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ORIGINAL ARTICLE

Depressive disorders in caregivers of dementia patients: A systematic review

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Abstract

Although depressive symptomatology has been well studied in caregivers of patients with dementia, depressive disorders have been examined much less. We conducted a systematic literature search in major bibliographical databases (Medline, Psychinfo, Dissertation Abstracts), and included studies examining caregivers of dementia patients that reported the prevalence of major depressive disorder, according to diagnostic criteria as assessed with a standardized psychiatric diagnostic interview. Ten studies with a total of 790 caregivers were identified (sample sizes: 22–147). In only one of the studies, a representative community sample was used. A total of 176 subjects (22.3%) had a depressive disorder (prevalence range from 0.15–0.32). In the three studies reporting differential prevalence rates for men and women somewhat smaller prevalence rates were found for men than for women. In six studies caregivers were compared to a (mostly matched) control group. The relative risks of having a depressive disorder in caregivers ranged from 2.80–38.68 (all RR's were significant). In the three prospective studies relatively high incidence rates were found (0.48). This study made it clear that prevalence and incidence of depressive disorders are increased in caregivers of dementia patients. More research is clearly needed in this population.

Introduction

It is well-established that caregivers of dementia patients suffer disproportionately from severe stress, associated with the necessity to cope with behavioural problems of the elderly person, inability to communicate, and feelings of intense loneliness and loss, comparable to losing a loved one (Schulz, Visintainer & Williamson, 1990; Schulz, O'Brien, Bookwala & Fleissner, 1995; Russo, Vitaliano, Brewer, Katon & Becker, 1995). Because of these serious disruptions in their lives, it is hardly surprising that caregivers of dementia patients often suffer from health problems (Vitaliano, Zhang & Scanlan, 2003), and especially from mental health problems, such as depressive symptomatology and anxiety (Martire & Hall, 2002; Pinguart & Soerensen, 2003). In the past few decades, dozens of studies have shown that levels of depressive symptomatology are seriously increased in caregivers of dementia patients (Schulz et al., 1990; 1995).

Prevalence and incidence of depressive disorders meeting diagnostic criteria, however, have been examined much less in caregivers. The presence of depressive disorders is important in caregivers, as it is a disabling condition that is associated with problems

in daily functioning and with a variety of psychological and somatic symptoms that tend to compromise caregivers' ability to continue to maintain themselves adequately in their role (Gallagher, Rose, Rivera, Lovett & Thompson, 1989). Furthermore, it is generally assumed that depressive disorders can be treated adequately in many cases, both with psychological (Churchill et al., 2001) and pharmacological (Anderson, 2001; Thase, 2003) interventions. And intervention studies have shown that major depression in caregivers can be treated effectively (Adkins, 1999; Gallagher-Thompson & Steffen, 1994; Lovett & Gallagher, 1988). As the number of caregivers of dementia patients will increase considerably over the next decades, it is important to assess the prevalence and incidence of depressive disorders in this population. Adequate knowledge about prevalence and incidence is necessary to estimate the need for services and the need to further develop specific treatments adapted to the specific needs of this target group.

In order to assess the problem of major depression and other mood disorders in caregivers in dementia patients, we conducted a systematic review of studies examining the prevalence and incidence of major depression in caregivers of dementia patients.

Methods

Literature search

We conducted a systematic literature search in major bibliographical databases (Medline and Psychinfo) in which we combined key words of caregiving (caregiv*) and depression (both key words, and text words). In order to identify grey literature, we also searched Dissertation Abstracts.

No time limits or language restrictions for the studies were used. The end date of the searches was 1 May 2004. The resulting abstracts were studied. Studies that possibly met inclusion criteria, studies with no abstract, and studies that could not clearly be excluded were retrieved and examined more extensively. We also collected earlier reviews of depression in caregivers (Martire & Hall, 2002; Schulz et al., 1990; 1995). Furthermore, we examined the reference lists of included studies. Studies that possibly met inclusion criteria were retrieved and examined for possible inclusion.

Inclusion and exclusion criteria

We included studies examining caregivers of dementia patients that at least reported the prevalence of major depressive disorder, according to diagnostic criteria (DSM; RDC; ICD) as assessed with a psychiatric or standardized diagnostic interview (such as the DISC, CIDI, or SCAN).

Studies that only reported depressive symptomatology, as measured with instruments such as the Centre for Epidemiological Studies-Depression scale (CES-D), or the Beck Depression Inventory (BDI), were not included. Studies examining caregivers of frail elderly without dementia were not included, nor were studies of caregivers of dementia patients in which depressed subjects were explicitly excluded.

Analyses

The designs, populations, measurement instruments and operationalizations of major concepts were too diverse to conduct formal meta-analyses, integrating the results of the studies statistically. In order to analyze the resulting studies systematically, we first examined the prevalence of depressive disorders for each study separately, and calculated the 95% confidence intervals around the prevalence. We also calculated incidence rates for each of the prospective studies, as well as the 95% confidence intervals. For the studies in which a comparison group was used, we calculated the relative risk of having a depressive disorder.

Results

Resulting studies

Ten studies met the inclusion criteria. Selected characteristics of these studies are presented

in Table I. Overall, 790 caregivers participated in the 10 studies. The sample size of the studies ranged from 22–147. A representative community sample was used in only one of the studies, which was recruited with a relatively accurate sampling technique (Livingston, Manela & Katona, 1996). All other studies used selective and unrepresentative samples, mostly recruited through referrals, community announcements, self-help organizations, and comparable methods. Initial non-response, or the numbers of subjects asking for information about the project, and reasons for exclusion were reported in only two studies.

Four studies included only spouses of dementia patients, one study only included adult children caring for a parent, and the other five studies included both types of caregivers. The definition of caregiver differed considerably between studies, as did the instruments measuring depression, the diagnostic criteria for depressive disorder (DSM-III, DSM-III-R, Research Diagnostic Criteria RDC; ICD-10), and the diagnostic tools for the assessment of dementia. In all studies, female caregivers were in the majority (percentages ranged from 60–85%).

Four studies were conducted by the same research group (Bodnar & Kiecolt-Glaser, 1994; Dura, Stukenberg & Kiecolt-Glaser, 1990; 1991; Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991), and these publications are all part of one large study. We contacted one of the researchers (Dr Kiecolt-Glaser) who was co-author of all the included papers, and asked whether there was overlap between the samples. She answered (personal communication, May 2004) that in the large study the caregivers were followed for 12 or more years, and that the cohort of spouses was reconstituted four or five times. The reason was that spouses would die and would be replaced in the cohort by another caregiving spouse. One of the four studies has included only adult children (Dura et al., 1991) and two studies have included only spouses (Dura et al., 1990; Kiecolt-Glaser et al., 1991), so not all subjects overlapped.

Prevalence of depressive disorders

Of the 790 caregivers included in the 10 studies, 176 had a depressive disorder (22.3%). The prevalence with 95% confidence intervals of each of the 10 studies are reported in Figure 1, and range from 0.15–0.32. As can be seen from Table II, the 95% confidence intervals (CI) of all studies overlap with each other.

In the three studies using RDC-criteria for depressive disorders (Coope et al., 1995; Gallagher et al., 1989; Lowery et al., 2000), a distinction was made between major, intermittent and minor depression. Major depression according to RDC-criteria is comparable to major depressive disorder according to DSM-III and DSM-III-R criteria. The prevalence of major depression (RDC-criteria) in these three

Table I. Studies examining major depression in caregivers of dementia patients.

Study	Population	Definition of caregiver	Diagnosis of dementia	INR	<i>n</i>	Depression measure	Type	% ♀	Country	Type of study
Coope et al., 1995; Ballard et al., 1996	Consecutive referrals to psychiatric services and memory clinic; only dementia patients	Relatives helping at least once per week	CAMDEX criteria for dementia	10%	109	GMS (RDC)	48% SP; 35% AC	62%	UK	- Prosp
Dura et al., 1990	Spouses caring for a dementia patient, recruited through referrals, support groups, self-help organisation, dementia evaluation centres	≥5 hours of care per week	Assessment at local hospital	Nr*	86	SCID-NP (DSM-III-R)	100% SP	67%	USA	- Contr - Cross
Gallagher et al., 1989	Non-help seeking volunteers in a study of biological and psychosocial changes in Alzheimer's disease	No specific definition	Not reported	Nr	51	RDC (SADS)	100% SP	60%	USA	- Other - careg
Livingston et al., 1996	Caregivers of patients with dementia, depression or physical disability; random sample of population (all subjects in selected districts in one local government area were approached)	Living with dementia patient	Short-CARE (ICD-10)	10%	22	Short-CARE (ICD-10)	Nr	Nr	UK	- Contr - Cross - Other - careg
Bodnar et al., 1994	Caregivers of dementia patients, recruited through referrals, support groups, self-help organizations, dementia evaluation centres	≥5 hours of care per week	Assessment at local hospital	Nr*	147	SCID-NP (DSM-III-R)	50% SP; 43% AC	71%	USA	- Contr - Prosp
Dura et al., 1991	Adult children caring for parent with dementia, recruited through hospitals, support groups, self-help organizations, respite care programs	≥5 hours of care per week	Assessment at local hospital	Nr*	78	SCID (DSM-III-R)	100% AC	85%	USA	- Contr
Kiecolt-Glaser et al., 1991	Caregivers of dementia patients, recruited through referrals, support groups, self-help organizations, dementia evaluation centres	≥5 hours of care per week	Assessment at local hospital	Nr*	69	SCID-NP (DSM-III-R)	100% SP	71%	USA	- Contr - Prosp
Russo et al., 1995	Mailings to physicians, case registry, self-help organizations, community announcements	Living with demented spouse	DSM-III dementia	Nr*	82	DIS	100% SP	65%	USA	- Contr - Cross
Cohen et al., 1988	Caregivers of elderly with diagnosed AD of multi-infarct dementia, who were seen in a geriatric treatment service, not receiving respite care or participate in a support group	Daily assistance	Diagnosed dementia (method NR)	Nr	46	Psychiatric interview (DSM-III)	18 SP, 22 AC	73%	USA	- Cross
Lowery et al., 2000	Consecutive referrals to old age psychiatry services of caregivers of patients with Alzheimer's disease (75%) or dementia with Lewy Bodies (25%); all caregivers living with patient	Regular contact (≥weekly)	CDR	Nr	100	MADRS + RDC or GMS/rdc	44% SP, 40% AC	68%	UK	- Cross

*Exact number of subjects asking for information not reported, reasons for exclusion not reported: INR, initial non-response; Nr, not reported; Prosp, prospective study; Contr, controlled study; Cross, cross-sectional study; Other careg, study comparing dementia caregivers to other caregivers; SP, spouses; AC, adult children; GMS, geriatric mental state schedule; RDC, research diagnostic criteria; SCID-NP, structured clinical interview for DSM-III-R; SADS, schedule for affective disorders and schizophrenia; DIS, diagnostic interview schedule; MADRS, Montgomery-Asberg depression rating scale; CDR, clinical dementia rating scale.

Table II. Studies reporting depressive disorders in caregivers of dementia patients: prevalence and relative risks.

Study	Prev	95% CI	Prev (95% CI)	RR	95% CI	Control group
Bodnar et al., 1994	0.18	0.12–0.24		38.68	2.38; 627.71	Matched control group (gender, age, education; n = 86)
Cohen et al., 1988	0.26	0.13–0.39		–		
Coope et al., 1995, Ballard et al., 1996	0.29	0.20–0.38		–		
Dura et al., 1990	0.15	0.07–0.23		27.00	1.63; 447.14	Matched control group (gender, age, education; n = 86)
Dura et al., 1991	0.18	0.09–0.27		29.00	1.76; 477.82	
Gallagher et al., 1989	0.18	0.07–0.29		–		
Livingston et al., 1996	0.32	0.12–0.52		2.94	1.46; 5.91	Co-residents (living with healthy person; n = 277)
Lowery et al., 2000	0.30	0.21–0.39		–		
Kiecolt-Glaser et al., 1991	0.25	0.15–0.35		35.00	2.15; 570.74	Matched control group (gender, age, education, income; n = 69)
Russo et al., 1995	0.20	0.11–0.29		2.80	1.15; 6.80	

Abbreviations: Prev: prevalence; 95% CI: 95 percent confidence interval; RR: relative risk.

studies was somewhat smaller than in the other studies (for Coope et al., 1995: 0.07, 95% CI: 0.02–0.12; for Gallagher et al., 1989: 0.10, 95% CI: 0.02–0.18; and for Lowery et al., 2000: 0.03, 95% CI: 0.00–0.06).

Prevalence of depressive disorders in specific subgroups

The four studies examining only spouses (Dura et al., 1990; Gallagher et al., 1989; Kiecolt-Glaser et al., 1991; Russo et al., 1995) included 288 subjects, of whom 55 (19.1%) had a depressive disorder. Three of the smaller studies (total *n* for the three studies: 95) reported differential prevalence rates for men and women (Cohen & Eisdorfer, 1988; Gallagher et al., 1989; Livingston et al., 1996). Of the 29 men in these three studies, three (10.3%) had a depressive disorder (the prevalence's were 0.06; 0.00; and 0.33); 25 of the 66 women had a depressive disorder (37.9%; prevalence: 0.23; 0.47; and 0.63).

In one study (Lowery et al., 2000), caregivers of patients suffering from dementia with Lewy Bodies were compared to caregivers of patients with Alzheimer's disease. Seven of the 25 caregivers of patients suffering from dementia with Lewy Bodies (28%) met RDC criteria for depressive disorder, compared to 23 of the 75 caregivers of patients with Alzheimer's disease (31%; RR = 0.91; 95% CI: 0.45–1.87; NS). In the RDC criteria a distinction is made between minor, intermittent and major depression. In the caregivers of patients suffering from dementia with Lewy Bodies three subjects (12%) met RDC criteria for major depression, compared to none of the caregivers of patients with Alzheimer's disease (RR = 20.46; 95% CI: 1.09–383.04),

which is significant but should be regarded with caution because of the small numbers.

Comparison of prevalence of depressive disorders in caregivers to control subjects

In six studies, a comparison group not consisting of caregivers was included. In five of these studies, the comparison subjects were matched on basic demographic characteristics (gender and age in all five studies, education in four studies). In the sixth study (Livingston et al., 1996), the comparison group consisted of co-residents of healthy subjects who did not need care. The relative risks resulting from the six studies ranged from 2.80–38.68 (Table II). All RR's were significant (none of the 95% confidence intervals overlapped with 1).

The four studies from the same research group (Bodnar & Kiecolt-Glaser, 1994; Dura et al., 1990; 1991; Kiecolt-Glaser et al., 1991) clearly had larger RR's (ranging from 27.00–38.68) than the other two studies (2.80 and 2.94). The four studies from the same research group had very high upper limits of the 95% confidence intervals (up to 627.71), because none of the subjects in the comparison groups had a depressive disorder.

Comparisons to other types of caregivers

In two studies, comparisons of the prevalence of depressive disorders could be made between caregivers of dementia patients and caregivers of patients with other disorders. In the first study (Gallagher et al., 1989) caregivers of dementia patients could be compared to caregivers of frail elderly in general,

who actively sought help and support for their problems. The RR of having a depressive disorder was smaller in the sample of caregivers of elderly people with dementia (RR=0.59; 95% CI: 0.31–1.13), but not significantly.

In the second study (Livingston et al., 1995), caregivers of dementia patients could be compared to caregivers of depressed elderly and to caregivers of elderly with limited activity. The prevalence of depressive disorders was higher in dementia caregivers than in caregivers of depressed subjects (RR=1.75; 95% CI: 0.68–4.51), and also than in caregivers of elderly with limited activity (RR=4.01; 95% CI: 1.42–11.34), but only the last RR reached significance levels.

Incidence of depressive disorders

The incidence of depressive disorders was measured in three studies (Ballard, Eastwood, Gahir & Wilcock, 1996; Bodnar & Kiecolt-Glaser, 1994; Kiecolt-Glaser et al., 1991). In the first study (Ballard et al., 1996), 28 of the 58 respondents who had no depressive disorder at the first measurement did have a depressive disorder one year later (incidence rate is 0.48). In the second study (Bodnar & Kiecolt-Glaser, 1994), no incidence rates were given for subjects who did not have a depressive disorder at baseline. But, four years after baseline 33 of 98 (33.7%) caregivers had had a depressive disorder, compared to 17 of 98 (17.3%) at baseline. In the third study (Kiecolt-Glaser et al., 1991), no incidence rates were given for subjects who did not have a depressive disorder at baseline either. At baseline 17 of 69 subjects met criteria for a depressive disorder, compared to 22 of 69 after 13 months.

Discussion

This study has several limitations. First, the number of studies examining depressive disorders in caregivers of dementia patients is small, and the studies that have been conducted have used relatively small samples. Second, almost all studies that have been conducted used selective and unrepresentative samples. Furthermore, the initial non-response, or the numbers of subjects asking for information about the project, and reasons for exclusion were reported in only two studies. Only one study used a representative community sample, which was recruited with a relatively accurate sampling technique. Third, there were major differences between studies in the definitions of caregiver, the research methods used, the measurement instruments, and the definition of depressive disorder. Fourth, all studies were conducted in the UK or the USA. Therefore, we cannot be sure that these results are also valid in other countries. Because of these limitations, the results of this study should be considered with caution.

On the other hand, the results of this review clearly indicate that the prevalence of depressive disorders in caregivers of dementia patients is considerable. The prevalence rates range from 0.15–0.32, which is considerably higher than is found in community studies among the elderly (Gallo & Lebowitz, 1999; Beekman, Copeland & Prince, 1999). Although reviews of depressive disorders in the elderly report high prevalence rates (15–20%), these studies do not all use strict diagnostic criteria, as we did in our review, and even then the prevalence rates are generally lower.

This high prevalence is confirmed in the studies in which comparison groups were used. All of these studies showed significantly increased prevalence rates of depressive disorders in caregivers, compared to the comparison subjects. The studies examining the incidence of depressive disorders again confirm that caregivers have a highly increased risk of getting a depressive disorder, as the incidence rates found in these studies are again much higher than incidence rates found in community studies of the elderly (Beekman et al., 1999).

Some indications were found that the prevalence of depressive disorders in men was lower than in women. This would be in agreement with the prevalence in the general population, which is about twice as high in women as in men. Future research is needed to confirm these indications. If these higher prevalence rates are indeed found in future research, this is an interesting issue, as it would be a further indication that it is not only the stressful situation of caregivers that causes a depressive disorder, but a combination of vulnerability, psychological factors and stressful life events (Harris, 2000; Ormel et al., 1994).

No clear indications were found that prevalence rates differ for differing types of caregivers, although the number of studies comparing types of caregivers was too small to reach definite conclusions. It would be plausible if indications were found that prevalence rates in caregivers of dementia patients were higher than caregivers of non-dementia patients. On the other hand, a large body of research has shown that the burden of caregivers is determined by many different factors, including behaviour problems, the earlier relationship, the personality of the patient, sleeping patterns, and social support. The type of disorder is only one of the factors determining caregiver burden. There is no reason to assume that this would be different for depressive disorders.

An important finding from this review is that so few studies have actually examined depressive disorders in this population, and that we know so little about the prevalence and incidence of these disorders. Depressive disorders cause problems in daily functioning and are associated with a variety of psychological and somatic symptoms that tend to compromise caregivers' ability to continue to maintain themselves adequately in their role

(Gallagher et al., 1989). And it may be very well possible that depressive disorders are not detected by professionals and are considered to be a 'normal' reaction to a very stressful situation, while adequate treatments may be available. If we want to support caregivers in their role to care for their relative, several questions have to be answered. We have to know how often these disorders occur and what chance a non-depressed caregiver has to get a depressive disorder within the next year. Furthermore, we have to know what risk factors increase the risk of getting such a disorder, what professionals can do to prevent these disorders, and how to treat existing disorders. Research so far has not answered these questions adequately, and because the number of dementia patients cared for at home will grow considerably in the next few decades, these important questions merit further research.

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