

Project Name:

Development and Assessment of Psychoeducational Group Interventions: (1) for Individuals with Alzheimer Disease Who Have Lost Their Driving Privileges and (2) for their Primary Caregivers

1. AIMS OBJECTIVES OF THE INVESTIGATION

Objectives:

1. To test the impact of a group intervention for individuals living with AD who have lost their driving privileges on: (a) affect of the individual, (b) behavioural problems, and (c) quality of life for the individual.
2. To test the impact of a group intervention for primary caregivers of individuals living with AD who have lost their driving privileges on (a) affect of the caregiver, (b) caregiver burden, (c) perceptions of caregiving competency, and on caregiver (d) stress management skills.

Hypotheses:

The hypotheses regarding all pre-intervention measures are for no differences between the groups. For the post-intervention measurements, the hypotheses are as follows:

Compared to the control group, the intervention group will have:

1. Decreased negative affect as measured by the GDS and the modified GDS
2. Decreased emotionality and behavioral disturbances as measured by the Revised Memory and Behavior Checklist
3. Increased positive affect as measured by the Pleasant Events Schedule
4. Increased quality of life as measured by the Quality of Life Scale

The hypotheses regarding all pre-intervention measures are for no differences between the groups. The post-intervention hypotheses are as follows:

Compared to the control group, the intervention group will have:

1. Decreased negative affect as measured by the CES-D
2. Decreased caregiver burden as measured by the Caregiver Burden Inventory
3. Increased caregiving competency as measured by the Caregiving Competency Scale
4. Increased coping skills (coping self-efficacy; coping effectiveness) (Measures developed)
5. Increased ability to match stressors with coping strategies (Measures developed)

2) METHODS USED

Research Design

An experimental-control, pre-test/post-test design was employed. There were five waves of data collection for the experimental phase, with each wave consisting of a 16 week support group intervention. Individuals with dementia and their caregivers/family members met concurrently, but independently each week. A clinical geriatric psychologist led the patient group, a social worker experienced in group interventions led the caregiver groups. Individuals entering the control arm of the study attended 6 week support groups offered by the Edmonton Alzheimer Society. Control group individuals with dementia and their caregivers/family members met concurrently, but independently each week. The groups were led by experienced group leaders employed by the Edmonton Alzheimer Society.

Enrolment and Data Collection

Participants were recruited based on inclusionary/exclusionary criteria. Following informed consent, demographic data (Care Recipient and Caregiver age, education, income, marital status, Care Recipient Mini-Mental State Exam [MMSE] and current medications, Caregiver relation to Care Recipient, length of caregiving, etc.) were obtained from each participant.

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Outcome measures relevant to the research (depression, quality of life, caregiver stress, etc.) were collected at baseline data, 16 weeks, and at 32 week follow-up. Criteria for experimental group interventions were developed (e.g., closed, time limited, etc.) and followed over the 5 waves of data collection. Similar criteria (e.g., closed, time limited, etc.) were followed for the control group.

Data Analyses

Multivariate analyses of variance (MANOVA's) were used to examine demographic differences for continuous variables; differences for categorical variables were tested using the chi-square test. A repeated measures MANOVA was used for the overall analysis of study variables. Overall significance of the MANOVA was followed up with analyses using MANOVA's/ANOVA's as appropriate.

3) RESULTS**A. Demographics**

Seventy-four individuals participated in the study. The breakdown, with the corresponding demographics, is shown in Table 1.

Table 1: Demographics of Experimental and Control Care Recipients and Caregivers (n = 74).

	Care Recipients		Caregivers	
	Exp (n = 28)	Control (n = 16)	Exp (n = 15)	Control (n = 15)
Age	77.78	77.23	72.60	70.20
Male	68%	44%	20%	40%
Female	32%	56%	80%	60%
MMSE	24.05	22.94	28.57	27.71
Marital Status				
Married ¹	50%	75%	87%	93%
Widowed/Divorced ²	50%	25%	13%	7%
Years Driving	53.50	54.06	--	--

¹ Includes married and common-law

² Includes single, widowed, divorced, separated

Demographics-Individuals with Dementia (Care Recipients)

As shown above, there were 44 individuals with dementia who participated in the study: 28 in the experimental group (specialized support group) and 16 in the control group (regular support group). The average age of the experimental and control group Care Recipients was 78 and 77 years, respectively, a difference that was not significant ($p > .05$). The mean MMSE was 24.05 for the experimental group and 22.94 for the control group, a difference that was not significant ($p > .05$). The MMSE average indicates that overall, the individuals were in the mild stages of dementia. Half of the experimental Care Recipients were married or living common-law, compared to 75% of control Care Recipients. The difference in marital status between the two groups was not statistically significant ($p > .09$). Both experimental and control Care Recipients had been driving for more than 50 years prior to license revocation.

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Demographics-Caregivers

There were 30 Caregivers who participated in the study: 15 in the experimental group (specialized support group) and 15 in the control group (regular support group). The average age of the experimental and control group participants was 73 and 70 years, respectively. The difference was not statistically significant ($p > .05$). There was a higher percentage of male caregivers in the control group (40%) compared to the experimental group (20%) but that difference was not significant ($p > .20$). The MMSE scores for the both groups of caregivers were in the normal range (e.g., above 24). The scores were not statistically different ($p > .26$). The majority of the caregivers in both groups were married. The difference between the two groups (87% vs. 93%) was not statistically significant ($p > .50$).

B. Results related to Hypotheses*Care Recipient Group*

An overview of the results is presented in Table 2. The results show the pattern of change in scores on the measures of depression (Geriatric Depression Scale [GDS] and Modified Geriatric Depression Scale [MGDS]), memory and behavioural problems, and quality of life (quality of life and pleasant events) at the end of the support group intervention (e.g., 16 weeks) versus baseline (prior to the start of the support groups) for the experimental and control Care Recipients. The pattern of data for the three time periods (baseline, 16 weeks, and 32 week follow up is similar. Due to spacing limitations, those data are not reported here.

Table 2: Overview of results between experimental and control Care Recipients on measures of depression (GDS and MGDS), memory and behavioural problems, and quality of life (quality of life and pleasant events): Baseline vs. 16 week follow-up.

Measure	Instrument	Specialized Support Groups (Exp)	Regular Support Groups (Control)	Significance
Depression	GDS*	↓	No change	$p = .05$
	Mod. GDS*	↓	↑	$p = .05$
Memory & Behavior Problems	Revised M & B Checklist***	↓	↑	$p = .001$
Quality of Life	Quality of Life*	↑	↓	$p = .05$
	Pleasant Events Schedule**	↑	↓	$p = .01$

As shown in Table 2, there were significant differences between the experimental and control group Care Recipients on all measures. Specifically, the experimental group Care Recipients exhibited a decrease on the two measures of depression between the two measurement periods (e.g., at the end of the 16 week intervention vs. prior to the start of the intervention), whereas the control Care Recipients showed no change on the Geriatric Depression Scale, but increases on the Modified Geriatric Depression Scale for the same time periods ($p < .05$). Notably, decreased scores indicate lower levels of depression.

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In terms of memory and behavioural problems, the experimental Care Recipient group exhibited reductions in memory and behaviour problems between the start and end of the intervention (e.g., the support groups) compared to the control Care Recipient group. The control Care Recipients, on the other hand, exhibited increases in memory and behaviour problems over the same time period. The difference between the two groups was statistically significant ($p < .001$).

There also were significant differences between the two groups on the quality of life measure. Experimental Care Recipients showed an increase in quality of life, compared to a decrease for the control Care Recipients. Lower scores on the measure indicate decreased quality of life. The difference was statistically significant ($p < .05$).

Finally, there were significant differences between the experimental and control Care Recipients on pleasant events as measured by the Pleasant Events Schedule ($p > .01$). The pattern was such that the experimental Care Recipients demonstrated increases on pleasant events ratings (e.g., greater enjoyment) between the two time periods, whereas the control Care Recipients' scores decreased between baseline and the end of the support group intervention.

Exit Measures – Care Recipients

Care Recipients from both groups also completed an exit survey at the end of the support group intervention period. Participants were asked if the group intervention (1) made a difference in their life, (2) helped them in coping with their illness, (3) helped them cope with not driving, (4) helped them talk with their spouse (or primary caregiver) about not driving, and (5) helped them in relationships with their family. Respondents rated each question using a Likert scale (strongly disagree to strongly agree). The results of those ratings are provided in Figure 1, with percentage agreeing or strongly agreeing reported in percentages. As can be seen, both experimental and control group Care Recipients indicated that the groups were effective in 'making a difference in their life' and in helping them 'cope with the illness'. Ratings from the experimental group Care Recipients, were, however, higher for the remaining three items: 'the group helping them cope with driving', in 'talking with their spouse about driving', and in their 'relationships with family'

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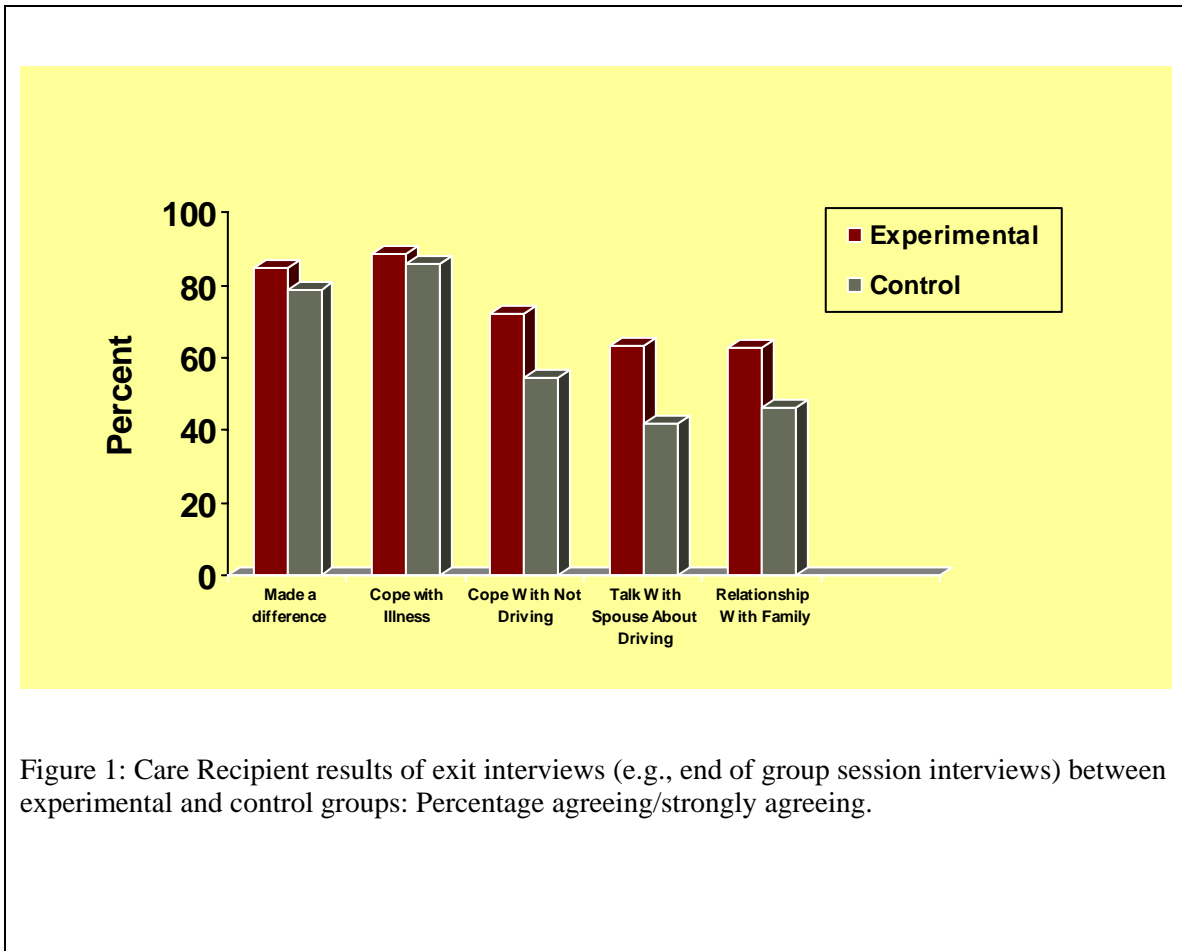


Figure 1: Care Recipient results of exit interviews (e.g., end of group session interviews) between experimental and control groups: Percentage agreeing/strongly agreeing.

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Caregiver Group

The pattern of results from the caregiver groups on measures of affect (depression), caregiver burden, perceptions of caregiving competency, and coping self-efficacy are provided in Table 3. The experimental caregiver group exhibited a reduction in depression scores between baseline and the end of the support group intervention compared to the control group. However, that difference failed to reach significance.

Secondly, caregiver burden scores increased for the experimental group, but did not change for the control group ($p = .04$). The reason for the increase in burden ratings for the experimental group is not clear. It may be that the focus on stressors taught with the coping effectiveness training program in the experimental group made experimental caregivers more aware of the stressors that they were experiencing, an awareness that was reflected in the 16 week ratings.

There were no differences between the two groups in caregiving competency or in a general measure of coping self-efficacy. However, scores from both caregiver group participants showed a small increase in coping self-efficacy, suggesting that the group interventions were beneficial in increasing their perceptions of self-efficacy in coping.

Table 3: Summary of Results: Overview of results between experimental and control Caregivers on measures of depression, caregiver burden, caregiving competency, and coping self-efficacy: Baseline vs. 16 week follow-up.

Measure	Instrument	Specialized Support Groups (Exper)	Regular Support Groups (Control)	Significance
Depression	CES-D Scale	↓	↗	NS
Caregiver Burden	The Burden Inventory	↑	No change	$p = .04$
C/G Competency	Perceived Caregiving Competency Scale	No change	No change	NS
Coping Self-Efficacy	Coping Self-Efficacy Scale	↑	↑	NS

One of the primary goals of the research was to determine if caregivers could be 'empowered' by teaching them effective coping skills. Toward that end, the foundation for the experimental group was the coping effectiveness training (CET) program, based on the theory of Lazarus and Folkman (1984). Importantly, there were significant differences between the experimental and control groups on overall coping effectiveness scores ($p = .02$). That is, over the course of the group interventions *and in 32 week follow-up*, the experimental caregivers' coping effectiveness scores increased (e.g., improved coping) whereas the control caregiver scores stayed approximately about the same (see Figure 2). There also were significant differences between the two groups on ability to identify stressors, as measured by the coping effectiveness training changeable/ unchangeable scores ($p < .01$) (see Figure 3). Again, experimental caregiver scores improved over the course of the study, whereas the control caregiver scores decreased.

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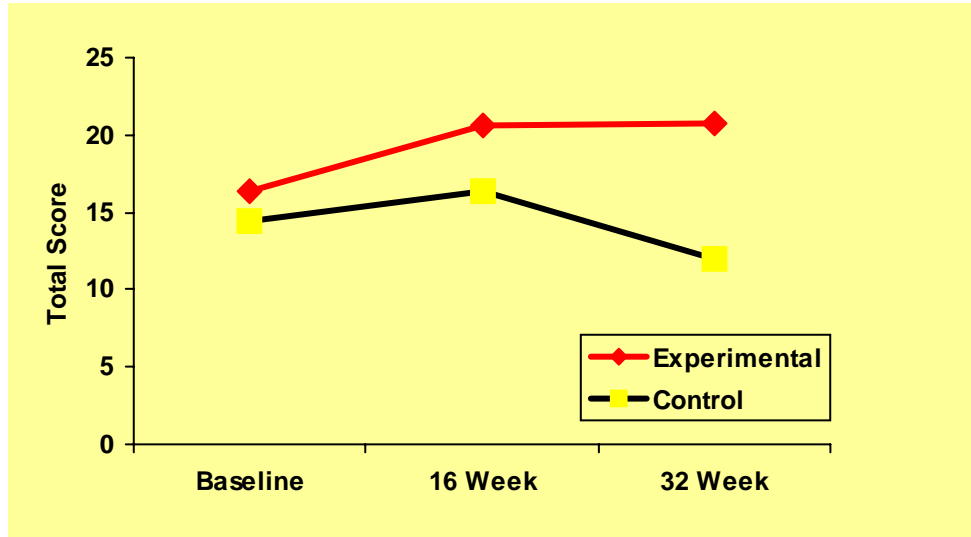


Figure 2: Caregiver coping effectiveness training scores (experimental and control) at baseline, 16 weeks, and 32 weeks (higher scores indicate increased coping effectiveness).

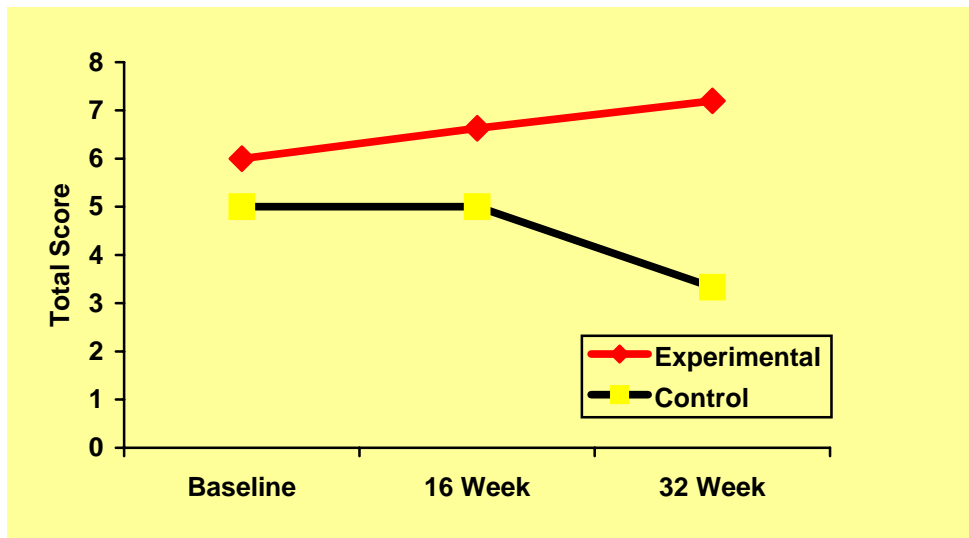


Figure 3: Caregiver Coping Effectiveness Training – Changeable/Unchangeable Scale Scores (experimental and control) at baseline, 16 weeks, and 32 weeks (higher scores indicate increased ability to identify stressors).

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Exit Measures (Caregivers)

Caregivers from both groups also completed an exit survey at the end of the support group intervention period. Caregivers were asked if the group intervention (1) made a difference in their life, (2) helped them in coping with their spouse/family member's illness, (3) helped them cope with their spouse/family member's not driving, (4) helped them talk with their spouse/family member about not driving, and (5) helped them in relationships with family members.

Respondents rated each question using a Likert scale (strongly disagree to strongly agree). The results of those ratings are provided in Figure 4, with percentage agreeing or strongly agreeing reported in percentages. As can be seen, both support groups were effective in 'making a difference in [the caregivers] life', in helping them 'cope with their spouse/family member's illness', and in 'relationships with family members'. The experimental Caregiver group participants, however, reported higher scores on 'helping them cope with their spouse/family member's not driving' and in 'talking with their spouse about driving' compared to controls.

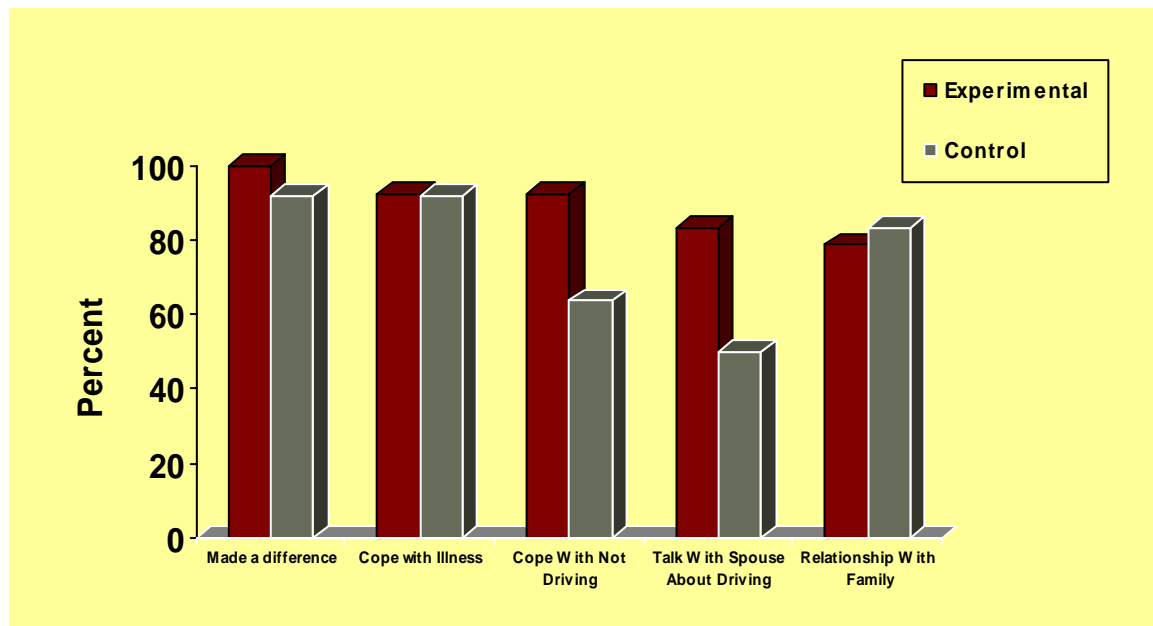


Figure 4: Results of exit interviews (e.g., end of group session interviews) between experimental and control Caregiver groups.

Lay Summary of Conclusions from the Study

- Support groups are effective for early stage dementia individuals.
- Continued support for the effectiveness of support groups for caregivers of individuals with dementia.
- Specialized support groups focusing on the driving issue are particularly effective for early stage dementia individuals and their caregivers in dealing with issues related to driving cessation.
- Specialized support groups also effective in other areas (quality of life, communication).
- Support groups effective in increasing caregiver stress management skills – an effect that endures following completion of the group.

The positive results of intervention, combined with the scope of the problem, underscore the need to take the research to practice.