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Expressive Writing as a Coping Mechanism for Caregivers of People with Parkinson's Disease

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Running Head: Expressive Writing for Parkinson's Caregivers

Expressive Writing as a Coping Mechanism for Caregivers of People with Parkinson's
Disease

By

Sarah Beck

Senior Thesis

A thesis presented in partial fulfillment
of the requirements for the degree of
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ABSTRACT

BECK, SARAH Expressive Writing as a Coping Mechanism for Caregivers of People with Parkinson's Disease.

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Caregivers face challenges that take a tremendous toll both mentally and physically, while also having to experience their changing relationship with a loved one who continuously deteriorates. (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 loved ones with Parkinson's disease. I hypothesized that EW would help alleviate caregiver burden, and decrease negative mood and healthier coping means, while caregivers who write within a positive framework will experience the greatest alleviation of burden, better reported mood, and coping means. In this study the caregivers' stress and coping skill were assessed before and after the EW intervention. Caregivers were provided with online journals in which they were instructed to write for twenty minutes a day for three consecutive days. They were given prompts to direct their writing. Participants were randomly assigned to one of two conditions: 1) writing only about the positive emotions experienced or 2) writing about the negative and positive emotions felt as a caregiver. 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. Trends showed that EW was most beneficial for participants caring for loved ones in the earlier stages of Parkinson's and placed in the positive framing condition. The finding suggests that future research should

Expressive Writing for Parkinson's Caregivers

focus on the impact of positive emotion focus and healthier coping styles and length of effective journaling.

TABLE OF CONTENTS

1. Introduction	1
2. Methods	11
3. Results	15
4. Discussion	19
5. References	22
6. Figure 1	22
7. Figure 2	25
8. Figure 3	26
9. Figure 4	27
10. Figure 5	28
11. Figure 6.....	29
12. Figure 7	30
13. Figure 8	31
14. Figure 9	32
15. Figure 10	33
16. Figure 11	34
17. Figure 12	35
18. Figure 13	36
19. Figure 14	37
20. Figure 15	38
21. Figure 16.....	39

22. Appendix A	40
23. Appendix B	41
24. Appendix C.....	42
25. Appendix D	43

INTRODUCTION

Parkinson's disease is a disabling, chronic condition with an indeterminate trajectory that takes its toll on not the diagnosed patient, but all involved (Family Caregiver Alliance, 2012). A highly individualized disorder, the experiences of patients and their families are all widely varied and difficult. Those diagnosed with Parkinson's disease experience a range of degenerative symptoms including tremors, bradykinesia, rigidity, depression and anxiety, MCI, and even dementia (NHS choices, *Parkinson's Disease-Symptoms*, 2014). This family disease is growing, as 50,000 to 60,000 new cases of PD are diagnosed each year in the United States alone, in addition to the one million people already diagnosed (National Parkinson Foundation, 2015).

As Parkinson's is more common in people aged 60 years and older, it is expected that the incidence of Parkinson's will surge with the aging of the baby boomer generation (Family Caregiver Alliance, 2012). With the magnitude of diagnoses, the demand for caregivers and the distress they carry will experience intensification, and easily accessible interventions will be needed. These caregivers of older adults tend to be close family members such as a spouse or a grown child (Family Caregiver Alliance, 2012). Taking care of a loved one with Parkinson's disease is an exceedingly trying task, as the spouse or child must watch their loved one slowly degenerate both physically and mentally. As a disease like Parkinson's progresses, people experience an increasing loss in motor and functional abilities, and in some cases, cognitive abilities that can include psychosis (National Parkinson Foundation, 2015). Caregivers are continuously met with new and increasing demands when assisting their loved one.

The hurdles a caregiver faces are often overwhelming emotionally and physically

stressful along with the anguish that comes with watching as a loved one loses their autonomy. Caregivers are faced with the loss of what is naturally taken for granted and the expectations of their future, and must reinterpret their past, present, and future to sustain a meaningful sense of self (Barken, 2014). This disruption deeply impacts all aspects of a caregiver's life, including their mental and physical wellbeing. In fact, caregivers face an increased risk for mental and physical health problems in comparison to their non-caregiving peers (Ornstein et al., 2013). The psychosocial consequences of caregiving for a loved one with PD has been studied, as research indicates that being the partner to someone with Parkinson's involves serious, complex challenges related to both caregiving and non-caregiving issues (Martin, 2015).

Caregiver Impact

Ricciardi and colleagues' study looked into the impact of spousal caregiving of people with Parkinson's in terms of relationship quality, and satisfaction from the perspective of both patient and their spousal caregiver. Fifteen patients with Parkinson's disease and their partners were asked to complete the Hamilton Depression and Hamilton Anxiety Rating Scale (HAM-A), the Dyadic Adjustment Scale, Couple Satisfaction Index (CSI), Toronto Alexithymia Scale (referring to the inability for one to express his or her emotions as well as deficits in recognizing emotion in others), and the Empathy Quotient. Results showed that patients were significantly less satisfied with their relationship than their partners and were more depressed and anxious (Ricciardi, Pomponi, Demartini, Ricciardi, Bruno, Bernabei, & Bentivoglio, 2015). Research such as this illustrates that not only do caregivers have to concern themselves with the everyday activities PWP are unable to do, but also experience the burden of the patients' stronger depression and

dissatisfaction with their relationship in addition to their own negative feelings.

One must also keep in mind when developing interventions for caregivers that caregivers may experience varying levels of stress depending on their relationship with the PWP and the severity of the symptoms they are experiencing. This draws attention to the fact that caregiver burden is highly individual just as symptoms and severity of PD varies.

Caregiver Burden in PWP Caregivers

A recent study conducted examined caregiver burden amongst Brazilian caregivers of people with Parkinson's disease (PWP) in order to analyze the main factors that influence burden and health related quality of life (HRQoL) in caregivers of PWP (Carod-Artal, Mesquita, Ziolkowski, & Martinez-Martin, 2013). Fifty patient-caregiver dyads were analyzed in the study. The participating caregivers of loved ones suffering from Parkinson's disease answered the Hospital Anxiety and Depression Scale (HADS), Zarit Caregiver Burden Interview, and a generic measure of HRQoL, the EQ-5D. Patients were given the Hoehn and Yahr (H&Y) staging which examines what stage of PD a patient is currently experiencing, Scales for Outcomes in Parkinson's disease (SCOPA) Motor, Cognition, Psychosocial, and Sleep scales, Non-Motor Symptoms Scale, HADS, Clinical Impression of Severity Index, EQ-5D and Parkinson's Psychosis Rating Scale (Carod-Artal, et al., 2013). Caregivers were significantly younger than the patients, 88% of caregivers were female, and 78% were spouses. ZCBI scores significantly worsened alongside severity of disease. Caregiver's mood was a significant determinate of reported quality of life, and mood and caregiver burden were significantly influenced by the

patient's psychiatric and sleep disorders (Carod-Artal, et al., 2013).

Caregiver Burden and Patient Impact

Research has been preformed to discover coping mechanisms that would aid in caregiver stress assuagement (Dunkin & Anderson-Hanley, 1998). The stress levels of caregivers are not only important for their own physical and mental wellbeing, but also, research indicates that in the case of patients with Alzheimer's disease, that those living with highly distressed caregivers may display greater frequency of agitation and behavioral problems than those cared for by less distressed individuals (Dunkin et al., 1998). While it has been shown to be beneficial for caregivers to receive outside support and therapeutic intervention to foster the development of coping mechanisms as described in Dunkin's 1998 review, unfortunately, many caregivers have limited time at their disposal due to their busy role, as some of these interventions may be too great of a burden and time consuming as it is difficult for a caregiver to find additional care to join a possible support group, or any activity that would require significant time away from the affected loved one.

Contributing Factors to Caregiver Burden

As high caregiver stress is not only detrimental to the caregiver his or herself but detrimental to the health of their care recipients, previous studies have looked specifically at the factors that contribute to caregiver stress and burden in those caring for loved ones suffering from Parkinson's disease. Santos-Garcia and de Fuente-Fernández looked to discover the main determinants of burden and stress in Spanish caregivers of those with Parkinson's disease. In order to assess their caregiver burden, patients were assessed in

the morning, one to two hours after taking their medication using the modified Hoehn & Yahr staging (ON-HY) and the Unified Parkinson's Disease Rating Scale, specifically looking at motor complications. Patients were then asked to fill out the Beck Depression Inventory, Schwab & England Activities of Daily Living Scale, Non-Motor Symptoms Scale, and a 39-item Parkinson's disease Quality of Life Questionnaire Summary Index. Caregivers were then asked to complete their own surveys, which included the Zarit Caregiver Burden Interview and the Caregiver Strain Index. Santos-Garcia and de Fuente-Fernández found that caregiver stress was consistently associated with the loss of patient independence as assessed by the Activities of Daily Living Scale. Duration of the disease, impaired mood of the patient, patient reported quality of life, and both higher motor and non-motor symptoms were related to greater caregiver strain.

Caregiver Burden and Executive Functioning

A diagnosis of Parkinson's disease does not mean only the experience of motor problems. One of the most commonly reported non-motor symptoms of Parkinson's disease is a cognitive deficit (Muslimovic, Post, Speelman, & Schmand, 2005). These cognitive deficits are important to consider in relation to the family of the care recipient. Not only is a family member caring for a loved one helping them with physical tasks they are no longer able to do, but they are also witnessing their loved one slip away mentally. Kudlicka and colleagues designed to study how executive functioning in peoples with Parkinson's disease contributed to the health status and quality of life of the caregiver. Sixty-five people with PD completed measures looking at reported quality of life, health status, and executive functioning, and 50 caregivers rated the executive functioning of their care recipient and their and their own burden (Kudlicka, Clare, & Hindle, 2014).

The results of the study suggested that while depression was the only individually significant predictor in the general life domain for care recipients, the data suggested that executive functioning related behavioral problems could influence quality of life in people with PD and influence caregiver burden.

Caregiver Burden and PD Impulse Control

As previous studies have researched, the neuropsychiatric complications of Parkinson's disease are just as, if not more important contributions to caregiver stress as the motor related symptoms. People with Parkinson's experience an increase in behavior disturbances as PD progresses, including disturbances in apathy and impulse control (Leroi, Harbisetar, Andrews, McDonald, Bryne, & Burns, 2011). The study conducted by Leroi and colleagues, aimed to examine the relationship between a patient's behavioral disturbances and caregiver burden. Seventy-one participants from the UK and their caregivers were included in the study. Apathy was assessed by the AES and impulsivity was measured using the Barratt Impulsiveness Scale. The motor subscale of the Unified Parkinson's Disease Rating Scale was used as well during the 'on' medication state. Caregiver data was measured through the ZBI. The study revealed that caregivers of loved ones with behavioral disturbances reported greater levels of burden than those caring for patients with PD and no behavioral disturbances. Those who cared for people with only motor related disturbances indicated little if any burden (Leroi et al., 2011). As behavioral disturbances in PD such as impulsivity tend to only be addressed after a crisis point has occurred, earlier interventions are therefore needed (Leroi et al., 2011).

Caregiver Burden and Relationships

Different relationships the caregiver has to the care recipient may experience different levels of stress and the stress may manifest itself in different ways in comparison to other types of relationships. An important factor to consider is that as the severity of symptoms increases in a person with a degenerative disease there are more daily demands placed onto the caregiver. Therefore, not all stress relief interventions work effectively for all caregivers. A study conducted by Reed et al. (2014) examined the different conditions spousal (n=985) and adult children (n=405) caregivers find stressful given their role as a caregiver to their spouse or parent to those suffering from Dementia. The study's aim was to look at how different factors add to perceived caregiver burden and how these factors differ between the spousal caregivers and adult children caregivers to those with a degenerative disease (Reed, Belger, Dell'Agnello, Wimo, Argimon. Bruno, & Vellas, 2014). Both the dementia patients as well as their caregivers were assessed at the beginning of the 18-month long study. Caregiver burden was measured using the Zarit Burden Interview (ZBI). The results show that during this preliminary assessment, adult children caregivers reported feeling more stress when caring for their parent in comparison to spousal caregivers even though they reported spending less time actively caregiving than those caring for their spouses (Reed et al., 2014). The same factors should be considered when conducting a study looking at caregivers of those with Parkinson's disease, as both PD and Dementia are degenerative diseases.

Expressive Writing

However, research has shown expressive journaling to be a promising therapeutic

Expressive Writing for Parkinson's Caregivers

alternative without leaving the home. Pennebaker & Beall's (1986) study of the benefits of expressive writing, which involved people writing in a journal uninterrupted and unconcerned about syntax, grammar and spelling, allowed participants to communicate their concerns, distress and fear with a private and non-judgmental medium. The original study by Pennebaker & Beall included college age adults (n=46) journaling one of two options (1) a traumatic life event (2) trivial topics for four sequential days in a 15 minute time frame. In the traumatic even category, participants were either to (1) focus on the feelings surrounding the traumatic event, (2) the facts surrounding the trauma, (3) Writing about both feelings and facts. While those who wrote of a traumatic event experienced greater negative feelings directly after writing, fewer health center visits were also reported over a six-month period, suggesting that journaling may have effective long-term impact on coping.

Expressive Writing and Caregiving

Williams and colleagues have more recently studied the effects of journaling in rural Canadian women. (Williams, Duggleby, Eby, Cooper, Hallstrom, Holtslander, & Thomas, 2013). Twenty-three female participants aged 18 and older, with a mean age of 59 years were selected for the study. The participants were caregivers of family members with advanced terminal cancer, and were either the patient's spouse (n=19), daughter (n=3), or mother (n=1). Caregivers were told to complete daily journal entries in order to write down their hopes and any challenges they were facing. The results showed that journaling is a significant and valuable tool in helping caregivers deal with stress in a healthy way (Williams et al., 2013). The self-reflection provided by journaling allowed the caregivers to promote and increase optimism. Another valuable facet of expressive

journaling is addressed in this study, as Williams et al. used rural Canadian women who were isolated from direct support due to distance. As expressive journaling showed benefits even isolated by distance, expressive journaling could be influential with caregivers with hectic schedules. Expressive writing would allow for stress alleviation that would be capable within the time constraints and limitations of their demanding lives.

Expressive Writing with a Positive Lens

While previous studies performed by Mackenzie have resulted in inconclusive data, a more recent study has shown that expressive writing with an optimistic lens can be effective in improving caregiver health (Mackenzie, Wiprzycka, Hasher, Goldstein, 2008). Participants (n=27) were caregivers of physically frail or cognitively impaired older adults randomly assigned either expressive writing (EW) or time management (TM). Caregivers assigned to EW were tested using the Linguistic Inquiry and Word count program, to analyze cause, exclusive, first person, future, optimism, insight, and positive affect words (Mackenzie et al., 2008). Pre-intervention, post intervention and in a one-month follow up, caregivers completed the Impact of Events Scale to measure distress, and the 28-item General Health Questionnaire to monitor physical and mental health. Results supported the hypothesis that expressive writing was beneficial to caregivers who used increasingly positive, optimistic, and future-focused language (Mackenzie et al., 2008).

Another study examined the role of prompt framing and the yielded amount of stress relief. A 2011 study conducted by Baikie, Geerlings, & Wilhelm aimed to examine

the results of expressive writing when participants were asked to focus on framing their writing on positive emotions in comparisons with a control and expressive writing groups. Participants of the study had been diagnosed with mood disorders and were told to write in order to alleviate stress (Baikie et al, 2011). For four days in a row, participants followed their prompts and wrote for twenty minutes about their deepest feelings regarding an intensively positive experience or their feelings on a traumatic event. The control group wrote about how they used their time in the day (Baikie et al., 2011). The results suggested that the writing intervention in all three groups improved mood as measured before and after journaling intervention.

The purpose of this thesis would be to assess if employing the coping mechanism of self-journaling can be beneficial to caregivers of older adults with Parkinson's disease, building upon previously conducted research. There has been little prior research investigating the influence of journaling for caregivers of Parkinson's patients. Based on prior findings about effective expressive journaling methods for those with or caring for those with either terminal illnesses or degenerative diseases, it is expected that participants in this study are going to report lower levels of stress surrounding their caregiving role after journaling. (Baikie, Geerligs, & Wilhelm, 2012).

Hypotheses

It is expected that:

1. Journaling for three days will significantly decrease reported negative mood
2. Journaling for three days will significantly decrease reported caregiver burden
3. Positive emotion condition caregivers will report a significantly greater reduction

in reported negative mood than mixed emotion participants

METHODS

Participants

Study risks and benefits were reviewed and all study participants signed an informed consent document approved by the Institutional Review Board at Union College. The sample size ($n=4$) meant that qualitative research only could be conducted. Participants were all caregivers of a loved one diagnosed with Parkinson's disease, and had been solicited through posted fliers in various nearby public locations such as a local PACE center, the Joan Nicole Prince Home, hospital geriatric wings, and hospice centers. Participants were also solicited via email, and all had given consent in study participation. Ages of the caregiver ranged from 29-57 years old. Four caregivers of patients with Parkinson's disease contacted the study and three of the four completed the study. Due to the small size of the study, data from the caregiver who did not complete the study was still included.

Procedures

The intervention period included five separate days of survey taking and journaling. Participants were asked to complete their journaling in no more than a week. Participants were randomly sorted into two separate groups; either placed in the positive emotions prompts or the mixed emotions prompts. They were contacted via email and linked the section that included their randomly assigned prompts. Section A included Mixed Emotion Prompts while Section B included Positive Emotion Prompts. Prior to journaling prompts, participants chose their unique user ID to identify their multiple day responses as their own. After choosing their user IDs, participants were told they were

able to stop participation in the study at any time and by continuing with the study, they were confirming their understanding. Immediately afterwards, caregivers completed a series of survey questions gauging their current mood, caregiver burden, coping mechanisms and the functioning capabilities of the loved one of whom they were caregiving. This initial survey was completed online through a link received by email. After completing the survey, participants were then directed to their journaling prompts the next day. Journaling prompts were set to direct the focus of the journals and journaling each day was to be completed over a span of twenty minutes.

Measures

Caregiver Burden Inventory (CBI: Novak & Guest, 1989). This 24-item scale requires participants to select an answer ranging from “Never” (0) to “Nearly Always” (4) to a variety of questions about their role as caregiver and relationship to their care recipient such as, “I feel embarrassed over his/her behavior.” and “I feel emotionally drained due to caring for him/her”. Scores between 0 and 20 suggest little or no burden, scores 21 to 40 suggest mild to moderate burden while scores ranging from 41 to 60 suggest moderate to severe burden while score 61-88 suggest severe burden. Scores near or above 36 indicate there is a greater need for respite and aid. Adequate reliability and validity has been indicated in prior research (ref).

Brief Cope (Carver et al., 1997). The Brief Cope scale used contained 28 questions in order to discover what coping means caregivers had been using and how often they used them. Whether or not the coping strategy was effective or healthy was not the concern, rather what was true to the participant. Participants reported if they had been employing a strategy by choosing options “I haven’t been doing this at all”, “I’ve been

doing this a little bit", "I've been doing this a medium amount", and "I've been doing this a lot". Statements participants responded to included "I've been getting help and advice from other people" and "I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping." Answers were then placed into subset categories that looked into type of coping mean. The scales included Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, and Self-blame.

Brunel Mood Scale (Terry & Lane, 2003). The Brunel Mood Scale (BRUMS) displays a list of 24 different words that describe feelings. Participants were prompted to choose the level to which they were feeling the word presented at the time of taking the survey. Levels of present feeling of the shown emotion ranged on a 5-point scale from "Not at all" to "Extremely". Feelings involved in the scale included "Downhearted" "Active" and "Anxious". To be scored, these feelings were then separated into the subtopics of tension, depression, anger, vigor, fatigue, and confusion.

Instrumental Activities of Daily Living (Cummings et al., 2002). The final measure used in the study consisted of seven questions assessing the level of independence the care recipient possessed. Prompts included "Using Telephone" "Shopping" and "Traveling". Participants chose the response that best fit their care recipient, on a three-point scale. I= able to independently, A=able with assistance, and D=unable to do so at all.

Journaling Prompts. Over the course of the three days of journaling, participants were randomly assigned to one of two different conditions. In the positive emotions

condition, participants were asked to focus on the positives of their caregiving role, while in the mixed emotions conditions, participants were asked to write about both negative and positive experiences and feelings. Prompts for the positive emotions condition included phrases such as “I would like you to focus on any satisfying emotions that have given you faith in your role” and mixed emotions condition included “I would like you to focus on both positive and negative emotions that give you hope given your role”.

Statistical Analysis

Data collected was analyzed using Microsoft Excel and Linguistic Word Count Software (LIWC). Each journal entry was run through LIWC, looking at the percent of positive words and negative words in relation to each other every journaling day and changing over the three-day period. Statistical Package for the Social Sciences (SPSS v. 12.0) was not utilized due to the limited sample size.

RESULTS

While twenty participants were expected, three completed the study. Participants had a mean age of 47.3 years ($SD=15.9$; range=29-57). As sample size was limited, only descriptive data was studied.

Caregiver One: Positive Emotions

Caregiver One was randomly assigned to the positive framing journaling, she was fifty-six years old, and had been caring for her spouse for two and a half years. Her care recipient was 65 years old and living with his caregiver. Over the course of the pre and post journaling surveys, Caregiver One's caregiver burden score decreased from a score of 5 on the Caregiver Burden inventory to a 4 (Figure 1).

Her Pre-BRUMS scores showed a Tension score of 65, Depression: 48, Anger: 58, Vigor: 56, Fatigue: 42 and Confusion: 57. Post journaling revealed a decline in reported negative mood. Depression decreased to a score of 44, Tension: 61, Fatigue: 40, and Confusion: 46. Most noteworthy was the decline in reported anger, which dropped 13 points (Figure 2).

Caregiver One's reported BriefCOPE scores showed an increase after positive frame journaling. Increases in coping means and frequency of use specifically occurred under the subscales of Active coping, Use of Instrumental Support, and Religion (Figure 3).

Reported Instrumental of Daily Living scores did not change as the participant reported her care recipient was able to perform all mentioned tasks independently.

Linguistic Word Count software looked at positive and negative word usage along the three days of journaling. Day one ($t=59.54$) recorded a positive word use of 6.55 and

a negative word use of .28. Day two ($t=58.57$) had a positive word score of 5.01 and a negative word score of 1.06. Day three ($t=55.39$) showed a positive word count of 5.39 and negative word count of 2.45. Average positive word usage was 5.56 and negative word usage 1.26 (Figure 4).

Caregiver Two: Mixed Emotions

Caregiver Two was randomly assigned to the mixed emotions journaling; he was a 29-year-old adult child caring for his father. His care recipient was 71 years old and living in his own home. Over the course of the pre and post journaling surveys, Caregiver Two's caregiver burden score remained the same at a score of 17, indicating little burden.

His Pre-BRUMS scores showed a Tension score of 58, Depression: 56, Anger: 45, Vigor: 43, Fatigue: 40 and Confusion: 50. Post journaling revealed only a decline in reported tension, falling to a score of 50. All other subsets remained constant (Figure 5).

Caregiver Two's reported BriefCOPE scores increased after mixed emotions journaling. Increases in coping means and frequency of use specifically occurred under the subscales of Active coping, and Use of Instrumental Support (Figure 6).

Reported Instrumental of Daily Living scores dropped in post survey results. The care recipient was unable to perform any activity without help, and post survey results showed a decline in ability to cook, dropping from A= Able to prepare light foods to D=Unable to prepare any meals.

Linguistic Word Count software looked at positive and negative word usage along the three days of journaling. Day one ($t=59.39$) recorded a positive word use of 3.2 and a negative word use of 4.03. Day two ($t=58.62$) had a positive word score of 4.46 and a negative word score of 3.85. Day three ($t=64.02$) showed a positive word count of 2.8

and negative word count of 3.27. Average positive word usage was 3.49 and negative word usage 3.72 (Figure 7).

Caregiver Three: Positive Emotions

Caregiver Three was randomly assigned to the positive framing journaling, she was fifty-seven years old, and had been caring for her spouse for seven years. Her care recipient was 70 years old and living with his caregiver. Over the course of the pre and post journaling surveys, Caregiver Three's caregiver burden score increased from a score of 55 on the Caregiver Burden inventory to a 68 (Figure 8).

Her Pre-BRUMS scores showed a Tension score of 56, Depression: 75, Anger: 65, Vigor: 36, Fatigue: 59 and Confusion: 50. Post journaling revealed an increase reported negative mood. Depression rose to a score of 106, Anger: 92 Tension: 72, Fatigue: 79, and Confusion: 74. The only positive emotion increase was in reported vigor with a reported score of 51. (Figure 9).

Caregiver Three's overall BriefCOPE increased after positive frame journaling. Positive coping methods increased; Planning rose from a score of four to seven, Acceptance four to six, and active coping five to six. Self-blame scores also rose post survey from a score of four to five and Instrumental Support decreased. (Figure 10).

Reported Instrumental of Daily Living scores rose slightly as Caregiver Three reported an increase in ability to take medication with aid. All other responses reported the care recipient was unable to do any of the activities stated (Figure 11).

Linguistic Word Count software looked at positive and negative word usage along the three days of journaling. Day one ($t=561.51$) recorded a positive word use of 5.92 and a negative word use of 1.48. Day two ($t=64.55$) had a positive word score of 5.37 and a

negative word score of 2.44. Day three ($t=64.69$) showed a positive word count of 2.96 and negative word count of 3.77. Average positive word usage was 4.75 and negative word usage of 2.56 (Figure 12).

Caregiver Four: Positive Emotions

Caregiver Four was randomly assigned to the positive condition journaling intervention. Caregiver Four was a 71-year-old woman who had been the caregiver of her 73-year-old spouse for the past four years. Only the pre-survey and the first two days of journaling were completed. Her pre-survey caregiver burden score was a 33, suggesting mild to moderate burden (Figure 13).

Her pre-survey BRUMS scores reported a Tension score of 45, Depression: 48, Anger: 48, Vigor: 33, Fatigue: 77 and Confusion, a score of 43. Depression scores indicated average to above average depression, while fatigue was well above average and vigor below average. All other scores were considered low (Figure 14).

Caregiver Four's pre-survey BriefCOPE scores showed greatest use of Acceptance as a coping mean. The following most often used coping means included Instrumental support and Positive Reframing. Least used coping means were Behavioral Disengagement, Religion, and Denial (Figure 15).

Reported Instrumental of Daily Living scores indicated that her care recipient was unable to perform all tasks without aid and unable to do housework or cook at all.

Linguistic Word Count software looked at positive and negative word usage along the two days of completed journaling. Day one ($t=67.79$) recorded a positive word use of 5.69 and a negative word use of 1.07. Day two ($t=69.50$) had a positive word score of 5.66 and a negative word use of .94, displaying a slight trend of a decrease in negative words used (Figure 16).

DISCUSSION

After three days of 20-minute journaling and a pre and post survey, three caregivers of people with Parkinson's disease yielded mixed trends. Caregiver One, placed in the positive emotions condition showed a decrease in negative emotions, most especially anger, after journaling. Reported caregiver burden decreased slightly as well from a reported 5 to 4. Positive coping mechanisms also increased following the three days of journaling. A noteworthy trend occurred for positive/negative word usage across the three days. The first day, Caregiver One appears to fully commit to the positive prompt task, and focuses solely on positive words. However, as the journaling days continued there was an increase in the amount of negative words used of 2.17.

Caregiver Two was randomly placed in the mixed emotions group. BRUMS scores remained the same, except for tension subset, which decreased by eight points. Caregiver burden remained constant over the pre and post survey entries. Word use trends showed a decrease in negative word use throughout the three days, while positive word use peaked at day two and declined the third day.

Caregiver Three yielded very interesting data. Contrary to expected results and prior research, caregiver burden scores and negative mood increased over the course of the journaling days and surveys. While one may be concerned that the study itself influenced reported burden and affect, a closer look at Caregiver Three's journaling showed that there had been a serious decline in her loved one during the days journaling took place, something of which the study did not take into account.

While Caregiver Four did not complete the journaling or post-survey measures, the data shown after running LIWC software suggest that positive framing could possibly

decrease negative word use or keep negative word use plateaued in caregivers experiencing mild to moderate caregiver burden.

While no significance tests could be run due to the limited sample size, trends show that in caregivers who report less severe caregiver burden, negative mood scores decrease, and most notably decrease in the positive framing condition. However, Caregiver Three experienced both a sharp spike in caregiver burden and negative mood during pre and post survey. Caregiver Three however reported a significant decline in her care recipient during the span of journaling, which could have influenced increased caregiver burden scores and increased negative mood. Also, positive/negative word usage shows an interesting trend in the both the positive framing and mixed emotions conditions. Participants in the positive emotion condition appeared to focus heavily on positive words on the first day of journaling and then level off the next two days. These findings could suggest that the schedule of the journaling was too intensive. Journaling may be more beneficial using less days, or shorter intervals of journaling. The implications of this study suggest that expressive writing may influence more healthy coping means and decrease negative mood subsets of the BRUMS in caregivers of those with lower reported caregiver burden. 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 situations and the progression of PD. One of the participants in this study succinctly explained what each caregiver faces:

"It hurts to see him struggle because I remember what he used to be like. Watching him eat makes me sad...even the simple action of lifting a chip to his mouth is a battle...I do however feel great when he tells me he's had a great day...that is the most rewarding part because I know he means it."

Strengths

The strengths of this study is that is spanned the length of five days. As the study took place over multiple days, data was more representative of caregiver experience rather than a single day. The participating caregivers also ranged in care recipient capabilities and relationship to their care recipient, allowing the study to see what trends exist depending on relationship and severity. All measures used in the study have been found to be reliable and valid.

Limitations

A major limitation to the study was the limited number of caregivers participating. As caregivers are extremely busy, dedicating enough time to partake in the surveys and multiple days of journaling was difficult. As this study was limited to three participants, no significance tests could be conducted. Another limitation of the study was that journaling doesn't take into account declines in care recipient functioning. As patient conditions worsened, reported burden or concerns could arise independent of the study.

Future Research

In the future, studies would include a larger sample size to extract significance from the data. Other studies could also look at the influence of numbers of journaling days or the length of journaling time and caregiver stress.

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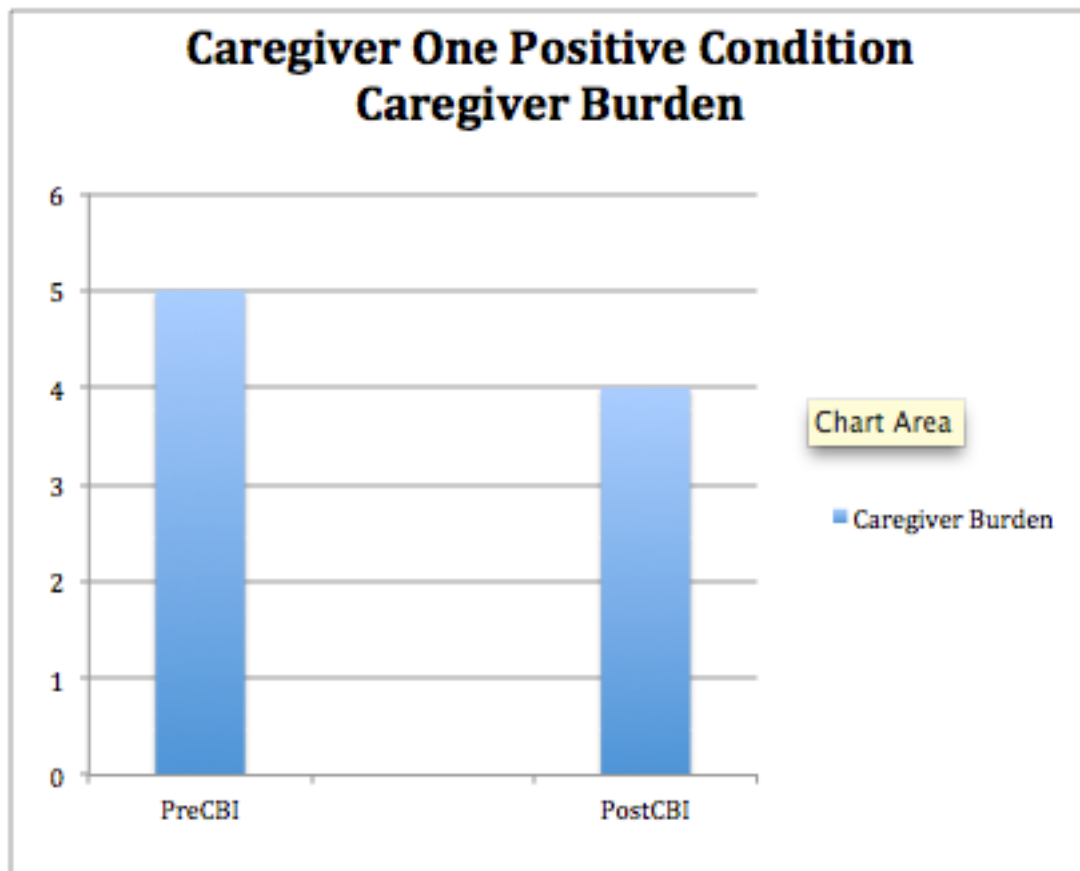


Figure 1. This figure shows the change in reported caregiver burden in Caregiver One before and after the journaling intervention. Caregiver One reported a slight decrease of one.

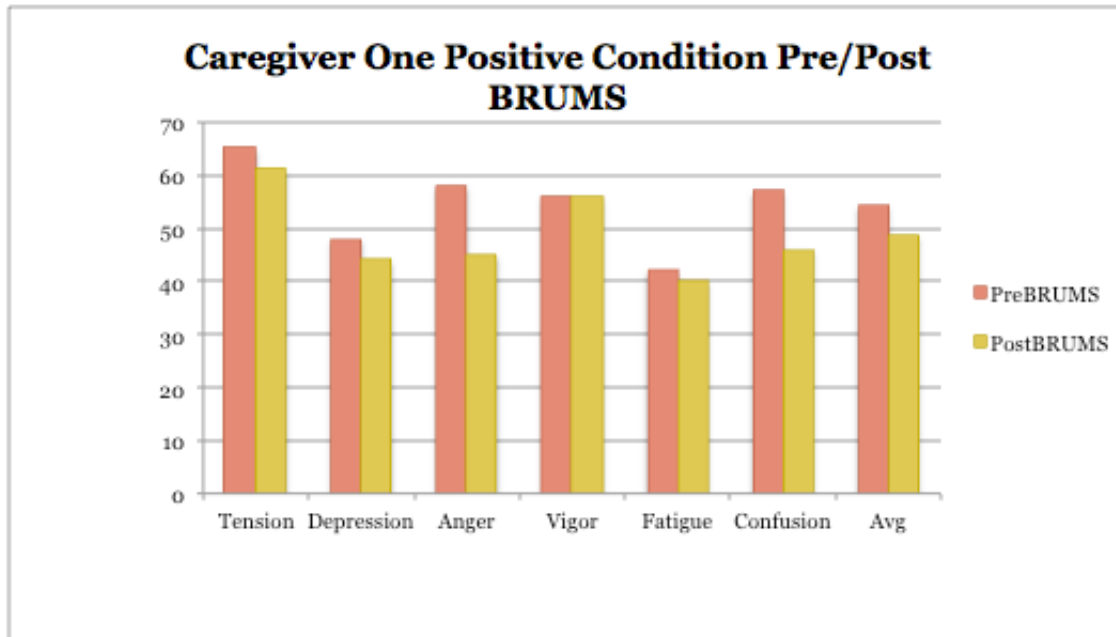


Figure 2. This figure shows the change in reported mood for pre and post journaling intervention. All negative mood subsets decreased in Caregiver One, with the greatest decrease in Anger.

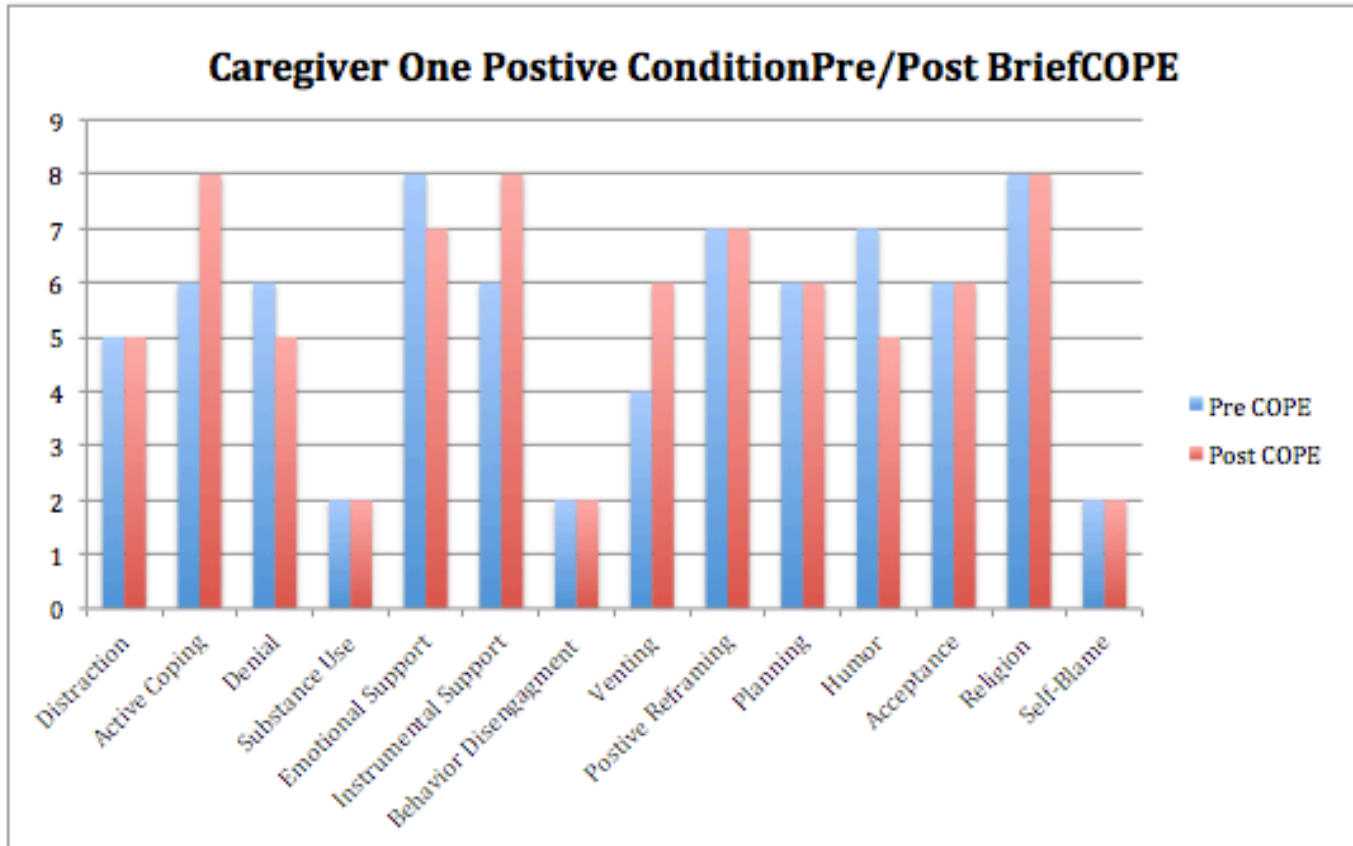


Figure 3. This figure shows the change over the course of the journaling intervention in BriefCOPE subsets. There was an increase in positive coping means including active coping, and instrumental support and a decrease in denial.

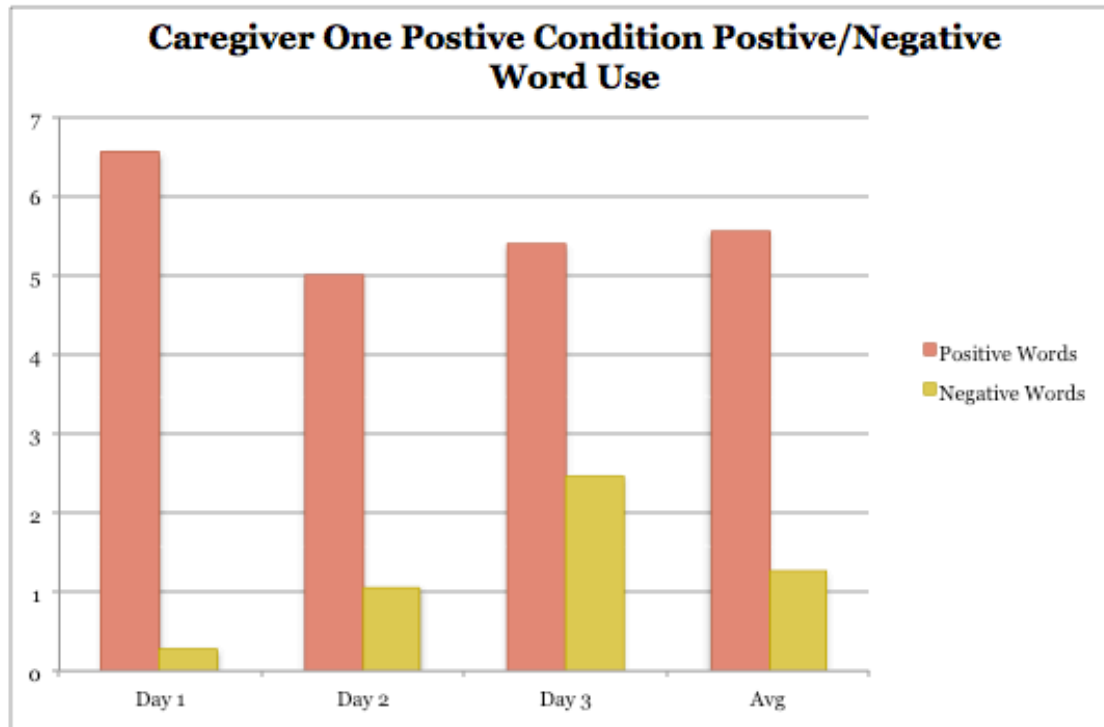


Figure 4. This figure shows the ratio of positive and negative words used by Caregiver One over the course of the journaling intervention. The figure shows Day One had the most extreme difference before leveling over the course of journaling.

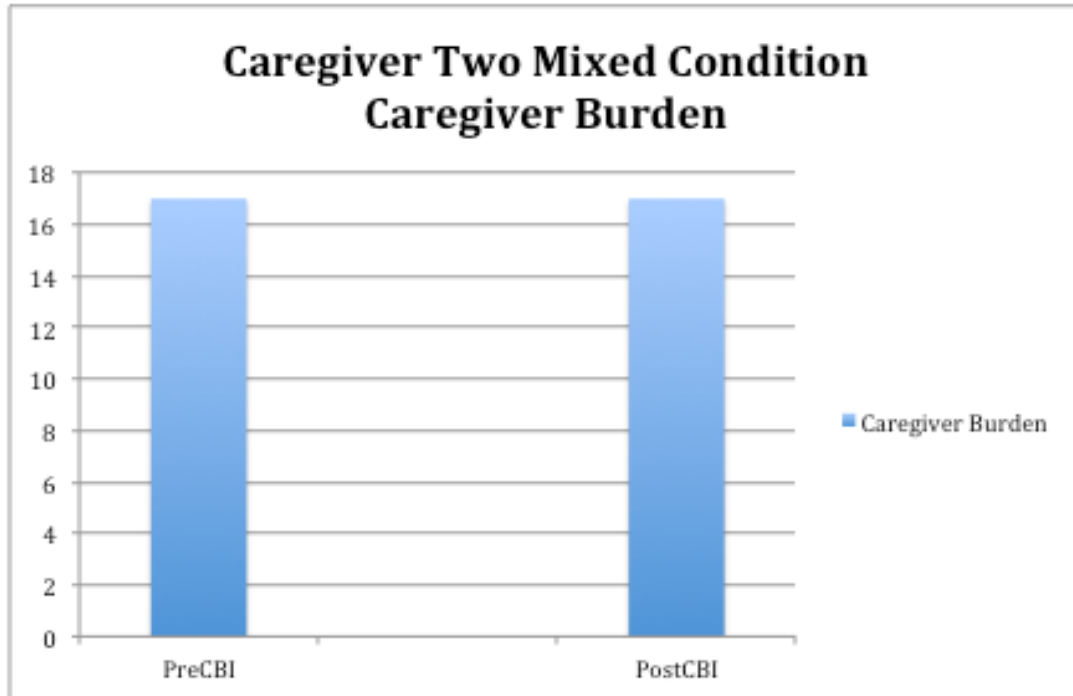


Figure 5. This figure shows the reported caregiver burden for Caregiver Two over the course of journaling. There was no change in reported burden.

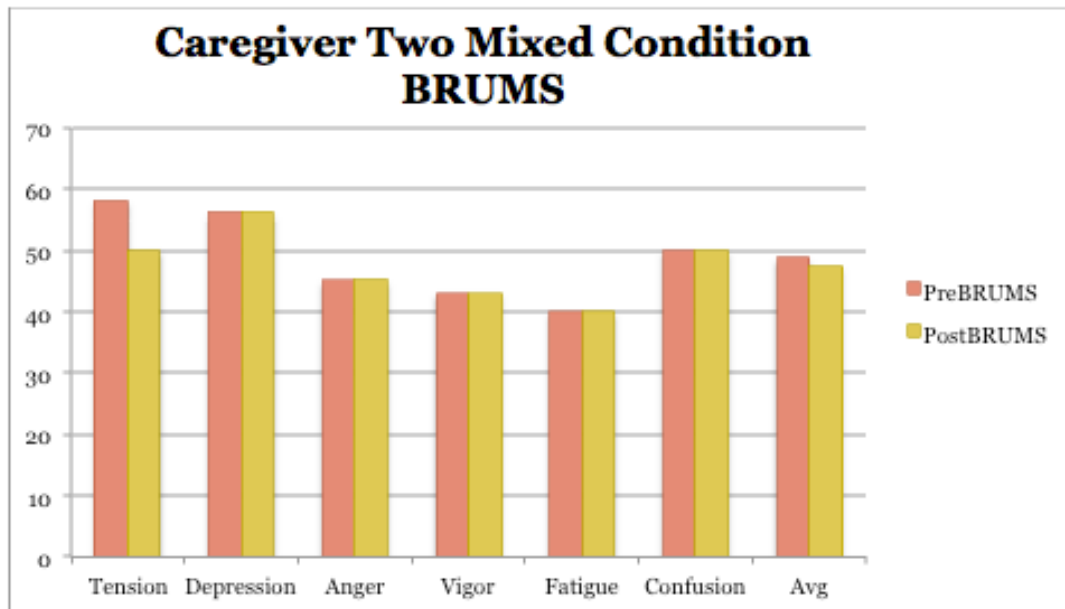


Figure 6. This figure shows the change in reported mood for pre and post journaling intervention. All mood subsets remained unchanged in Caregiver Two, expect a decrease in Tension.

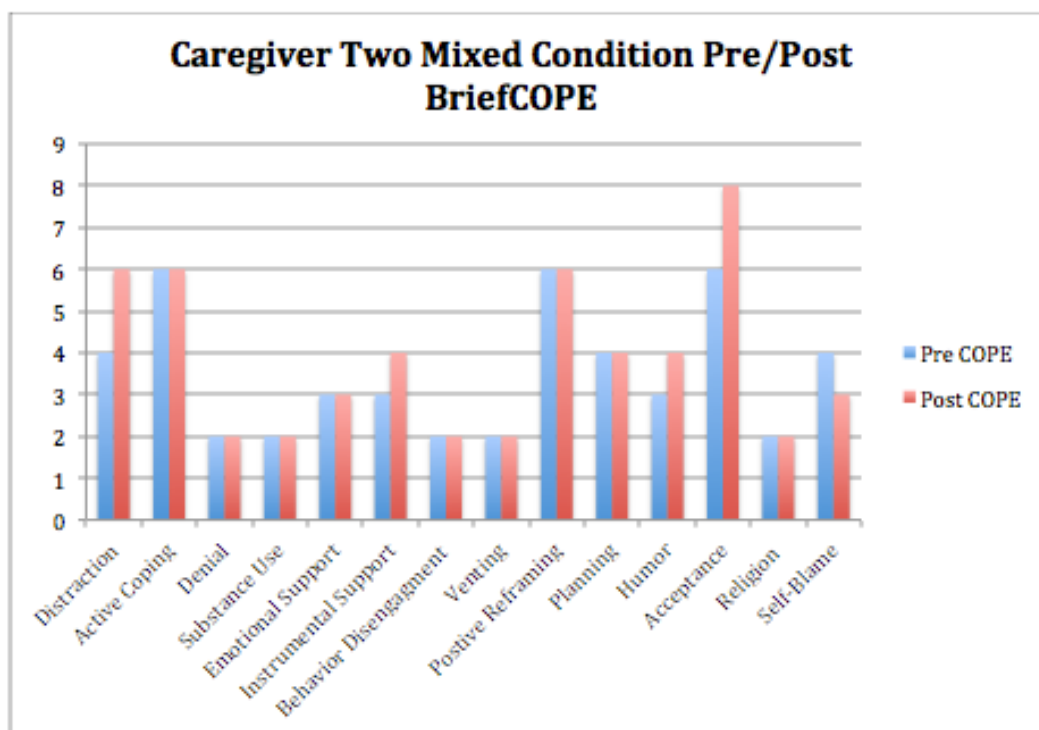


Figure 7. This figure shows the change over the course of the journaling intervention in BriefCOPE subsets. There was an increase in positive coping means including acceptance, humor, and instrumental support and a decrease in self-blame.

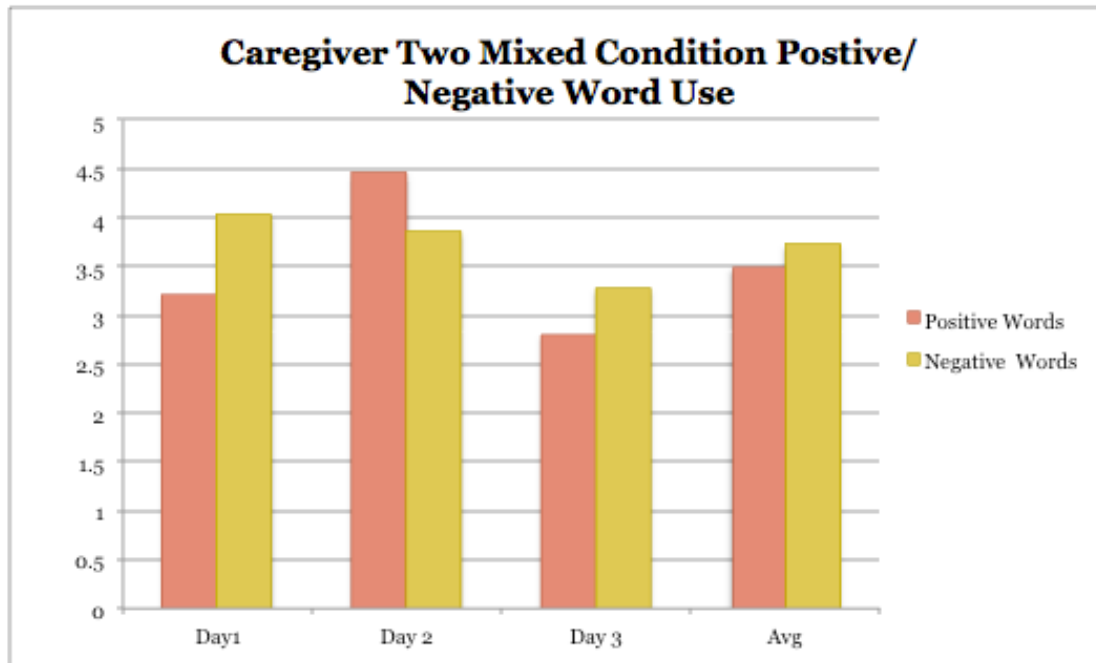


Figure 8. This figure shows the ratio of positive and negative words used by Caregiver Two over the course of the journaling intervention. The figure shows a decrease in negative words used.

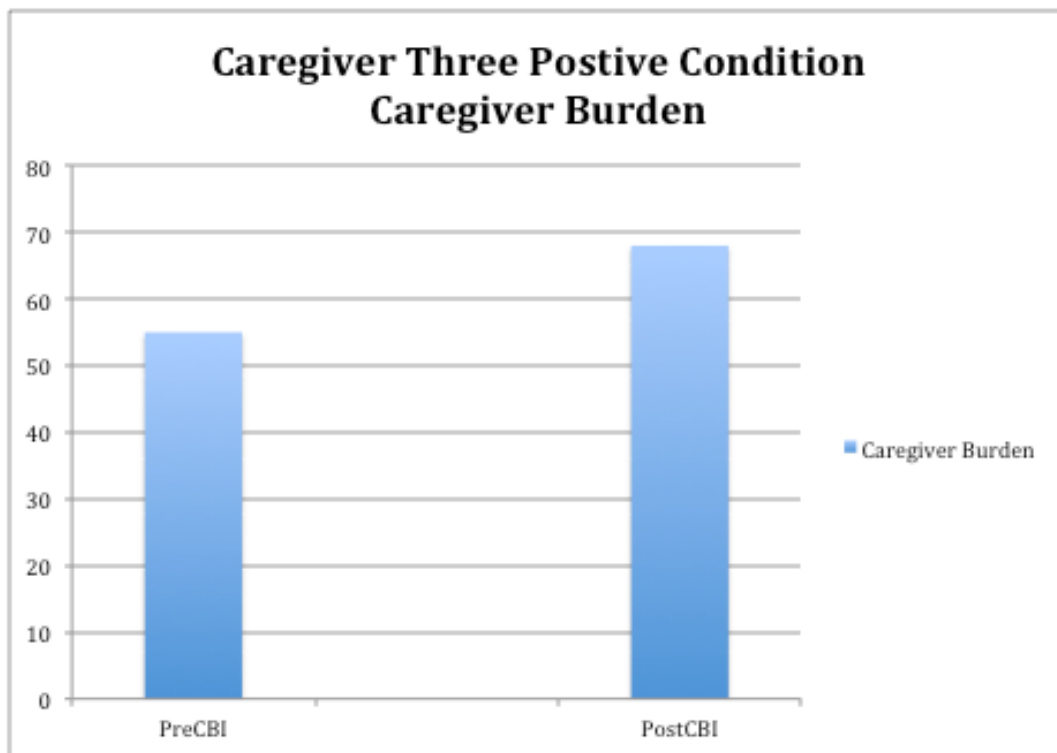


Figure 9. This figure shows the reported caregiver burden for Caregiver Three over the course of journaling. There was a sharp increase in caregiver burden over the course of journaling.

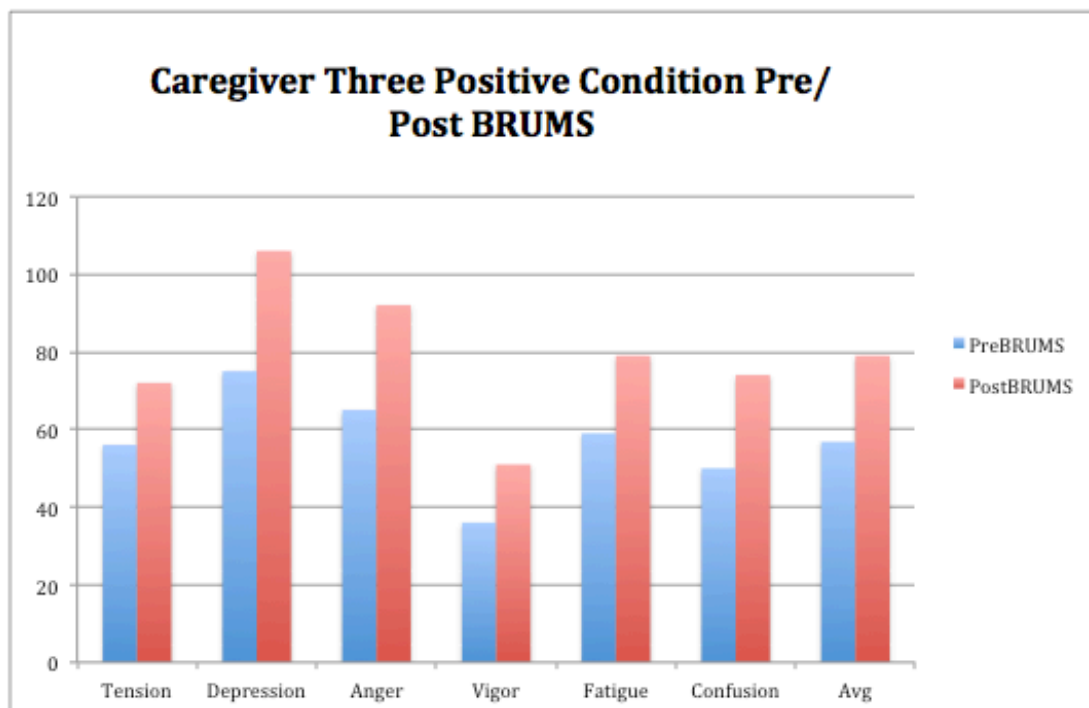


Figure 10. This figure shows the change in reported mood for pre and post journaling intervention. All mood subsets increased over the course of journaling.

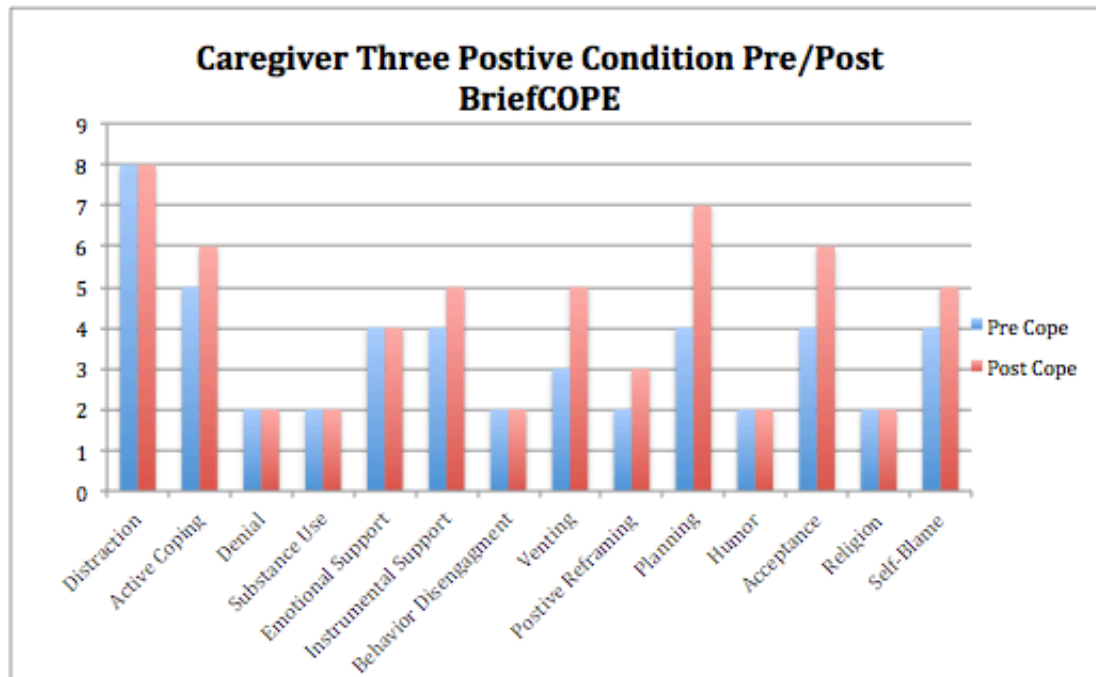


Figure 11. This figure shows the change over the course of the journaling intervention in BriefCOPE subsets. There was an increase in positive coping means including planning, active coping, instrumental support, positive reframing and acceptance. However there were also increases in self-blame.

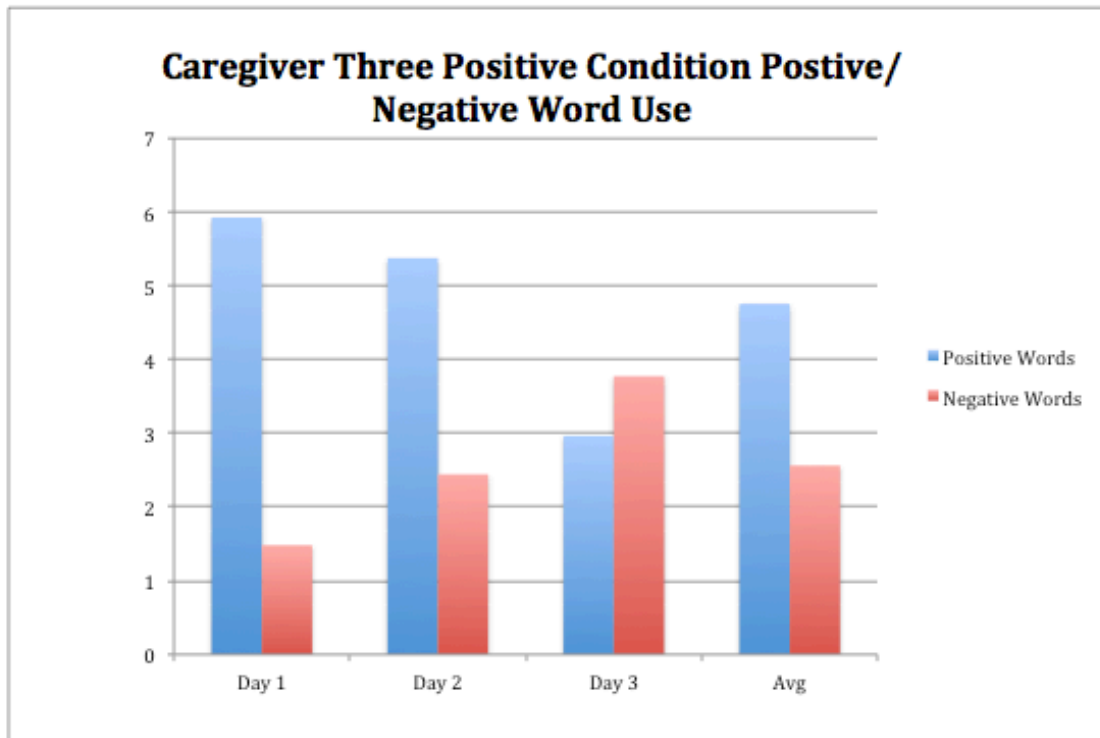


Figure 12. This figure shows the ratio of positive and negative words used by Caregiver Three over the course of the journaling intervention. The figure shows the largest variation of positive to negative words on the first day, while positive words declined and negative words increased.

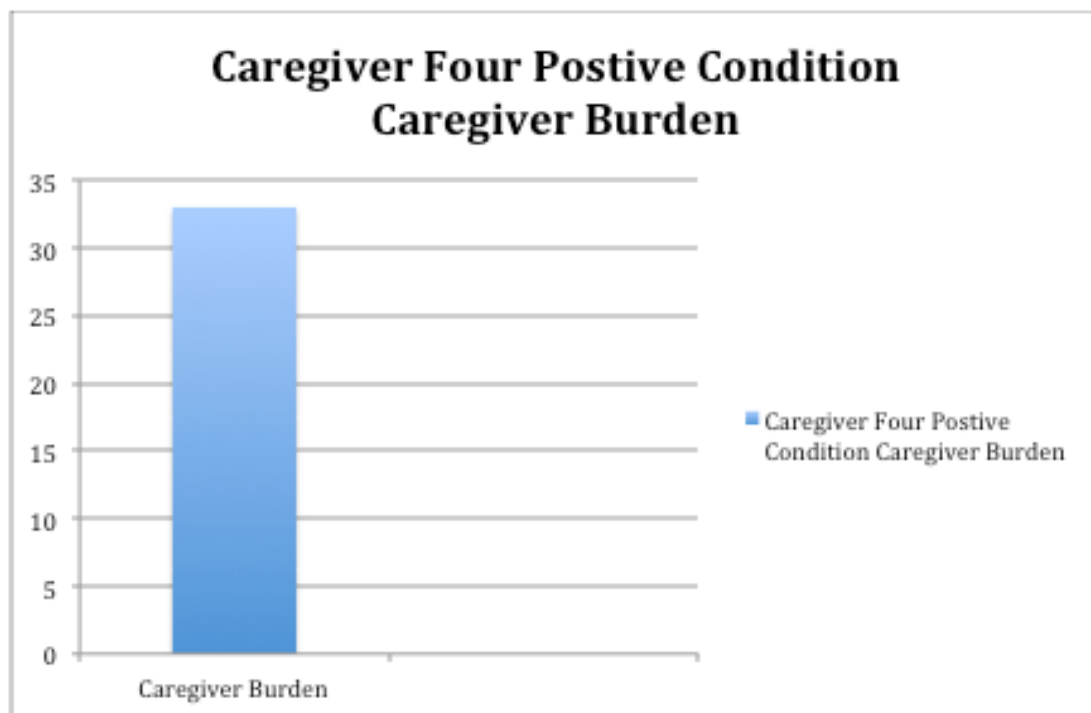


Figure 13. This figure shows the reported caregiver burden for Caregiver Four. A score of 33 indicated mild to moderate burden.

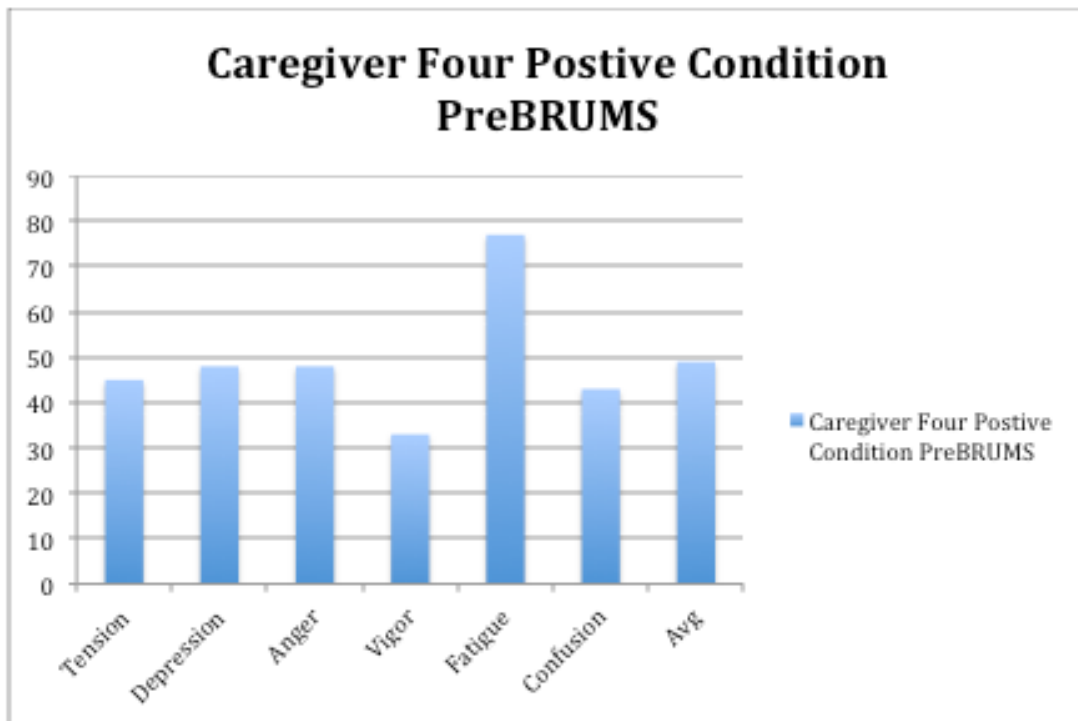


Figure 14. This figure shows the reported mood for pre and post journaling intervention. Data shows the greatest strain on depression, vigor and fatigue.

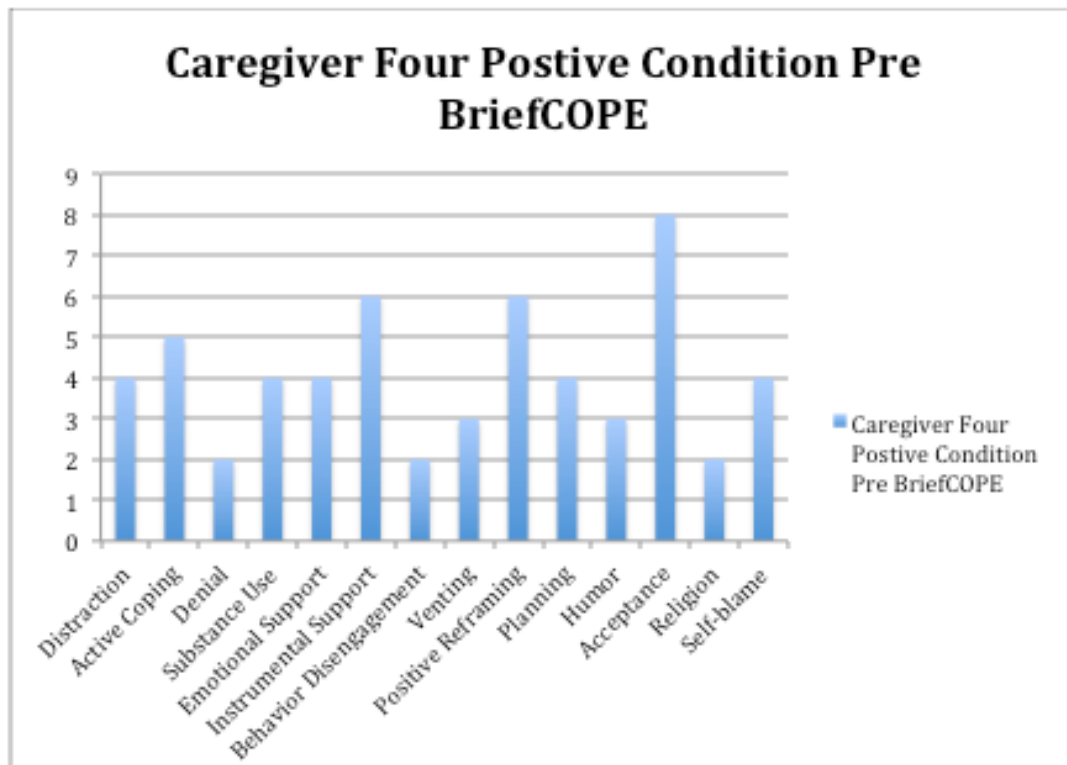


Figure 15. This figure shows reported BriefCOPE subset scores. The most often used coping mean was acceptance, followed by Instrumental Support and Positive Reframing. The least used coping means were Denial, Religion, and Behavior Disengagement.

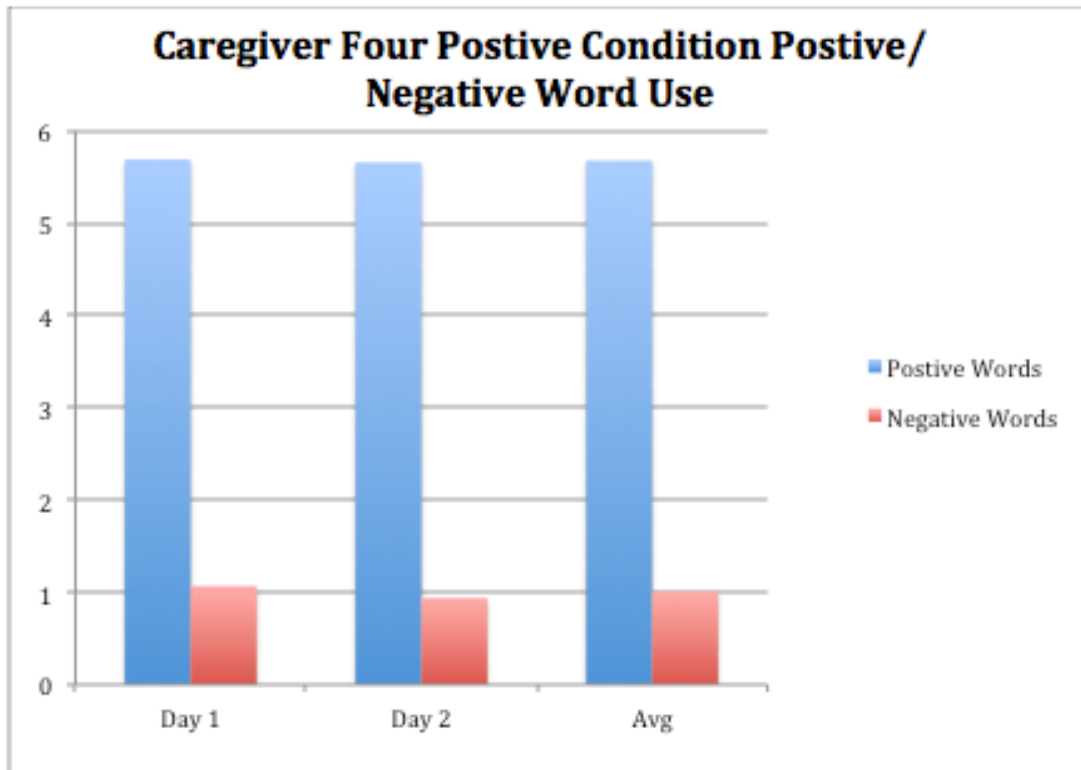


Figure 16. This figure shows the ratio of positive and negative words used by Caregiver Four over the course of the two days of journaling completed. The figure shows a steady use of positive words in comparison to negative words used.

Appendix A 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** _____

Time Dependency Items	
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
Development Items	
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

Physical Health Items	
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

Emotional Health Items	
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

Social Relationships Items	
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

Expressive Writing for Parkinson's Caregivers

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"/>	<input type="checkbox"/>
2. Lively	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
4. Worn out	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
6. Downhearted	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
8. Exhausted	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
10. Sleepy	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
12. Unhappy	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
14. Worried	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
16. Miserable	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
18. Nervous	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
20. Active	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
22. Bad tempered	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
24. Uncertain	<input type="checkbox"/>	<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: ____

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SURVEY 4

Instrumental Activities of Daily Living (Cummings et al., 2002)

Subject Number _____

This form may help you assess the functional capabilities of your older patients. The data can be collected by a nurse from the patient or from an informant such as a family member or other caregiver. (I = independent; A = assistance required; D = dependent)

<i>Obtained from:</i>		<i>Activity</i>	<i>Guidelines for assessment</i>
<i>Patient</i>	<i>Informant</i>		
I A D	I A D	Using telephone	I = Able to look up numbers, dial telephone, and receive and make calls without help A = Able to answer telephone or dial operator in an emergency, but needs special telephone or help in getting numbers and/or dialing D = Unable to use telephone
I A D	I A D	Traveling	I = Able to drive own car or to travel alone on buses or in taxis A = Able to travel, but needs someone to travel with D = Unable to travel
I A D	I A D	Shopping	I = Able to take care of all food and clothes shopping with transportation provided A = Able to shop, but needs someone to shop with D = Unable to shop
I A D	I A D	Preparing meals	I = Able to plan and cook full meals A = Able to prepare light foods, but unable to cook full meals alone D = Unable to prepare any meals
I A D	I A D	Housework	I = Able to do heavy housework (i.e., scrub floors) A = Able to do light housework, but needs help with heavy tasks D = Unable to do any housework
I A D	I A D	Taking medicine	I = Able to prepare and take medications in the right dose at the right time A = Able to take medications, but needs reminding or someone to prepare them D = Unable to take medications
I A D	I A D	Managing money	I = Able to manage buying needs (i.e., write checks, pay bills) A = Able to manage daily buying needs, but needs help managing checkbook and/or paying bills D = Unable to handle money