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Characteristics and Correlates of Caregivers' Perceptions of Their Family Members' Memory Loss

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Abstract

Background—Understanding caregiver's perceptions of their family member's memory loss is a necessary step in planning nursing interventions to detect and address caregiver burden.

Objective—The purpose of this paper is to characterize caregivers' perceptions of their family members' memory loss and identify potential correlates within Leventhal's common-sense model (CSM).

Methods—This secondary analysis used baseline data from a larger randomized controlled trial. Patients with memory loss and their caregivers ($N = 83$ dyads) from the community were included. The adapted Brief Illness Perception Questionnaire (BIPQ) assessed caregivers' illness perceptions. Eight additional instruments measured correlates within the CSM. Responses were described; multiple linear regression was used to predict BIPQ dimension scores and logistic regression was to predict dichotomized BIPQ scores.

Results—Most caregivers were female, White, and spouses of the patients; they reported a range of perceptions on the nine BIPQ dimensions. Patients' cognitive function consistently emerged as a significant correlate of caregivers' illness perceptions, explaining the most variance in caregivers' perceived consequences, identity, and treatment control ($p < .01$). Caregivers' reactions to patients' behavioral symptoms and caregivers' trait anxiety were associated with perceived illness coherence ($p < .01$). Caregivers with higher severity of daily hassles and White caregivers perceived that their family members' memory loss would last longer ($p < .001$).

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Discussion—Caregivers’ perceptions of family members’ memory loss varied; distinct dimensions of caregivers’ illness perception were associated with a range of clinical and psychosocial factors. This exploratory study demonstrates the complexity of applying the CSM to caregivers of persons with memory loss.

Keywords

caregivers; common sense model; illness perception; memory loss

Illness perception refers to “the beliefs an individual holds about an illness, including both the perceived reality of the health threat and emotional reactions to this threat” (Diefenbach & Leventhal, 1996). Although initially proposed to describe the perception of one’s own illness, illness perception has since been used to explore how informal caregivers perceive the illness that their family members may be experiencing. Possibly, an informal caregiver’s perception of a patient’s illness may influence the caregiver’s psychological response, role functioning related to caregiving (Barrowclough, Lobban, Hatton, & Quinn, 2001; Bassi et al., 2016), or even impact the patient’s well-being (Dempster et al., 2011). These associations may be especially salient in the context of caring for an individual with memory loss given the demanding nature of such caregiving and its associated burden (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014). Understanding caregivers’ illness perceptions of patients’ memory loss may better enable nurses to support these caregivers.

The common-sense model (CSM) of illness representation addresses both cognitive and emotional representations of an illness (Diefenbach & Leventhal, 1996). The five key dimensions of the cognitive aspect include identity, timeline, causality, control, and consequences of a disease; the emotional aspect focuses on negative emotional reactions. Additionally, the CSM outlines three categories of factors associated with an individual’s illness perception: illness history, personality traits, and sociocultural context.

To date, limited literature has focused on the illness perceptions of caregivers of patients with memory loss. Among 152 family carers of people with dementia in the UK, illness representation in the caregivers of patients with dementia was associated with caregivers’ sense of coherence, physical health, and psychological distress (Lo Sterzo & Orgeta, 2015). Focusing specifically on the CSM illness perception dimension of causality, patients with mild cognitive impairment and their caregivers most frequently attributed cognitive symptoms to uncontrollable factors like normal aging (Rodakowski, Schulz, Gentry, Garand, & Lingler, 2014). Caregivers of persons with dementia participating in the Memory Impairment and Dementia Awareness Study (MIDAS) responded to semistructured interviews to describe illness representations; caregivers described uncertainty about the cause, timeline, and controllability of patients’ dementia (Quinn, Jones, & Clare, 2016). However, to our knowledge, no studies have comprehensively explored caregivers’ perceptions of their family members’ memory loss. To bridge this gap, we used the CSM to characterize and explore potential correlates of illness perception among such caregivers.

Purpose

Therefore, the purposes of this exploratory study were to: (a) characterize caregivers' perceptions of their family members' memory loss; and (b) explore potential correlates of caregivers' perceptions of family members' memory loss (adapting the correlates proposed in the CSM, as shown in Figure 1).

Methods

Design and Participants

We conducted a descriptive correlational secondary analysis using baseline data from a larger randomized controlled trial addressing the efficacy of a problem-solving intervention to assist caregivers of patients with memory loss to manage the patients' medications (Lingler et al., 2016). Published papers using this dataset have discussed factors associated with caregivers' medication management (Erlen et al., 2013) and reported that these caregivers' self-efficacy mediated the pathway from their daily hassles to depressive symptoms (Tang, Jang, Lingler, Tamres, & Erlen, 2015). This current study adds evidence on caregivers' illness perception of patients' memory loss, which may facilitate nurses' understanding of caregivers' self-efficacy and medication management behaviors. For the parent study, 173 patient-caregiver dyads were screened for possible inclusion and 91 dyads were enrolled and gave informed consent. This study includes 83 dyads who responded to the Brief Illness Perception Questionnaire (BIPQ) at baseline and, to examine test-retest reliability, those control subjects who also responded at 8 weeks. The University of Pittsburgh Institutional Review Board approved the research protocol.

Variables and Instruments

Caregiver assessment of patient illness—Illness perceptions of caregivers was assessed using the BIPQ (Broadbent, Petrie, Main, & Weinman, 2006) adapted to assess caregivers' perception of patients' illness. The BIPQ has nine items. Each item measures one dimension of illness perception. The first eight items assess the dimensions of consequence (effect of memory loss on caregiver's life), timeline, personal control (caregiver's perceived personal control over memory loss), treatment control, identity, concern (caregiver's concern about memory loss), coherence (caregiver's perceived understanding of memory loss), emotional response (negative emotional effect of memory loss on the caregiver). Items are rated on a scale of 0–10. For severity, for example, 0 = *not at all* and 10 = *severely affects my life*. Higher scores indicate greater concern, greater severity of symptoms, or increased emotional impact. The values of four dimensions were found to have severely skewed distributions and were dichotomized. For personal treatment and emotional response, a score of 10 was assigned as 1, with scores of 0 to 9 assigned as 0; for treatment control and identity, a score of 0 was assigned as 0, with scores of 1 to 10 assigned as 1. The final item asks respondents to list the three most likely causes of memory loss. In this study, the 8-week test-retest reliability using the first eight items of the BIPQ ranged from .49 to .79, comparable to those of the original BIPQ.

Correlates—Eight additional instruments were used to collect data on the potential correlates listed in Table 1; additional information is available in Erlen et al. (2013) and Tang et al. (2015). The ninth item on causality in the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) was reworded to analyze caregivers' first-ranked causes of memory loss. Caregivers' responses were categorized using the four causal factors from the IPQ-R with the addition of medical conditions as a fifth factor, representing those diseases or medical treatments that caregivers consider as attributes of patients' illness (Rodakowski et al., 2014).

Data Analysis

SPSS (v. 24.0, Armonk, NY) was used for data analysis. Descriptive statistics were calculated for all variables. Frequency counts and percentages of rated causes of memory loss were calculated.

Applying Little's (1988) test showed that missing data in the Life Orientation Test-Revised (LOT-R) and the Spielberger State-Trait Anxiety Inventory were not missing completely at random ($p = .004$). Therefore, a total of 24 continuous or categorical variables of the outcomes and correlates in our study were used in the EM algorithm method to establish a predictive model for missing data imputation (Pigott, 2001). All other assumptions were satisfied.

Simple linear or univariate binary logistic regression was first used to explore crude correlations between each dimension of illness perception (dependent variables) and each potential correlate to screen candidate correlates (with $p < .10$ in univariate analyses) for multivariate modeling. Multiple linear or binary logistic regression was then used to identify independent correlates of each dimension of caregivers' illness perception. To control the overall type I error rate, Bonferroni adjustment was used to set the entry level of α at $.05/k$ and removal at $.10/k$ (k means the number of candidate correlate variables in each model) for the multiple regression analyses (Mundfrom, Perrett, Schaffer, Piccone, & Roozeboom, 2006). Standardized regression coefficients (b^*) and R^2 assessed a correlate's contribution to a multiple linear regression model. Odds ratio (OR) measured a correlate's effect size for a multiple binary logistic regression model.

Results

Of the 83 caregivers, 59 were women, 72 were White, 48 were the spouse of the patient, and most of them had more than a high school education. Caregiver age ranged from 42–93 years. Eight caregivers (9.64%) did not respond to the cause question in the BIPQ, and statistical tests showed the eight caregivers reported a lower level of understanding of patients' memory loss than other caregivers who responded to the causality item ($p = .04$). Responses to the primary cause were classified into six categories with 15 subcategories (Table 2). Over 40% of the perceived identified causes fit with uncontrollable factors, like heredity and aging, and 34.7% were various medical conditions. Descriptive statistics for the BIPQ are available (see Table, Supplemental Digital Content 1).

Univariate analyses are also available in Supplemental Digital Content 1. A range of candidate correlates were included for multivariate modeling of caregivers' illness perception. Table 3 presents three multiple linear regression models and two multiple binary logistic regression models. Patient's cognitive function explained the most variance in the models of consequence. Caregivers of patients with poorer cognitive function were more likely to perceive that treatments could not help and less likely to endorse the presence of typical memory loss symptoms within patients. Caregivers who endorsed more distress in reaction to patients' behavioral symptoms reported a higher level of perceived coherence of memory loss. Caregivers' trait anxiety was also positively related to their sense of illness coherence. Severity of daily hassles was positively associated with caregivers' perceived timeline, and White caregivers also perceived that memory loss would last longer. (For comparison, estimates based on complete case data are available in Supplemental Digital Content 2.)

Discussion

Our study is among the first to report characteristics and correlates of caregivers' perceptions of their family members' memory loss. Similar to the findings of Lo Sterzo and Orgeta's (2015) study, high scores were reported on the dimensions of consequence, timeline, and emotional response, suggesting that caregivers viewed memory loss as likely to have serious consequences, last indefinitely, and evoke emotional distress within oneself. This pattern of illness perception is reflective of the features of late-life cognitive disorders. A high level of perceived personal control suggests a sense of empowerment, possibly facilitating positive coping and psychological adjustment among caregivers (Hagger & Orbell, 2003). The high percentage of uncontrollable factors endorsed by caregivers' as the primary cause of memory loss was consistent with results reported by Rodakowski et al. (2014). This finding may help to explain why treatment was perceived as being of little help to patients' memory loss. The high percentage of caregivers attributing the patients' memory loss to medical conditions is consistent with findings of Lingler et al.'s (2006) qualitative investigation in a mild cognitive impairment sample, and may be reflective of the multiple comorbidities of the patients enrolled in the current study.

Considering the correlates of caregivers' illness perception, the Mini-Mental State Examination (MMSE) score, which served as one proxy measure of patients' illness feature, was included in the models of consequence, treatment control, and identity. Lee, Fan, Hung, Pai, and Chou (2016) also found that caregivers of patients with more severe illness perceived treatment to be less helpful. Interestingly, we found caregivers of patients with more severe cognitive impairment perceived fewer symptoms within their care recipients. This is possibly due to the longer caregiving experiences of these caregivers and their gradual adaptation to the illness. Alternatively, it may be that fewer symptoms are exhibited within patients whose memory loss has progressed to a point wherein they are less verbal and less active. The positive relationship between caregivers' reaction to patients' behavioral symptoms and their perceived coherence could be explained by the assumption that caregivers having a better understanding of memory loss and are more likely to detect patients' behavioral symptoms and/or that the presence of increased behavioral symptoms motivates caregivers to seek a clearer understanding of the patient's illness.

Caregivers with higher trait anxiety perceived that they had a clearer understanding of memory loss. Fischer et al. (2012) demonstrated a positive association between the trait anxiety of caregivers and their education levels in a different population, which may provide a rationale for why trait anxiety was a correlate of caregivers' perceived coherence. Similar to Lin, Gleason, and Heidrich's (2012) findings from a sample of older adults with mild cognitive impairment, our results showed that White caregivers perceived memory loss as more chronic, suggesting the influence of sociocultural factors within caregivers. Severity of caregivers' daily hassles was operationalized in this study as another sociocultural factor, and found to be related to perceiving the timeline of memory loss as chronic. Presumably, depressive symptoms experienced by caregivers may act as a mediator of the relationship between daily stress and perceived illness chronicity (Kuipers et al., 2007; Tang et al., 2015).

In our study, optimism and social support were not included in the models. However, the two correlates were associated with illness perception of patients with coronary disease (Bekke-Hansen, Weinman, Thastum, Thygesen, & Zachariae, 2014). This discrepancy may be explained by the different populations and the features of memory loss. Lo Sterzo and Orgeta (2015) reported caregivers' age, gender, educational status, and relationship to the patient were related to their perceptions of patients' dementia, while our study did not affirm these relationships.

Limitations

This study had some limitations. The BIPQ used to rate one's own illness has had psychometric testing; however, this is the first use of our adapted version of the BIPQ for caregivers of persons with memory loss. Most participants were recruited from the community; thus, we did not have access to medical records concerning diagnosis or duration of illness for the patients.

Conclusion

In this exploratory analysis, caregivers of patients with memory loss reported both positive and negative cognitive perceptions of the patients' illness. Caregivers generally perceived themselves to experience a negative emotional response to that illness. Overall, the categories of correlates of caregivers' illness perception proposed in the CSM and adapted to the caregiver context were supported by our analyses. Future studies in larger populations are required to validate our exploratory findings. Using prospective designs, the adapted categories can guide further research to identify causal relationships between potential predictors from the common-sense model and caregivers' illness perception. Nurses can use the findings from this study to support assessing caregivers' perceptions and to help those caregivers who are perceiving patients' memory loss more negatively. Assisting informal caregivers to understand patients' memory loss and manage their negative emotional responses may potentially have a favorable impact on caregiver role functioning and their overall well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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FIGURE 1.

Adapted categories of correlates of caregivers' perception of family members' memory loss. In the context of caregivers' perception of their family members' memory loss, the three categories of correlates of illness perception proposed in the CSM were adapted to fit the caregiver population in our study. *Individual's illness history* was adapted as *patients' illness features*; *individual's personality traits* was adapted as *caregivers' personality traits*; *individual's sociocultural context* was adapted as *caregivers' sociocultural context*. Based on previous literature, *caregivers' demographic characteristics* was proposed as the fourth category of correlates.

TABLE 1

Potential Correlates: Instrumentation

Category/variable	Instrument	Items	α^d	Scoring	
				Low	High
Patient illness features					
Cognitive functioning	MMSE ^b	30	.93	0 = <i>incorrect</i>	1 = <i>correct</i>
Patient behavioral symptoms	RMBPC ^c	24	.86	0 = <i>never occurred</i>	4 = <i>daily or more often</i>
Caregiver reaction	RMBPC ^c	24	.94	0 = <i>not at all</i>	4 = <i>extremely</i>
Caregiver personality traits					
Anxiety (trait)	STAI ^d	20	.92	1 = <i>almost never</i>	4 = <i>almost always</i>
Optimism	LOT-R ^e	10	.83	0 = <i>strongly disagree</i>	4 = <i>strongly agree</i>
Caregiver sociocultural context					
Social support (perceived)	ISEL ^f	40	.94	0 = <i>definitely false</i>	3 = <i>definitely true</i>
Daily hassles and uplifts	CHUS ^g	53	.92	0 = <i>none or not applicable</i>	3 = <i>a great deal</i>
Race	SDDQ ^h	1		0 = <i>non-White</i>	1 = <i>White</i>
Caregiver demographics					
Age (years)	SDDQ ^h	1	n/a		
Gender	SDDQ ^h	1	n/a	0 = <i>male</i>	1 = <i>female</i>
Relationship to patient	SDDQ ^h	1	n/a	0 = <i>non-spouse</i>	1 = <i>spouse</i>
Formal education (years)	SDDQ ^h	1	n/a		
Health literacy	NVS ^j	6	.70	0 = <i>incorrect</i>	1 = <i>correct</i>

Note. Multi-item scale scores or subscale scores are obtained by summing item scores. CHUS = Combined Hassles and Uplifts Scale; ISEL = Interpersonal Support Evaluation List; LOT-R = Life Orientation Test-Revised; MMSE = Mini-Mental State Exam; n/a = not applicable; NVS = Newest Vital Sign; RMBPC = Revised Memory and Behavior Problems Checklist; SDDQ = Self-Designed Demographic Questionnaire; STAI = Spielberger State-Trait Anxiety Inventory;

^a Coefficients values in this study.

^b Folstein, Folstein, and McHugh (1975).

^c Teri et al. (1992).

^d Spielberger (1983).

^e Scheier, Carver, and Bridges (1994).
^f Cohen and Hoberman (1983).
^g Lazarus and Folkman (1989).
^h Sereika and Engberg (2006).
ⁱ Weiss et al. (2005).

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TABLE 2**Caregiver Perceived Primary Cause of Patient Memory Loss**

Category/subcategory	<i>n</i>	(%)	Narrative example
Psychological attribution			
Stress or worry	2	(2.7)	Stress: husband was sick
Emotional state ^a	2	(2.7)	Depression: death of spouse
Risk factors			
Hereditary	12	(16.0)	Got the genes from his mom
Poor past medical care	2	(2.7)	Over-medicated
Ageing	21	(28.0)	Old age
Alcohol	1	(1.3)	Possibly alcohol
Immunity			
A germ, a virus	1	(1.3)	Urinary infection
Pollution	2	(2.7)	Chemical exposure
Accident, chance			
Chance, bad luck	1	(1.3)	Bad luck
Accident, injury	1	(1.3)	Hit head (injury)
Medical conditions			
Dementia, Alzheimer's	8	(10.7)	Alzheimer's disease
Other neurodegenerative	4	(5.3)	Parkinson's disease
Cerebrovascular disease	7	(9.3)	Micro-strokes
Diseases of other systems	4	(5.3)	Diabetes/hypertension
Previous treatment	3	(4.0)	Anesthesia during heart bypass
Do not know	4	(5.3)	I don't know but I am interested

Note. *n* = 75.

^aFeeling down, lonely, anxious, empty.

TABLE 3

Dimensions of Caregiver Illness Perception: Multivariate Models

Dimension	Correlate	<i>b</i>	95% CI	<i>p</i>	<i>b</i> *	<i>R</i> ²
Consequences Timeline	MMSE	−0.13	[−0.19, −0.06]	<.001	−0.39	0.15
	Hassles severity	2.52	[1.36, 3.68]	<.001	0.41	0.15
	Race (White) ^a	3.03	[1.55, 4.52]	<.001	0.38	0.15
Coherence	RMBPC: Reaction	0.87	[0.26, 1.47]	.006	0.29	0.14
	Anxiety: Trait	0.08	[0.02, 0.13]	.007	0.29	0.07
<i>OR</i>						
Treatment control ^b	MMSE	1.10	[1.03, 1.18]	.003		
Identity ^b	MMSE	1.09	[1.02, 1.16]	.007		

Note. *N* = 83. *b** = standardized regression coefficient; MMSE = Mini-Mental State Examination; RMBPC = Revised Memory and Behavior Problems Checklist; *OR* = odds ratio.

^aCoding scheme: 0 = non-White, 1 = White.

^bCoding scheme: 0 = score of 0, 1 = score of 1–10.