CREATIVE INTERVENTIONS WITH CAREGIVERS

The Midwestern Conference on Health Care in the Elderly

Iowa City, Iowa

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Alzheimer’s Disease and Related Disorders (ADRD) was described by a family caregiver as witnessing the “most terrifying illness on the face of the earth.”

New York Times, June 1, 2010
5.3 million persons with ADRD and there are 10.9 unpaid caregivers. The estimated number of caregivers will triple by 2050.
Negative consequences of caregiving are well documented in the research literature with caregivers being more burdened, depressed, and stressed than non-caregivers. Furthermore, the combination of losses, prolonged distress, physical demands of caregiving, and the biological vulnerability of older caregivers compromise their physiological functioning and increase their risk for health problems.
The Stress of Family ADRD Caregiving

Seventy percent of caregivers reported a decline in physical health. Caregivers also report more chronic illnesses, a higher prevalence of physical symptoms, poorer self-ratings of health than non-caregivers, and poorer overall health than a matched group of non-caregivers.

Caregivers expressing strain had mortality rates 63% higher than non-caregivers (Schulz & Beach, 1999).

High levels of stress, such as those found in spousal ADRD caregivers, have been associated with elevated cortisol.

Since many ADRD caregivers are older, alterations in the HPA (hypothalamic-pituitary-adrenal) axis are of even greater importance. Age-associated changes in neuroendocrine function are of particular concern for older adults because of putative relationships between hormones such as cortisol, cognitive functioning, cardiovascular disease, and immunocompetence.
Depression in ADRD Caregivers

In a meta-analysis of 31 caregiver studies, Schulz and Williamson (1994) concluded that family ADRD caregivers experienced substantially elevated rates of clinical depression compared to population norms.

At least two reports indicate depression symptoms are twice as common among caregivers than noncaregivers.
ADRD and Caregiver Burden

A substantial body of literature documents the negative psychological, physical, and social consequences associated with providing care to a relative with ADRD.

The stress of ADRD caregiving often leads to high levels of caregiver burden.

In a review of over 40 studies, Schulz and colleagues (1995) found caregiving to be burdensome and psychologically distressing.
The development and testing of interventions designed to improve the quality of caregiving, particularly in diverse populations is a major area of research emphasis identified by The National Institute of Nursing Research (NINR).
Family Caregiver Writing Study
Does writing improve health?
Structured written emotional expression (SWEE) is a promising, innovative low cost, and easily administered intervention that involves asking participants to share brief written accounts of their deepest thoughts and feelings about a traumatic experience.
Structures Written Emotion Expression Intervention (SWEE)

Involves asking participants to write a brief essay that expresses their deepest thoughts and feelings about a traumatic experience in their life (J. W. Pennebaker & J. Smyth)
It is May in Iowa. Manifestations of summer are emerging. The rolling countryside hills of deep dark corn are being stilled, transforming winter’s corn stubble into gardenlike rows and rows of corn. The thick stands oak, red elm, hickory and cottonwoods are spreading leaves turning the grey of winter into the sparkling green of spring. The calls of goldfinches, cardinals, warblers, blue jays, and sparrows break the bush of leaves blowing in the breeze. The first spring rains transform the yellow grass into a carpet of glowing deep green. Native prairie grass begin their assent and soon fields will be shimmering with the purple coneflowers, blooming butterfly weed, shooting stars, little bluestem grass, blue-eyed grass, blazing stars, lavender spikes, white balls of rattlesnake master, golden rays of black-eyed Susan, and Pasque flowers marina and hissina in the summer winds.

Journaling for Health

1. Provides Catharsis
2. Rinses pain
3. Integrates experience
4. Reveals deepest Self
5. Provides perspective
6. Enhances meaning-making
It is May in Iowa. New shoots of perennials are emerging. The rolling countryside hills of deep dark earth are being tilled, transforming winter’s corn stubble into gardenlike rows and rows of corn. The deciduous woods oak, red elm, hickory and cottonwoods are spreading leaves turning the grey of winter into the sparkling green of spring. The calls of goldfinches, cardinals, warblers, blue jays, and sparrows break the hush of leaves blowing in the breeze. The first spring rains transform the yellow grass to a coppery glowing deep green. Native grasses massed in their assent and soon fields will be shimmering with the purple coneflowers, blooming butterfly weed, shooting stars, little bluestem grass, blue-eyed grass, blazing stars, lavender spikes, white balls of rattlesnake master, golden rays of black-eyed Susan, and Pasion flowers waning and hissing in the summer winds.

Journaling for Health

Automatic Writing

DO

Go wherever the pen leads you

Write what feels easy

Write in the order things occur to you

Stray off the path

Allow everything in

Be wild and messy
It is May in Iowa. Monarch butterflies are emerging. The rolling countryside hills of deep dark earth are being tilled, transforming winter’s corn stubble into garden-scale rows and rows of corn. The thick stands oak, red elm, hickory and cottonwoods are spreading leaves turning the grey of winter into the sparkling green of spring. The calls of goldfinches, cardinals, cardinals, blue jays, and sparrows break the hush of leaves blowing in the breeze. The first spring rains transform the yellow grass into a patch of green, green, green. Notice something new begins its assent and soon fields will be shimmering with the purple coneflowers, blooming butterfly weed, shooting stars, little bluestem grass, blue-eyed grass, blazing stars, lavender spikes, white balls of rattlesnake master, golden rays of black-eyed Susan, and Pasque flowers waning and hissing in the summer winds.
Journaling for Health

1. Write about your deepest thought and feelings
2. Write in a place where you won’t be interrupted
3. Write frequently (3-4 times a week)
4. Write for yourself only, not for an audience
5. Seek help if you are struggling with serious depression

It is May in Iowa. Manifestations of summer are emerging. The rolling countryside hills of deep dark earth are being tilled, transforming winter’s corn stable into a verdant carpet of green. The black walnut, oak, hickory, and cottonwoods are spreading leaves turning the grey of winter into the sparkling green of spring. The calls of goldfinches, cardinals, warblers, blue jays, and sparrows break the hush of leaves blowing in the breeze. The first spring rains transform the yellow grass into a carpet of glowing deep green. Native prairie grass begin their ascent and soon fields will be shimmering with the pinks, coneflowers, blooming butterfly weed, shooting stars, little bluestem grass, blue-eyed grass, blazing stars, lavender spikes, white balls of rattlesnake master, golden rays of black-eyed Susan, and Pasque flowers. Wanina and hissina in the summer winds.
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Research on Written Emotional Expression

Typical Outcome Measures

↓↓Physician Visits
↓↓Epstein-Barr Virus antibody
↑Hepatitis B antibody
↑Natural Killer Cell Activity
↑CD-4 (t-lymphocyte) levels
↑GPA
↑↑Re-employment following Job Loss
↓↓Absenteeism from work
↓↓Physical Symptoms (Self-report)
↓↓Distress, negative affect, or depression (self-report)
Report Findings for Meta-Analysis of SWEE

- 146 studies (Frattaroli, 2006)
- Effect on physical health, psychological health, and subjective impact: average effect size r = 0.075 (Cohen’s d = 0.151)
Samples in Written Emotional Expression Studies

College Students (Medical Students)
Holocaust Survivors
Rape, family violence, and other traumas
Distressed crime victims
Maximum-security prisoners
Chronic pain suffers
Patients with asthma and rheumatoid arthritis
Patient’s diagnosed with cancer
Persons laid off from their jobs
Children (3rd and 5th graders)
Across Social Classes/Ethnicity
Mexico, New Zealand, Belgium, Netherlands
Physiological and Psychological Foundations for the Effectiveness of Written Emotional Expression

Cognitive Processing as a Meaning-Making Process

Reorganization of affective and cognitive schemes of traumatic experiences and memories

Release of the physiological/psychological stressors / tensions of inhibition

Leading to decreased neuroendocrine stress-response and more normalized immune system function
Specific Aim

Test the effects of the SWEE intervention on finding meaning, caregiver burden, physical symptoms of stress, depression, neuroendocrine function, and caregiver burden in a diverse population of ADRD family caregivers.
R15 Pilot Study

• Population=44 ADRD Family Caregivers
• All Caucasian
• Three 20 minute writing sessions
• Outcome measure: 4\textsuperscript{th}/5\textsuperscript{th} day and 30\textsuperscript{th}/31\textsuperscript{st} day
Background and Contextual Conditions

Age, gender, ethnicity, relationship, marital status, length of time, caregiving, education, family network, social roles, duration of caregiving activities

Stressors

Severity of illness, caregiving activities, family conflicts, losses, changes, economic strains

Coping Process

Management of Meaning (Meaning-Making)

Finding Meaning

Intervention

Structured Written Emotional Expression

Psychological Function

Depression
Caregiver Burden

Physical Function

Physical Symptoms

Neuroendocrine Function

Salivary Cortisol
## Design

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre-Tests</th>
<th>Intervention</th>
<th>4th Day</th>
<th>5th Day</th>
<th>1 Month</th>
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<tbody>
<tr>
<td>Experimental (SWEE)</td>
<td>R 0₁ 0₂  X₁</td>
<td>X₂ X₃</td>
<td>0₃</td>
<td>0₄</td>
<td>0₅ 0₆</td>
</tr>
<tr>
<td>Comparison</td>
<td>R 0₁ 0₂  C₁</td>
<td>C₂ C₃</td>
<td>0₃</td>
<td>0₄</td>
<td>0₅ 0₆</td>
</tr>
</tbody>
</table>

R = Randomization; 0 = observation point; X = experimental intervention points (every other day); C = Comparison intervention points (every other day)
## Instrument and Data Collection Times

<table>
<thead>
<tr>
<th>Variables</th>
<th>Pre-Test</th>
<th>Post-Intervention</th>
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<tbody>
<tr>
<td></td>
<td>Day 1</td>
<td>Day 2</td>
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<tr>
<td>Demographic Data Questionnaire</td>
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<td>Global Deterioration Scale (GDS)</td>
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<tr>
<td>Finding Meaning Through Caregiving Scale (FMTCS)</td>
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<td>Burden Interview (BI)</td>
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<tr>
<td>Center for Epidemiological Studies Depression Scale (CES-D)</td>
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<tr>
<td>Pennebaker Inventory of Limbic Languidness (PILL)</td>
<td>X</td>
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<tr>
<td>Salivary Cortisol (QID)</td>
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<tr>
<td>Writing Study Post-Test Questionnaire</td>
<td>X</td>
<td></td>
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</table>
Key Findings

• 44 Participants
• 27 Experimental/17 Control
• 37 Females / 7 Males
• Caregiver Age Mean = 64
• Education Ave = 15 years
• Time since onset = 6 years
1) increasing the dose of the intervention by adding an additional (4th) 20 minute writing session and adding one weekly 20 minute writing session over a three month period;

2) testing the intervention in a larger and more diverse sample (N=180) of ADRD family caregivers and,

3) testing the lasting effect of the intervention at three months (90 days) post intervention. We plan to test the central hypothesis and thereby accomplish the objective of this application by pursuing the following specific aim.