

Running Head: Expressive Writing and Caregiver Stress

Does Positive Reframing Lead to Better Coping Styles: Examining the effects of two different writing prompts on self-reported stress of caregivers of people with Dementia.

By

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## ABSTRACT

THURIN, MARISA Does Positive Reframing Lead to Better Coping Styles: Examining the effects of two different writing prompts on self-reported stress of caregivers of people with Dementia.

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The challenges caregivers face are often overwhelmingly mentally and physically stressful, and layered in is the grief that comes with watching a loved one slip away (Ornstein, Gaugler, Devanand, Scarmeas, Zhu, & Stern, 2013). The purpose of my study will be to examine if utilizing expressive writing (EW) can benefit caregivers of older adults with mild cognitive impairment (MCI), before a patient might progress to dementia. I hypothesize that EW during early stage decline will be more beneficial than later since it is may be an easier time to use this skill, before caregivers are in the most demanding phases of providing care for their loved one. In this study the caregivers' stress and coping skill were assessed before and after the EW intervention. Caregivers were provided with journals (either online or paper) in which they were instructed to write for twenty minutes a day for three consecutive days. They were given instructions according to current EW strategies for writing about their feelings and experiences related to their caregiving role. Participants are randomly assigned to one of two conditions: 1) writing about the negative and positive emotions felt as a caregiver or 2) writing only about the positive emotions experienced. After the end of their intervention participants' journal entries were analyzed using a linguistic word count program (LIWC) to test hypotheses regarding benefits of varied EW strategies and stage of cognitive decline. Those following the positive emotion focus showed a trend in

the alleviation of dysfunctional coping mechanism. This finding suggests that future research should focus on the impact of positive emotion focus and healthier coping styles.

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The rate of older adults with dementia is rapidly increasing (Larson, 2010). With this increase in diagnoses, the demand for caregivers will exponentially rise as well. Caregivers of older adults in the earlier stages of dementia tend to be close family members like an adult child or a spouse (Alzheimer's Association, 2012). Taking care of a loved one with dementia (PWD) is a trying task, as the caregiver is watching their loved one slowly disintegrate into a shell of the person they used to be. As a disease like Alzheimer's progresses, people experience a loss in cognitive and sometimes motor and functional abilities. Caregivers are continually met with new demands when assisting their loved one.

The challenges caregivers face are often overwhelmingly mentally and physically stressful along with the grief that comes with watching a loved one slip away; in fact, they are increased risk for mental and physical health problems compared with non-caregiving peers (Ornstein et al., 2013). Being one's caregiver generally requires spending a significant amount of time with the individual, causing emotions to be influenced by one another. A longitudinal study conducted by Ornstein involved 160 caregiver-patient pairs and examined how the presence of certain negative symptoms in the PWD affected the caregiver. Researchers measured both of the individuals in each dyad level of depression before and after the study. The results showed that in those dyads where the PWD already had symptoms of depression, their caregiver was more likely to develop depression or worsening depression during the time of follow-up. Other studies have looked at the propensity caregivers of PWD have for developing mental disorders, such as depression, given their demanding role (Brodaty, & Donkin, 2009). Depression and substance abuse commonly develop as a result of the stress of taking care of a loved one (Lavretsky, 2005).

The impact that caring for a loved one who is declining both in physical and mental health can be overlooked as the focus often falls on the person developing the dementia. There have been quite a few recent developments to raise awareness for the caregivers of dementia (Brodaty, Green, & Koschera, 2003). Support groups meet to allow other caregivers to disclose their concerns to others going through a similar challenge. There are education programs specifically designed to equip caregivers with the tools they need to take care of themselves while dealing with the task of caregiving. Counseling and therapy are also often used as an intervention to help caregivers confront and address whatever emotional stress is being put on them. Fostering the development of coping mechanisms have been studied that aid in the alleviation of caregiver stress (Dunkin & Anderson-Hanley, 1998). However, some of these interventions can be considered time consuming and burdensome. For example, it may be challenging to leave a loved one with dementia alone while one goes to a caregiver support group or education program.

A study by Lavretsky (2012) examined a more alternative method for caregiver stress relief involving yoga. Caregivers (n=39) involved in the study were experiencing depressive symptoms. The study compared the benefits of Kundalini yoga Kirtan Kriya meditation with listening to instrumental music. Participants were randomly assigned and performed their respective tasks for twelve minutes a day for eight weeks. Participants were screened so that any who may be on psychotropic drugs to treat depression were not included. The results showed that the group involved in meditation had improved mental health (43%) after the conclusion of the intervention when compared with the instrumental music group (3.7%,  $p=0.05$ ). These findings suggest that the more effective interventions involve the caregiver be actively involved and that inflection is an important aspect of successful stress relief

associated with caregiving. Although these findings are interesting, the procedure may not have been followed as closely as the researchers had intended and the results were similar to interventions that are easier to follow.

When developing interventions for caregivers, it is important to keep in mind that people with different relationships to the caregiver may experience different levels of stress and the stress may manifest itself in different ways. Another factor to consider is that as the severity of symptoms the person with Dementia is experiencing increase, the more demands the family caregiver is faced with. This draws attention to the fact that not all stress relief interventions will be appropriate for all caregivers. A recent study by Reed et al. (2014) examined the different situations spousal (n=985) and adult children (n=405) caregivers find stressful given their fairly new role as a caregiver and the different relationship dynamic with the one they care for. The goal of the study was to look at how different factors add to perceived caregiver burden and how these factors differ between the two different categories of caregiver. Both the dementia patients as well as their family caregivers were assessed at the beginning of the 18-month long study. Caregiver burden was measured using the Zarit Burden Interview (ZBI). This publication discusses the information collected at the baseline analysis. The results show that during this preliminary assessment, adult children caregivers reported feeling more stress when caring for their parent even though they also reported spending less time caring for them when compared with the spousal caregivers. Within the respective groups, differences in perceived burden were also found. For example, the results suggested that female spouses, as well as those who were younger than their sick loved one, reported feeling more burden.

There have been studies showing that caregivers who possess certain levels of

personality characteristics will experience less benefit from exercises involving expressing the emotional burden of being a caregiver. Ashley, O'Connor, & Jones (2011) studied the way in which alexithymia moderates the effectiveness of expressive journaling. Alexithymia refers to the inability for one to express his or her emotions as well as deficits in recognizing emotion in others. This study measured participant's (n=150) level of alexithymia (low or high), along with measures of depression and anxiety before introducing a journaling intervention. Participants were asked to journal about (1) their true thoughts and feelings related to being a caregiver as well as any difficulties they may experience, (2) explore their innermost feelings relating to the positive experiences of being a caregiver, or (3) write about a neutral landscape picture including as much detail as possible excluding any personal opinion. The writing intervention asked participants to journal, following their given prompt, disregarding spelling or grammar for three days in a row for twenty minutes. Results showed that, as predicted, those who scored lower for alexithymia in the positive and neutral condition experienced less anxiety and depression post-intervention.

Other studies have focused on identifying the caregivers who will experience higher levels of perceived burden in an attempt to provide early intervention. One study examined how self-reported locus of control caused varying degrees of burden to caregivers (Bruvik, Ulstein, Ranhoff, & Engedal, 2013). Participants were caregivers (n=39) that lived with a loved one with dementia as well as those they were caring for. The caregivers' burden was assessed using the Relatives' Stress Scale, and higher scores indicate a person is more likely to develop psychological distress due to the demands of their loved one (Ulstein, Wyller, & Engedal, 2007). Caregivers were also instructed to complete a measure which assessed each individual's locus of control. The results of this study showed that locus of control could be



used as a valid way of screening for potential caregiver burden during the early stages of the caregivers new role.

With the limitations in availability and time that caregivers face, it is important to develop a method of stress intervention that can easily be worked into a hectic lifestyle. There has been recent research in support of expressive journaling as one alternative and easy method of stress relief that can be accomplished in the privacy of one's home. Pennebaker & Beall (1986) were pioneers in the study of the benefits of expressive writing, which involves people writing in a journal uninterrupted and unconcerned about syntax, grammar, etc. Expressive journaling allows people to put their feelings and emotional distress on paper in a private and non-judgmental manner. Pennebaker & Beall's (1986) original study involved college age adults (n=46) journaling about either (1) a traumatic life event or (2) trivial topics for four consecutive days, fifteen minutes per session. The subsets of the traumatic category were to (1) focus on the feelings surrounding the traumas, (2) the facts surrounding the trauma, or (3) writing about both the feelings and the facts. The results showed that those who wrote about a traumatic event, regardless of which subset they were in, had stronger negative feelings immediately following the journaling, but had fewer health center visits than the other writing group six months after the intervention. These findings suggest that although the immediate effects of journaling about a traumatic topic yields negative feelings immediately after, journaling may serve as a convenient and effective coping mechanism in the long run.

The recent research looks at the effects of journaling on emotional distress for those who have a life-threatening illness as well as the caregivers of the terminally ill. A study by Smith, Hanley, Langrock, & Comaps (2005) examined the effects of including expressive

journal writing in a twelve week support group for women (n=43) who had recently been diagnosed with breast cancer. The researchers wanted to evaluate the effects that the characteristics of journaling had on the women's mood. The average word count, number of journal entries over the course of the support group, positive/negative words, and the use of cognitive mechanism related words were the characteristic focused on. Anxiety and depression measures were administered before the start of the intervention. The participants were given fairly liberal instructions; they were directed to write about their thoughts and feelings related to breast cancer and support group experiences three times a week. Data was analyzed using a computer software that analyzed the aforementioned characteristics. The results showed that the women who tended to focus mostly on negative emotion throughout the intervention were more likely to experience anxiety and depression levels that were greater than they were before the intervention. These findings were slightly inconsistent with prior research that suggested the ratio of positive and negative words was indicative of the emotional outcomes following the intervention (Pennebaker, 1997).

Studies such as Smith et al (2005) yield promising results, but also highlight the importance for more controlled journaling studies. A study by Williams et al. (2013) examined the effects of journaling on 23 caregivers of people with terminal cancer. The instructions for writing in the journal were specific and allowed for the researchers to be more in control of the mindset caregivers were asked to write in. The study encouraged participants to focus on the aspect of hope as well as keep a journal about their experience and motivation. For two weeks, the participants were asked to write in their journal for five minutes a day. They were instructed to write down what challenges they faced as well as what gave them hope. The results showed that journaling is a significant and valuable tool in

helping caregivers deal with stress in a healthy way. Self-reflection allowed those journaling to expand their hope and encouraged self-care.

Not only has the act of expressive writing been shown to be cathartic, the prompt assigned to participants has also been examined and different focuses have yielded different amounts of stress relief. Baikie, Geerligs, & Wilhelm (2011) examined the effects of expressive writing when participants are asked to focus on framing their writing in regard to positive emotions when compared with a control and expressive writing group. Participants had diagnosed mood disorders and were instructed to write in order to alleviate stress. Participants were asked to journal following their respective prompt for twenty minutes for four days in a row. The instructions for the emotion focused condition (i.e. Positive feelings only and Expressive Writing about any and all feelings) asked participants to write their deepest feelings regarding an intensely positive experience in their lives or their deepest feelings about a traumatic event in their lives, respectively. The control group was asked to write about how they use their time throughout the day, concentrating on different details as given through instruction each day. The results suggested that the writing intervention in all three groups improved mood as measured by the pre- and post-surveys.

The purpose of this thesis was to develop a writing intervention that would build upon previous studies examining how expressive journaling could aim to alleviate stress. The model of Pennebaker and Beale's (1986) original study was followed such that participants would need to write for a predetermined amount of time for a set amount on consecutive days. Preliminary as well as post intervention surveys were taken to be able to compare scores and determine if the intervention had been successful. Prior studies have examined how journaling might alleviate stress in family caregivers of people with a terminal illness,

such as cancer (Williams et al., 2013) with hopeful results. The focus of this study was to examine how expressive journaling affects the family caregivers of people with dementia; specifically, the effectiveness of two different journaling prompts was examined to determine if one alleviated more stress than the other. Based on prior findings about effective expressive journaling methods, it is expected that participants in this study are going to report lower levels of stress surrounding their caregiving role, and those writing about both positive and negative emotions are going to experience even lower levels of stress post-intervention (Baikie, Geerligs, & Wilhelm, 2012).

## METHODS

### *Participants*

Various recruiting resources were used to seek participants. To be a participant in the study, one had to be either the spouse, partner, or child of a person with Dementia and considered their primary caregiver. Given the exclusionary criteria, recruitment happened via caregiver internet forums, the Alzheimer Association Caregiver Conference, and contacting local organizations who work with this population. Before posting information on an online forum about the study, the researcher contacted administrators of the websites to acquire permission to post.

Completed data sets in this study were acquired through a website offering support for caregivers of people with Frontotemporal Dementia (FTD) and also by recruiting caregivers a craft fair hosted by the American Joint Care Foundation. Seven participants completed the intervention. All participants were female except for 1 and had been caring for their loved one ranging from 1.4 to 8 years (avg=3.6 years). Four participants were caring for their parent (s) and four were caring for a spouse. One participant did not complete

the study in its entirety, and thus only their recorded data was used due to the small sample size.

### *Writing Intervention*

The intervention consisted of three days of writing for twenty minutes following a prompt given to participants at the beginning of the study. Participants were randomly assigned to one of two writing conditions which were adapted from Pennebaker and Seagal (1999):

Mixed Emotion Condition (ME): Please spend 20 minutes focusing on your experience as a caregiver. Specifically, I would like you to focus on any emotions (either positive or negative) that have arisen given your new role. Try to be as specific as possible about why you are feeling a certain way about a specific incident/situation. Try to not be concerned with spelling/grammar and focus on just writing throughout the entire twenty minutes.

Positive Emotion Condition (PE): Please spend 20 minutes focusing on your experience as a caregiver. Specifically, I would like you to focus on any positive emotions that give you hope given your role. Try to be as specific as possible about why a particular event/emotion/idea is keeping you optimistic and providing a silver lining. Try to not be concerned with spelling/grammar and focus on just writing throughout the entire twenty minutes.

Participants had the option of either completing the study on paper or using a website that had all the necessary measures and journaling tools needed. In both cases, participants were given a subject number to ensure anonymity. Choosing either method did not affect which writing prompt they were randomly assigned. All data reported in this paper was from

participants who completed the study online. Submitting the journal entry required the participants to enter their subject number on the study's website and then type up their response to the prompt previously assigned to them.

### *Measures*

Before beginning the journaling intervention, participants were asked to fill out a survey that included the Caregiver Burden Inventory (CBI), the Brief Cope, and the Brunel Mood Scale (all described in measures). These have been used in prior studies and have been found useful in constructing an overall picture of the level and type of stress each caregiver faces.

*Caregiver Burden Inventory* (Novak & Guest, 1989) This inventory consists of a 14 item list of statements which directly pertain to caregivers that requires a person to answer on a five point scale (0-4, with 0 meaning 'never' and 4 meaning "nearly always"). Statements are broken up by category; these categories include physical health, mental health, social relationships, development issues, and time dependency issues. Some statements include, "I feel that I am missing out on life," and "I resent [the person I am caring for]." This test has been proven reliable and has good validity (Mavardi et al., 2005).

*BriefCOPE* (Carver, 1997) This is a self-completed measurement made up of 14 subscales which measures different psychological factors of coping strategy. The reformulation of this measure involved removing two scales which were found to be not useful in prior clinical studies as well as the addition of a scale, not previously found in the COPE, due to research suggesting it was an important measurement of coping. Previous studies have found this measurement to be a reliable measure of coping strategy of those caring for someone with dementia (Cooper, Katona, & Livingston, 2008).

*Brunel Mood Scale (BRUMS)* (Terry & Lane, 2003) The BRUMS is a self-report questionnaire that utilizes subscales to assess mood. The inventory consists of 24 items, which are able to be examined through six different mood states to accumulate to an overall estimation of one's mood. Each item on the scale is rated using a 5 point Likert scale. The measure can be scored either by adding up each individual scale or by totaling the answer to all questions to determine a Total Mood Distress.

### *Procedure*

Before beginning the study, participants were asked to contact the researcher in order to obtain their subject number and journaling prompt. They were then asked to complete a pre-journaling survey. This included the participants providing their informed consent and completing the three previously mentioned surveys which have been previously used in caregiver stress studies (Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, & Glossop, 2004; McMillan, Small, Weitzner, Schonwetter, R., Tittle, Moody & Haley, 2006; Pillai, Ambike, Husainy, Vaidya, Kulkarni, & Aigollikar, 2006).

Participants then were able to begin the three day journaling intervention. Participants were instructed to visit the website for three consecutive days to complete their twenty minute journal entry, timed by themselves. Once finished with all three entries, the participants were contacted by the researcher using to complete the post-journaling survey, which includes the same 3 surveys along with demographic information such as age, number of years they have been caring for their loved one, location, gender, and relationship to the person they were caring for.

### *Data Analysis*

All responses to the surveys were recorded online through Google Forms. Once all the data was completed, the pre- and post-survey questionnaires were scored accordingly. A raw score was created for each measure by totaling the answers to each question since each measure consists of a likert-type scale. The journal entries were analyzed using the Linguistic Inquiry and Word Count (LIWC; Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007). The LIWC is a computer program that analyzes text by searching for ‘target words’ relating to human emotion and cognitive domains (Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007). These domains are broken into sub-domains such as positive emotion, negative emotion, cognition and stress (Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007). After totaling the number of words from each domain, it compares that with the total number of words in the text sample, computing a ratio. Since the purpose of this study was to examine stress relief, the ratios considered most important was that of positive and negative emotion words.

## RESULTS

### *Descriptive statistics*

Three participants completed the journaling intervention following the positive emotion only prompt and five participants completed the journaling intervention focusing on a combination of emotions (both positive and negative). One participant in the positive emotion only group only did not complete the post-journaling survey, but data was still included in analysis of this group using their pre-survey data due to limited sample size. The average age of the four participants who elected to provide this information was participants was 61 (SD=10.61). The average amount of time all participants reported caring for their loved one was 3.34 years (SD=2.42). Four participants reported their relationship to their



loved one as a child (all daughters), and the other four reported being a spouse (3 wives and 1 husband).

The dependent variables in this study were defined as the pre-and post-surveys (CBI, BRUMS, and BriefCOPE). There were no significant differences found between groups in regard to their pre-measure scores. On the CBI, PE scored an average of 35.57 ( $SD=15.57$ ) and the ME scored 42.4 ( $SD=11.33$ ). The Brief COPE has been broken down in previous literature into three different subscales which correspond to three different styles of coping: dysfunctional, emotion-focused, and problem-focused (Cooper, Katona, & Livingston, 2008). The BRUMS provided an in-depth look at the different types of emotions caregivers face as it includes six subscales: fatigue, vigor, anger, confusion, depression and confusion (Terry & Lane, 2003). Both groups scored similarly in both the pre- and post-intervention BRUMS, the biggest difference being the report of fatigue in the post-intervention survey (PE  $M=11.5$   $SD=0.71$ , ME  $M=6.8$   $SD=4.66$ ).

The writing intervention was assessed using the LIWC and included the program reported ratios of the use of positive words to negative words. This report was used to reassign the participants to the groups their writing style more closely resembled (even if this was not their originally assigned group). Therefore, subject 4 was included in the PE group, although they had originally been instructed to write about mixed emotions. The average number of words each group wrote per journal entry varied tremendously such as PE wrote fewer words ( $M=136.5$   $SD=61.89$ ) than the ME ( $M=490.25$   $SD=259.34$ ). The journal entries were also analyzed based on the ratio of positive and negative emotion words to all words in each entry. The average ratio of positive words across the three days in the PE ( $M=5.32$   $SD=2.46$ ) was larger than the use of positive words in the ME ( $M=3.95$   $SD=1.65$ ).

the average ratio of negative words used was surprisingly higher in the PE group ( $M=2.49$   $SD=0.63$ ) than the ME ( $M=1.69$   $SD=0.56$ ).

A general linear model was created to analyze the difference between groups in the pre- and post-intervention measures using the three different surveys. It was hypothesized that both groups would experience some benefit from writing in the form of alleviation of negative emotion. However, no statistically significant difference was found between groups on all three measures ( $p > 0.05$ ). This causes me to conclude the null hypothesis that journaling did not improve scores on these measures as a whole.

### *Trends*

There were trends present when the dependent variables were that, with a larger sample size, may become statistically significant. The self-reported measure of perceived burden was shown to be approaching statistical significance ( $p=0.096$ ) as those in the ME group were shown to be experiencing more burden over time than those in the PE (see Figure 1). The BriefCOPE was broken into three different coping styles (emotion-focused, dysfunctional, and problem-focused). This allowed for analysis of the different coping styles and the writing intervention's effect on them between groups. Originally I hypothesized that the ME group would get more benefit from the intervention. However, results suggested that the PE group might have experience more benefit as they were shown (Figure 2) to greatly reduce their use of dysfunctional coping mechanisms post-intervention while those in the ME remained relatively the same ( $p=0.079$ ). There was also a trend towards the use of emotion-focused coping (See Figure 3), with those in the PE group depending less on this coping style than the ME group ( $p=0.083$ ).

## DISCUSSION

The potential benefits of journaling about the feelings surrounding being the family caregiver of a person with dementia were examined in this study. Prior to this study, there has been little research on how focusing on different emotions when journaling about the burdens of caring for a loved one with dementia. Eight participants were randomly assigned to one of two expressive writing interventions which instructed them to either write using a positive frame of reference (PE) or to focus on a mix of emotions (ME) for three consecutive days, twenty minutes per writing session. Through extensive analysis of data, the null hypothesis must be accepted, but the findings do not completely contradict those of previous studies. Particularly, the writing interventions did not alleviate stress as measured by the broad scales administered pre- and post-intervention (i.e. CBI, BRUMS, BriefCOPE). The study does suggest a trend that the intervention could help curb dysfunctional coping mechanisms for those who focus on writing about the positives of their experience. This finding calls for more research on the importance of frame of attitude when utilizing an intervention like this in such a diverse population.

The extremely limited sample size of this study could have led to the necessity of accepting the null hypothesis. Since the sample was so small, this led to a difference in the number of participants assigned to each group, causing an unequal balance between groups. About 30 emails were sent to the leaders of caregiver support groups in the capital district as well as its surrounding counties. About five followed up with the researcher; however these did not lead to the enrollment of participants. Information regarding the study was also posted (with prior administration permission) to 10 online forums targeted at family caregivers of those with dementia, and one website ([www.ftdsupportforum.com](http://www.ftdsupportforum.com)) yielded 3

enrollments and 2 completed data sets. A table was also set up and staffed by the researcher as a craft fair sponsored by the American Joint Care Foundation where incentive in the form of a \$10 Dunkin Donuts gift card was advertised (even though it previously had not been). Given these different avenues of recruitment, it was expected that about 40 participants would enroll, but only 11 ultimately did with 7 fully completing the study. Although shocking, this is very telling about the time that caregivers have. The demands placed on them by their loved one severely limits the time for outside activities that might not directly benefit the one they care for. Even though the survey was completely accessible online, caregivers may feel so burdened that the thought of doing something seemingly ‘extra’ could be intimidating. Many of the excuses given for participant drop-outs were time constraints, with one participant beginning the study and then simply not completing it despite repeated reminder emails. The time commitment (3 days, twenty minutes a day) might have also seemed overwhelming to this population who base their entire days around their loved ones’ care.

Due to time constraints of the present study, the post-intervention measure of stress and burden may not be an accurate reflection as the post-survey was completed one week after the completion of the final journal entry. Prior studies (Stanton, et al., 2002, Pennebaker & Beall, 1986, Smith, et al., 2005) waited upwards of 4 weeks post-intervention to measure benefit from expressive writing. This suggests that since the post-intervention waiting period was so short comparatively to prior research, there may actually be a certain time period that is crucial for caregivers to experience benefit from writing.

Although there are many limitations to this pilot study, there are also valuable trends that, with further research, could add to the growing literature on alleviating caregiver stress.

Dividing the BriefCOPE into the three subdivisions shed light on an important (and often overlooked) part of stress which is the way in which individuals deal with it. Recent studies have looked at the ill-effects of relying on dysfunctional coping mechanisms within this specific population (Li, Cooper, Bradley, Shulman, & Livingston, 2012). Li et al. (2012) found that caregivers of people with dementia who relied heavily on dysfunctional coping mechanisms (i.e. self-blame) were more likely to experience depression and anxiety due to their role. The present study has potential to provide a way to correct this if positive emotion-focused expressive writing is introduced as an early intervention since the results suggest a trend towards those in the PE group steadily decreasing their use of this coping strategy. Emotion-focused coping, which is also measured using the BriefCOPE, has also been found to be beneficial for the caregiver population (Li et.al., 2012). This finding is in corroboration with prior research (Billings, Folkman, Acree, & Moskowitz, 2000; Burton, & King, 2004). The present study could also provide a way to help caregivers develop this positive coping strategy which simultaneously reducing the dysfunctional strategy which only leads to negative outcomes. Future studies should be sure to include a larger sample of participants and focus on positive writing as the experimental group rather than mixed emotions in order to determine if this intervention could be beneficial in shaping coping mechanisms.

Although the original hypotheses were not supported, the findings of this study raise important questions about catering to the specific needs of family caregivers in order to effectively help them with their unique stressors. One of the participants in this study succinctly explained what each caregiver faces:

*This disease is not just about [my spouse]-it's about everyone who his life has touched. I know that today I am a stronger person with*

*greater life wisdom. And it is due in part to my role in [my spouse's] Frontotemporal Dementia journey. I hope that I will soon be a person with greater joy and peace.*

Prior research may have found that mixed emotion writing yielded greater benefits in other populations, but family caregivers may need a different intervention geared toward their new and extremely stressful role. The stress felt and emotions experienced are so complex and thus need to be measured accordingly, using multifaceted scales and interventions introduced early on in their loved one's diagnosis that can accurately measure the magnitude of caregiver stress and subsequently aid them in their journey with their loved one.

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Table 1

Variable	Mixed Emotion Group= <i>M (SD)</i>		Positive Emotion Group= <i>M (SD)</i>		P value	
	<i>Pre</i>	<i>Post</i>	<i>Pre</i>	<i>Post</i>	<i>Pre</i>	<i>Post</i>
CBI	40.51 (2.12)	41.5(7)	45.33 (9.86)	37(21.70)	0.38	0.71
BRUMS	29(12.52)	26.5(9.25)	36.33(8.08)	28.67(0.57)	0.36	0.71
Dysfunctional Coping	20.75(2.36)	19(1.63)	20.75(4.27)	17(2.64)	>.99	0.27
Emotion-focused Coping	25.25(2.22)	21.33(2.52)	21.5(2.52)	23.5(1.29)	0.07	0.24
Problem-focused Coping	18.25(4.11)	18(2.45)	19.5(4.43)	18.67(7.51)	0.69	0.87

Table 1 shows the means and standard deviations of the different variables described in more detail under the *Results* section.

Figure 1

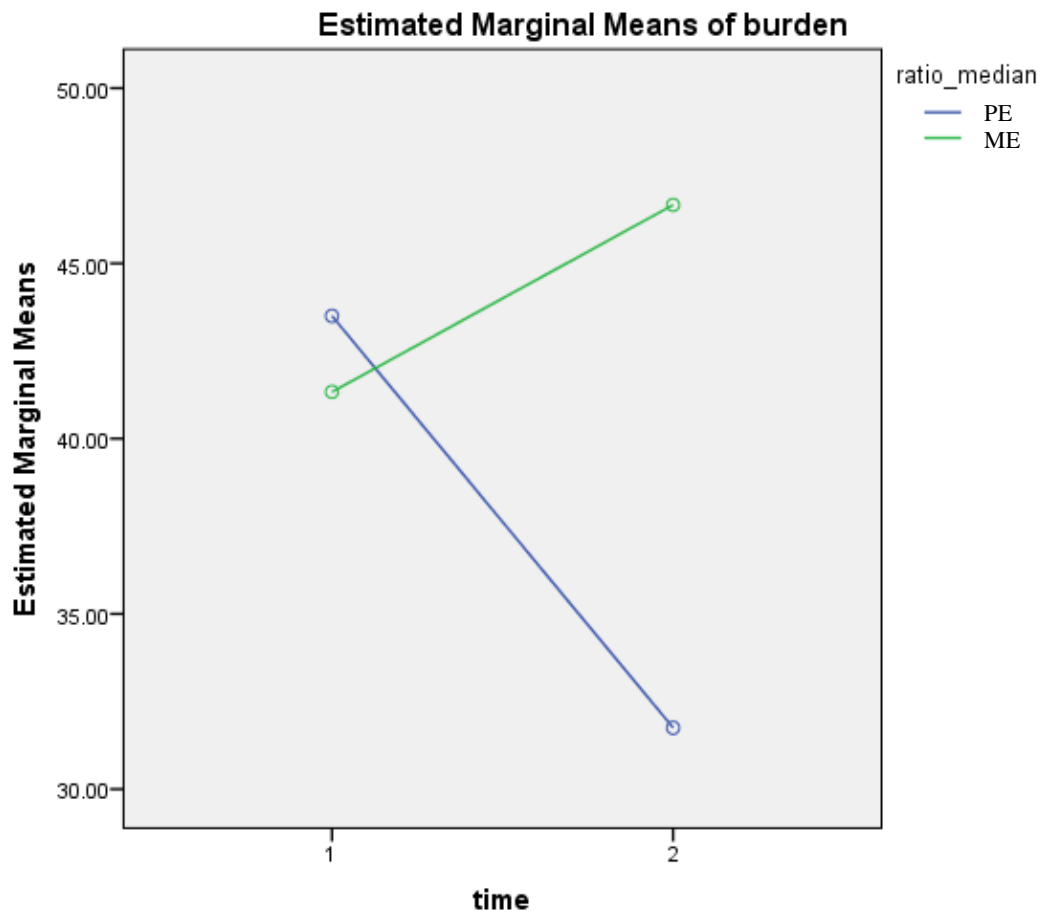


Figure 1. This figure shows the estimated marginal mean of perceived caregiver burden (as measured by the CBI) before and after the journaling intervention. Those in the PE group reported feeling less burden at the post-intervention surveys while those in the ME group seemed to be more aware of their burden post-intervention.

Figure 2

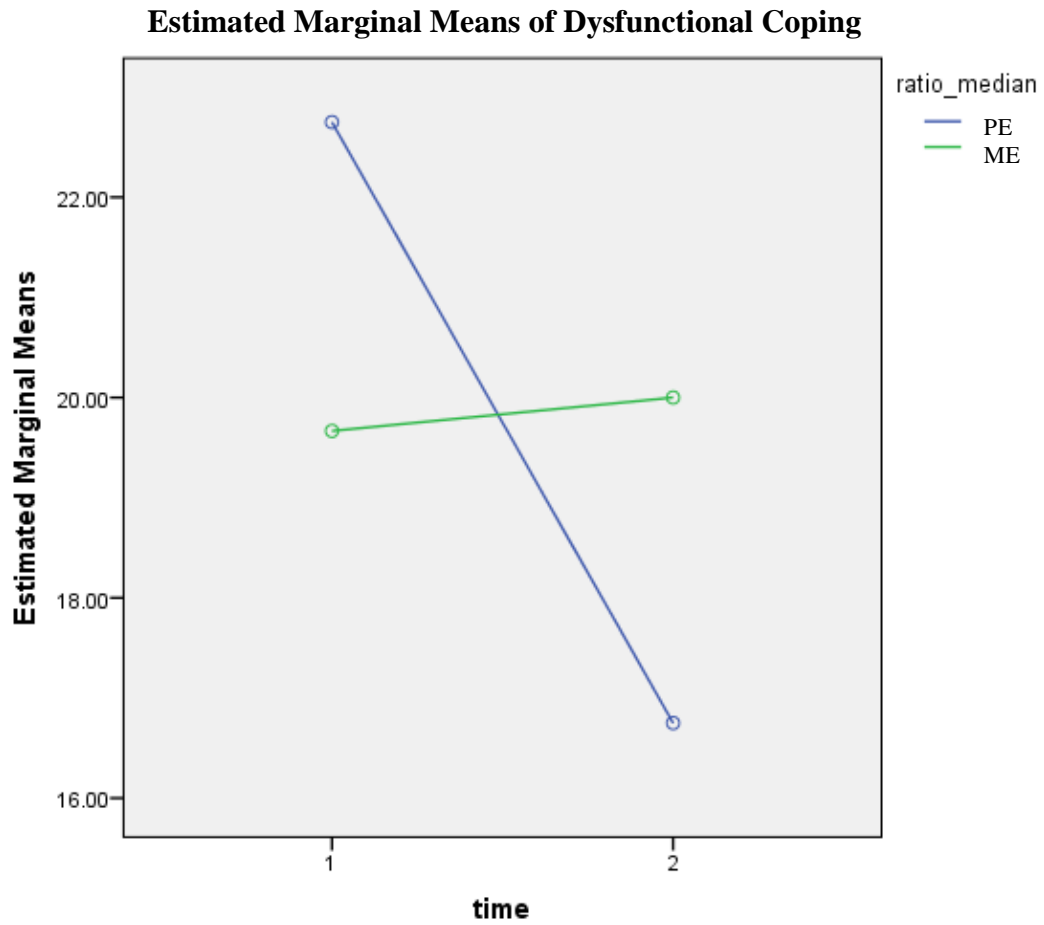


Figure 2. This figure shows the estimated marginal mean of dysfunctional coping mechanism before and after the journaling intervention. Those in the PE show a decline in the use of this harmful coping strategy while those in the ME remain the same across both time points.

Figure 3

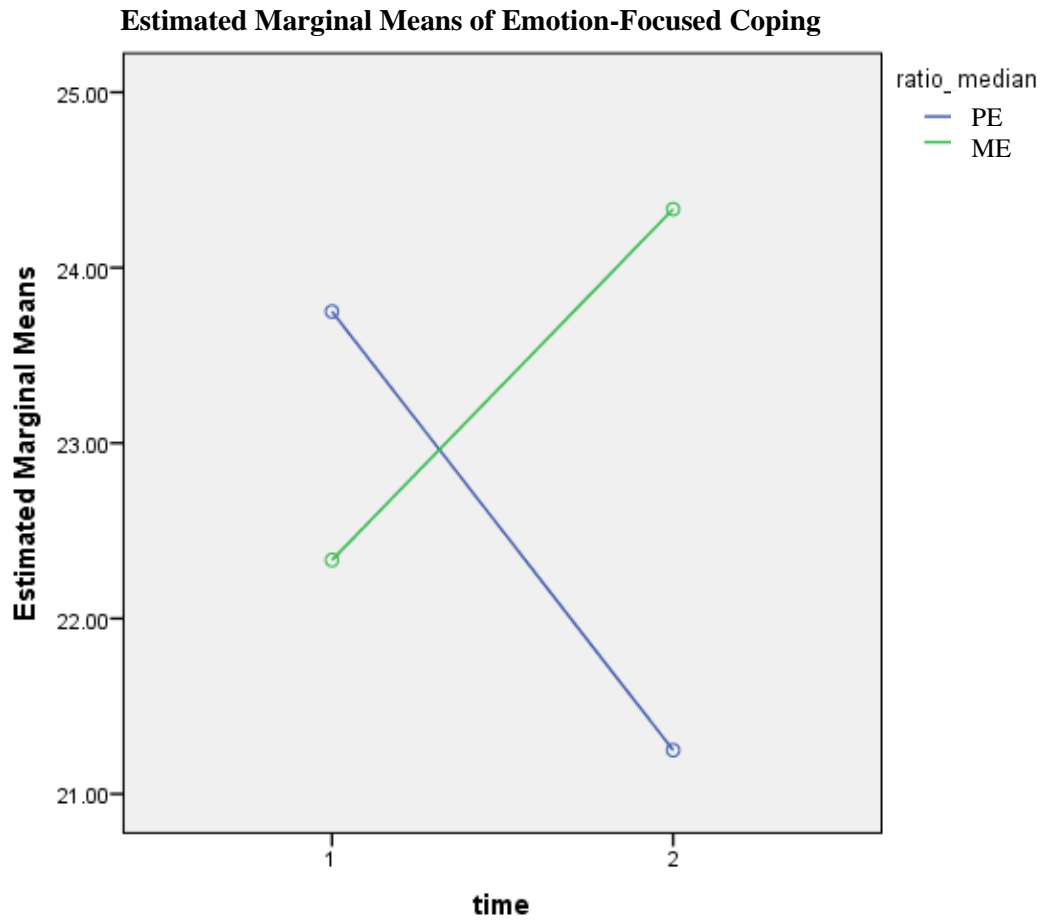


Figure 3. This figure shows the estimated marginal mean of perceived emotion focused coping before and after the journaling intervention. Those in the PE group show a decline in the use of this coping style while those in the ME group show an increase.

APPENDIX A  
Website Homepage

www.caregiverstudy2015.weebly.com

Home Pre-Journaling Survey Journaling Contact

## Welcome to the Caregiver Study Website

Thank you for your interest in my study! My name is Marisa and I am a senior at Union College in Schenectady, NY. I created this website to help me conduct my Senior Thesis which focuses on how expressive writing can help alleviate stress, particularly looking at the caregivers of people with Dementia. To participate in the study, please click on the CONTACT tab above and fill out the form to receive your subject number and instructions.

**If you have already contacted the researcher**, please feel free to begin! Above you will see four different options (Home, Pre-Journaling Survey, Journaling, Post-Journaling Survey, and Contact). Please make the proper selection. Remember, you need to complete the pre-journaling survey first, then complete three days of journaling following the prompt given previously given to you. Once you complete your journaling, you will be given further instruction about when and how to complete the post-journaling survey.



Appendix B  
Caregiver Surveys

**Survey 1**

Choose the number that best represents how often the statement describes your feelings.

- 0 - Never**
- 1 - Rarely**
- 2 - Sometimes**
- 3 - Quite Frequently**
- 4 - Nearly Always**

**Subject Number** \_\_\_\_\_ **Date** \_\_\_\_\_

<b>Time Dependency Items</b>	
He/she needs my help to perform many daily tasks	① ② ③ ④
He/she is dependent on me	① ② ③ ④
I have to watch him/her constantly	① ② ③ ④
I have to help him/her with many basic functions	① ② ③ ④
I don't have a minute's break from his/her chores	① ② ③ ④

<b>Development Items</b>	
I feel that I am missing out on life	① ② ③ ④
I wish I could escape from this situation	① ② ③ ④
My social life has suffered	① ② ③ ④
I feel emotionally drained due to caring for him/her	① ② ③ ④
I expected that things would be different at this point in my life	① ② ③ ④

<b>Physical Health Items</b>	
I'm not getting enough sleep	① ② ③ ④
My health has suffered	① ② ③ ④
Care giving has made me physically sick	① ② ③ ④
I'm physically tired	① ② ③ ④

<b>Emotional Health Items</b>	
I feel embarrassed over his/her behavior	① ② ③ ④
I feel ashamed of him/her	① ② ③ ④
I resent him/her	① ② ③ ④
I feel uncomfortable when I have friends over	① ② ③ ④
I feel angry about my interactions with him/her	① ② ③ ④

<b>Social Relationships Items</b>	
I don't get along with other family members as well as I used to	① ② ③ ④
My care giving efforts aren't appreciated by others in my family	① ② ③ ④
I've had problems with my marriage (or other significant relationship)	① ② ③ ④
I don't get along as well as I used to with others	① ② ③ ④
I feel resentful of other relatives who could but do not help	① ② ③ ④

## Survey 2

### Subject Number \_\_\_\_\_

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to care for this loved one. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with being a caregiver. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

- \_\_\_ 1. I've been turning to work or other activities to take my mind off things.
- \_\_\_ 2. I've been concentrating my efforts on doing something about the situation I'm in.
- \_\_\_ 3. I've been saying to myself "this isn't real."
- \_\_\_ 4. I've been using alcohol or other drugs to make myself feel better.
- \_\_\_ 5. I've been getting emotional support from others.
- \_\_\_ 6. I've been giving up trying to deal with it.
- \_\_\_ 7. I've been taking action to try to make the situation better.
- \_\_\_ 8. I've been refusing to believe that it has happened.
- \_\_\_ 9. I've been saying things to let my unpleasant feelings escape.
- \_\_\_ 10. I've been getting help and advice from other people.
- \_\_\_ 11. I've been using alcohol or other drugs to help me get through it.
- \_\_\_ 12. I've been trying to see it in a different light, to make it seem more positive.
- \_\_\_ 13. I've been criticizing myself.
- \_\_\_ 14. I've been trying to come up with a strategy about what to do.
- \_\_\_ 15. I've been getting comfort and understanding from someone.
- \_\_\_ 16. I've been giving up the attempt to cope.
- \_\_\_ 17. I've been looking for something good in what is happening.
- \_\_\_ 18. I've been making jokes about it.
- \_\_\_ 19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
- \_\_\_ 20. I've been accepting the reality of the fact that it has happened.
- \_\_\_ 21. I've been expressing my negative feelings.
- \_\_\_ 22. I've been trying to find comfort in my religion or spiritual beliefs.
- \_\_\_ 23. I've been trying to get advice or help from other people about what to do.
- \_\_\_ 24. I've been learning to live with it.
- \_\_\_ 25. I've been thinking hard about what steps to take.
- \_\_\_ 26. I've been blaming myself for things that happened.
- \_\_\_ 27. I've been praying or meditating.
- \_\_\_ 28. I've been making fun of the situation.

### The Brunel Mood Scale

Below is a list of words that describe feelings. Please read each one carefully. Then cross the box that best describes HOW YOU FEEL RIGHT NOW. Make sure you answer every question.

	Not at all	A little	Moderately	Quite a bit	Extremely
1. Panicky .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Lively .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Confused .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Worn out .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Depressed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Downhearted .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Annoyed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Exhausted .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Mixed-up .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Sleepy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Bitter .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Unhappy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Anxious .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Worried .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Energetic .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Miserable .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Muddled .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Nervous .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Angry .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Active .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Tired .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Bad tempered .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Alert .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Uncertain .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For official use only:

Ang: \_\_\_\_ Con: \_\_\_\_ Dep: \_\_\_\_ Fat: \_\_\_\_ Ten: \_\_\_\_ Vig: \_\_\_\_

Thank you for completing these surveys. Please follow the journaling prompt you received when you got your subject number. Please write for three days in a row, 20 minutes at a time, using the blank pieces of paper provided.