



Diagnostic Assessment & Prognosis

Carers' diaries in dementia: Is there a role in clinical practice?

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Introduction: Carers' diaries have been used in very few instances in dementia to assist with gathering information about persons with dementia in the community. The main aim of this study was to compare problems identified using diaries kept by family carers for a week with carers' oral recollection of problems.

Method: Carers were randomly allocated into two groups, diary and control groups. In the diary group, carers received a diary and instructions on how to complete it for 7 days.

Results: A total of 78 carers completed the study. The frequency of problems identified in the carers diaries was greater than in the carers' narrative accounts at day 1 and day 8. The most common problems were behavioral and cognitive problems.

Discussion: Carers' diaries may complement the assessment of dementia as they can provide more information on the problems faced by the persons with dementia.

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Keywords:

Carers' diaries; Assessments; Dementia

1. Introduction

At the onset of presentation to dementia care services, initial assessments often involve taking a history from both persons with dementia and their carers who are often family members. It is not uncommon that the reason for presentation is based on observations of memory loss by family carers or carer distress or breakdown. What carers recollect at an initial assessment may be quite variable and they, along with their loved ones, may find it difficult to retain and recall all the problems in the initial assessments or follow-up appointments. Some carers attend clinic with written unstructured account of problems they face in caring to help provide information at the initial assessment. From the literature reviewed, there were very few studies on the use of carers' diaries in the assessment and management of dementia.

It has been reported that diaries can be used as a primary method of data collection with family caregivers, and they

found completing a diary both therapeutic and pleasurable [1]. Four types of diaries were described:

1. Meager diaries—brief with only few lines recorded.
2. Reporting diaries—written like reports of daily time-tables
3. Descriptive diaries—the type where family caregivers describe their daily tasks.
4. Reflective diaries—contained information about family caregivers' daily lives and emotions.

In a study examining the unstructured diaries of carers over the first 6 months after diagnosis of dementia, the two core themes found in the diaries were that the meaning of the onset of Alzheimer's disease has on the lives of carers and the restructuring of their lives [2]. In another diary study to examine relationship between caregiver-burden, leisure satisfaction, and affect in dementia caregivers, a positive correlation between leisure satisfaction and positive effect among care givers was reported. Diary records capture rich source of data, but it has been suggested that solicited diary recording should be limited to 1 to 2 weeks in older adults as there will not be sufficient data if it is less than a week and for

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periods more than 2 weeks, the participants will get bored or tired of making entries which would make the data inadequate or unreliable [3].

There are drawbacks and limitations when people with dementia record their thoughts in written diaries. People with dementia became aware of their diminishing skills, frustrated, and not sure what to record in their diaries [4]. Diary recording relies on participants to be self-motivated and inspired to notice and records their thoughts. Therefore, it has been suggested that this method should be in conjunction with other methods like interviews and also to include photo and audio diaries to help the researcher to understand the many facets of a person's life [5].

In a study using a diary method in conjunction with an interview to collect data from 14 family carers, the process of normalization was described, in which the family carers continuously defined and redefined their relationship with the persons with dementia as was normal for them [6]. The strategies taken up by family carers with the support of professional carers were said to be able to facilitate this process of normalization. The research also showed the diary method to be valuable as it provided a detailed account of factual, emotive, personal, and sensitive events and emphasized the importance of it, when used in conjunction with interview data.

This present study aimed to examine a novel hypothesis that asking carers to record dementia patients' problems and symptoms as they occur in everyday life, may aside from recording more problems, have therapeutic effects on caregivers' mood and well-being by giving them better insight into the problems and how to cope or prevent them.

2. Method

2.1. Study design

This was a mixed qualitative and quantitative, randomized controlled study in which experimental (diary group) and control participants completed various questionnaires assessing behavior and psychological problems in people with dementia living with family carers, as well as the carers' health-related quality of life and mood. In addition, participants randomly allocated to the diary group were given a diary to complete of patient problems for 1 week (between day 1 and day 8), and the control group was not asked to keep a diary. The carers were randomly allocated to two groups, control and diary groups, respectively.

2.2. Study participants

The study participants were recruited from the local memory clinic. It involved carers of patients newly diagnosed and follow-up patients with Alzheimer's disease referred to the clinic. Both patients and carers were provided with information sheet about the study and invited to participate. Patients were informed that their medical records would be reviewed for information pertaining to the study,

which would be kept anonymous, and that they would not be interviewed. If both patients and carers expressed an interest, follow-up visits at home were arranged for day 1 and day 8. Informed consent was obtained on day 1 with both patients and carers being reminded they could opt to withdraw from the study at any time and that would not impact on their treatment in the memory clinic.

2.2.1. Inclusion criteria

1. Carers aged ≥ 20 years who cared for a person diagnosed with dementia and resided with them at home.
2. Participation of only those persons where consent was obtained from both carer and the person with dementia being cared for.

2.2.2. Exclusion criteria

1. Any carer who did not give an informed consent.
2. Any carer who was unable to speak, read, or write in English to fully participate in the study.

2.3. Assessment tools

The following assessment tools were used

1. The Clinical Dementia Rating Scale includes six domains consisting of memory; orientation; judgment and problem solving; community affairs; home and hobbies; and personal care [7,8]. Each domain is rated on a 5 point scale with the following scale points: 0—healthy; 0.5—questionable; 1—mild; 2—moderate; and 3—severe. Total scores give a global measure of dementia. It was used to evaluate the severity of dementia by carers in the person they cared for at the onset of study on day 1.
2. The Neuropsychiatry inventory (NPI) is a relatively brief interview with a carer, rating 12 behavioral areas in dementia [9,10]. It is scored from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed by a clinician, based on information provided by carers. Both the severity and frequency of each symptom are rated on a three (1–3) and four point (1–4) Likert scale, respectively. It was used by carers to rate severity of problems in persons with dementia and their own distress at day 1 and 8.
3. The EuroQol is a measure of health-related quality of life and is designed for self-completion by respondents and is ideally suited for postal surveys, in clinics and face-to-face interviews [11]. This measure was completed by the carers to rate their own quality of life at days 1 and 8.
4. The Hospital Anxiety and Depression Scale is a 14-item scale that is self-administered and used to assess for possible anxiety or depressive symptoms [12].

Table 1
Background variables for patients in the control and diary groups

	Control (n = 41)	Diary (n = 39)	Statistical test	P
Mean age in years	78.02 (5.24)	79.64 (6.09)	F = 1.626	.206
Gender	M, 23 (56.1%); F = 18 (43.9%)	M, 25 (64.1%); F, 14 (35.9%)	λ = 0.534	.308
Severity	Mild, 21 (51.2%); moderate, 18 (43.9%); severe = 2 (4.9%)	Mild = 14 (35.9%); moderate = 24 (61.5%); severe = 0	λ = 0.521	.157
Duration of symptoms in years	3.33 (2.71)	3.38 (2.53)	F = 0.008	.93
Mean total initial NPI score	18.58 (16.55)	23.59 (19.64)	F = 1.524	.221

NOTE. F—Analysis of variance; λ —Chi-squared test.

There are seven items each for depression and anxiety, respectively. This was completed by carers to rate severity of anxiety and depressive symptoms at days 1 and 8.

- The 6-CIT Dementia Test is a brief and simple test of cognition [13]. It reportedly performs well as a screening instrument for dementia and is widely used in primary care and only takes approximately 2 minutes. It consists of six questions, with a total score of 28. Scores of 0–7 are considered normal and 8 or more as significant. It was used as a screening tool in carers on day 1 to identify if any of them had possible dementia.
- A proforma was also developed collecting sociodemographic details of patients and their carers which was completed on day 1 obtaining information from carers and the patients' medical records.
- The diary was adapted for use in carers of patients with dementia from previous diary studies of autobiographical and intrusive memories involuntary and everyday memory failures in young and old participants [14,15]. The diaries were semistructured to allow free flowing responses and ratings of severity of problems or distress using Likert scales. The diary was an A5 size booklet containing seven questions per page, with participants in the diary group expected to record one problem or difficulty per page.

At days 1 and 8, carers in both groups were asked to give verbal narrative account of the problems the person with dementia that they cared for had in the preceding week.

3. Results

3.1. Recruitment of participants

Over the 1 year period of recruitment from 1 May, 2014 to 30 April, 2015, 97 couples were identified and approached to take part in the study after which 84 couples agreed and gave written informed consent to take part and were subsequently recruited. The participants on recruitment were randomly allocated into the diary and control groups. Forty one participants in the control group and 39 participants in the diary group completed the eighth day assessments and/or diaries. The background variables of patients in the diary and control groups, in terms of age, gender, severity, and duration were not significantly different at day 1 (Table 1). Likewise, among the carers, there were also no significant differences in the background variables (Table 2).

3.2. Outcomes in diary and control groups

The problems identified in the narratives and diaries were coded and counted by two raters who came to a mutual agreement where there were any discrepancies. The

Table 2
Background variables for carers in the control and diary groups

	Control (N = 41)	Diary (N = 39)	Statistical test	P
Mean Age	75.87 (7.76)	75.08 (7.97)	F = 0.208	.65
Gender	M, 15 (36.6%); F, 26 (63.4%)	M, 12 (30.8%); F, 27 (69.2%)	λ = 0.302	.377
Relation to patient	Spouse, 37 (90.2%); child, 3 (7.3%); carer, 1 (2.4%); daughter in law = 0	Spouse, 36 (92.3%); child, 2 (5.1%); carer, 0; daughter in law, 1 (2.6%)	λ = 2.165	.539
Employment Status	In employment, 1 (2.4%); retired, 34 (82.9%); housework, 6 (14.6%); gave up work to care, 0	In employment, 5 (12.8%); retired, 29 (74.4%); housework, 4 (10.3%); gave up work to care, 1 (2.6%)	λ = 4.416	.22
Six-CIT Score	1.83 (3.02)	2.2 (2.67)	F = 0.347	.56
Mean total NPI Carer distress score	9.58 (8.66)	11.49 (10.12)	F = 0.813	.37
HAD-Anxiety Score	6.88 (3.8)	6.72 (4.1)	F = 0.033	.857
HAD-Depression score	4.37 (2.85)	4.74 (3.27)	F = 0.304	.583
EuroQoL score	71.19 (18.59)	72.72 (21.07)	F = 0.118	.732

Abbreviation: HAD, Hospital Anxiety and Depression Scale.

NOTE. F—Analysis of variance; λ —Chi-squared test.

Table 3
Grouping of problems in dementia

Groups of problems or symptoms	Symptoms
Behavioral problems	Aggression, violence
Cognitive problems	Memory difficulties such as forgetfulness repetitiveness
Emotional or affective symptoms	Anger, low mood, anxiety
Psychiatric problems	Hallucinations, delusions
Other problems	Eating problems, sleeping difficulties, apathy, incontinence

problems identified were classified under behavior, cognitive, emotional, psychiatric, and other problems (Table 3).

Of the 39 carers randomly allocated to the diary group, 12 were male and 27 were female carers. The mean number of diary entries (pages) was 4.3 (SD = 3.97) pages; 8 (20.5%) carers made no entries claiming there were no problems to record. The maximum number of diary entries (pages) by a carer was 17, and the mean number of problems identified per diary page was 1.8. The mean number of diary pages completed by female carers was 5.2 pages (SD = 4.1) of diary entries and by the male carers 2.3 pages (SD = 2.9) which was significantly different ($P < .05$) using the analysis of variance. The number of problems identified in the diary entries was significantly greater for all five groups compared to the narratives in the carer group (Table 4). However, there were no significant differences between the total number of problems in the diary and control groups in the carers' verbal narrative accounts at both days 1 and 8. There were no significant differences between diary and control groups' mean scores in the Neuro Psychiatry Inventory, EuroQoL, and Hospital Anxiety and Depression Scale at days 8 and 28 (Table 5).

4. Discussion

This is an original study that involves the use of carers' diaries in dementia with a mixed qualitative and quantitative design. It is a randomized control study comparing real-time recording of problems using carers' diaries with the retrospective information gathered in the usual clinical assessments in clinics or domiciliary visits of persons with dementia living at home. The findings revealed that the

Table 4
Comparing number of problems in diary entries with the narrative accounts of carers in the diary group at day 8 (paired *t* test)

Problems	Diary entries (SD)	Narratives (SD)	Statistical test	<i>P</i>
Behavior	2.77 (3.5)	0.31 (0.57)	$T = -4.659$	$<.001^*$
Cognition	2.69 (3.66)	1.49 (1.29)	$T = -0.109$.032*
Emotional	1.03 (2.19)	0.26 (0.5)	$T = -0.046$.038*
Psychiatric	0.49 (1.02)	0.26 (0.55)	$T = -2.042$.048*
Others	0.87 (1.54)	0.31 (0.61)	$T = -2.042$.021*
Total	7.82 (9.2)	2.62 (1.66)	$T = -3.878$	$<.001^*$

NOTE. T—paired *t* test.

*Level of significance <0.05 .

Table 5
Comparing the diary and control groups' mean scores in the Neuropsychiatry Inventory (NPI), EuroQoL, and Hospital Anxiety and Depression Scale (HAD) at day 8 (analysis of variance)

	Diary	Control	Statistical test	<i>P</i>
NPI score	17.436 (15.87)	14.95 (17.3)	$F = 0.447$.506
NPI carer distress score	8.49 (8.3)	7.17 (8.39)	$F = 0.498$.48
EuroQoL score	74.87 (19.56)	74.71 (15.29)	$F = 0.002$.97
HAD—A score	6.51 (3.57)	6.02 (3.7)	$F = 0.36$.55
HAD—D score	4.56 (2.41)	4.19 (3.1)	$F = 0.35$.56

carers' diaries identified a greater number of problems compared to retrospective information gathered from carers with forgetfulness and behavior problems being the two most common problems. Carers' diaries identified more problems in the areas of behavior, cognition, emotional and psychiatric, as well as, problems grouped under others such as insomnia and incontinence. Despite identifying more problems, the use of the carers' diaries in dementia did not appear to make a difference in carers in terms of carer distress, carers' health-related quality of life or their mood.

In contrast, earlier studies involving carers' diaries in dementia were mainly qualitative and involved the use of unstructured diaries in comparison to this study [1,2,16]. They found that there were beneficial effects on carers affects and experience of caring. These earlier studies mainly focused on carers' problems and impact of caring, whereas this present study investigated both carers and the person being cared for with dementia.

An incidental finding noted was that the male carers in this study tended to under report problems in their narratives and diary entries which became apparent when reports were compared with the Neuropsychiatry Inventory scores. This under reporting may have an impact on the usefulness of diaries and narrative accounts in male carers or the need to put this into consideration, when taking accounts from male carers. It may be that male carers tend to normalize things much more than female carers or a reflection though not confirmed in this study or the literature, that female patients with dementia may be less demanding on family carers.

Our findings suggest that there may be a potential use of carers' diaries in the assessment of dementia, in that they may identify more problems compared to relying solely on the retrospective account of patients and carers in clinic. More research using carers' diaries in dementia covering longer period than a week may be required to ascertain other benefits.

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RESEARCH IN CONTEXT

1. **Systematic review:** A standard literature search was carried out using PsychInfo, PubMed, CINALH plus, Cochrane library, Scopus, and Web of Science databases using various search terms, such as carers diaries and dementia. We did not find any articles which was relevant to the proposed study of using carers' diaries in assessment of dementia. Several studies used patients' diaries in dementia and a few used unstructured carers' diaries for other purposes.
2. **Interpretation:** The study found that carers' diaries did identify more problems in dementia than the verbal retrospective account of carers. Identifying more problems did not lead to an improvement for carers' quality of life.
3. **Future directions:** There is need for further research on the use of carers' diaries over a longer period of time, to see if there are any other benefits of carers' diaries such as assessment and/or screening for dementia in the community.

References

- [1] Valimaki T, Vehvilainen-Julkunen K, Pietila AM. Diaries as research data in a study on family caregivers of people with Alzheimer's disease: methodological issues. *J Adv Nurs* 2007;59:68-76.
- [2] Valimaki T, Vehvilainen-Julkunen K, Pietila AM, Koivisto A. Life orientation in Finnish family caregivers of persons with Alzheimer's disease: a diary study. *Nurs Health Sci* 2012; 4:480-7.
- [3] Jacelon C, Imperio K. Participant diaries as a source of data in research with older adults. *Qual Health Res* 2005;15:991-6.
- [4] Bartlett R. Modifying the diary interview method to research the lives of people with dementia. *Qual Health Res* 2012;22:1717-26.
- [5] Dewing J. Participatory research: A method for process consent for people who have dementia. *Int J Soc Res Pract* 2007;6:11-25.
- [6] Clarke CL. Family care-giving for people with dementia: some implications for policy and professional practice. *J Adv Nurs* 1999; 29:712-20.
- [7] Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry* 1982; 140:566-72.
- [8] Morris J. The CDR: current version and scoring rules. *Neurology* 1993;43:2412-3.
- [9] Wood SA, Cummings JL, Barclay T, Hsu MA, Allahyar M, Schnelle JF. Assessing the impact of neuropsychiatric symptoms on distress in professional caregivers. *Aging Ment Health* 1999;3:241-5.
- [10] Wood S, Cummings JL, Hsu MA, Barclay T, Wheatley MV, Yarema KT, et al. The use of the Neuropsychiatric Inventory in nursing home residents. Characterization and measurement. *Am J Geriatr Psychiatry* 2000;8:75-83.
- [11] EuroQol Group. A new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199-208.
- [12] Zigmund A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983;63:361-70.
- [13] Brooke P, Bullock R. Validation of the 6 item Cognitive Impairment Test. *Int J Geriatr Psychiatry* 1999;14:936-40.
- [14] Kvavilashvili L, Brewin C. Therapeutic effects of recording intrusive memories in non-clinical participants: A diary study. Poster Presented at the 2013 Annual Convention of American Psychological Association (APA), Honolulu, Hawaii, US.
- [15] Laughland A, Kvavilashvili L. A study of involuntary autobiographical memories: Comparing paper and electronic diary methods. Poster presented at 2013 Annual Convention of American Psychological Association (APA), Honolulu, Hawaii, US.
- [16] Mausbach BT, Harmell AL, Moore RC, Chattillion EA. Influence of caregiver burden on the association between daily fluctuations in pleasant activities and mood: A daily diary analysis. *Behav Res Ther* 2011;49:74-9.