Accuracy of Caregivers’ Recollections of Caregiving Hassles

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Despite their common use in clinical settings, caregivers’ recollections of the hassles they face in caregiving have not been examined in previous research. Ninety-seven spousal caregivers of persons with dementia were assessed for 6 consecutive months concerning caregiving hassles and numerous other issues. A multi-pass rank order assessment identified the most stressful event in caregiving over each month-long interval. Each month via telephone interview, caregivers’ recollections of the most stressful event in the previous month were assessed; no retrieval cues were provided. Of a total of 582 retrieval events examined, 378 (65%) were correct, 84 (14%) were incorrect, and 120 (21%) were not remembered. These data indicate that a majority of caregivers are capable of accurate recollection of caregiving hassles after a delay of one month following very careful ranking procedures, but also that individual differences in accuracy are present.

Some of the most common questions that clinicians ask caregivers of people with dementia concern the nature and type of problems they face as a result of providing care. Such questions involving retrospective recall are considered to be clinically important from several perspectives, as they provide clinicians the opportunity to (a) gather potentially useful diagnostic information about the care recipient, and (b) assess how well the caregiver is doing. Indeed, clinicians often use discrepancies between care recipient and caregiver reports as one way to distinguish dementia and dementia-like disorders (Cavanaugh & Nocera, 1994).

Despite the widespread use of such questions, virtually no research has examined the accuracy of caregiver reports (Cavanaugh & Nocera, 1994). Given that some research indicates a discrepancy between caregivers’ ratings of the degree of cognitive impairment demonstrated by their spouse with dementia and estimates based on cognitive screening batteries (e.g., McGuire & Cavanaugh, 1992), the issue of the accuracy of caregivers’ reports of problems faced in caregiving becomes even more important.

The present study employed a detailed systematic rating procedure of initial identification of the major caregiving hassle experienced by the caregiver in a given month. This procedure was developed as a way to help minimize the effects of cognitive heuristics, such as availability. Two to three weeks after making these ratings, telephone interviews were used to obtain caregivers’ recollections of their major hassle. A relatively strict performance standard (i.e., the requirement to recall the hassle exactly) was adopted to provide a conservative estimate of the accuracy of caregivers’ recollections.

Method

Participants

A total of 97 spousal caregivers of persons with dementia (i.e., care recipients) were recruited from diagnostic centers, support groups, and Alzheimer’s Association mailing lists in the Toledo, Cleveland, Findlay (OH), Detroit, Wilmington (DE), and Newark (DE) metropolitan areas. Couples had been married on average for 43.5 (SD = 10.6) years. Caregivers were mostly female (n = 61), European American (84.5%; 12.4% African American), averaged 68.3 years of age (SD = 7.8), and typically had slightly more than a high school education (M = 13.1 years, SD = 2.3). Caregivers had been providing care for an average of 4.8 years (SD = 3.3). Care recipients averaged 70.3 years of age (SD = 7.7) and had an average score of 54.9 (SD = 39.6) on the Mattis Dementia Rating Scale (indicating moderate-severe levels of cognitive impairment). Participants from Midwest locations were paid $125 per couple for their participation; East Coast participants were paid $100. (The differential in payment to participants was due to budget constraints resulting from transfer of funds from Bowling Green State University to the University of Delaware connected with the relocation of the principal investigator.)

Measures and Procedure

The data reported here were collected as part of a longitudinal investigation of caregiving that focused on marital relationship variables, various aspects of caregiving stress and coping, and dyadic problem-solving strategies on cognitive tasks. The larger investigation included face-to-face
interviews, videotaped interactions between caregivers and care recipients, and caregivers' monthly completion of a survey. Only those measures directly related to the memory variables of interest in this study are described here; details concerning the other aspects of the project are available on request.

Caregiving Hassles Scale (CHS). — Each month for six consecutive months, a survey packet was mailed to caregivers that included the Caregiving Hassles Scale. The CHS (Kinney & Stephens, 1989) consists of 42 events that typically occur in caregiving. For each event that occurred during the past week, caregivers indicate the extent to which the event was a hassle using a 4-point scale ranging from 0 ("not at all") to 3 ("a great deal"). The scale assesses caregiving hassles in five domains of caregiving: care-recipient's cognitive impairment, care-recipient's problem behavior, assisting care-recipient with activities of daily living (ADLs), assisting care-recipient with instrumental activities of daily living (IADLs), and the caregiver's social network. The scale yields hassle frequency and intensity scores for overall hassles and for each domain. General psychometric data for the CHS are reported in Kinney and Stephens (1989).

Caregivers in the present sample reported that, in the previous week, an average of 7.4 (SD = 6.9) events had occurred that were appraised as a hassle. For each subscale, the number of events were: Cognitive (M = 3.2, SD = 2.7), Behavior (M = 2.2, SD = 2.4), IADL (M = 1.0, SD = 1.4), ADL (M = .94, SD = 1.4), and Social Network (M = .5, SD = .89). For the present sample, the overall CHS intensity score mean was 25.8 (SD = 18.3), indicating that the care-giver's major hassle was always in the same caregiving domain and 62 were interdomain errors (i.e., caregivers recalled a different hassle from the same caregiving domain), and 62 were interdomain errors (i.e., caregivers recalled a hassle from a different caregiving domain). Of the remaining 120 occasions (21%), caregivers reported that they could not recall the hassle from the previous month, constituting an omission error.

Of the 97 caregivers, 9 failed to recall any of the major hassles correctly, whereas 13 correctly recalled all hassles at each of the six follow-up assessments. Of the 13 with perfect recall, however, only 3 caregivers experienced a change in the domain of their major hassle (i.e., 10 caregivers' major hassle was always in the same caregiving domain). The remaining 75 caregivers made at least one error each: 14 caregivers made only one error; 25 made two errors; 17 made three errors; 17 made four errors; and 2 made five errors. No significant association was observed between errors and the ratings of the "biggest hassle" on the subsequent survey. There was no evidence that number of errors was related to either the type of hassle, whether the biggest hassle changed over the 6-month period, level of care recipients' cognitive impairment as measured by the Mattis Dementia Rating Scale, total score on the CHS, or length of time since diagnosis.

DISCUSSION

These data indicate that virtually all of the caregivers were able to recall their major hassle from the previous month on at least one occasion over a 6-month period. Indeed, 52 caregivers had two or fewer errors in their recall. However, this also means that 45 caregivers were in-
correct at least half of the time. Taken together, these data present a “good news, bad news” picture. On the bright side, caregivers as a whole were able to remember nearly two-thirds of all the “biggest hassles” over a one-month delay, and a majority were correct at least two-thirds of the time. Reliance on the retrospective reports of these relatively accurate caregivers may be warranted in clinical settings to the extent that the focus is on recent events. In contrast, a substantial number of caregivers were inaccurate most of the time. Retrospective reports from these individuals should be viewed with caution to the extent that accuracy is an issue. As our data failed to indicate a reliable way to distinguish accurate from inaccurate caregivers, clinicians should exercise caution in using retrospective reports from caregivers as a source of diagnostic information.

Although the current study was not specifically designed to examine sources of the individual differences in the retrospective reports, it is possible to speculate about particularly fruitful avenues for future research. Caregivers’ accuracy may be a reflection of their own memory abilities; thus, inclusion of memory performance data would be helpful. Additionally, how caregivers frame the hassle (i.e., whether the hassle is perceived as being intentional or as a by-product of the disease) may also be important.

One especially intriguing question the present data raise concerns why caregivers whose major hassle remained unchanged for 6 consecutive months would not have perfect recollection; indeed, one could argue that the “memory load” in this case would not be high, nor would there be “interference” due to changing hassles. The lack of systematic patterns of errors for these caregivers poses a number of possibilities, such as situational factors that preclude either encoding or retrieval. The lack of connections between errors and subsequent ratings of the “biggest hassle” supports this possibility. Nevertheless, reasons for memory failures for consistently occurring hassles remain to be discovered in future research.

Additional research is needed to determine the effects of different retention intervals on accuracy of caregivers’ reports. Indeed, the relatively high overall accuracy rate may be more reflective of maximum performance (as opposed to average or typical performance) for several reasons. For example, the hassles examined here were identified through a rigorous rating procedure that is atypical of caregivers’ usual experience. Additionally, the retention interval of one month is shorter than those often used in clinical settings, which may extend over years. It remains to be seen whether longer intervals, with the higher potential for interference from intervening events, would reduce accuracy.

In conclusion, the present data present a mixed view of caregivers’ accuracy in remembering caregiving hassles. When considered in aggregate, the majority of caregivers are correct most of the time. At an individual level, however, most caregivers are wrong some of the time. Thus, although caregivers’ reports of problematic aspects of caring for spouses with dementia provide useful information, they should be viewed with caution.

ACKNOWLEDGMENTS

This research was supported by grants from the National Institute on Aging (AG-09265) and the AARP/Andrus Foundation. The authors appreciate comments on earlier drafts by Lisa Dunlap.

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