

A Different Kind of

Caregiving Support Group

Therapeutic writing was used to decrease stress and help group members cope.

The U.S. Census Bureau's 2000 demographic trends indicate that a rapidly increasing elderly population is living well beyond younger, more functional ages and into the "old-old" stage (\geq age 75), when debility is more common (Hetzel & Smith, 2000). Increasingly, family members and friends are being called on to provide complex levels of care for older loved ones, which leads to both psychological and physiological stressors for the caregivers (Donelan et al., 2002). A variety of interventions have been implemented to help caregivers cope with the stresses associated with this demanding role. This article describes a demonstration project that evaluated the effects of a writing support group for caregivers of frail older adults.

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LITERATURE REVIEW

Caregiver Stress

The literature on caring for aging relatives documents the burden, stresses, and consequences of caring for older adults in the home setting (Kaasalainen, Craig, & Wells, 2000; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). Although rewards are gained from caregiving for an older relative or friend (Eliopoulos, 2001; Martin-Cook, Trimmer, Svetlik, & Weiner, 2000), providing constant care for frail older adults in the home can also be physically and mentally debilitating (Chenier, 1997; Travers, 1996).

In a study of informal caregivers supported by the Robert Wood Johnson Foundation (Foundation for Accountability & Robert Wood Johnson Foundation, 2001), caregivers were described as a population at risk because of high rates of emotional illness. For example, the incidence of depression was reported at 22%, or nearly twice the rate for the general popula-

tion. Nolan and Dellasega (1999) found that even after caregiving ceases due to death or institutionalization, exhausted caregivers continue to report health problems.

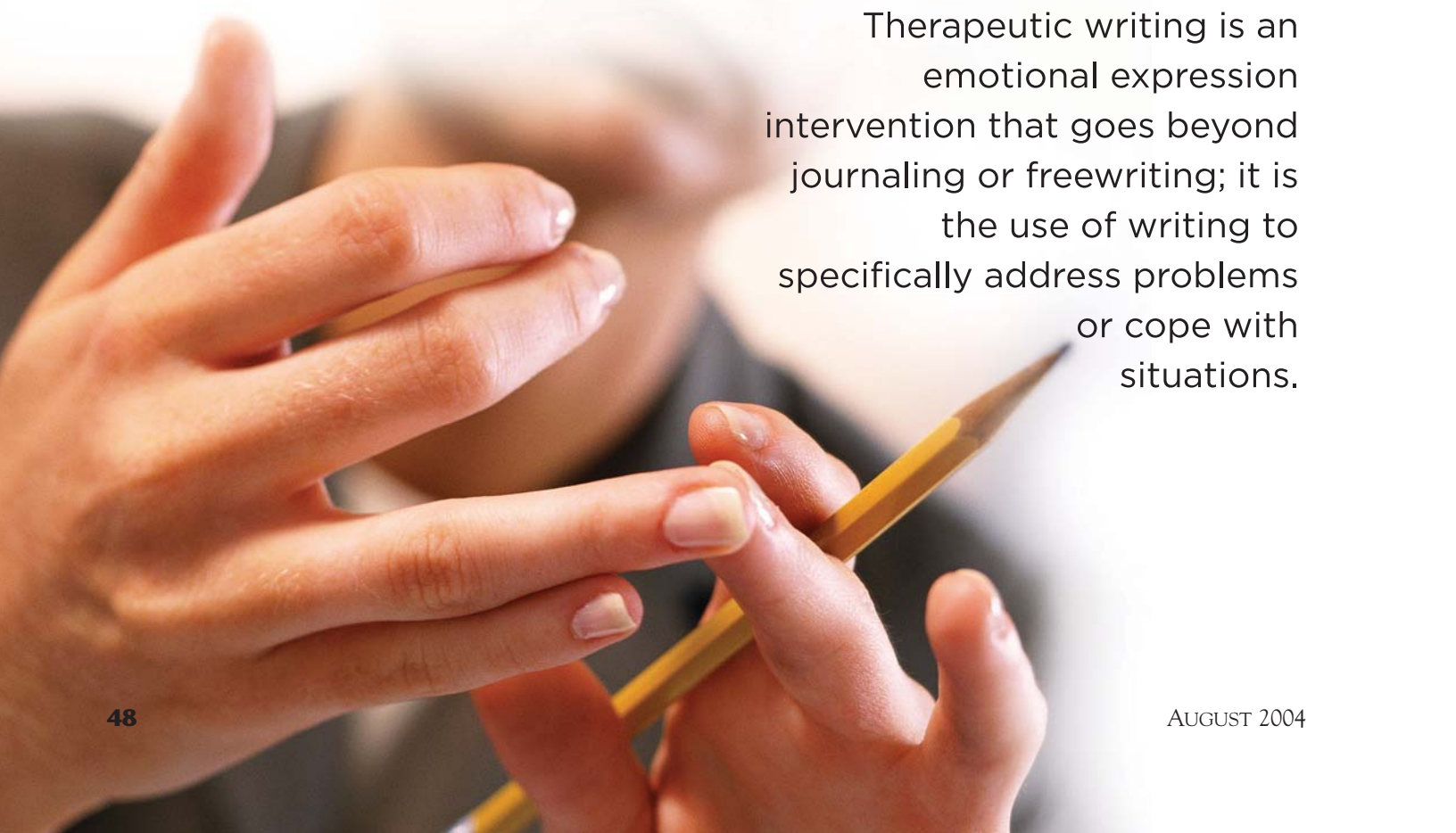
There are many psychosocial issues related to caregiving. Social isolation is common and is caused by the numerous time-consuming, care-related activities that may preclude caregivers' contact with others (Boland & Sims, 1996; Hardy & Riffle, 1993). Similarly, role strain can occur from balancing the multiple tasks of caregiving with other responsibilities such as employment, providing for other family members, and personal commitments (Ruppert, 1996; Scharlach, 1994). Family issues, which often focus on negotiating caregiving responsibilities with siblings and managing spousal and child relationships, are pervasive (Martin-Cook et al., 2000; Smith, Smith, & Toseland, 1991). Financial issues are also a reported stressor for caregivers because out-of-pocket expendi-

tures for health care of older adults can accumulate to the point of being burdensome. In addition, the time spent providing care may interfere with or preclude employment. (Dean, 1995; Donelan et al., 2002; Robinson, 1997; Travers, 1996).

Interventions for Caregiver Stress

A variety of approaches have been used to address problems associated with caregiving stress. Skill training interventions can help caregivers acquire the necessary behavioral, cognitive, and social competencies that aid in caring (Farran, 2001; Ostwald et al., 1999). Stress management techniques have also been used to help caregivers cope with the multiple stresses and strains of caregiving (Bourgeois, Schultz, & Burgio, 1996).

Other interventions have been symptomatically focused to provide caregivers with psychiatric therapies, such as individual counseling or medication management. Respite care has been



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found to be effective in providing short-term relief for caregivers (Labrecque, Peak, & Toseland, 1992), and caregiver support programs have a positive effect on morale (Kaasalainen et al., 2000). In tailoring a support group to address the needs of caregivers, Nolan and Dellasega (1999) found that an expert-led group that incorporated principles of stress management was able to improve the use of beneficial coping behaviors.

Support Groups

For many caregivers, support groups are their primary source of help with stress and burden (Toseland & Rossiter, 1989). Support groups are effective in mediating the social isolation that results from caregiver responsibilities (Hardy & Riffle, 1993; Toseland, 1990). Increased social contact can alleviate depressive symptoms, which allows caregivers to derive more satisfaction from their social networks and feel a sense of decreased burden (Labrecque et al., 1992; Mittelman et al., 1995). In support groups, the opportunity to reflect on significant personal and emotional stressors related to caregiving may offer caregivers a means of integrating these experiences. Sharing feelings, receiving affirmation, and exchanging information are other positive outcomes of these groups (Hardy & Riffle 1993; Labrecque et al., 1992).

Support groups can be led by either laypeople (i.e., self-help groups) or professionals. Self-help groups are initiated and conducted by the participants, while groups led by professionals are conducted by clinicians with group skills. Both types of groups have been found to be effective (Humphreys, 1997; Kessler, Mickelson, & Zhao, 1997). The

general principles of support groups (i.e., social networking, exploring problem-solving methods, and encouraging participants to view themselves in a more positive light) may make them an effective method for intervening with many of the problems associated with caregiving (Haber, Krainovich-Miller, McMahon, & Price-Hoskins, 1997).

However, support groups may be problematic because they rely on verbalization of thoughts and feelings in the presence of others, many of whom may be strangers. Some caregivers may have difficulty speaking in a group setting due to their perceived lack of communication skills or self-confidence. Similarly, concern about confidentiality may impede or prevent verbal participation (Johnson, 1997). Even after group cohesion has been obtained, some people would rather keep their feelings contained.

Therapeutic Writing

McGihon (1996) suggested that writing is a particularly effective therapeutic tool for people reluctant to speak in a group setting. Therapeutic writing is an emotional expression intervention that goes beyond journaling or freewriting; it is the use of writing to specifically address problems or cope with situations (McArdle & Byrt, 2001). Decades of study by Pennebaker and colleagues (Francis & Pennebaker, 1992; Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990; Pennebaker & Susman, 1988) have demonstrated that the simple act of writing for 20 minutes per day for four consecutive days can reduce stress and improve health. A clinical trial by Smyth, Stone, Hurewitz, and Kaell (1999) showed that use of therapeutic writing could improve physical

TABLE 1
DEMOGRAPHICS OF STUDY
PARTICIPANTS (n = 8)

Characteristic	n (%)
Gender	
Male	2 (25.0)
Female	6 (75.0)
Education	
High school	4 (50.0)
Trade school	1 (12.5)
College	3 (37.5)
Employment	
Full time	2 (25.0)
Part time	2 (25.0)
Retired	4 (50.0)
Marital Status	
Married	4 (50.0)
Not married	4 (50.0)
Relationship to older care recipient	
Spouse	5 (62.5)
Parent	2 (25.0)
Other	1 (12.5)
Caregiving location	
At home	2 (25.0)
In nursing home	5 (75.0)
Missing data	1 (12.5)

health parameters for people with rheumatoid arthritis and asthma. Therefore, combining structured writing experiences with a caregiving support group is an approach that could facilitate increased emotional expression. The purpose of this study was to determine whether such an intervention would alleviate caregiver stress.

STUDY PURPOSE

This demonstration project was designed to test the effects of a caregiving support group that incorporated therapeutic writing exercises. The goals were to:

- Study the effects of writing on caregiver stress.
- Test the feasibility of using writing in the support group context.

METHOD

Setting

This project was implemented in an urban area of central Pennsylvania. The sessions were held in the lounge of an assisted living facility that was handicapped accessible, well lit, and private. The room contained comfortable furniture and cages of birds.

Sample

Participants were recruited from the central Pennsylvania community. Any individual who lived independently and self-identified as a caregiver for an older adult was eligible to participate. Potential participants were notified through the local Alzheimer's Association, fliers to nursing homes, and newspaper advertising. To facilitate participation, the facility offered free daycare for the care recipients while the sessions were in progress. One participant chose to bring her care recipient with her. Although the response rate cannot be determined using

these procedures, the most common reason for nonparticipation among those approached directly was lack of time.

Ten caregivers participated in the program, but only 8 provided usable data for all times of measurement. Their demographic details are listed in Table 1. Most participants were women of late middle age who were providing care for a spouse.

Procedure

The project was submitted to and approved by the Pennsylvania State University Institutional Review Board. A single group pretest-posttest design was used to address the study goals. Prior to the first session, a research assistant obtained informed consent and administered two questionnaires: the Caregiver Information Form (CIF) (Nolan & Dellasega, 1999) and the Perceived Stress Scale (PSS) (Cohen, Karmarck, & Mermelstein, 1983).

The CIF is a 30-question informational sheet that gathers

self-report data on caregiving context. It has been used in a number of previous studies and is a valid measure of key caregiving demographics. Among the items is a request for self-rating of mental and physical health.

The PSS is a 14-item Likert scale that asks participants to rate how often they have felt dimensions of stress during the past month. Response categories ("never," "almost never," "sometimes," "fairly often," and "very often") were scored on a 4-point scale. A lower score indicates less stress. The PSS was selected to specifically capture stress-related emotions immediately before program participation and compare them to participants' perceptions after the program. At the conclusion of the four sessions, these questionnaires were re-administered. Internal reliability for the PSS was .87.

The intervention consisted of four 90-minute sessions designed by the first author (C.D.), an experienced support group facilitator, writer, and geriatric nurse

TABLE 2
WRITING PROGRAM CONTENT

Session	Content Focus	Readings During Session
Session 1: "Taking On"	Assuming the caregiving role. How caregiving is (and is not) like a career.	Essay on changing roles from Bagnall (1994).
Session 2: "Learning the Ropes"	Learning caregiving tasks and emotional responses.	An article that describes the "tasks" of caregiving experienced by one woman (Levine, 1999).
Session 3: "Acceptance"	Accepting the caregiving situation.	<i>10 Tips for Family Caregivers</i> (National Family Caregivers Association, n.d.). Guest speakers and authors read from their published books on caregiving and acceptance of their loved ones' illness or disability.
Session 4: "Sharing Your Story"	Sharing with others or continuing to write on their own.	The essay "Moving On" by Susan Kushner Resnick (1992) and the poem "Repayment" by Marsha Owens Hood (1999).

practitioner. The framework for the sessions was the Stress Process Model of family caregiving, which details difficulties specifically associated with care of older adults (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Therapeutic reading and writing exercises designed to accomplish the goal of each session were incorporated into each meeting.

After introductions were made and the program explained, the first session began. Each session was structured to include an opening discussion, reading or writing activities, and processing of content. Writing was optional, as was sharing what one had written, but all participants chose to complete all of the activities, and even wrote additional pieces, which they shared. Readings from published material about caregiving were discussed during each session. A brief summary of the session format can be found in Table 2. A more detailed description of the

TABLE 3

COMPARISON OF PARTICIPANTS' PERCEIVED STRESS SCALE (PSS) SCORES AND SELF-RATED PHYSICAL AND MENTAL HEALTH SCORES BEFORE AND AFTER THE WRITING PROGRAM

Score	Before the Program	After the Program	p Value
Emotional health rating	3.75	6.80	.487
Physical health rating	5.75	8.00	.656
Summed PSS score	20.75	18.63	.004*

* p < .05.

format, or a copy of the booklet *A Writing Support Group for Caregivers* can be obtained from the first author.

RESULTS

PSS and CIF Scores

To measure achievement of goals, participants' PSS scores from before and after the program were compared using a paired *t* test. As an additional measure of stress reduction, scores from two items on the CIF that asked participants to self-

rate their physical and mental health (on a scale of 1 to 10, with 10 being the best) were also compared. These results are shown in Table 3.

The results indicate that participants' physical and mental health improved, but not significantly. There was a significant reduction in stress scores for the immediate time when the program was taking place. However, given the extremely small sample, these results are very preliminary.

<i>In-Session Activity</i>	<i>Take-Home Assignment</i>
Create a poem on what it means "to care."	Write about "my caregiving career."
Free write on one caregiving task and the emotional response to it.	Write a poem, story, or letter that begins with the words "in for the long haul."
While listening to music from the CD <i>When It's Time for Letting Go</i> (1997), participants think about the moment they said "good-bye" (i.e., realized the person for whom they were caring was no longer the same person he or she was) and write about the experience.	Write about any topic covered so far or continue with the in-session activity related to "the moment I said good-bye."
Discussion of continued writing opportunities, either personal or public.	As inclined.

EXAMPLES OF PARTICIPANTS' WRITINGS

From Session 1

Some of the ways in which caregiving is like a career:

- Challenging
- Demanding
- Anguishing
- Time consuming
- Tedious
- Repetitious

Some of the ways in which caregiving is not like a career:

- Not by choice
- Burdensome
- Lack of dialogue
- A one-way street

The demands are non-relenting, mandating a strong inner strength, which is often lacking 24 hours a day, never ending. Always expecting the expected and always disappointed with the ever-reinforced diminutions of ability.
~ A male caregiver

From Session 4

There are many moments when I say "good-bye." From denial to acceptance is a long journey. As long as he knew who I was, I felt he was still there. Yesterday, he seemed to know me from the way that he looked at me, for the first time in months. From the beginning, it was difficult to assess if he knew where he was. The first year he was in nine places, including hospitals. His decline was swift. I'll never know if he could have been kept home if his descent would have been as rapid. I feel poor medicine has [had] a great hand in this. He was [an] intelligent and good-humored person with a sharp sense of humor, a wonderful husband, and [a] caring father.

~ Female caregiver for spouse

Open-Ended Evaluation

In addition to the questionnaire data, open-ended questions about the group were asked after completion. Participants agreed that the support group and use of

writing was beneficial in helping them to cope with the stresses of caregiving, and identified specific advantages over traditional support groups (e.g., they were able to maintain privacy about their feelings if they desired). They also felt that writing enabled them to process their feelings in a different way than they otherwise may have.

LIMITATIONS

Because posttest scores were obtained immediately after the intervention, the duration of any effects cannot be determined. A follow-up evaluation several months after the intervention and replication with a larger sample are both indicated. It would also be of interest to assess whether participants continued to write after the group ended and whether this continuation had any effect on stress.

IMPLICATIONS FOR CAREGIVERS AND NURSES

Data from this preliminary study support the efficacy of using writing within the support group context for caregivers of frail older adults. Therapeutic writing exercises can provide an effective adjunct to traditional support groups by enabling participants to more fully process their thoughts and feelings about caregiving. In addition, this method may be ideal for caregivers who are not comfortable speaking in a public forum. Therapeutic writing also has the benefit of promoting a coping skill that can be used in the home setting.

Caregivers may find the use of therapeutic writing as a method of coping with stress especially attractive as it is free of the constraints that could otherwise hamper their attendance in support groups, such as lack of time, transportation, or group avail-

ability. Several participants, as well as two local published authors, commented on the fact that writing can be done anywhere, any time. Adding the clinical dimension of structured therapeutic exercises, which address specific caregiving mental health issues, has the potential to further such benefits. Thus, writing has the potential to offer a method of stress relief that can be used on a long-term basis.

Nurses, through their contacts with older adults, are in a unique position to identify caregivers who may benefit from this type of group or individual work, using the same principles. Referrals to writing groups could help caregivers obtain the support necessary to cope with the stress and strain of caregiving. In addition, nurses with experience and knowledge of group process and an interest in conducting groups have an opportunity to provide a valuable service to their clients.

CONCLUSIONS

Although this was a small demonstration project that lacked scientific rigor, it held concrete benefits for the participants. A booklet developed from some of the participants' writings has been distributed free of charge and has led to feedback on the value of capturing "real-life" caregiving experiences. Several requests for additional programs have been made. Examples from the booklet can be found in the Sidebar on this page.

The findings of this study suggest a need for future research. Follow-up studies could examine the long-term benefits of writing support groups, and future studies could include a larger sample and identify the effects of variables such as age, gender, and sociocultural factors.

Nurses are naturally creative. Many of the approaches used to help individuals achieve more optimal states of mental or physical health are based on scientific principles but are delivered in innovative ways that make them attractive and feasible. Considering alternative approaches to ongoing problems such as caregiving is a hallmark of the nursing profession. Perhaps this sentiment is best captured by the words of one participant, whose main expression of feelings during the program was the voluntary reading of a poem she wrote after Session 2:

"In for the Long Haul"

Alzheimer's caregivers are in it for the long haul
It's a never-ending process
Some days are good, others bad
We're in it for the long haul.

The patient's days can be full of repetition
or they can be long and tedious.
They don't realize what they are doing
But we're in it for the long haul.

Caregivers put up with a lot
If we're not careful,
We could end up with depression.
We're in it for the long haul.

Watching our loved ones day by day
Is like a long roller coaster ride
Lots of ups and downs
But we're in it for the long haul.

~ A female caregiver of a spouse with Alzheimer's disease

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KEYPOINTS

1. Support groups are an important and frequent source of help for caregivers of older adults who experience a high degree of physical and emotional stress. However, not every participant feels comfortable speaking in a group setting.
2. Writing is a form of emotional expression that has been shown to produce both physiological and psychological benefits. Use of narrative writing as an adjunct to traditional group therapy methods has not been studied.
3. In this pilot project, use of writing within the support group format provided caregivers with an additional strategy for coping with the stressors of caregiving. Participants' physical and mental health improved significantly after participating in the group.
4. Therapeutic writing can be used independently or in a group to enable emotional expression. Nurses who work with caregivers can help develop interventions that use narrative writing as a method to improve coping.

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