

THE EFFECTS OF A SPECIFICALLY DESIGNED ALZHEIMER'S WORKBOOK ON THE BURDEN OF CARE, PROBLEM-SOLVING ABILITIES, AND DEPRESSION LEVELS OF HOME CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE

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Alzheimer's Disease (AD) is a chronic, long-term, debilitating, disease that currently affects millions of people worldwide. Most of the people afflicted with this disease are cared for in the home setting by family members and many do not have access to formal community education. Due to the erratic behavioral responses and steady declines in self-care abilities of persons with AD, caregivers face high degrees of physical and psychological stress. With limited options and choices, caregivers fall back on behaviors that do not preserve self-care behaviors in the person with AD, which adds to their stress. The AD workbook, designed by the author for this study, allows caregivers to plot the current abilities and future declines of the person they are caring for in the holistic mental, emotional, physical, social, and spiritual domains. This methodology provides the caregiver with choices that can be matched to individual needs and utilized as problem-solving modalities.

This study tested the hypothesis that the use of this self-directed holistic health workbook would decrease the perceived burden of care and levels of depression as well as increase positive perceptions of problem-solving skills in home caregivers of persons with AD. Forty-nine volunteer caregivers were randomly assigned to either a treatment group or a control wait-list for the program. Subjects in the treatment group were given a copy of the Alzheimer's Holistic Workbook and an instruction sheet (Figure 1).

All caregivers were given pre- and post-test measures on Novak and Guest's Caregiver Burden Inventory (CBI), Heppner's Problem Solving Inventory (PSI), and Zung's Depression Scale. Pre- and post-test score differences were analyzed by using 2 X 2 mixed ANOVAs, examining the repeated measures between and within group factors. Of the three test totals and eight sub-tests, only the levels of Personal Control (a sub-test of the PSI measuring perceived control of one's emotions while problem solving) changed significantly. This factor was significant at $p < 0.05$ level (Table II) and

represents the first one to change in a positive way. Experimental group participants may have found this to be the first move toward constructing rational paradigms preceding fully engaging the problem solving process.

Personal Confidence closely related to PC was trending toward significance ($p < 0.5$) as well as the total PSI score ($p < 0.5$). Of the problem solving scores only Approach Avoidance (AA) was not trending toward a positive change. AA would seem to be a more intractable measure. If a caregiver has built up defense mechanisms to such an extent that avoiding problems is his/her approach, then reversing that process would take some time, energy, and focused retraining. The higher p value of this score would seem to support this view.

In examining the raw scores for this study, a noticeable amount of variability was observed. Participants in both the experimental and control groups went up and down in seemingly random fashion. Several participants in the control group with very high problem solving scores did experience significant drops in their scores (i.e. 174 to 145 = 16% and 155 to 118 = 24%). It is likely that this is due to a test/re-test interaction. The PSI was structured with questions that could guide someone into the steps of problem solving. The CBI can raise a person's awareness of their feelings and possibly precipitate a period of introspection that leads to some moderation of feelings. The Zung also contains strong emotional content and could also possibly bring a person to similar awareness of feelings. In a true experimental design this factor should be controlled for by randomization, but with results this close it is likely to have pushed the means closer together.

The flatter than expected mean scores of the experimental group may have been due to an emotional upheaval cause by trying a new system of approach to daily activity. In this case the participants past knowledge may have initially caused them to be more judgmental about their previous modes of behavior and former approaches to problems. Essentially a period of excitability was created where their emotions were labile, as were their self-assessments. This changeable state could account for diverging scores depending on the state of the individual's life at the time, thus canceling out each other's scores and creating flatter means between the groups. It is also possible that there is another secondary gain from this variability. Instability is at times, designed into aircraft to make them more agile and maneuverable. It could be that this "agility factor" might have a parallel in the realm of human performance and behavior change. When a person engages a behavior change, there is undoubtedly energetic disruption. Old less useful behaviors are no longer employed in favor of newer more positive adaptations. In some respects, one needs to become more emotionally agile in order to maneuver amongst the various behavioral choices. Initial variability on scores such as the ones used in this study in the beginning periods of behavior change, may be

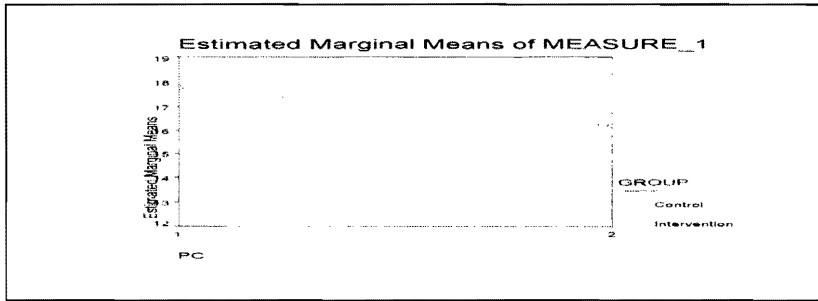


Figure 1. PSI: Personal Control. Tests of Between-Subjects Effects.

Table I
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	19542.430	1	19542.430	367.395	.000
GROUP	324.157	1	324.157	6.094	0.018
Error	2234.059	42	53.192		

Table II
Levels of Engagement

Level 1 15% (3) <i>n</i> = 20	Tackling Blockers Intra-psychic strain-fear, anger, resentment, stress, confusion, fatigue; excessive time burden; general role strain; self-judgement & guilt over negative responses; ability to accept the positive instead of the “should be,” poor reading and organizing skills. <i>Low readiness for change.</i>
Level 2 40% (8)	Trial Engagement Still working with level 1 blockers but able to commit some time to the task; still ambivalent but interested in some new information; still worries about time commitment. <i>Low to moderate readiness for change.</i>
Level 3 20% (4)	Experienced Evaluation Individuals in this category have been caregivers for many years (5-15 years); not interested in a full commitment to a new system but always interested in new resources, enthusiastic evaluators of informational materials, more easily attached to concept information. They have been practicing skills in real life situation for many years—may not perceive need to change physical activity but can adopt information easily. <i>Moderate readiness for change.</i>
Level 4 25% (5)	Open Engagement May still be working with level 1 blockers but have some readiness for change; looking for new ideas and possibly ways of being; easily engaged in the trial and error process, may experience chaos of change, potential transcendent experience. <i>Moderate to high readiness for change.</i>

evidence of the presence of and the need for this “agility factor” in moving toward long term change.

Another factor working to diminish differences in the means was the levels of engagement within the experimental population. The workbook evaluations expressed a great deal of positive acceptance of the text and informational content, but also a variable rate of engagement of the requested exercises. Random selection was not an asset in this circumstance. A number of the experimental participants exhibited a low readiness for change, which would occur in any random grouping of caregivers. Table II illustrates the levels of engagement found in this study. The workbook evaluations were used to produce this data.

As one can see, fully 55% of the experimental sample (Level 1 and 2) did not engage or only partially engaged the workbook exercises, which were hypothesized to lead to the levels of behavior change desired in this study. These participants fell into the low to moderate readiness for change levels. From their responses on the evaluations, they could be seen as being very susceptible to self-judgment and defensive conclusions promoted by some level of guilt for not fully participating in the experiment though not dropping out. All of these participants rated the workbook as a good resource for a future time.

The rest of the results (beyond the significant score on the Personal Control subtest of Heppner’s Problem Solving Inventory), although not statistically significant, did indicate trends toward reductions in burden and improvements in the perception of problem solving abilities. There were also anecdotal reports of positive experiences in a number of the experimental participants.

No significant reduction was found in levels of depression, but this sample was not highly depressed—on pre-test-only 34% of the sample had some level of depression and 66% of that was mild. This lack of significance on certain tests may be due to random sampling without controlling for either readiness to learn or the threshold of emotional engagement needed to accept new information and adopt new ways of conceptualizing care. All participants in the treatment group rated the Workbook as an excellent resource for managing care.

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