

FEATURE

ARTICLE

Online Support for Employed Informal Caregivers

Psychosocial Outcomes

PAULA R. KLEMM, PhD, RN
EVELYN R. HAYES, PhD, MPH, FNP-BC
CYNTHIA A. DIEFENBECK, PsyD, APRN, BC
BARRY MILCAREK, PhD

More than 65 million Americans care for family members with chronic illness; most are middle-aged women who are employed.¹ Family caregivers provide almost 75% of caregiving support in the United States and receive little or no help from family members or healthcare professionals.² Unpaid care provided by informal family caregivers is estimated in value at more than \$450 billion a year, which is more than was spent on Medicaid in 2009.^{1,3} The number of family (informal) caregivers is expected to surge as the population ages and traditional federal and state support diminishes.

The burdens placed on informal caregivers include the physical, emotional, social, and financial costs related to caring for a loved one, all of which can affect quality of life (QOL).^{4–8} Physical demands of caregiving include time spent in hands-on care of the recipient and transportation to medical appointments. Other examples of the physical demands of caregiving include lifting, bathing, and ambulating that can result in caregiver exhaustion, weakness, or tiredness. Family caregivers may suffer from

Author Affiliations: School of Nursing, University of Delaware (Drs Klemm, Hayes, and Diefenbeck); and College of Health Sciences & Delaware Rehabilitation Institute, 25 N. College Ave. University of Delaware (Dr Milcarek), Newark, DE.

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Corresponding author: Paula R. Klemm, PhD, RN, School of Nursing, 25 N. College Ave. University of Delaware, Newark, DE 19716 (klemmpa@udel.edu).

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The overall objectives of this project were to evaluate whether psychosocial outcomes in employed family caregivers of people with chronic disease, who participate in online support, differ from non-active participants and whether psychosocial outcomes differ based on the format of online group support. A randomized longitudinal design comparing two types of online support groups and nonactive participants, on the basis of three principal measures, was utilized. Eighty-six self-reported family caregivers of people with chronic disease, who spoke English and had Internet access, took part in the study. Subjects were randomly assigned to professionally facilitated/psychoeducational or moderated/peer-directed online support groups for a period of 12 weeks. The setting was a password-protected Web page housed on a university server. Independent variables were type of online support groups and level of participation; the dependent variables were depressive symptoms, caregiver burden, and caregiver quality of life. There were significant differences in depressive symptoms and quality of life among nonactive participants and either of the two intervention groups, but not between the two intervention groups. Results suggest that professionally facilitated/psychoeducational and moderated/peer-directed online support groups help reduce depressive symptoms and improve quality of life for those who actively participate and that both types of online support groups provided similar benefits. Men and minorities should be targeted in future caregiver research.

KEY WORDS

family caregivers • Online support groups • psychosocial outcomes

lack of appetite and changes in sleep patterns related to disruptions in their sleep-wake cycle.^{9–11} The emotional effects of providing care for people with chronic illness include feelings of sadness, depression, loneliness, and lack of hope.^{6,12} Several studies note the association between caregiver responsibilities and depressive symptoms.^{13–15} One study, which focused on caregivers of community-dwelling older people, reported increased depressive symptoms in their caregivers.¹⁶ A recent systematic review highlighted the commonalities faced by caregivers of

community-dwelling elderly, which included physical, mental, and financial problems.¹⁷ Out-of-pocket costs and limited insurance benefits that cover custodial care can place a strain on the financial health of caregivers.

The emotional, physical, and financial toll on caregivers may be magnified in those who have other role obligations, including being employed. Almost 57% of family caregivers are employed, and most of these have been forced to make changes in their job schedules to accommodate caregiving responsibilities.^{13,18} Informal caregivers who work full or part-time must reconcile the responsibilities of both activities in addition to the other role obligations in their lives. Work responsibilities coupled with caregiver duties have been associated with detrimental health effects of caregivers.^{13,18} For some, the physical, emotional, and financial impacts of caregiving are overwhelming. As a result, many seek outside support to help them cope with the disruptions of caregiving in daily life.

Eighty percent of Americans have sought health-related information online.¹⁹ Among informal caregivers, 79% have access to the Internet, and 88% of those seek information online to find information related to caregiving.²⁰ E-caregivers listed support groups as one of the top 20 essential sources of information found online.²¹ Most online support groups (OSGs) do not use a professional healthcare facilitator (nonfacilitated). Nonfacilitated (peer-led, self-help) OSGs are easy to set up and inexpensive to run; enrollment is immediate, and limits are usually not placed on the number of participants in the group or the length of time members may belong to the group. In contrast, online groups that use a professional facilitator may be restricted in size, be offered for a limited period (eg, 12 weeks), or place potential participants on a waiting list until a new group is formed.^{14,22–25} Regardless of the format, OSGs depend on active participation and supportive exchanges between members.^{14,23,24,26,27} A few studies report that nonparticipants (ie, lurkers) may benefit from online groups.^{28–30} However, lurkers benefited only if they actively read messages posted to the online groups, even if they posted few or no messages of their own.

Information on how the format of online support affects psychosocial outcomes is limited, and reports on the efficacy of online support are mixed. Several studies indicated that online support helped reduce depressive symptoms, lower response to pain, empower patients, and reduce stress.^{23,31–33} Two reports argued that the format of online support was not as important as the support itself.^{14,34} Other research suggested that there was no difference in outcomes between online peer-led support groups and controls or those who used online support and those who did not.^{35,36} A systematic review of the efficacy of online support for cancer patients conducted by Hoey and colleagues³⁴ indicated that the overall quality of the available research on online support was fair to poor and was primarily focused on women with breast cancer. Another

systematic review by Griffiths and associates²⁷ cited a lack of high quality evidence to support efficacy of online support to reduce depressive symptoms (Griffiths, Calcar, Banfield, & Tam, 2009).

Given the demands placed on employed family caregivers and the burdens associated with their role, non-traditional (online) and innovative support programs that address their needs are warranted. The literature provides scant information on the efficacy of online support for employed family caregivers. No research on family caregivers has explored differences in psychosocial outcomes between employed family caregivers who participate in OSGs and nonactive participants. Nor is there information on whether psychosocial outcomes differ based on the format of online support (eg, professionally facilitated/psychoeducational or moderated/peer directed). Outcomes from this study will build knowledge on the efficacy of online support for employed informal caregivers and provide a foundation for developing targeted online intervention strategies to meet their needs.

Purpose

The overall objectives of this project were to evaluate (1) whether psychosocial outcomes in employed family caregivers of people with chronic disease who participate in online support differ from nonactive participants and (2) whether psychosocial outcomes in employed family caregivers of people with chronic disease differ based on the format of online group support. The hypotheses were as follows:

- H1a: Caregivers who participate in professionally facilitated/psychoeducational online support will report fewer depressive symptoms than will nonactive participants.
- H1b: Caregivers who participate in moderated/peer-directed online support will report fewer depressive symptoms than will nonactive participants.
- H1c: There will be no difference in depressive symptoms between caregivers who participate in professionally facilitated/psychoeducational online support and caregivers who participate in moderated/peer-directed online support.
- H2a: Caregivers who participate in professionally facilitated/psychoeducational online support will report less perceived burden than will nonactive participants.
- H2b: Caregivers who participate in moderated/peer-directed online support will report less perceived burden than will nonactive participants.
- H2c: There will be no difference in caregiver stress between caregivers who participate in professionally facilitated/psychoeducational online support and caregivers who participate in moderated/peer-directed online support.

- H3a: Caregivers who participate in professionally facilitated/psychoeducational online support will report better QOL than will nonactive participants.
- H3b: Caregivers who participate in moderated/peer-directed online support will report better QOL than will nonactive participants.
- H3c: There will be no difference in QOL between caregivers who participate in professionally facilitated/psychoeducational online support and caregivers who participate in moderated/peer-directed online support.

search study. Only caregivers assigned to the group and members of the research team had access. Study questionnaires were completed online from a university-sponsored link. The independent variables were the treatment conditions (ie, OSGs) (professionally facilitated/psychoeducational, moderated/peer-directed, and nonactive participants). The professionally facilitated/psychoeducational OSGs were led by a member of the research team in a semistructured format for a period of 12 weeks using asynchronous communication. The moderated/peer-directed OSGs were monitored by the principal investigator (PI) in an unstructured format for a period of 12 weeks, using asynchronous communication. Two groups were run in each format (total of four groups). Nonactive participants completed the research questionnaires online over the course of the study but did not participate in an OSG. The dependent variables were depressive symptoms, caregiver burden, and QOL.

METHODS

Research Design

This study incorporated a randomized longitudinal design, comparing two types of OSGs and active and nonactive participants on the basis of three principal measures. Each measure was obtained at baseline and at two later time points. Randomization to type of online support (professionally facilitated/psychoeducational or moderated/peer directed) was used to create comparison groups of caregivers for each type of online support. Nonactive participants were those who completed informed consent and answered the study questionnaires, but who did not participate in the online discussions. These “nonactive participants” posted and/or read four messages or fewer on the OSGs.

Sample

Eighty-six participants, who were employed caregivers for people with chronic illness, were randomly assigned to one of two treatment conditions (ie, OSGs): professionally facilitated/psychoeducational or moderated/peer-directed. The OSGs were run over a period of 12 weeks, and guidelines for running OSGs put forth by the American Cancer Society were followed.^{37,38}

Inclusion/Eligibility Criteria

The inclusion/eligibility criteria were self-reported caregiver for a person with chronic disease; employed full or part-time, 40 years or older, with Internet access, and able to read and write English.

Setting

The OSGs were accessed from a password-protected university-owned Web page devoted exclusively to the re-

Measures and Instruments

A personal profile form was utilized to collect demographic data and information related to caregiving (eg, relationship to care recipient, type of care provided). Depressive symptoms were defined as self-report scores on the Center for Epidemiologic Studies–Depression Scale (CES-D), a 20-item self-report scale widely used in the assessment of depressive symptoms.³⁹ Scores may range from 0 to 60. Cutoff scores of 16 or greater are associated with more depressive symptoms, although some sources suggest a score of 27 as a cutoff for further evaluation for depression.^{40,41} Caregiver burden was defined as scores on the Modified Caregiver Strain Index (CSI), consisting of 13 items designed to measure the effects of caregiving in major domains that include employment, finances, physical, social, and time. Scores range from 0 to 26, with higher scores indicating higher caregiver stress. Internal consistency reliability was reported between $\alpha = .86$ and $.90$.^{42,43} Quality of life was defined as scores on the Caregiver Quality-of-Life Index (CQoL-I), a four-item scale that measures caregiver QOL in four domains: physical, psychological, social, and financial.^{39,44–46} Scores range from 0 to 100, with higher scores indicating greater QOL.

Procedure

Once human subjects approval was obtained, employees of the University of Delaware 40 years or older were identified by the Office of Human Resources (HR). In order to ensure privacy, HR directly contacted potential subjects by e-mail and invited them to participate in the study. Those who wished to participate contacted the PI via e-mail. Once eligibility was confirmed, the PI sent an

e-mail with a direct Internet link to the informed consent form. After informed consent was submitted electronically, participants were assigned to a professionally facilitated/psychoeducational OSG or moderated/peer-directed OSG and given a password in order to access the study Web page. Random assignment was made by group, rather than individually, in order to avoid long wait times for participants. Using a coin flip, it was determined that the first online group would be run in a “moderated/peer-led” format. Subsequently, the second group was run in a professionally facilitated/psychoeducational format and so forth until four groups were completed.

Each of the four (two professionally facilitated/psychoeducational and two moderated/peer directed) OSGs began as soon as 26 subjects were randomly assigned. We chose 26 members as a baseline because the literature indicated that not all participants who signed up for a study would participate, and second, participation in longitudinal studies decreased over time.^{25,27,30,47} All OSGs were accessed from a university-owned Web page designed by the PI and devoted exclusively to this research. Security for each group was provided by a protective release mechanism and a password. The demographic form, CES-D, CSI, and CQoL-I were completed online prior to participation in the 12-week online groups. In addition, participants were asked to complete the CES-D, CSI, and CQoL-I at 6 and 12 weeks. As an incentive to take part, each participant who completed the study and answered all of the questionnaires was awarded a \$25.00 gift certificate.

Professionally facilitated/psychoeducational groups were led by a member of the research team who was a clinical nurse specialist in psychiatric nursing (PMHCNS-BC) with expertise in addressing psychological/psychosocial problems associated with caregiving. They were run in a semistructured format over 12 weeks. Each week, the facilitator introduced a different discussion topic that was pertinent to caregiving. Topics (eg, caregiving tips, depression, fatigue, financial concerns) were chosen based on research that focused on family caregivers of people with chronic illness.^{5,6,48–51}

Moderated/peer-directed groups were run in a self-help format over 12 weeks with no set agenda or weekly topics (peer directed) and were monitored by the PI. At the beginning of each 12-week group, the PI reminded participants of the peer-led format, and topics of discussion would be chosen by the group. The PI indicated that she would monitor the group discussion and act primarily in an observational role but would answer questions that the participants posted specifically to her. The PI posted an open-ended question in week 1 to encourage the subjects to share their experience as caregivers. A welcome message was posted to all OSGs by the PI and provided information about the format for the online discussions and rules of net etiquette. A group of nonactive participants (ie, those who did not read or post messages)

emerged after the end of the 12-week OSGs. Even though these individuals completed the study questionnaires, they were not active in the online groups as they posted and/or read fewer than four messages over the 12 weeks of the intervention.

Data Analysis/Methods

This study was designed to test the significance of differences on three psychosocial scales, between those engaged in either type of OSG (professionally facilitated/psychoeducational or moderated/peer directed) and those who did not take an active part in the online groups. Each of the three groups was described by demographic and caregiving activities. The mean differences among paired groups were tested for age, length of time providing support (years), and hours per week providing support using independent-samples *t* tests. Median differences on total scale scores for CSD, CSI, and CQoL-I scales were tested for significance between nonactive participants and intervention groups (combined) by the Mann-Whitney *U* test, a nonparametric method based on mean rank differences between groups. A Kruskal-Wallis nonparametric analysis of variance (ANOVA) was used to test median differences across all three groups. Mann-Whitney *U* test was used for post hoc contrast tests between groups where indicated by a significant Kruskal-Wallis χ^2 .

RESULTS

Eighty-six caregivers of people with chronic disease took part in the study (moderated/peer directed = 27, professionally facilitate/psychoeducational = 20, nonactive participants = 39). Seventy-seven (89.5%) of 86 were employed full or part-time. Nine participants, who were retired or full-time caregivers, asked to take part in the study and were enrolled. The average age of all participants was 52.23 years (range, 32–76 years) and did not significantly differ by group. Seventy-one (82.5%) were married, five (5.8%) were single, six (6.9%) divorced, and four (4.6%) never married. Eighty-two (95.3%) were white, three (3.4%) were African American, and one (1%) was Hispanic/Latino. Female caregivers outnumbered male caregivers (78 [90.6%] to 8 [9.3%]) (Table 1). Participants provided from less than 1 to 168 hours of care a week, which were not significantly different by group.

Caregivers described themselves most often as a daughter (*n* = 34), spouse (*n* = 17), or mother (*n* = 14) to the care recipient. The most common diseases of the care recipients were dementia, diabetes, stroke, cancer, and heart disease. The most frequent caregiving activities were taking the care recipient to healthcare visits, shopping, paying bills,

Table 1



Demographic Variables for Participants

Variable	n	%	Mean	Range
Age			52.23 y	32–76 y
Race				
White	82	95.3		
African American	3	3.4		
Hispanic Latino	1	1.1		
Gender				
Female	78	90.6		
Male	8	9.3		
Marital status				
Married	71	82.5		
Single	5	5.8		
Divorced	6	6.9		
Never married	4	4.6		
Length of time providing care				
Professionally facilitated/psychoeducational			8.9 y	12 wk to 3 y
Moderated/peer directed			7.6 y	2 wk to 33 y
Nonactive			5.1 y	8 wk to 25 y
Mean hours of care per week				
Professionally facilitated/psychoeducational			78.5 h/wk	1–168 h/wk
Moderated/peer directed			42.15 h/wk	<1–168 h/wk
Nonactive			53.9 h/wk	3–168 h/wk
Relationship to care recipient				
Daughter	34	39.5		
Spouse	17	19.7		
Mother	14	16.2		
Son	5	5.8		
Daughter-in-law	3	3.4		
Granddaughter	3	3.4		
Grandson	1	1.1		
Sister	1	1.1		
Disease of care recipient				
Dementia	20	23.2		
Diabetes	16	18.6		
Stroke (cerebrovascular accident)	13	15.1		
Cancer	12	13.9		
Heart disease	12	13.9		
Alzheimer's disease	3	3.4		
Type of care provided				
Take to appointments (eg, physical therapy)	74	86		
General shopping	68	79		
Food shopping	65	75.5		
Pay bills	59	68.6		
Prepare meals	58	67.4		
Take to laboratory tests (eg, blood, radiograph)	58	67.4		
Prepare medicines	43	50		
Answer mail	41	47.6		
Help getting dressed	29	33.7		
Give medicines	27	31.3		
Help to toilet	20	23.2		
Change bandages	10	11.6		
Feed meals	7	8.1		
Other: pay attendants, wash hair, laundry, put to bed, emotional support, visit				
Currently belong to Internet support group				
Yes	3	3.4		
No	83	96.5		
Currently belong to face-to-face support group				
Yes	14	16.2		
No	72	83.7		
Currently taking medicine for treatment of depression				
Yes	20	23.2		
No	66	76.7		

Table 2

Baseline CES-D, CSI, and CQoL-I, Mean Scores, SDs, and Ranges by Group



Instrument	Professionally Facilitated Psychoeducational	Moderated Peer Directed	Nonactive participants
CES-D			
Mean	17.40	17.41	19.87
SD	13.008	12.036	13.590
Range	0–45	1–46	1–45
CSI			
Mean	12.00	13.78	11.82
SD	6.366	4.726	5.872
Range	4–24	2–22	1–23
CQoL-I			
Mean	61.00	55.70	52.16
SD	20.204	20.957	23.499
Range	32–95	21–87	9–96

preparing meals, taking to laboratory tests, preparing medicines, and answering mail. Only 3% (n = 3) of caregivers reported that they belonged to another OSG, whereas 14

(16%) attended face-to-face support groups at least occasionally. Twenty of the caregivers (23%) reported that they took medication for the treatment of depression, which did not differ by group (Table 1).

Active participation was described in this study as those who read and/or posted more than four messages over 12 weeks. Using a software program that was able to track the number of messages that were read and posted by members of the OSGs during the study the groups of active and nonactive participants were identified. The mean numbers of messages read by active participants in the professionally facilitated/psychoeducational groups were 99.85 (range, 8–221) and 156.25 (range, 5–360) for the moderated/peer-directed groups. The mean numbers posted by the professionally facilitated/psychoeducational groups were 5.5 (range, 0–20) and 9.5 (range, 0–34) for the moderated/peer-directed groups. These differences were not significant. The attrition rate over 12 weeks was 12% in the moderated/peer-directed groups and 20% for the professionally facilitated/psychoeducational groups. This was in comparison to the nonactive participants group, with an attrition rate of 61.5%.

Table 3Mann-Whitney *U* Test: Participation in Either a Professionally Facilitated/Psychoeducational or Moderated/Peer-Directed Group as Intervention Versus No Intervention (Nonactive Participants)

Time	Scale	Group	n	Mean Rank	Mann-Whitney <i>U</i> Test (<i>P</i>)	
Baseline	Sum CES-D	Nonactive	39	45.81	.435	
		Either group	47	41.59		
		Total	86			
	Sum CSI	Nonactive	38	40.18		
		Either group	47	45.28		
		Total	85			
	Sum CQoL-I	Nonactive	38	39.43		.343
		Either group	47	45.88		
		Total	85			
6 wk	Sum CES-D	Nonactive	17	36.21	.231	
		Either group	40	25.94		
		Total	57			
	Sum CSI	Nonactive	16	26.63		
		Either group	41	29.93		
		Total	57			
	Sum CQoL-I	Nonactive	15	18.80		.499
		Either group	41	32.05		
		Total	56			
12 wk	Sum CES-D	Nonactive	11	31.86	.007	
		Either group	35	20.87		
		Total	46			
	Sum CSI	Nonactive	11	16.45		
		Either group	35	25.71		
		Total	46			
	Sum CQoL-I	Nonactive	11	13.23		.018
		Either group	35	26.73		
		Total	46			
	Sum CES-D	Nonactive	11	13.23	.046	
		Either group	35	26.73		
		Total	46			
	Sum CSI	Nonactive	11	13.23		
		Either group	35	26.73		
		Total	46			
	Sum CQoL-I	Nonactive	11	13.23		.004
		Either group	35	26.73		
		Total	46			

Table 4

Kruskal-Wallis Nonparametric ANOVA: Differences Between Groups



Time	Scale	Group	n	Mean Rank	Kruskal-Wallis χ^2 (P)		
Baseline	Sum CES-D	Nonactive	39	45.81	.732		
		Peer led	27	41.96			
		Professionally facilitated	20	41.08			
		Total	86				
	Sum CSI	Nonactive	38	40.18			
		Peer directed	27	49.44			
		Professionally facilitated	20	39.65			
		Total	85				
	Sum CQoL-I	Nonactive	38	39.43		.257	
		Peer directed	27	43.93			
		Professionally facilitated	20	48.53			
		Total	85				
6 Weeks	Sum CES-D	Nonactive	17	36.21	.094		
		Peer directed	21	26.95			
		Professionally facilitated	19	24.82			
		Total	57				
	Sum CSI	Nonactive	16	26.63			
		Peer directed	22	31.11			
		Professionally facilitated	19	28.55			
		Total	57				
	Sum CQoL-I	Nonactive	15	18.80		.704	
		Peer directed	22	32.70			
		Professionally facilitated	19	31.29			
		Total	56				
12 Weeks	Sum CES-D	Nonactive	11	31.86	.026		
		Peer directed	21	19.98			
		Professionally facilitated	14	22.21			
		Total	46				
	Sum CSI	Nonactive	11	16.45			.053
		Peer directed	21	24.24			
		Professionally facilitated	14	27.93			
		Total	46				
	Sum CQoL-I	Nonactive	11	13.23		.099	
		Peer directed	21	27.21			
		Professionally facilitated	14	26.00			
		Total	46				
					.014		

Mean scores for the three groups on depressive symptoms (CES-D), caregiver burden (CSI), and caregiver QOL (CQoL-I) at baseline are listed in Table 2. Table 3 summarizes Mann-Whitney *U* test results based on participation in either a professionally facilitated/psychoeducational or moderated/peer-directed group as intervention versus nonactive participants. No significant baseline differences were observed between groups. At 6 weeks, the intervention respondents reported significantly lower CES-D scores and significantly higher CQoL-I scores. At 12 weeks' intervention (ie, OSGs), respondents reported significant differences on all three instruments, compared with nonactive respondents (eg, lower CES-D and higher CQoL-I). These results support the idea of a "broadening" effect of peer and professional support (combined) over time.

Kruskal-Wallis nonparametric ANOVA results are presented in Table 4. No significant differences among the three groups were observed at baseline. At 6 weeks, CQoL-I shows a significant difference. At 12 weeks, CES-D and CQoL-I show a significant difference among groups. Table 5 summarizes post hoc contrast results based on Mann-Whitney *U* test. At 6 weeks, CQoL-I scores for both professionally facilitated/psychoeducational and for moderated/peer-directed groups were significantly higher than those for nonactive participants. The significant result for CSI at 12 weeks was considered uninterpretable because the omnibus Kruskal-Wallis test for group differences on this scale did not achieve significance at $P \leq .05$. At 12 weeks, CQoL-I and CES-D scores for both professionally facilitated/psychoeducational and moderated/peer-directed groups were

Table 5Mann-Whitney Post Hoc for Kruskal Wallis (*P* Values)

	Sum CES-D	Sum CSI	Sum CQoL-I
Nonactive vs moderated/peer directed			
Baseline	.557	.135	.536
6 wk	.103	.514	.007
12 wk	.028	.095	.008
Nonactive vs professionally facilitated/psychoeducational			
Baseline	.471	.935	.145
6 wk	.034	.596	.041
12 wk	.043	.051	.012
Moderated/peer directed vs professionally facilitated/psychoeducational			
Baseline	.940	.181	.643
6 wk	.735	.521	.875
12 wk	.521	.371	.711

significantly different from those of nonactive participants (CQoL-I higher and CES-D lower).

DISCUSSION

In summary, there were significant differences in CES-D scores between nonactive participants and either of the two intervention groups (H1a and H1b) but not between the two intervention groups (H1c) at week 12. Therefore, H1a, H1b, and H1c were supported. Counter to the initial hypotheses, no significant differences in CSI scores between nonactive participants and either of the two intervention groups (H2a, H2b) were found. Therefore, H2a and H2b were not supported. As hypothesized, no significant differences between the two intervention groups (H2c) at week 6 or 12 were found. Therefore, H2c was supported. There were significant differences in CQoL-I scores between nonactive participants and either of the two intervention groups (H3a and H3b), but not between the two intervention groups (H3c) at weeks 6 and 12. Therefore, H3a, H3b, and H3c were supported.

The characteristics of the sample for this study reflect others in which employed caregivers were primarily female, middle-aged, white, and married.^{13,15,52,53} It is also reflective of the employees at the university at which this study was conducted. Giovannetti et al¹³ designed a cross-sectional study on work productivity and activity impairment in informal caregivers to older and chronically ill patients. The average age of the employed caregivers ($n = 125$) was 53.4 years similar to the current study. However, the mean on the CES-D at baseline (7.1/6.9) was lower than that reported by caregivers in the current study (Table 2). In addition, the number of hours of care assistance provided per week was considerably lower (mean, 16.6 h/wk) than the overall mean found in the current study (mean, 55.32 h/wk). Nonemployed caregivers ($n = 183$) in the study of Giovannetti et al provided 30.0 hours of care per week,

which is still lower than that in the current study. Therefore, even though the demographic characteristics of the caregivers in these two studies were similar, the baseline CES-D scores and hours of care that were provided were noticeably different. The reasons for these differences may be related to an intervention specifically designed to support informal caregivers called the Guided Care Program for Families and Friends (GCPFF) and from which the participants were recruited.^{13,54} An RN worked closely with primary care physicians to help meet the needs of patients and caregivers. The program included an assessment of the patient in his/her home, monitoring the patient's condition, coaching the patients to healthy behaviors, facilitating access to community resources, and educating and supporting the patient's informal caregiver(s). These interventions may have helped streamline healthcare to patients, thus reducing the number of hours of care that might otherwise be provided by informal caregivers. The study of Giovannetti et al utilized a cross-sectional design, and it is not known at what point in the GCPFF program the caregivers were recruited. It may be that the lower caregiver CES-D scores and hours of care provision were measured after some participation in GCPFF intervention.

According to a 2009 report, informal caregivers who provided 46.9 or more hours of care per week were considered to provide a "high" level of care and have a "high" care burden.¹⁸ The mean hours of caregiving per week provided by participants in the current study exceeded this number in both the professionally facilitated/psychoeducational and nonactive participants. The moderated/peer-directed group mean was lower (mean, 41.76), but might be considered at the upper end of the "medium" burden category.

The high degree of caregiver burden in the current study may help explain the modestly elevated CES-D scores (≥ 17) for all groups at baseline (Table 2). A cutoff score of 16 is commonly used as a measure of more depressive symptoms.³⁹⁻⁴¹ Over the course of this study, the CES-D means of the nonactive participant group increased from 19.87 at baseline to 26.09 at 12 weeks. This compared with baseline mean CES-D scores for both OSGs (professionally facilitated/psychoeducational mean, 17.40; moderated/peer-directed mean, 17.41) dropping after 12 weeks (professionally facilitated/psychoeducational mean, 13.43; moderated/peer-directed mean, 12.43). These numbers suggest that both professionally facilitated/psychoeducational and moderated/peer-directed OSGs helped decrease depressive symptoms over time as compared with nonactive participants and that the format of the OSGs may not be as important as active participation in a group, regardless of format.

A cross-sectional study of state-wide community-dwelling residents in Connecticut yielded 767 caregivers, most of whom cared for older relatives (79%) or spouses (12%).¹⁵ The researchers reported on the impact of caregiving on health and psychosocial outcomes including depressive symptoms

and social isolation. As in the current study, most of the caregivers were middle-aged, working females. The CES-D was used to measure depressive symptoms in the community sample of caregivers, but statistical means were not reported. Rather, CES-D scores were entered into a series of logistic regressions, which indicated that depressive symptoms were associated with inadequate income and reported unmet needs for caregiving services. Caregivers who reported inadequate income were four times more likely to have depressive symptoms. In addition, those who reported unmet caregiving needs were 65% more likely to have depressive symptoms. In the current study of employed caregivers, income and financial need were not tracked over time. Therefore, it was not possible to explore whether financial issues affected CES-D scores.

Giovannetti and colleagues measured several baseline caregiver characteristics including caregiver strain and utilized the same instrument (CSI) as in the current study.¹³ Baseline mean score for employed caregivers on the CSI was 7.5 (SD, 5.7), lower than those found in the current study (Table 2). The lower mean may be a function of the hands-on GCPFF interventions provided by the healthcare team as described by Giovannetti and colleagues. It makes sense that caregivers who have more depressive symptoms and more perceived caregiver strain at baseline are more likely to join an OSG than those who are less affected psychologically by caregiving.

In the current study, CSI scores reflected moderate caregiver burden, which did not differ significantly by group. Overall, the baseline CSI means of the nonactive participants and those in the two OSGs were higher than those in a report that focused on the health-related QOL and strain in a study of 97 caregivers of patients with Parkinson's disease, where the reported mean was 5.0.⁵⁵ Interestingly, CSI scores for the nonactive participants in the current study decreased from baseline to week 12, whereas their CES-D scores increased. Conversely, CSI scores for the two OSGs increased over 12 weeks, and CES-D decreased. One explanation for this may be that the number of hours of care and extent of care provided by caregivers in the current study were reported at baseline only. It is possible that objective caregiver burden (eg, number of hours of care per week or kind of care) changed and led to differences in perceived (subjective) burden over 12 weeks. A larger sample may have distinguished significant differences in CSI scores over time or a predictive relationship between CSI and CES-D scores. Even though CSI scores increased for participants in the OSGs, the results suggest that the OSGs were beneficial to QOL and helped reduce depressive symptoms despite increased caregiver burden.

Research on 231 women with breast cancer, who took part in online support, was the focus of a 2012 study to examine social support exchanges among the online group participants.²⁴ The mean age of the participants was 51.37 years, and they were primarily white, similar to the

current study. The online groups in this study were text based and asynchronous and allowed women to share information and support anonymously. As in the current study, the participation in the online groups was tracked. Of the 231 women who took part in the study, 177 were described as "active" participants if they read at least one message. One could argue that "active participation" (ie, reading or posting one message), as described by Kim and colleagues,²⁴ would be unlikely to provide psychosocial benefits to participants. However, the researchers emphasized the importance of supportive exchanges in the online group and their positive effects on psychosocial outcomes. Given this information, it should not be surprising that active OSG participants in the current study reported fewer depressive symptoms and higher QOL than did nonactive participants, who did not participate in the online groups.

Quality-of-life scores differed over time between groups in the current study. Scores on the CQoL-I decreased over the 12 weeks of the study for the nonactive participants, whereas scores increased for the two OSGs. These differences were significant. Salzer and colleagues³⁶ described a randomized controlled study of a nonmoderated peer-to-peer OSG for women with early-stage breast cancer. Although the study was underpowered, the findings suggested that the sample of women with breast cancer (N = 51) who participated in a nonmoderated Internet support group had decreased QOL. The authors suggested that this might be due to the absence of a trained group moderator and the fact that all of the women in the group had early-stage cancer. Thus, they may not have had access to long-term breast cancer survivors in the group who might provide additional support to them. In the current study, caregivers in both the moderated/peer-directed groups and the professionally facilitated/psychoeducational groups reported higher QOL after 12 weeks of online participation. This may be partially explained by the fact that the groups were composed of caregivers with a wide range of caregiving experience. Perhaps those who were caregivers for longer periods offered experiential support to those who were new to caregiving.

Attrition rates in the current study varied by group (professionally facilitated/psychoeducational = 20%, moderated/peer directed = 12%, nonactive participants = 61.5%). Overall attrition was 34.8%. Given the higher than anticipated attrition of sampled participants over the 12-week time frame of this study, post hoc power for Mann-Whitney *U* tests was calculated as follows: CES-D = 0.60, CSI = 0.43, and CQoL-I = 0.78. The absence of differences in the CSI scores among groups cannot rule out low power and therefore may be false-negative findings. A larger sample size may be needed in future studies to determine this. Attrition is a common problem in longitudinal studies and in research that focuses on online interventions with repeated measures.^{27,30,47,56} A systematic review of available evidence was conducted by researchers in Australia

to help determine the effect of OSGs on depressive symptoms.²⁷ Twenty-eight articles were included in the review. The authors noted dropout (attrition) rates of up to 37% for studies that included intervention and control conditions. High attrition rates are commonplace in online research and should be expected when planning study parameters and recruitment activities.

LIMITATIONS

This study had several limitations. Although participants were randomized by group, they were self-selected employed caregivers primarily from a single work environment that may be unique. Most participants were middle-aged, white women who read and spoke English, which limits the generalization of the results. Attrition rates, especially in the nonactive participant group, may have biased the results but are generally consistent with those in similar studies of online groups. Finally, the OSGs were limited to those who had computer access and some degree of computer literacy.

CONCLUSIONS

This study provided information about the effects of format of OSGs as well as active versus nonactive participation on informal caregivers providing care for patients with a variety of chronic conditions. Results suggest that both professionally facilitated/psychoeducational and moderated/peer-directed OSGs help reduce depressive symptoms and increase QOL for active participants, but not for nonactive participants. There were no significant differences in median scores on the CSI between groups, although scores for nonactive participants decreased, whereas those for the two OSGs increased. This may be because only a one-time objective measurement of caregiver burden (eg, length of time providing care, care activities, number of hours of care per week) was made, so any changes in caregiving burden over time (which may have affected CSI scores) are not known. Scores on any of the outcome measures between the two OSGs were not significantly different at baseline, 6 weeks, or 12 weeks (Table 5). This suggests that the format of online support may not matter as much as providing support itself to informal caregivers. This conclusion seems to be supported by the fact that nonactive participants, who did not actively participate in the OSGs, had significantly higher median scores on the CES-D and CQoL-I at the end of the 12-week intervention.

RECOMMENDATIONS FOR PRACTICE

The results of this study suggest that the formats of the OSGs (professionally facilitated/psychoeducational,

moderated/peer directed) provided similar benefits to participants. However, at least one study indicated that nonmoderated peer-to-peer OSGs may have negative effects.³⁶ Future research should compare unmoderated, moderated, and professionally facilitated groups for psychosocial outcomes. This knowledge would inform recommendations by healthcare professionals to patients and/or caregivers who are interested in online support.

The group interventions in this study lasted for 12 weeks. The long-term benefits are unknown. Additional research should target long-term effects of caregiver participation in OSGs. Attrition rates in online groups are frequently high. Perhaps individuals who join online groups are less committed to active participation because there is no face-to-face interaction with the associated pressure to attend. A group moderator or group facilitator could track participation and contract those whose participation has decreased or stopped entirely. Lack of participation may be due to a variety of reasons (eg, change in health status of the caregiver, group is not perceived to be helpful, care recipient has died), which would be useful to know and may help make the group more receptive to the needs of participants.

Researchers should actively overrecruit when planning online longitudinal studies. Men and minorities are underrepresented in caregiver reports. Therefore, these groups should be targeted in future research on caregivers. The current study focused on caregivers who provided care for patients with a wide variety of chronic conditions. It may be that caregivers of patients with specific conditions (eg, stroke, heart disease, cancer) may have different needs that should be addressed in disease-specific OSGs.

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