p < 0.01$

Very few studies have investigated the association between caregivers' coping and patients' cognitive impairment. One recent study in patients with dementia reported an association between higher patient neuropsychiatric symptoms at baseline with less use of behavioral and mental disengagement strategies by caregivers [51]. Another study indicated that caregivers tend to fall back on emotion and avoidance style coping strategies as cognitive impairment increases [24]. One could assert that dysfunctional coping strategies utilized in highly stressful situations associated with cognitive impairment or neuropsychiatric symptoms aggravate perceived caregiver burden subsequently leading to poorer caregiver outcomes, i.e., depression, illness, and diminished QOL [51].

Most literature exploring caregiver coping strategies emphasizes the moderating or mediating effect of coping on caregiver burden and/or long-term outcomes in patients who are recipients of care or in caregivers themselves [51, 52]. One perspective that we wanted to highlight based on the results of our study is the causal relationship between variables. The results that we have presented in this paper show a correlation between acceptance as a coping strategy and the caregivers' report of occurrence and their reaction to the patients' memory problems and disruptive behavior; but correlation does not necessarily establish causation. It can be argued that caregivers who have fewer resources and/or more perceived distress are coping more and therefore have higher coping scores.

### Cognitive impairment and caregiver resilience

Our data showed that the occurrence of memory problems in patients with brain metastases had a significant negative correlation with caregiver resilience. This association has also been shown in a study in caregivers of patients with dementia [24]. In the absence of a previous study in patients with brain metastasis, this finding should be carefully taken into consideration in the context of evaluating caregiver coping strategies and patient's cognitive impairment because caregivers who use problem-focused coping strategies generally perceive themselves as more resilient [24]. In addition, the observation

that caregivers tend to fall back on emotion and avoidance-style coping strategies as cognitive problems increase should be further studied. Resilient caregivers of patients with dementia were found to have a better outlook; higher quality relationship with the care recipient; and well-informed, adequately supported, and appropriate users of healthcare resources [53].

### Limitations and future research

This study is not without its limitations. We have a small sample that precluded more complex analyses, such as regression analyses for each type of coping and resilience scores (not categories). The cross-sectional design of our study also prevented us from capturing changes that may occur over time, an important concept to integrate in a patient population that may exhibit worsening cognitive function during their disease course. The lack of diversity in the demographic characteristics of our sample and in the patient-caregiver relationship adds to the limitations of our study. Over 70% of our participants self-reported as White/Caucasian and have an income above the federal poverty level for a family of three. These variables have been shown to differentially impact the caregiving experience. In addition, the cross-sectional design restricted the analysis of causality and directional relationships among the variables. Another limitation is that cognitive impairment was measured using a proxy rating by the caregiver; however, it is important to note that the conceptual framework takes cognitive appraisal into consideration. We want to emphasize that the coping strategies utilized by the caregivers will be in response to their personal appraisal of the situational factors contributing to the stressful situation.

We have already planned to conduct future replication studies with larger and more varied samples to confirm the generalizability of our findings. We recognize that the caregiver's perception of the patients' cognitive impairment may still be independent of the clinical assessment of the patients' cognitive functioning by a neuropsychologist or through a battery of neurocognitive assessment tests. We suggest that congruence of

caregiver assessment with clinical assessment by trained neuropsychologists or with the use of validated battery of standardized neurocognitive tests need to be further explored. In addition, we acknowledge that a more comprehensive analysis of the relationship between variables is warranted. Future research should include longitudinal studies to measure how the variables change over time.

## Conclusion

Patients with brain metastases often endure a variety of neurological, cognitive, and emotional problems which, even with the slightest impairment, can significantly alter QOL. In the past years, these problems have not been adequately addressed due to the dismal prognosis.

In the age of precision medicine, the care of the caregiver is several years behind the powerful advances in the diagnosis and treatment of cancer. Family caregiver support needs to be integrated in the care of patients with brain metastases to allow for a meaningful encounter between healthcare providers and caregivers in a busy clinic setting, alerting clinicians to their needs as well as empower them to more efficiently co-manage the practical consequences of the patient's disease and its treatment.

In this study, we gained insight into the complex relationships between the patient's cognitive dysfunction and the caregiver's coping styles and resilience. Given the protective effect of problem-focused coping in resilience and the high likelihood for caregivers to utilize less effective coping strategies in instances of worsening cognitive dysfunction, healthcare providers need to systematically assess the coping strategies of caregivers and deliver a more personalized approach to enhance effective coping among caregivers of patients with brain metastases. This ultimately should lead to better patient care.

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## Compliance with ethical standards

**Conflict of interest** Dr. Marlon Garzo Saria has received academic scholarship grants from the American Cancer Society and the Oncology Nursing Society Foundation while completing this study as part of his doctoral work. In addition, the study was supported by a research grant from The Daisy Foundation. None of the organizations had a role in the study design, data collection and analysis, report writing, and decision for manuscript submission for publication. The authors have full access to all of the data in this study and take complete responsibility for the integrity of the data and the accuracy of the data analysis.

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## References

- Mariotto AB et al (2011) Projections of the cost of cancer care in the United States: 2010–2020. *J Natl Cancer Inst* 103(2):117–128
- Hutter A et al (2003) Brain neoplasms: epidemiology, diagnosis, and prospects for cost-effective imaging. *Neuroimaging Clin N Am* 13(2):237–250 x-xi
- Levin VA, Leibel SA, Gutin PH (2001) Neoplasms of the central nervous system. In: DeVita Jr VT, Hellman S, Rosenberg SA (eds) *Cancer: principles and practice of oncology*. Lippincott Williams & Wilkins, Philadelphia, pp. 2100–2160
- National Cancer Institute (2010) Adult brain tumors treatment (PDQ). [cited 2010 August 21]; Available from: <http://www.cancer.gov/cancertopics/pdq/treatment/adultbrain/HealthProfessional/page2#Reference2.11>.
- Saria MG et al (2015) Current perspectives in the management of brain metastases. *Clin J Oncol Nurs* 19(4):475–479
- Warren JL et al (2008) Current and future utilization of services from medical oncologists. *J Clin Oncol* 26(19):3242–3247
- Sherwood PR et al (2008) Guiding research in family care: a new approach to oncology caregiving. *Psychooncology* 17(10):986–996
- Munoz C et al (2008) The quality of life of patients with malignant gliomas and their caregivers. *Soc Work Health Care* 47(4):455–478
- Locke DE et al (2008) Cognitive rehabilitation and problem-solving to improve quality of life of patients with primary brain tumors: a pilot study. *J Support Oncol* 6(8):383–391
- Klein M et al (2003) The prognostic value of cognitive functioning in the survival of patients with high-grade glioma. *Neurology* 61(12):1796–1798
- Farace E (2008) Role of neuropsychological assessment in cancer patients. In: Meyers CA, Perry JR (eds) *Cognition and cancer*. Cambridge University Press, New York, pp. 33–43
- Meriggi F et al (2015) Assessing cancer caregivers' needs for an early targeted psychosocial support project: the experience of the oncology Department of the Poliambulanza Foundation. *Palliat Support Care* 13(4):865–873
- Maqbool T et al. (2016) Informational and supportive care needs of brain metastases patients and caregivers: a systematic review. *J Cancer Educ*
- Del-Pino-Casado R et al (2011) Coping and subjective burden in caregivers of older relatives: a quantitative systematic review. *J Adv Nurs* 67(11):2311–2322
- Raggi A et al (2015) The burden of distress and related coping processes in family caregivers of patients with Alzheimer's disease living in the community. *J Neurol Sci* 358(1–2):77–81
- Scott CB (2013) Alzheimer's disease caregiver burden: does resilience matter? *J Hum Behav Soc Environ* 23(8):879–892
- Rosenberg AR et al (2013) Promoting resilience among parents and caregivers of children with cancer. *J Palliat Med* 16(6):645–652
- Earvolino-Ramirez M (2007) Resilience: a concept analysis. *Nurs Forum* 42(2):73–82
- Foster K (2010) 'You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness. *J Clin Nurs* 19(21–22):3143–3151
- Harmell AL et al (2011) A review of the psychobiology of dementia caregiving: a focus on resilience factors. *Curr Psychiatry Rep* 13(3): 219–224
- O'Rourke N et al (2010) Psychological resilience predicts depressive symptoms among spouses of persons with Alzheimer disease over time. *Aging Ment Health* 14(8):984–993
- Wilks SE (2008) Psychometric evaluation of the shortened resilience scale among Alzheimer's caregivers. *Am J Alzheimers Dis Other Demen* 23(2):143–149

23. Wilks SE, Croom B (2008) Perceived stress and resilience in Alzheimer's disease caregivers: testing moderation and mediation models of social support. *Aging Ment Health* 12(3):357–365
24. Wilks SE et al (2011) Alzheimer's aggression: influences on caregiver coping and resilience. *J Gerontol Soc Work* 54(3):260–275
25. Zauszniewski JA, Bekhet AK, Suresky MJ (2010) Resilience in family members of persons with serious mental illness. *Nurs Clin North Am* 45(4):613–626 vii
26. Taylor SE, Stanton AL (2007) Coping resources, coping processes, and mental health. *Annu Rev Clin Psychol* 3:377–401
27. Chen HM et al (2015) Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics* 15(1):20–25
28. Nyamathi A (1989) Comprehensive health seeking and coping paradigm. *J Adv Nurs* 14(4):281–290
29. Pearlin LI et al (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 30(5):583–594
30. Lazarus RS, Folkman S (1984) *Stress, appraisal, and coping*. Springer Pub. Co., New York xiii, 445 p
31. Schlotfeldt R (1975) *The need for conceptual framework*. Nursing research. Little & Brown, Boston
32. Berg J et al (2005) Predictors of screening results for depressive symptoms among homeless adults in Los Angeles with latent tuberculosis. *Res Nurs Health* 28(3):220–229
33. Nyamathi AM, Stein JA, Bayley LJ (2000) Predictors of mental distress and poor physical health among homeless women. *Psychol Health* 15(4):483–500
34. Nyamathi AM et al (2010) Perceptions of women living with AIDS in rural India related to the engagement of HIV-trained accredited social health activists for care and support. *J HIV AIDS Soc Serv* 9(4):385–404
35. Washington OG, Moxley DP, Taylor JY (2009) Enabling older homeless minority women to overcome homelessness by using a life management enhancement group intervention. *Issues Ment Health Nurs* 30(2):86–97
36. Saria MG et al. (2016) An exploratory study of caregiver burden among caregivers of cancer patients with brain metastasis. Unpublished raw data
37. Roth DL et al (2003) Psychometric analysis of the revised memory and behavior problems checklist: factor structure of occurrence and reaction ratings. *Psychol Aging* 18(4):906–915
38. Teri L et al (1992) Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychol Aging* 7(4):622–631
39. Wagnild GM, Young HM (1993) Development and psychometric evaluation of the resilience scale. *J Nurs Meas* 1(2):165–178
40. Carver CS, Scheier MF, Weintraub JK (1989) Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 56(2):267–283
41. Stanton AL et al (2000) Coping through emotional approach: scale construction and validation. *J Pers Soc Psychol* 78(6):1150–1169
42. Hanly P et al (2015) Examining the role of subjective and objective burden in carer health-related quality of life: the case of colorectal cancer. *Support Care Cancer* 23(7):1941–1949
43. Hartnett J, Thom B, Kline N (2016) Caregiver burden in end-stage ovarian cancer. *Clin J Oncol Nurs* 20(2):169–173
44. Herman MA et al (2003) Neurocognitive and functional assessment of patients with brain metastases: a pilot study. *Am J Clin Oncol* 26(3):273–279
45. Robinson KM, Adkisson P, Weinrich S (2001) Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease. *J Adv Nurs* 36(4):573–582
46. Sherwood PR et al (2006) Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health* 29(2):105–120
47. Pinquart M, Sorensen S (2003) Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 58(2):P112–P128
48. Weller M (2011) Neurocognitive function: an emerging surrogate endpoint for neuro-oncology trials. *Neuro-Oncology* 13(6):565
49. Wagnild GM (2009) A review of the resilience scale. *J Nurs Meas* 17(2):105–113
50. Wagnild GM, Collins JA (2009) Assessing resilience. *J Psychosoc Nurs Ment Health Serv* 47(12):28–33
51. Snyder CM et al (2015) Dementia caregivers' coping strategies and their relationship to health and well-being: the Cache County study. *Aging Ment Health* 19(5):390–399
52. Tschanz JT et al (2013) Caregiver coping strategies predict cognitive and functional decline in dementia: the Cache County dementia progression study. *Am J Geriatr Psychiatry* 21(1):57–66
53. Joling KJ et al (2015) What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. *Aging Ment Health* 21:1–9