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Examining the Role 1

Running head: EXAMINING THE ROLE

Examining the Role of Agitation and Aggression in Perceived Caregiver Burden

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Abstract

Recent research efforts in the area of dementia have revealed that the affected patients are not the only people that are impacted by this disorder. There are hidden victims that, more often than not, go unnoticed. These people are the caregivers, often family members, of a dementia patient. More and more attention is being focused on caregiver burden because it has been found that caring for a dementia patient can lead to medical and psychological problems in the caregiver. The purpose of this study was to determine if a positive correlation exists between the caregiver's perceived burden and the patient's degree of agitation and aggression. Preliminary results do indicate a positive correlation between agitation and perceived caregiver burden. The results of this study will be important in helping the neuropsychologist develop appropriate intervention for the dementia patient and his/her caregiver.

Examining the Role of Agitation and Aggression in Perceived Caregiver Burden

The number of reported cases of dementia has grown rapidly in the last few years. As a person ages, his/her chance of being diagnosed with dementia increases exponentially. It is estimated that 6-7% of the population over age 65 is affected with some form of dementia, with 2-4 % of the population being affected specifically with dementia of the Alzheimer's type (Baumgarten, Hanley, Infante-Rivard, Battista, Becker, & Gauthier, 1994). By age 85, it is estimated that 20% of the population is affected with a form dementia, the most common being dementia of the Alzheimer's type (Diagnostic and statistical manual of mental disorders, 4th ed., 1994). It has been estimated that in the near future the number of people who will be diagnosed with dementia, particularly of the Alzheimer's type, is going to triple. This results in part from the fact that the segment of persons over age 85 is currently the fastest growing age group in the United States (Lipkin, Faude, 1987).

The diagnosis of dementia is dependent upon the presence of a number of different symptoms. The most salient symptom is a generalized memory impairment. This may result from deficits in recall of old information or storage of

new information. Beyond the overall memory impairments, a person must also show at least one of the following cognitive disturbances: Aphasia (deterioration in language ability), apraxia (inability to perform motor functions even though sensory and motor pathways are still intact), agnosia (inability to recognize objects or people), or a disturbance in executive functioning (which includes abstract thinking among other higher level functions). It is important to note that these problems must be severe enough to impair social or occupational functioning in a person and must reflect a decline from a previously higher level of functioning. Dementia can result from a variety of etiologies including vascular lesions (vascular dementia), dementia of the Alzheimer's type, dementia due to HIV, dementia due to head trauma, dementia due to Parkinson's disease, multi-infarct dementia, etc.. Dementia can be caused by medical conditions, prolonged substance abuse, or a combination of these and other conditions (DSM-IV).

Traditionally, the main focus of treatment in dementia has centered on the person with dementia. This seems logical, due to the fact that health professionals normally focus treatment on the person with the immediate problem. We do find, however, that there are a great number of people who more often than not go unnoticed as being affected by dementia. These people are the caregivers of the dementia patient. Recent research on the treatment of dementia has directed more

attention to the demented patient and the primary caregiver of that patient instead of the patient alone. The primary caregiver of a demented patient, as the name suggests is the person that spends the most time caring for the patient. This person is traditionally the demented person's spouse; however, it could be a child, a sibling, a friend; whoever spends the most time with the patient. This interest in the caregivers has been fueled by the recognition that the time and energy involved in caring for a demented individual may have repercussions for the caregivers as well. Caring for a demented patient is so difficult that one author said that a typical day in the life of a caregiver of a dementia patient seems like it is 36 hours long (cf. Morris, Morris, and Britton, 1988 b). This is due to the seemingly endless responsibilities of caring for a demented person such as, constantly having to watch the demented person to make sure he/she does not wander off, helping him/her bathe, toilet, clean, etc..

"Caregiver burden" has been defined as "the physical, psychological, emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986). Dementia patients often need help managing such daily activities as dressing, feeding, bathing and management of bowel and bladder control. This type of constant attention that must be provided to the dementia patient can make for long, tiring days. Not

surprisingly, such significant demands rapidly exhaust the typical caregiver's resources. Studies have shown that the majority of dementia patients do not live in an institutional setting, therefore this places more pressure on the family to care for the demented person (Lipkin & Faude, 1987)

There are a number of factors which contribute to the burden experienced by caregivers including lack of social support for the caregiver, a change in the caregiver's social life, a change in financial situation, the embarrassment which the caregiver may experience due to the demented person, and so forth.

The literature describing the behavior of demented people suggests that many demented patients are agitated and aggressive (Cohen, Eisdorfer, Gorelick, Paveza, 1993; Cohen-Mansfield, Billings, Lipson, Rosenthal, 1990; Cohen-Mansfield, Marx, Rosenthal, 1990). Previous studies have examined the role of many factors that may be contributing to caregiver burden. Zarit et al. (1980) stated that the largest contributing factor to perceived caregiver burden in their population was the lack of social support and help from other family members. Other findings, as well as Zarit et al. (1980), showed that behavioral problems did not play a large role in perceived caregiver burden, however, we were not able to find a study that specifically examined the role of agitation and aggression in impacting caregiver burden. Because the literature on dementia shows that there

are high levels of agitation and aggression in the demented population, examining the role of these two behaviors might lead to increased understanding of caregiver burden. Given these high level of agitation and aggression and the negative effects of these variables on other people, we hypothesize that there will be a positive correlation between the level of agitation and aggression in the patient and the perceived burden of the caregiver.

Method

Participants

The participants for the present study ($n=7$; 4 males & 3 females) were drawn from the outpatient neuropsychology clinic at Carle Foundation Hospital in Urbana, Illinois. The mean age of the participants was 69.3. The patients who participated in this study were generally referred to the clinic for initial dementia testing by a physician, family member, or him/herself. Patients who were found to have any medical or psychological conditions that would compromise the mental health of that patient were excluded from the study.

The primary caregiver of each patient was also used in the study. The primary caregiver is defined as the person who provides the most supportive care for the demented patient.

Materials

Several tests and evaluations were administered during the study. All of the evaluations are part of an extensive routine neuropsychological examination that is administered to all outpatient neuropsychology patients at Carle Foundation Hospital during the initial visit. The measures that were used in this study consisted of the following: The Iowa Screening Battery for Mental Decline, Agitation Behavior Scale, and the Overt Aggression Scale. The caregiver's level of perceived burden was determined using the Caregiver Interview.

The Iowa Screening Battery for Mental Decline (ISBMD) was used to assess the patient's overall cognitive decline based on a normative sample. This test consists of three different parts : 1) a test for temporal orientation, 2) the Benton Visual Retention Test (BVRT), and 3) the Controlled Oral Word Association Test (COWA). The temporal orientation part of the test assesses a person's awareness of him/herself within a temporal context (ie. day, date, time of day) (See Appendix A). The visual retention test is employed to test a person's short-term memory, because memory impairments are the most salient features associated with dementia. The COWA subtest of the ISBMD is used to test a person's capability to produce words that begin with a certain letter. The COWA is employed to assess word fluency. When all of its subtests are taken together,

the ISBMD has been shown to be extremely sensitive to the differences between a normal population and a demented population (Eslinger, Damasio, & Benton, 1984). The ISBMD is administered to all patients referred to the neuropsychology clinic at Carle to test for the presence of dementia in the patient. In addition to the test's ability to screen out dementia patients, it is relatively short compared to other tests which assess mental decline. The total test can be administered in under 15 minutes.

The patient's overall level of agitation and aggression was assessed using the Agitated Behavior Scale (ABS) and the Overt Aggression Scale (OAS). Both of these assessment measures are concise and can be administered quickly and with relative ease. The ABS requires the caregiver to rate the frequency (on a scale of 1 - 4) of certain behaviors acted out by the patient in the recent past (See Appendix D). These are behaviors such as: violent behavior, sudden changes of mood, or wandering around. The OAS calls for the caregiver to indicate the presence or absence of certain aggressive behaviors, such as "slams doors", or "bangs head" (See Appendix E).

The level of perceived caregiver burden was assessed using the Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). This 29 item test was designed to cover all areas of burden equally, it does not focus on any one type of problem

area. Problem areas include disruptions in social activities, feelings of hopelessness, financial difficulties, etc. (See Appendix F). All three measures that the caregiver is asked to fill out can be completed in under 10 minutes.

Procedure

Each member of the participant-caregiver diad was tested within the same testing period at the outpatient neuropsychology clinic at Carle Foundation Hospital. All of the tests that were administered to the participants were done so in the absence of the other member of the diad. The tests and the evaluations were all administered and scored according to their respective manuals. All tests were administered by a clinical neuropsychologist or a trained assistant.

Results

Of the seven patients assessed, only two tested as *highly probable dementia* as determined by the ISBMD, therefore, any analysis between a demented population and a non-demented population will require more data. Almost all of the patients (n=5) were reported as having no aggression what so ever. Those who were reported as having some aggression only manifested one of the several behaviors listed on the OAS. Because of this finding, no statistical analysis was performed on the levels of aggression present in the patients.

A Pearson Product-Moment Correlation was performed to examine a

possible correlation between the level of agitation in the patient and the level of perceived caregiver burden ($r = 0.712$). Post hoc analysis was performed to take into account the small number of participants ($t = 2.267, p < .05$).

Insert Figure 1 Here

Discussion

The results of this study indicate a probable positive correlation between the level of agitation in the patient and the level of burden in the caregiver. These results could possibly impact the strategies used in treating dementia leading to a more efficient method of treatment. If therapists focus their attention on the difficulties that the caregiver sees as being most problematic, other problems associated with dementia could be more easily handled. If the level of agitation is lowered in the patient, it is likely that the level of burden will also lower in the caregiver. This would logically lead to a more efficient treatment strategy, because the caregiver would then be in a better position to take an active role in the recovery of the patient, due to the fact that the caregiver is not feeling as burdened as he/she once did. Studies have shown that a strong social support group will help the patient on his/her road to recovery (Morris, Morris, and Britton, 1988a).

In addition, since caring for a dementia patient has been found to pose mental and psychological problems for the caregiver, a reduction in the perceived level of burden would reduce the chance of any of these (medical or psychological) problems developing in the caregiver.

One limitation of this study which must be addressed is the small number of participants used. The study should be continued to see if the same significant results can be obtained from a larger sample of people. After obtaining a larger sample of people, it would then be possible to compare the results from the dementia patients with the non-dementia patients and their respective caregivers. This would be interesting to see given the recent findings that agitation and aggression tend to be at high levels in the demented population. A larger sample of people may also allow for analysis between the level of aggression in the patient and perceived burden.

All of the evaluations on the patients were done at the initial or pre-stages of dementia. Patients who are detected so early in the development of this disorder may not manifest the high levels of agitation and aggression noted in the literature. It would be interesting to assess the patient at several times following the diagnosis of dementia. We may find that patients who are well into the development of dementia exhibit very high levels of agitation and aggression and

comparing the level of burden with these variables at a later time in the patient may shed more light on the issue of caregiver burden.

A final limitation of the study, which should be mentioned, is the fact that all of the accounts of the patient's behavior is given by one caregiver. Even though it seems logical to assume that the primary caregivers would give the most accurate account of the condition of the patient, we have to take into account the possibility that the primary caregiver's account of the situation may be affected by a number of variables. It could be possible that the caregiver is affected by something or someone other than the patient in question (ie. work related stress, other physiological problems, etc.). If this is the case, his/her reports of the patients condition may be distorted. We may find it helpful in the future to take into account the reports from other members of the family as well as the primary caregiver.

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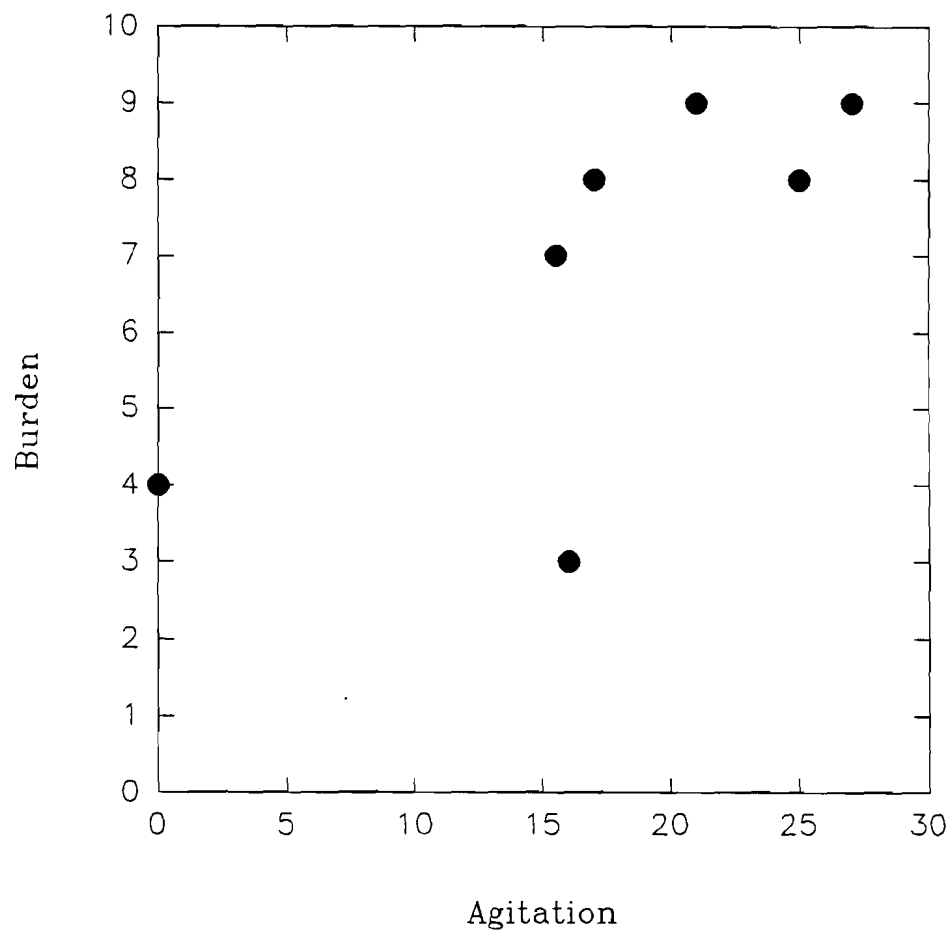


Figure 1. Level of agitation in the patient and level of perceived caregiver burden reported by the caregiver

Appendix A.

**Iowa Screening Battery
For Mental Decline
Record Form**

Name _____ Age _____ Sex _____ Date _____

Complaint/History _____

Place of Testing _____ Examiner _____

TEST 1. TEMPORAL ORIENTATION

WHAT IS TODAYS DATE?

Patient Response	Correct Response	Error Score
---------------------	---------------------	----------------

Month: -5 for each month (max:-30).
Give full credit if within
15 days of correct date.

_____	_____	-- _____
-------	-------	----------

Day of Month:-1 for each day (Max:-15).

_____	_____	-- _____
-------	-------	----------

Year: -10 for each year (Max: -60).
Give full credit if within
15 day of correct date.

_____	_____	-- _____
-------	-------	----------

Day of Week: -1 for each day (Max: -3).

_____	_____	-- _____
-------	-------	----------

Time of Day: -1 for each 30 min. from
correct time(Max:-5).

_____	_____	-- _____
-------	-------	----------

TOTAL ERROR SCORE -- _____

Interpretation (circle one)

0, -1, -2
-3+

(normal range)
(abnormal range)

Appendix B.

TEST 2. VISUAL RETENTION TEST

Administration

Design	Score (0or1)	Errors	Design	Score (0or1)	Error
1			6		
2			7		
3			8		
4			9		
5			10		
Total Number Correct _____					

Appendix C.

SUMMARY

a) Temporal Orientation Score= _____ (_____ range)

b) Discriminant Function Formula:

$$(\text{VRTScore}) + (.0765 \times \text{COWA Score}) - 5.1572 = \text{Composite Value}$$

$$(\text{_____}) + (\text{_____}) - 5.1572 = \text{_____}$$

If composite value is zero or less, classify as questionable performance.

If composite value is between zero and +1.52, classify as highly probable dementia

If composite value is +1.52 or greater, classify as highly probable normal.

c) Final Classification: _____

Remarks: _____

Appendix D

Patient Name _____ Clinic # _____
Date _____ Name of Rater _____
Relationship to Patient _____

CAREGIVER INTERVIEW

Answer yes or no to each of the following questions. Note that family member refers to patient.

Yes No

1. ____ I feel resentful of other relatives who could but who do not do things for my family member.
2. ____ I feel that my family member makes requests which I perceive to be over and above what s/he needs.
3. ____ Because of my involvement with my family member, I don't have enough time for myself.
4. ____ I feel stressed between trying to give to my family member as well as to other family responsibilities, job, etc.
5. ____ I feel embarrassed over my family member's behavior.
6. ____ I feel angry about my interactions with my family member.
7. ____ I feel that I don't do as much for my family member as I could or should.
8. ____ I feel guilty about my interactions with my family member.
9. ____ I feel that in the past, I haven't done as much for my family member as I could have or should have.
10. ____ I feel nervous or depressed about my interactions with my family member.
11. ____ I feel that my family member currently affects my relationships with other family members and friends in a negative way.
12. ____ I feel resentful about my interactions with my family member.
13. ____ I am afraid of what the future holds for my family member.
14. ____ I feel pleased about my interactions with my family member.
15. ____ It's painful to watch my family member age.
16. ____ I feel useful in my interactions with my family member.
17. ____ I feel my family member is dependent.
18. ____ I feel strained in my interactions with my family member.
19. ____ I feel that my health has suffered because of my involvement with my family member.
20. ____ I feel that I am contributing to the well-being of my family member.
21. ____ I feel that the present situation with my family member doesn't allow me as much privacy as I'd like.
22. ____ I feel that my social life has suffered because of my involvement with my family member.
23. ____ I wish that my family member and I had a better relationship.
24. ____ I feel that my family member doesn't appreciate what I do for him/her as much as I would like.
25. ____ I feel uncomfortable when I have friends over.
26. ____ I feel that my family member tries to manipulate me.
27. ____ I feel that my family member seems to expect me to take care of him/her as if I were the only one who s/he could depend on.
28. ____ I feel that I don't have enough money to support my family member in addition to the rest of our expenses.
29. ____ I feel that I would like to be able to provide more money to support my family member than I am able to now.

Zarit, et al 1980

Patient Name _____ Clinic # _____
Name of Rater _____ Relationship to Patient _____
From Date ____/____/____ To Date ____/____/____
Today's Date ____/____/____

Agitated Behavior Scale

At the end of the observation period, indicate whether each behavior was present and, if so, to what degree: slight, moderate, or extreme. The degree can be based on either the frequency of the behavior or the severity of a given incident. Use the following numerical values for each behavior listed. PLEASE DO NOT LEAVE BLANKS.

1. Absent
2. Present to a slight degree
3. Present to a moderate degree
4. Present to an extreme degree

- ___ 1. Short attention span, easy distractability, inability to concentrate.
- ___ 2. Impulsive, impatient, low tolerance for pain or frustration.
- ___ 3. Uncooperative, resistant to care, demanding
- ___ 4. Violent and/or threatening violence toward people or property.
- ___ 5. Explosive and/or unpredictable anger.
- ___ 6. Rocking, rubbing, moaning or other self-stimulating behavior.
- ___ 7. Pulling at clothing, hair, etc.
- ___ 8. Wandering from treatment areas or from room to room.
- ___ 9. Restlessness, pacing, excessive movement.
- ___ 10. Repetitive behaviors, movement and/or speech.
- ___ 11. Rapid, loud or excessive talking.
- ___ 12. Sudden changes of mood.
- ___ 13. Easily initiated or excessive crying and/or laughter.
- ___ 14. Self-abusiveness: physical, (i.e., hitting self); or verbal, (i.e., self-critical).

Comments:

Corrigan and Mysiow, 1988.

Appendix F

Patient Name _____ Clinic # _____
Name of Rater _____ Relationship to Patient _____
Sex of Patient Male _____ Female _____
From Date ____/____/____ (mo/da/yr) To Date ____/____/____ (mo/da/yr)

No aggressive incident(s) (verbal or physical) against self, others, or objects during this period _____

Please check all that apply and indicate approximate number of occurrences within the designated time period.

AGGRESSIVE BEHAVIOR

Verbal Aggression

- _____ Makes loud noises, shouts angrily.
- _____ Yells mild personal insults, e.g., "You're stupid!"
- _____ Curses viciously, uses foul language in anger, makes moderate threats to others or self.
- _____ Makes clear threats of violence toward others or self ("I'm going to kill you") or requests help to control self.

Physical Aggression Against Objects

- _____ Slams door, scatters clothing, makes a mess.
- _____ Throws objects down, kicks furniture without breaking it, marks the wall.
- _____ Breaks objects, smashes windows
- _____ Sets fires, throws objects dangerously.

Physical Aggression Against Self

- _____ Picks or scratches skin, hits self, pulls hair (with no or minor injury only).
- _____ Bangs head, hits fist into objects, throws self onto floor or into objects (hurts self without serious injury).
- _____ Small cuts or bruises, minor burns.
- _____ Mutilates self, causes deep cuts, bites that bleed, internal injury, fracture, loss of consciousness, loss of teeth.

Physical Aggression Against Other People

- _____ Makes threatening gestures, swings at people, grabs at clothes.
- _____ Strikes, kicks, pushes, pulls hair (without injury to them).
- _____ Attacks others, causing mild-moderate physical injury (bruises, sprain, welts).
- _____ Attacks others, causing severe physical injury (broken bones, deep lacerations, internal injury).

Intervention/Action Taken in Response to Aggressive Behavior:
Comments: