Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia

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OBJECTIVES: To review published reports of interventions for caregivers (CGs) of persons with dementia, excluding respite care, and provide recommendations to clinicians. DESIGN: Meta-analytical review. Electronic databases and key articles were searched for controlled trials, preferably randomized, published in English from 1985 to 2001 inclusive. Thirty studies were located and scored according to set criteria, and the interventions' research quality and clinical significance were judged.

SETTING: Home or noninstitutional environment.

PARTICIPANTS: Informal CGs—persons providing unpaid care at home or in a noninstitutional setting.

MEASUREMENTS: The primary measures were psychological morbidity and burden. Other varied outcome measures such as CG coping skills and social support were combined with measures of psychological distress and burden to form a main outcome measure.

RESULTS: The quality of research increased over the 17 years. Results from 30 studies (34 interventions) indicated, at most-current follow-up, significant benefits in caregiver psychological distress (random effect size (ES) = 0.31; 95% confidence interval (CI) = 0.13–0.50), caregiver knowledge (ES = 0.51; CI = 0.05–0.98), any main caregiver outcome measure (ES = 0.32; CI = 0.15–0.48), and patient mood (ES = 0.68; CI = 0.30–1.06), but not caregiver burden (ES = 0.09; CI = -0.09-0.26). There was considerable variability in outcome, partly because of differences in methodology and intervention technique. Elements of successful interventions could be identified. Success was more likely if, in addition to CGs, patients were involved. Four of seven studies indicated delayed nursing home admission.

CONCLUSION: Some CG interventions can reduce CG psychological morbidity and help people with dementia

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stay at home longer. Programs that involve the patients and their families and are more intensive and modified to CGs' needs may be more successful. Future research should try to improve clinicians' abilities to prescribe interventions. J Am Geriatr Soc 51:657–664, 2003.

Key words: meta-analysis; family caregivers; dementia; interventions

ost people with dementia have at least one supporter or caregiver (CG), usually a spouse or relative. CGs experience adverse psychological, physical, social, and financial consequences, 1,2 such as higher rates of depression, 3,4 poorer physical health than non-CG controls, 5 social isolation, 6 and direct (e.g., medications) and indirect (e.g., loss of earnings due to relinquishing of paid work) financial costs. CGs are crucial for maintaining people affected with dementia in the community. When there is no CG, or when the CG is stressed, the likelihood of nursing home admission rises sharply. 7

Clinicians and researchers have devised many methods of trying to help CGs such as education and training programs, support groups, and counseling. Successful interventions have been reported to reduce CG distress, depression, and psychological morbidity; to delay nursing home admission of patients; and to improve patients' psychological well-being. The aim of this study was to review the evidence for the outcome of CG interventions (excluding respite care, which is a patient-targeted intervention—see Gottlieb et al. for a review)⁸ and to provide recommendations for clinicians. The review has been restricted to studies involving informal CGs (persons providing unpaid care, at home or in a noninstitutional environment).

METHOD

Key words (caregiver, carer, self-help groups, support groups, education, training, skills training, counseling, psychotherapy, intervention, and therapy) were used to search published literature in English for controlled studies of interventions for CGs of people with dementia and were each combined with the search terms "random allocation" and/or "control group" and "dementia" or "Alz-

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heimer's disease." The following electronic databases were searched: Medline (1985–Week 4, December 2000), PsychInfo (1984–Week 2, December 2000), Ageline (1985–2000/12), CINAL (1985–2000), Cochrane Library 1998 (Issue 3 Database), EBM Reviews—Best Evidence (1991—November/December 2000), EBM Reviews—Cochrane Database of Systematic Reviews (4th Quarter 2000), EMBASE (1988–Week 51, 2000).

All randomized or quasi-experimental trials in which CGs were allocated to intervention or nonintervention (control) groups were selected. Participants in the selected studies were informal CGs of people diagnosed with Alzheimer's disease.

One of the investigators (AG) scrutinized the resulting abstracts, and papers judged relevant were obtained. If doubt existed regarding an article's relevance, a second investigator (HB) reviewed the abstract. References of obtained papers were reviewed to locate any additional papers. Fifty-two articles met criteria for inclusion, seven of which, as shown in brackets in Table 2, were excluded because they were descriptions of earlier studies published by the same research group and added no new information.

The primary outcome measures were psychological morbidity and burden. Measures of psychological morbidity included the General Health Questionnaire, Hamilton Depression Rating Scale, Brief Symptom Inventory, Self-Rating Depression Scale, Hopkins Symptom Checklist, Center for Epidemiological Studies Depression Scale, and the Positive and Negative Affect Scale. Burden was measured using the Burden Interview, Rankin Scale, Caregiver Hassles Scale, Screen for Caregiver Burden, or other objective burden scales.

For those studies that did not include a measure of psychological morbidity or burden, the varied outcome

Table 1. Criteria for Rating Quality of Studies

Criterion	Score
Design	
Randomized	1
Controlled (or comparison group used)	1
Subjects	
Use of standardized diagnostic criteria	1
All subjects accounted for/withdrawals noted	1
Outcomes	
Well-validated, reliable measures	
(caregiver and/or patient)	1
Objective outcome	
(e.g., institutionalization or death)	1
Questionable/unreliable outcome measures	0
Statistics	
Statistical significance considered	1
Adjustment for multiple comparisons	1
Evidence of sufficient power	1
Results	
Blind ratings	1
Follow-up assessment 6 months or beyond	1
Good quality	>7
Poor quality	<5

measures used were combined with measures of psychological distress and burden to form "any main outcome measure." These included measures of CG coping skills (Health Specific Family Coping Index) and social support (Instrumental and Expressive Social Support Scale). Knowledge of Alzheimer's disease was examined separately and was measured using the Alzheimer's Disease Knowledge Test, Dementia Quiz, Dementia Knowledge Test, and other individual knowledge measures. "Study success," categorized as a dichotomous dependent variable, was defined as significant change in one of the main outcome measures or an effect size (ES) of 0.5 or greater.

A small number of studies looked at patient mood as an outcome, measured using the Cornell Scale for Depression in Dementia and the Geriatric Depression Scale. Finally, the effects of CG interventions on nursing home placements were examined.

Follow-up points were classified as posttest, 3- to 6-month follow-up, more than 6-month follow-up, and most-current follow-up of each study. For the statistical analyses of study characteristics (see below) the most-current follow-up was the dependent variable.

Both reviewers (AG and HB) independently rated the methodological quality of the included studies according to criteria based upon Cochrane Collaboration Guidelines⁹ (Table 1). Characteristics of the design, subjects, outcomes, statistics, and results were used to evaluate the quality of studies (Table 2, quality scores).

Interventions were also rated in terms of their "dosage" or the "strength" of the intervention (Table 2), where the number of sessions/occasions of contact were rated as a minimal (1–2 sessions), moderate (3–5 sessions), mediumhigh (6–10 sessions), or high/intensive (>10 sessions).

Meta-analysis was performed using MetaView version 4.0 (Cochrane Collaboration, Oxford, England). ES for continuous data was calculated as standardized mean difference (SMD (Cohen's d) with 95% confidence intervals (CIs)) between treatment and control group. 48,50,51 An ES of 0.2 may be statistically significant but is considered weak, 0.5 is considered moderate, and 0.8 or above as strong. 52 ESs for dichotomous outcome data were reported as odds ratios (ORs). 53 Weighted average ESs were calculated weighting each individual ES by the inverse of its variance. 53 All pooled calculations included a test of homogeneity of means. Results were compared for fixed-effects and random-effects models. 54

In most cases, there was no substantial difference between fixed-effects and random-effects models. Results for random-effects models are displayed because tests for homogeneity and heterogeneity of studies under examination in terms of methods, type of intervention, sample characteristics, and outcome measures support the use of a random-effects model for most of the pooled estimates. ^{48,49,54} Sensitivity analyses were conducted using various combinations of trials and estimates.

SPSS version 10.0 (SPSS Inc., Chicago, IL) was used to analyze predictors of ES. Chi-square (χ^2) analysis was employed for dichotomous data and Mann-Whitney U tests (two-tailed; denoted as U) for continuous data. Spearman rank correlation coefficient (Spearman rho) was used as a measure of association.

Where studies contained more than one intervention

(Continued)

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Table 2. (Continued)							
Study	Design	Outcome Measure*	Instrument	Number of Subjects Randomized [†]	Intervention Type	Quality	Dosage
McCallion et al. 1999 ²⁸	RCT	Burden Patient mood	CHS	66 (tmt = 32, control = 34) withdrawals = 9	Е, Р	10	ဇာ
McCurry et al. 1998 ²⁹	RCT	Psychological morbidity	CES-D	36 (tmt1 = 7, tmt2 = 15, control = 15) withdrawals = 2	S, T, SM	9	ო
Mittelman et al. 199630 (same sample as Mittelman et al. 1993, 1995)31,32	RCT	Delay to nursing home	1		S, C, F	_	4
Mittelman et al. 1995 ³² Mohide et al. 1990 ³³ (same sample as Drummond et al. 1991) ³⁴	RCT	Psychological morbidity Psychological morbidity Delay to nursing home	GDS CES-D	206 (withdrawals = 9) 60 (30 each group)	, Э, Э, С, Э, Т,	~ ~	4 4
Moniz-Cook et al. 199835	R R	admission [‡] Psychological morbidity	ВНQ	30 (15 each group) withdrawale = 5	۵	ω	က
Morris et al. 1992³⁵	R R	Psychological morbidity Knowledge	BDI Knowledge	39 (tmt = 13, control = 18) withdrawals = 8	SM	4	α
Ostwald et al. 1999 ³⁷	RCT	Psychological morbidity	CES-D	117 (tmt = 72, control = 45) withdrawals = 23	Щ Н	22	က
Quayhagen et al. 1989³8	R E	Psychological morbidity Burden	HSC BI	Withdrawals $= 20$ 16 (tmt = 10, control = 6) withdrawals $= 4$	Т, Р	9	4
Quayhagen et al. 2000 ³⁹ – Day care – Dyadic counseling – Cognitive stimulation	RCT	Psychological morbidity Burden	BSI MBPC-B	with drawars = 4 103 (group n's = 21, 29, 22, 16, 15)	ပ် ဟ် ပ မ မ လ	^	Day care = 4 Dyad counsel = 3 Cog stim = 3
Riordan et al. 1998 ⁴⁰	N R	Delay to nursing home		38 (19 each group) withdrawals = 15	L Ø	Ŋ	4
Ripich et al. 1998 ⁴¹	E E	Psychological morbidity Burden Knowledge	PANAS CHS Knowledge	37 (tmt = 19, control = 18)	ш	ω	8
Roberts et al. 1999 ⁴²	RCT	Psychological morbidity	PAIS	77 (tmt = 38, control = 39) withdrawals = 19	O	_	က
Robinson et al. 1988 ⁴³ (same sample as Robinson & Yates, 1994) ⁴⁴	RCT	Burden	Objective burden scale	20 (tmt = 11, control = 9)	S,	4	7
							(Continued)

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Table 2. (Continued)							
Study	Design	Outcome Measure*	Instrument	Number of Subjects Randomized†	Intervention Type Quality	Quality	Dosage
Teri et al. 1997 ⁴⁵ Problem solving Pleasant events	RCT	Psychological morbidity Burden Patient mood	HDRS BI CDS	88 withdrawals = 16	Ч, Р	7	Problem solving = 3 Pleasant events = 3
Zanetti et al. 1998 ⁴⁶	Z Z	Psychological morbidity Burden Knowledge	BSI Rankin scale ADKT	23 (tmt = 12, control = 11) withdrawals = 2	S, T	4	ဇ
Zarit et al. 1987 ⁴⁷ Counseling Support group	RCT	Psychological morbidity Burden	BSI BI	184 (group n 's = 44, 36, 39) withdrawals = 65	o o m ⊤	^	Counseling = 3 Support = 3

Category of outcome in which this measure was included

Intention-to-treat figures.

ADKT = Alzheimer's Disease Knowledge Test; BDI = Beck Depression Inventory; BI = Burden Interview; BSI = Brief Symptom Inventory; C = counseling of carer; CAT = Caregiver Appraisal Tool; CES-D = Center for Epidemi-CDS = Cornell Depression Scale; CHS = Caregiving Hassles Scale; CSDD = Cornell Scale for Depression in Dementia, DKT = Dementia Knowledge Test; E = education; F = family counseling/ = Geriatric Depression Scale; GHQ = General Health Questionnaire; HDRS = Hamilton Depression Rating Scale; HSC = Hopkins Symptom Checklist; HSFCI = Health Specific Family Coping = randomized controlled trial; S = support group/program; SCB ndex for Non-Institutional Care; IESS = Instrumental and Expressive Social Support Scale; MBPC-B = Memory sychosocial Adjustment to Relative's Illness; PANAS = Positive and Negative Affect Scale; RCT Time/delay to nursing home admission was a separate analysis, not part of meta-analysis. SM = stress management; T = training; tmt = treatment. ological Studies-Depression Scale;

group (e.g., support group compared with counseling group vs control), each intervention group was entered into the analysis separately. The following studies were excluded: (1) two studies^{55,56} with a sample size of five or fewer in treatment or control group, (2) 11 studies⁵⁷⁻⁶⁷ with insufficient outcome information to calculate ES or nursing home delay, and (3) two interventions with extreme values (values more than three times the interquartile range; dual seminar intervention (SMD for Brief System Inventory depression = -1.86);³⁹ the other three interventions for this study were included in the analysis), and Perkins et al. 199068 (SMD for caregiver morale = 3.09).51 Therefore, of the 45 studies that met criteria for inclusion, 30 (34 interventions) were included in at least one analysis.

RESULTS

= Screen for Caregiver

The 30 controlled studies involved 2,040 CGs (intentionto-treat; range 16-206, median = 53), who were predominantly spouses (of persons with dementia), female, and aged 55 and older (see Table 2 for included studies).

Quality ratings, which ranged from 3 to 10 (mean \pm standard deviation = 6.4 ± 1.5), tended to improve over time (Spearman rho = 0.3; P = .07). There was no significant correlation of quality of research on ES (any outcome, distress, burden) using nonparametric measures (Spearman rho = 0.2, 0.3, and 0.2, respectively).

The ESs for psychological morbidity are shown in Table 3. Although 77% of the studies showed a positive ES for psychological morbidity (range -0.59-1.81), this was only statistically significant in five of the 20 positive interventions. The ES for burden ranged from -0.6 (95% CI = -1.33-0.14) to 1.07 (95% CI = 0.12-2.03). Only one intervention of 20 (a social skills training program)⁴³ showed a statistically significant effect on burden. Overall, 23 of 34 (68%) interventions met the criteria for study success.

Weighted average ESs (95% CI; number of studies) were calculated for CG psychological morbidity, 0.31 (0.13-0.50; n = 26); CG burden, 0.09 (-0.09-0.26; n =20); changes in patient mood, 0.68 (0.30–1.06; n = 5); CG knowledge, 0.51 (0.05-0.98; n = 8); and overall effect on "any main outcome measure," 0.32 (0.15-0.48; n =30). The weight used here was the inverse of its variance (i.e., larger studies are given more weight). 53,69 Low but significant ESs on most outcome measures (apart from burden) suggest a low but positive overall effect of these CG interventions, but the variability between studies is substantial. The pooled estimates displayed were calculated for the most-current follow-up assessment, which was posttest for most studies. Eight studies reported results for additional follow-up assessments (mean = 27 weeks; range = 12–48 weeks). Pooled estimates for time intervals of 3 to 6 months and more than 6 months are available upon request.

Sensitivity analyses for the most-current assessment point were performed, excluding extreme values (see above), dropping one study at a time and obtaining CIs for the remaining studies.⁵¹ Certain studies proved more influential than others, yet discrepancies in CIs for pooled calculations were small and did not result in a change of significance when compared with the overall result. An 662 BRODATY ET AL. MAY 2003–VOL. 51, NO. 5 JAGS

Table 3. Effect Size for Psychological Morbidity at Most Current Follow-Up Assessment

Standardized Mean Difference* (95% Study Confidence Interval) Moniz-Cook et al. 1998 (GHQ) 1.81 (0.94-2.67) Marriot et al. 2000 (GHQ) 1.57 (0.69-2.45) Hinchliffe et al. 1995 (GHQ) 1.42 (0.64-2.21) Teri et al. 1997; problem solving (HDRS) 1.10 (0.27-1.92) Quayhagen et al. 1989 (HSC) 0.92(-0.16-2.00)Brodaty and Gresham 1989 (GHQ) 0.77 (0.27-1.28) Quayhagen et al. 2000; cog. stimulation (BSI) 0.59(-0.09-1.27)Teri et al. 1997; pleasant events (HDRS) 0.53(-0.23-1.29)Zanetti et al. 1998 (BSI) 0.46 (-0.42-1.34) 0.45(-0.04-0.95)Chang et al. 1999 (BSI) Mittelman et al. 1995 (GDS) 0.29(0.02 - 0.60)Mohide et al. 1990 (CES-D) 0.26(-0.35-0.87)Ostwald et al. 1999 (CES-D) 0.25(-0.20-0.70)McCurry et al. 1998 (CES-D) 0.21(-0.58-1.00)Hebert et al. 1994 (BSI) 0.20(-0.47-0.86)Ripich et al. 1998 (PANAS) 0.15(-0.50-0.81)Quayhagen et al. 2000; day care (BSI) 0.12(-0.58-0.83)Kahan et al. 1985 (SDS) 0.09(-0.53-0.72)Gendron et al. 1996 (HSC) 0.07(-0.60-0.73)Zarit et al. 1987; counseling (BSI) 0.02(-0.43-0.48)-0.09 (-0.80-0.63) Morris et al. 1992 (BDI) -0.16(-0.71-0.38)Brodaty et al. 1994 (GHQ) Zarit et al. 1987; support group (BSI) -0.17(-0.60-0.27)Logiudice et al. 1999 (GHQ) -0.18(-0.87-0.52)Roberts et al. 1999 (PAIS) -0.24(-0.75-0.28)Quayhagen et al. 2000; dyadic counseling (BSI) -0.59(-1.23-0.05)-2 0 2

GHQ = General Health Questionnaire (Goldberg & Williams, 1988); BSI = brief symptom inventory (Derogatis et al. 1983); SDS = Self-rating Depression Scale (Zung, 1965); HSC = Hopkins Symptom Checklist (Derogatis et al. 1974); CES-D = Center for Epidemiological Studies Depression Scale (Radloff, 1977); PANAS = Positive and Negative Affect Scale (modified version; Watson et al. 1988); PAIS = Psychosocial Adjustment to Illness Scale.

exception was the sensitivity analysis for knowledge, for which the overall SMD for random effect models was significant, whereas removal of any of the more successful studies led to nonsignificant results.

A post hoc analysis of study characteristics was used to test possible predictors of positive ES. The following predictor variables were examined: whether the intervention involved support/help from extended family; counseling of the CG; and involvement of CG and patient in intervention (e.g., teaching the caregiver skills applicable to the patient such as pleasant event planning, cognitive stimulation), support group, and stress management. Continuous dependent variables were the ES (SMD for random effect models) for CG psychological morbidity and the ES on any main outcome measure.

Using univariate analyses, the study characteristic "involvement of CG and patient in the intervention" showed an effect on any outcome measure (U = 43.0; P = .01), on CG psychological morbidity (U = 28; P = .01) and on study success ($\chi^2 = 4.0$; df = 1; continuity correction: P = .05). No other study characteristic showed a significant effect.

The dosage of interventions ranged from minimal (n = 1), to moderate (n = 4), medium-high (n = 17), and high/intensive (n = 12). Higher dosage was associated with de-

creased psychological distress (Spearman rho = 0.6; P = .003), but there was a nonlinear tendency with interventions with a dosage of greater than 3.5 being less effective than interventions around 3.5.

Seven studies used time until nursing home placement as an outcome measure. 12,18,20,22,30,33,40 Two of these showed significant ESs (Brodaty et al.¹² OR = 5.0, 95% CI = 1.72-14.70; Mittelman et al.³⁰ SMD = 3.21, 95% CI = 2.80-3.63), and two reported a longer median time of home care until institutionalization in the intervention group than in the control group (Eloniemi-Sulkava et al.²⁰ 2-year follow-up: median time of home care in those patients who were institutionalized 473 vs 240 days, respectively; P = .02; Riordan et al.⁴⁰ 326 vs 160 days, respectively). Chu et al.18 divided patients into very mildly and mildly to moderately impaired. Those in the latter class who received treatment remained in the community an average of 52.53 days longer than control group patients. Delays in nursing home admission of between 53 and 329 days were reported. 12,18,20,30,40 Two studies 35,40 reported that significantly more control patients received permanent residential care at follow-up assessment. Qualitatively, a continuing relationship between helper and CG, flexibility of the intervention, and a variety of interven-

 $^{^\}star$ Effect size measured as standardized mean difference between treatment and control group.

tions that should meet the varied needs of CGs appeared to characterize the four studies that delayed nursing home admission. 12,20,30,40

DISCUSSION

CG interventions have modest but significant benefits on CG knowledge, psychological morbidity, and other main outcome measures (such as coping skills and social support). At the most-current follow-up, there was a mean ES of 0.3 for all CG outcomes and for CG psychological morbidity in particular, meaning that the average patient in the treatment group was less depressed than about 62% of patients in the control group. There was an even stronger ES (0.7 for posttest and 0.5 for most-current follow-up) in the increase in CG knowledge (about dementia and how to cope with it). There was also a strong ES for patient mood, but interventions did not appear to influence CG burden.

The findings regarding the predictors of positive ES are based on small numbers and should be interpreted with caution. The heterogeneity of sample characteristics and study design contribute a considerable amount of variance but cannot be controlled because of lack of information and the small number of studies. Additionally, the power of the analyses to detect small to medium ESs with a t-test was less than 0.5 ($\alpha = .05$).⁵²

Despite these modest findings, CGs were frequently satisfied or very satisfied with the their interventions, 15,21,22,25,36,40,42 appraised their own coping skills as improved, 17 reported that their relationship with the patient had improved, 28 identified helpful training elements, 39 and mostly (71%) reported that they would use training again. 43 CG interventions can have effects on delaying nursing home admission, which for many is desirable. Unsuccessful interventions are short educational programs (beyond enhancement of knowledge); 14,27 support groups alone, single interviews, and brief interventions or courses that were not supplemented with long-term contact do not work.

The variability in outcomes is attributable to many factors. Patients were heterogeneous with regard to age, sex, and living arrangements; type and severity of dementia; and prevalence of behavioral and psychological symptoms associated with dementia. CGs also differed significantly with regard to demographic variables, relationship to patient (e.g., spouse vs adult child vs other), other demands on their time (working, other family members to care for), and practical and social supports. The different methods of recruitment (volunteers, clinics, advertisements, and Alzheimer's associations) may have introduced bias. Whether the different follow-up periods influenced the results was considered. Eleven studies had more than one posttest assessment. In these studies, the average ES for psychological distress improved, whereas the ES for burden decreased, but these findings would have to be corrected for many covariates and could not be considered representative of all 30 studies. Finally, the number of subjects in trials was small; there was limited power, statistical comparisons were multiple (corrections for these were few), and intention-to-treat analyses were largely not performed.

Despite these limitations, it is clear that some inter-

ventions can make a difference. What are the important elements? Statistically, the only feature that emerged as significant was involvement of the patient in addition to the CG in a structured program, such as teaching the CG problem-solving skills in the care of the patient.⁴⁵ The small numbers of subjects in a large number of trials may have militated against the emergence of other features that appear qualitatively important: practical support for the CG, involvement of the extended family, structured individual counseling, and a flexible provision of a consistent professional to provide long-term support. Ceiling and floor effects prevented the realization of beneficial effects. For example if only a minority of CGs were significantly depressed before intervention, this limited the possibility of demonstrating a significant reduction in depression score. The difficulty in recruiting and treating sufficient numbers of subjects precluded the examination of interactions between which intervention for which CG supporting which patient with what dementia at what time in the course of the condition.

The implications from this meta-analysis are that CG interventions have the potential to benefit patients and CGs. The quality of research is advancing, but there is considerable room for methodological improvement. Future research should be conducted with more rigor: randomized, controlled, blind outcome assessments, follow-ups for at least 6 months, and use of well-validated and reliable outcome criteria measuring outcomes proximally (burden, knowledge) and distally (depression, quality of life). The next steps include evaluation of more-intensive interventions and interactions with drug therapies.

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