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EVALUATION OF AN INTERVENTION PROGRAM FOR ASSISTING
FAMILY CAREGIVERS WITH PLACEMENT DECISIONS

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Psychology:
Life-Span Development Psychology

by
Adriana Raquel Bailey

June 2002

1120

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ABSTRACT

Family caregivers make decisions relating to the needs of the care recipient on a daily basis. Among the most difficult decisions caregivers make is the decision to place a loved one in out-of-home care. The purpose of the current study was to evaluate a seven-week psychoeducational program designed to assist family caregivers with the decision-making process when placing a loved one in out-of-home care. The course focused on helping caregivers identify and understand their own feelings about placement, and providing information about the placement system. Thirty-nine family caregivers participated in the study. Participants were in two groups: treatment and control. A pre-test was administered using three measurement tools: 1) The Coping Inventory for Stressful Situations: Situation Specific Version (CISS), 2) The Center for Epidemiological Studies-Depression Scale (CES-D), and 3) The Placement Decision Questionnaire. After seven weeks, participants received a post-test. Results of the study showed that while coping skills and depression scores did not improve, knowledge of the placement process increased significantly for the treatment

group. Surprisingly, there were no significant differences in the post-test scores between the treatment and control groups for any of the measures. The results of this exploratory study supported the expectation that this psychoeducation class could assist caregiver making placement decisions, particularly in the knowledge domain.

ACKNOWLEDGEMENTS

"With your help I can advance against a troop; with my God I can scale a wall." Psalms 18: 29. "I will give thanks to the Lord because of His righteousness and will sing praise to the name of the Lord Most High." Psalms 7:17. All the glory and honor belong to Him!

I wish to express my gratitude to Inland Caregiver Resource Center for their support and resources in the research and development of this project.

My committee professors provided invaluable support and guidance for this project and I am very grateful for their efforts. Thank you Dr. Laura Kamptner for being my mentor and bringing me this far. Thank you Dr. Joanna Worthley for your insightful feedback. And last, but not least, thank you Dr. Charles Hoffman for believing in me. You provided unconditional support.

I also want to thank my husband, Regan Scott Bailey, who has been by my side through thick and thin. He is the wind beneath my wings.

DEDICATION

The caregiver in our society is an unsung hero that deserves our praise and admiration for a task that is challenging and heart wrenching with infrequent rewards.

"But the greatest of these is Love." 1 Corinthians
13:13

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CHAPTER ONE

INTRODUCTION

Deciding to place a loved one in out-of-home care is often a difficult and emotionally-charged process. Most families are unprepared to make this difficult decision, and they often are forced to make such decisions during a crisis. Many caregivers find the placement experience surrounded by a lack of information, a sense of urgency, and a lack of validation for the feelings they experience. The purpose of this study was to evaluate the effectiveness of a psychoeducational class designed to assist family caregivers with the placement decision.

The Caregiver Experience

The caregiving experience is complex and multifaceted. Providing care to a physically- or mentally-dependent loved one can present a variety of challenges for the caregiver. The caregiver will need to solve daily problems that affect the well-being of the care receiver, but also make a variety of long-term decisions affecting the care receiver (Wackerbarth, 1999). The caregiving experience can be rewarding and satisfying; however, there is no doubt that

it is paved with emotional as well as physical challenges and difficulties (Schulz & Beach, 1999).

Problems Caregivers Face

Family caregivers face an endless array of novel problems generated by some aspect of in-home care, including physical care of the patient, the care receiver's behavior, and the caregiver's emotional responses to providing care. Some of these problems or challenges are tangible, such as those related to providing physical care (Gallaher-Thompson, Lovett, Rose, McKibbin, Coon, Futterman, & Thompson, 2000; Wachterbarth, 1999), while others are of an emotional nature, such as making the decision to place a loved one in out-of-home care (Matthiesen, 1989; McAuley & Travis, 2000; Penrod & Dellasega, 1989; Wackerbarth, 1999).

As functional status deteriorates, the care receiver's ability to provide for his or her own needs will regress. The caregiver must compensate for the care recipient's deficiencies by providing for that person's physical care needs. For example, when the care receiver loses the ability to transfer from the bed to a chair, the caregiver must physically enable the transfer for the care receiver. Other areas where the care receiver may need physical help

could be in eating, bathing, grooming, dressing, and using the toilet.

The care receiver's behavior may also challenge the caregiver (Bathgate, Snowden, Varmar, Blackshaw, & Neary, 2001; Bedford, Melzer, & Guralink, 2001). Disabling diseases often affect the patient's attitudes and behavior, creating a challenging experience for the caregiver. For example, a patient with Alzheimer's Disease may become disoriented and wander from their home. The caregiver must take appropriate steps to constrain this potentially dangerous behavior. Such patients can also become paranoid, argumentative, and combative (Bathgate et al. 2001). The caregiving experience constantly demands that the caregiver evaluate the care recipient's status and find solutions to typically escalating problems.

The emotional aspect of caregiving is extremely complex and caregivers face tremendous emotional challenges as they react to the reality of their loved one's increasing disability. Caregivers report a number of emotional responses including feelings of depression, grief, loss, anger, and guilt (Matthiesen, 1989; McAuley & Travis, 2000; Penrod & Dellasega, 1989; Wackerbarth, 1999). As both care recipient and caregiver respond to their

changing roles, grieving for the loss of the original relationship occurs and may lead to guilt and depression. For example, caregivers may react to their situation with anger and then experience a wave of guilt for feeling angry, or they may experience guilt feelings because they are not able to meet the care receiver's increasing needs.

Under such a physical and emotional load, even family caregivers with generally effective problem-solving skills can become overwhelmed and have difficulty making decisions regarding the care recipient's long-term care arrangements. In effect, when it comes to making the placement decision, caregivers have frequently reached a burnout point in making decisions (Travis & McAuley, 1998; Yesner, 1998).

Decisions Caregivers Make

Caregiving decisions vary in complexity and intensity, ranging from simple decisions in the early stages of caregiving to more complex decisions that are made during the later part of the caregiving continuum (Wackerbarth, 1999). To better understand the challenges family caregivers face, Wackerbarth (1999) first identified the common decisions made by caregivers, then established which decisions caregivers consider especially challenging. Among the common decisions caregivers face are decisions

about providing direct care, health care issues, use of community resources, community relocation, limiting the care receiver's freedom, and nursing home placement. The two most difficult decisions caregivers face are limiting the care receiver's freedoms and the placement in out-of-home care.

The daily decisions involved in providing direct care involve the nutrition, hygiene, safety, and social well-being of the care receiver (Wackerbarth, 1999). These are the personal decisions one makes every day such as what to have for dinner, what clothes to wear, when to bathe, etc. While some of these decisions may not be critical, they do add to the challenge of caregiving.

Other decisions caregivers make are not as simple as those of daily living and they carry significant consequences. According to Wackerbarth (1999), caregivers are faced with making health care decisions for the care receiver. The caregiver becomes a health care manager who makes decisions about seeking and choosing medical and dental providers for the care receiver. Working with professionals, the caregiver must decide on drug therapy, experimental therapies, and managed care options.

As part of the care plan, the caregiver must consider resources to assist with the daily care. The caregiver must search out community resources and evaluate their benefit (Wackerbarth, 1999). Examples of some resources that the caregivers may consider are use of a day care center, in-home care attendant, and home delivered meals.

Community relocation is another area where the caregiver is involved in making decisions for the care receiver. As the care receiver becomes more dependent, the need to change the environment for a more suitable fit may occur (Wackerbarth, 1999). Among the many options in this dilemma are downscaling, moving closer to services or support, assisted living, senior apartments, or moving in with another family member. While we live in a society where there are several options, the caregiver is faced with making an appropriate choice that would be suitable to the care recipient's needs and financial resources.

As the care receiver's abilities diminish and he or she is no longer able to make sound decisions, the concern for safety increases. The caregiver inherits the responsibility to make decisions ensuring the safety of the care receiver and others whom the care receiver's actions may affect. Such decisions involve limiting the care

receiver's independence and autonomy. For example, the caregiver may need to limit the care receiver's freedom by removing driving privileges, limiting cooking activities, restricting the care receiver from making their own financial decisions, and placing the care receiver in an out-of-home care facility (Gallaher-Thompson et al. 2000; Halpert, 1991; Harkreader, 1984; Liken, 2001; Penrod & Dellasega, 1998; Wackerbath, 1999).

Decisions in the Caregiving Continuum

Making decisions for the care receiver often begins with decisions that impact some aspect of daily living. These decisions are usually made during the early part of the caregiving continuum. As the care recipient's disease progresses and abilities decrease, decisions to limit the care recipient's freedom become necessary. Thus, decisions that limit freedom are made toward the middle of the caregiving continuum. Approaching the later section of the continuum, caregivers are often challenged with decisions involving out-of-home care (Yesner, 1998). Life-affecting decisions, such as placing a loved one in a care facility, are influenced by the entire caregiving experience and not one particular event. That is, families consider this type

of decision over a long period of time, as the disease progresses (Wakerbarth, 1999).

In summary, a review of the literature suggests that the decisions caregivers make are extremely complex and involve many factors. However, the caregiving continuum is characterized by one central theme: making decisions for the care receiver's care at each level. As the care recipient's dependency increases, the decisions the caregiver needs to make become more complex and have more serious consequences for all involved.

Nature of Decisions in Caregiving

The literature, overall, advocates a rational approach to reaching a decision (Dellasega & Mastrian, 1995). Janis and Mann (1977) proposed that to make a decision, the decision-maker must gather valid information, evaluate alternative solutions, and then take the most appropriate course. According to Rashkis (1981), decisions that are based on reason, not emotion, have a higher likelihood of being viewed as positive over time. In the decision-making process for family caregivers, gathering information and evaluating alternatives are centrally important; however, the decisions associated with caregiving have an additional component: emotional. The decision-making process for

caregivers involves the ability to process conflicting feelings and emotions (e.g., guilt and grief, which are often associated with the caregiving experience) as well as gathering factual information and considering alternatives. Thus, for the family caregiver cognitive and affective issues are equally important factors in influencing the decision making process.

Factors Influencing the Caregiver's Decision-making Process

Wakerbarth (1999) identified three factors influencing caregivers' decision-making: emotional, structural, and learning factors. Emotional factors are typically those conflicting emotions experienced by the caregiver in the decision-making process. For example, a caregiver may feel resentment that they are responsible for providing care to their loved one and then feel guilty for their resentment. A caregiver may experience conflicting emotions when deciding which medical treatment or drug therapy to choose for their loved one. Emotional barriers may also surface when the caregiver is faced with placing the loved one in out-of-home care. Structural factors focus on the structure of the decision, or deciding between alternatives. In the placement decision, the structural

components are based around legal and financial issues. For example, many caregivers do not understand the financial resources available to assist with the cost of nursing home care. Finally, learning is a key component in the decision-making process. In the placement decision, the caregiver will need to focus on two preparatory activities: learning how to collect information about the issues surrounding placement and learning how to cope with the emotional aspects of choosing out-of-home care.

The Placement Decision

On the caregiving continuum, a point is reached where the care receiver's needs exceed the caregiver's resources and abilities. At this point, out-of-home care must be considered. The out-of-home care decision involves relinquishing the direct physical care of the care receiver to a nursing facility (Halpert, 1991; Johnson, 1990) and centers around "is now the right time to act?" (Wackerbath, 1999).

The "right time to act" can be subjective, as each caregiver has different physical, emotional, and financial resources. The caregiver may become physically unable to continue to provide the care needed in the home. In a

four-year longitudinal study, Schulz and Beach (1999) examined the effects of caregiving on the caregiver's health and they concluded that the combination of factors associated with caregiving (e.g., loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers) have a detrimental effect on the caregiver's physiological functioning. Long-term caregivers tend to have increased physical health problems that in turn lead to higher morbidity (Schulz & Beach, 1999).

As noted, emotions are inevitably involved in the placement decision (Matthiesen, 1989). Often caregivers feel that if they relegate the physical care of their loved one to a facility they have failed as a caregiver. These caregivers do not understand that caregiving has many facets and is not limited to the physical or direct care of the care receiver. Some caregivers struggle with a promise they made long ago that they would never place their loved one in a nursing facility. Faced with the placement dilemma, they experience feelings of guilt for considering breaking their promise (Gaugler, Pearlin, Leitsch & Davey, 2001). These are just a few examples of the feelings or

emotions some caregivers experience when they consider placement.

Financial resources have an impact on the decision to place a loved one in an out-of-home care facility. According to a recent study conducted by Metlife's Mature Market Institute, an average residency in a nursing home of 2.5-years can cost from \$82,000 to \$270,000 depending on where you live ("Nursing home costs vary by state," 2000). The cost of nursing home care can often discourage a caregiver from considering placement as a possible care option. Although there may be financial assistance for nursing home care through government programs, the guidelines are complicated, confusing, and they can be intimidating. Thus, few caregivers have a clear understanding of the financial options of paying for nursing home care (Stum, 1997).

Health Issues as the Precipitating Factor in Placement

Groger (1994) conducted personal interviews with care receivers who had been recently placed in a nursing facility. In most of the cases she interviewed, the decision for out-home-care was made as result of a crisis involving the care receiver's health. In fact, most

nursing home placement occurs after an acute stay in a hospital and is often done in a crisis situation (Dellasega & Mastrian, 1995; Halpert, 1991; Johnson, 1990).

Caregivers may delay making the decision to place their loved one until they are faced with a crisis. At such time, the decision is made for the caregiver by medical professionals. Many caregivers are not prepared to face separation from the care receiver. Out-of-home placement under these conditions can add to the caregiver's emotional burden that precipitates caregiver stress. Having a better understanding of the steps in the placement process may be helpful in avoiding a "crisis" decision situation.

Coping Skills and the Decision to Place in Out-of-Home Care

Endler and Parker (1990) defined "coping" as a conscious response to an external stressful or negative situation. These responses may include cognitive strategies or behaviors. Coping skills seem to play an important role in mediating between stressful events and outcomes of anxiety, depression, psychological distress, and somatic complaints. Several studies (Dellasega & Mastrian, 1995; Gallaher-Thompson et al. 2000; Groger,

1994; Harkreader, 1984; McAuley & Travis, 2000; Penrod & Dellasega, 1998; Smerglia & Deimling, 1997) have identified the importance of coping skills in the placement decision.

Positive coping skills include seeking services and support to assist the caregiver with the many challenges of caregiving. These behaviors can lead to the acceptance of the present circumstances and to caregiver well-being.

Conversely, poor coping skills include stagnation or lack of initiative to deal with the challenge, which can lead to the caregiver's isolation and increased depression.

Researchers conclude that sound coping skills are necessary to keep caregivers from being emotionally depleted as they face the placement decision.

Personal Experience in the Placement Process

Caregivers typically face the transition to out-of-home care with uncertainty, lack of knowledge and lack of information about the placement process, and a lack of understanding of the fluid or dynamic nature of the caregiving role. These factors predispose the caregiver to experience feelings of anxiety, confusion, and helplessness.

Penrod and Dellasega (1998) conducted an in-depth qualitative study focusing on the caregiver's experience and the actual process of placing their loved one in a nursing home. Ten participants who had recently placed their loved one in a care facility were interviewed about their personal experience during this process. The findings of this study revealed several interesting and common themes. The interviewees consistently identified three salient concerns during their placement experience: uncertainty surrounding the placement process, urgency in making the decision, and a need to have their decision validated. The uncertainty surrounding the placement process reflects gaps in information available to family caregivers when they make the placement decision. There may be a pervasive lack of understanding of the role that medical professionals have and their involvement in the placement process (Dellasega & Mastrian, 1995).

Additionally, there may be a lack of understanding of the payment methods for out-of-home care (Yesner, 1998). Caregivers also identified a sense of urgency in their placement experience. They reported feeling pressured and rushed to make the decision to place after an acute or crisis medical situation (Penrod & Dellasega, 1998; Travis

& McAuley, 1998). Typically, an acute medical condition mandates that a decision to place be made within a day or two. The limited time in which to make the decision to place leaves the caregiver bewildered and forced to make a decision that he or she is clearly not prepared to make.

Finally, the need for caregivers to have emotional support and validation of their decision through this process was seen as necessary for a positive outcome. The researchers reported that caregivers were acutely aware of the reactions of others responding to their placement decision. Caregivers sought encouragement from others, such as friends, family, and professional staff, to assure themselves that their experience was normal (much like others) and that they had made the right decision (Penrod & Dellasega, 1998).

Intervention

The Professional's Role in the Placement Decision-making Process

Professionals can play an important role in helping family caregivers with the decision-making process involving out-of-home care for the care recipient. Yesner (1998) identified that professionals can be instrumental in

helping family caregivers by providing structure to the decision-making process, keeping caregivers focused on the necessary steps for action, and helping the family caregiver adapt to the changing circumstances. She believes that professionals can provide support, information that proactively helps the caregiver make long-term care plans, and direction through the decision process for out-of-home care. However, Penrod and Dellasega (1998), through interviews with caregivers who had placed their loved one, identified that professionals were not providing optimum support through the placement process. They concluded that professionals lacked an understanding of the decision-making process and strategies that could enhance the effectiveness of the process.

Considering the results of Penrod and Dellasega (1998) and other similar studies, an intervention program providing caregivers with information and assistance through the out-of-home placement process may relieve some stress caused by the lack of knowledge. It may also help to avoid crisis-driven decision-making and help caregivers better cope with the decision to place their loved one in out-of-home care. The literature clearly articulates the caregiver's need for clear information and emotional

support during the out-of-home placement decision-making process.

Types of Intervention Programs

There are several types of intervention programs that have been implemented to assist families with the challenges of caregiving. Such programs include support groups, individual and/or family counseling, case management, respite and day care services, skills training and educational programs, and some combinations of these approaches (Biegel & Schulz, 1999). The most widely used interventions are support groups and psychoeducational programs.

Support groups are the most common type of intervention and typically are community based, meet once or twice a month, and provide a forum for open discussion and peer support (Gallaher-Thompson et al. 2000). There are perceived benefits in participating in a support group, but there is no clear indication that caregivers are able to learn specific skills that will enhance their experience in managing their situation (Gage & Kinney, 1995). Thus, support groups would not be the ideal forum to introduce an intervention program to assist families with the placement decision.

A more current and comprehensive review by Gatz, Fiske, Fox, Kaskie, Kasl-Godley, McCallum and Wetherell (1998) revealed an encouraging view of psychoeducational programs on caregiver distress. Their study evaluated late-life problems, including depression, substance abuse, anxiety, and caregiver distress. They concluded that a psychoeducational model of treatment was effective in improving the caregiver's psychological status.

Whitlatch, Zarit, Goodwin and von Eye (1995) replicated a study by Mittleman, Ferris, Steinberg, Shulman Mackell, Ambinder, and Cohen (1993). These studies focused on interventions meant to delay the out-of-home placement. The focus of their intervention was to relieve caregiver stress, thereby delaying placement. Both studies found that when caregivers had a positive response to the psychoeducational intervention, lower rates of placement were noted within the following year after treatment. These findings are encouraging and support the use of psychoeducational programs with placement issues.

Gallagher-Thompson and her colleagues (2000) summarized the findings in the literature, concluding that a successful psychoeducational program must include a sound research

design, teach a small number of coping skills, and use measures that target the skills being taught.

The psychoeducational class under consideration in this study was designed to assist family caregivers in assessing care options and processing conflicting feelings or emotions that are present when considering out-of-home care for a loved one. The curriculum of this class focused on increasing the caregiver's knowledge of the placement process, helping them understand their feelings and beliefs regarding the placement decision, and helping them clarify the caregiver role on the caregiver continuum, especially as it relates to caregiver depression and coping skills. Using a pre- and post-test assessment, the evaluation of this class measured the effect of the intervention program in three domains: 1) coping skills with the placement decision-making process, 2) caregiver depression and 3) knowledge of the placement process.

Coping Skills with the Placement Process

Three factors were considered in coping skills: 1) task-oriented coping, 2) emotion-oriented coping, and 3) avoidance oriented coping. Task-oriented coping is aimed at altering the relationship between person and environment. Emotion-oriented coping is aimed at

regulating emotional distress. Avoidance-oriented coping seeks out social diversions or distractions.

Caregiver Depression

A major reason to focus on caregiver depression is the documented relationship between caregiver depression and the decision-making process (Travis & McAuley, 1998; Yesner, 1998).

Knowledge of the Placement Process

A clear understanding of the caregiver's changing role during the caregiving continuum, the resources available in the community, as well as the placement process, is thought to facilitate the placement decision-making process.

Summary and Purpose of Study

Studies to date have provided a better understanding of the decisions caregivers make during their caregiving journey and of the timing of these decisions in the caregiving continuum. Recent research has indicated that the decision to place a loved one in out-of-home care is one of the most difficult decisions a caregiver has to make and that caregivers are often ill-prepared to make this important decision. In fact, most decisions to place a loved one are precipitated by a crisis and forced upon the

caregiver. Caregivers have reported feelings of guilt, grief, loss, and confusion as they consider the placement option.

Several studies have identified a gap in services provided to caregivers during the out-of-home placement process (Penrod & Dellasega, 1998, Yesner, 1998). The caregivers interviewed expressed confusion and a lack of information and direction in their placement experience. They found that professionals involved in the placement process failed to provide information and support in the decision-making process. These researchers advocated for proactive caregiver education, information on available options, and decision-making techniques.

The purpose of this study was to evaluate the effectiveness of a psychoeducational class designed to address the particular needs of family caregivers facing the decision to place a loved one in out-of-home care.

Based on the literature review, it was first expected that caregivers who participate in this psychoeducational intervention will increase knowledge of the placement process (e.g., understanding changing caregiver role, identification of resources, understanding of financial options in placement, understanding of how to choose a

nursing facility). By increasing knowledge, it was expected that coping skills would improve and caregiver depression would decrease.

This study will contribute to the literature by determining if a psychoeducational class designed to assist family caregivers with the placement decision can have a positive influence in the caregiving experience by helping the caregiver through the placement decision-making process.

CHAPTER TWO

METHOD

Participants

The participants for this study were recruited through Inland Caregiver Resource Center (ICRC), an independent member of a network of Caregiver Resource Centers in California, established statewide under special legislation signed into law in 1984. ICRC is a private nonprofit, tax-exempt corporation under a contract grant from the California State Department of Mental Health. The Center provides assistance, support, information, and guidance to family caregivers of adults with an organic brain impairment (e.g. Alzheimer's, Parkinson's, Huntington's Chorea, brain tumor, stroke, traumatic brain injury (TBI)).

Thirty-nine subjects, 10 males and 29 females, participated in this study. The average age of the participants was 65 years (range: 25 to 85 years) and more than half (63%) were spouses. All participants were caring for a loved one with a brain impairment. (See Table 1 for demographic information).

Subjects were not randomly assigned to the treatment group (i.e., those attending the psychoeducational

Table 1. Demographic Information (n=39)

	<u>Group</u>	
	Treatment (n = 21)	Control (n = 18)
<u>Gender:</u>		
Male	8	2
Female	13	16
<u>Ethnicity:</u>		
White	19	16
Black	2	1
Asian	0	1
<u>Age:</u>		
25-40	1	1
41-50	0	3
51-60	1	2
61-70	9	7
71-80	10	3
81-85	0	2
<u>Relation to Care Receiver:</u>		
Wife	6	9
Husband	7	2
Mother	1	0
Father	1	0
Daughter	5	3
Daughter-in-law	1	2
Other	0	2
<u>Care Receiver's Illness:</u>		
Alzheimer's	8	7
Parkinson's	1	1
Stroke	4	5
Brain Injury	3	1
Degenerative Dementia	5	3
Epilepsy	0	1

class) and the control group (those not attending the psychoeducational class).

Treatment Group

Twenty-one subjects participated in the treatment group. Class participants were self-selected; they responded to the announcement flyer advertising the class (Appendix A). To be eligible to participate in the class, caregivers had to meet the following criteria: (a) participants were adults who were caring for a loved one who acquired a brain impairment or other debilitating chronic illness after age 18, (b) the care recipient was receiving care in the home, and (c) participants were willing to attend a two-hour class, once a week for a period of seven weeks.

Control Group

The control group was obtained through ICRC's mailing list. These participants were active ICRC clients whose loved one was at risk for placement. "At risk for placement" was defined as any dependent adult receiving care in the home. Seventy invitations to participate in the study were mailed out. Twenty-one caregivers responded by returning the signed informed consent statement (Appendix B) agreeing to participate in the study.

Eighteen completed the pre- and post-tests. One participant was disqualified because their loved one was placed during the course of the study. Two participants did not return the post-test questionnaire.

Materials and Procedures

Prior to the First Class Session

For the treatment group, an intake was done on each participant which included demographic information and information about the caregiving situation (Appendix C). Many participants of the class were already clients of ICRC and this step was therefore not necessary.

Upon completion of the intake, a packet of information was mailed to each participant containing information about the class. This packet included a confirmation letter that acknowledged the participant's registration in the class and an informed consent statement (Appendix D).

Participation in the study was voluntary. Unwillingness to participate in the study did not affect the eligibility to participate in the class. A paper and pencil pre-test was mailed out requesting that the participant complete and bring it with them to the first class. The pre-test tool

required an estimated 15 minutes to complete. There were three parts to the pre-test.

The first part of the pre-test was the Coping Inventory for Stressful Situations - CISS: Situation Specific Version (Endler & Parker, 1990), a scale for measuring multidimensional aspects of coping with stress (Appendix E). This is a 21-item self-report measure of coping designated for a particular stressful situation and norms are given for situations involving social evaluation, change in social situation, relationship or interpersonal conflict, and general stress. This instrument is based on an interaction model of anxiety, stress, and coping; it focuses on the impact of person and situational variables. The coefficient alpha ranged from .92 - .73. The test-retest reliabilities ranged from .73 - .51.

The second measure used in this study was the Center for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977) (Appendix F). This tool measures symptoms of depression in the general population, including the elderly. This 20-item, 4-point scale has been used in many caregiving studies (Whitlatch & Feinberg, 1997). Sixteen of the items measure a negative mood state such

as, "I felt fearful" or "I felt sad." Four items measured a positive state such as, "I was happy" or "I feel hopeful about the future." Significant depression symptoms were shown by a score of 16 or higher (Radloff & Teri, 1986). Split-halves correlation and coefficient alpha were high (.85 - .92). Reliability coefficients were also high (.85 - .91). The primary advantage to using this measure is that its scores can be compared to those obtained from other studies of adult populations and is not limited to the elderly population (Lewinsholn, Seeley, Roberts, & Allen, 1997). Additionally, it has been used extensively in other studies involving caregivers (Whitlatch & Feinberg, 1997).

The third measure of the pre-test was the Decision-making and Placement Knowledge Questionnaire. This tool is an 11-item, 5-point Likert-type scale designed to measure baseline knowledge about the placement decision-making process and placement issues (Appendix G). The questionnaire directly reflected the material covered in the class and was designed by the clinical staff at ICRC. Examples of the questions in this measure: "I can identify the personal reasons why I might place my loved one in a care facility;" "I can identify the feelings and

reasons why I may feel uncomfortable about making the decision to place my loved one in out-of-home care;" "I know what level of care/type of facility my loved one would need should he or she need to enter out-of-home care."

The fourth measure was a demographic assessment that was taken from the initial ICRC intake. This tool revealed information on the caregiver's age, gender, ethnicity, relationship to care recipient, and care recipient's diagnosed illness.

The Control Group

The participants in this group received the same questionnaire that was administered to the treatment group. The pencil and paper pre-test described in the section above was sent by mail to each person in the control group.

The Class Sessions

The program "To Place or Not to Place, That is the Question" is a psychoeducation intervention program designed by the Assistant Director/Clinical Supervisor at ICRC in cooperation with the Ombudsman's Office of San Bernardino County and the Volunteer Center/Ombudsman's Program of Riverside County. The goals of this course

included the following: to provide information about the placement options and the payment mechanisms for long-term care, to teach caregivers how to recognize the appropriate level of care the care recipient needs throughout the disease progression, and to assist the caregiver in recognizing, processing, and coming to terms with the feelings and emotions associated with making the placement decision.

The psychoeducational intervention classes were held once each week for seven consecutive weeks, with each session lasting two hours. The instructors were social service professionals employed by ICRC. Two instructors each facilitated three separate classes for a total of six classes. The same course outline and procedures were followed for each class taught. The classes were small, with each class being limited to no more than eight participants. The number limit was intended to assure a high teacher-student ratio. The classes were intended to create a safe environment in which participants shared their experiences and feelings with others who were also facing this difficult decision. Participants enjoyed the benefit of a professional facilitator who assisted and guided the experience.

The classes had a registration fee of \$20 per participant. This fee covered the materials used in the class. Scholarships were provided to participants who could not afford the tuition. Since the participants were active in their caregiving role, respite grants were made available. Participants were supported and assisted in making care arrangements for their loved one while they attended the class by the clinical staff at ICRC.

The classes were hosted in different communities throughout Riverside and San Bernardino Counties. Each class was held in conference rooms of professional buildings, such as the Alzheimer's Association office, the Visiting Nurses Association, Senior Centers, and local hospitals in the community. Special care was taken not to host any of the classes at a nursing facility.

Each class participant received a workbook with seven sections clearly divided that outlined each class session and identified the objectives to each class. Appropriate handouts, worksheets, and related articles were also included in the workbook. At the end of each class session, a short homework assignment was given to continue the exposure and reinforce materials learned in class.

Week 1: "The Caregiver Role." The first meeting focused on understanding the developmental and transitional nature of the caregiver's role, and developing an awareness of formal and informal support systems to assist the caregiver while caring for a loved one. Upon completion of the first class session, the participant was expected to be able to: (a) discuss the transitional nature of their caregiving role; (b) identify at least one resource that could assist the caregiver in this role; (c) identify the level of care their loved one requires; and (d) evaluate their caregiving responsibilities. The outline for the first class session is presented below.

I. The Caregiver Role

A. Class Format

1. Review of the class rules covering attendance, positive and constructive interaction, and confidentiality regarding each participant

B. Introductions

1. Instructor introduced herself and gave a brief background of her professional experience

2. Participant introduction: each participant stated their name, who they were caring for, how long they have been providing care, what they expected to get out of the class, what their hobbies or interests were, and how they relaxed

C. What it Means to be a Caregiver

1. Definition of "caregiver"
2. Types of caregivers

D. Utilizing Support Systems

1. Identify formal support systems such as day care, nutrition programs, senior centers, etc.
2. Identify informal support systems such as friends, relatives, neighbors, etc.

E. Relaxation Exercise

1. Breathing exercises
2. Guided relaxation exercise

F. Homework

1. Practice relaxation exercise at home
2. Review the material covered in class #1 at home

3. Read the Parent Care article "Caregivers Need Help to Cope with Transitions"

Week 2: "Why Placement?" In the second meeting, the discussion centered on caregivers identifying reasons for placing and for not placing (i.e., the pros and cons of placement). At the end of this session, participants were expected to be able to: (a) identify at least one benefit and one limitation in caring for their loved one at home; (b) identify at least one reason for considering placing their loved one in out-of-home care; and (c) identify one "quality of life" issue for caregiver and for care receiver. The outline for the second class session is presented below.

II. Why Placement?

A. Review of Homework

1. Discussion on the assigned article

B. Benefits and Limitations of Care at Home

1. Caregiver compiled a list of "pros" and "cons"

C. Quality of Life

1. Vignette describing a caregiving situation
2. Class discussion on quality of life for both caregiver and care receiver

D. Self-care

1. Physical
2. Social
3. Family
4. Money
5. Mental
6. Spiritual

E. Relaxation exercise

F. Homework

1. Danger signals that say...warning: caregiver needs help!-- self assessment
2. Do you take care of yourself? Assessment for caregivers

Week 3: "The Decision-Making Process." The purpose of this class session was to help caregivers identify specific thoughts and feelings involved in the placement decision. They shared and discussed how they were affected by the placement decision-making process. At the end of this session, participants were expected to be able to: (a) identify who is/will be involved in the decision about placement; (b) describe at least one feeling and one belief/thought that affect their decision about placement; (c) identify at least one barrier to

their own decision-making process. The outline for the third class session is presented below.

III. The Decision-Making Process

A. Review of the Homework

1. Review and discussion on self-administered questionnaires assigned the prior week

B. Whose Decision is it, anyway?

C. Avoiding the Crisis Point

D. Common Barriers to the Decision-making Process

1. Feelings that go "bump" in the night - caregivers identified the feelings that they experienced when they considered placement

E. Relaxation Exercise

F. Homework

1. Read articles: "The Hardest Decision", "Today I Placed My Father...", and "Letting Go of Guilt"

Week 4: "Understanding Residential Care." In the fourth meeting, participants were introduced to the different levels of care offered in the community and the means of payments for these facilities. The fourth session focused on the lower level of care facilities, specifically Assisted Living and Board and Care. At the

end of this session participants were expected to be able to: (a) describe the types and levels of care provided in Board and Care and Assisted Living facilities; (b) understand method of payment for these facilities; (c) determine if this is the right level of care for their loved one; (d) know how to find these facilities; and (e) have information on how to evaluate a facility. The outline for the fourth class session is presented below.

IV. Understanding Residential Care

- A. Review Homework
- B. The Continuum of Residential Care
- C. Custodial Care versus Skilled Care
- D. When is Assisted Living the Right Placement Choice?
- E. Paying for Residential Care
- F. Relaxation Exercise
- G. Homework

Week 5: "Understanding Residential Care- SNF." In this session, participants discussed the role of Skilled Nursing Facilities (SNF) in the Caregiving continuum. They considered how the caregiver role changes when a loved one enters nursing home care and how the caregiver can incorporate the facility's staff into the care team.

At the end of this class, participants should be able to:

- (a) discuss the types/levels of care provided in a SNF;
- (b) identify methods of payments for a SNF; (c) determine if this is the right level of care for their loved one;
- (d) identify which person/position in the facility to talk with about the services provided in that facility;
- and (e) discuss what to look for when evaluation a facility. The outline for the fifth class session is presented below.

V. Understanding Residential Care - SNF

- A. Review of Homework
- B. Custodial Care versus Skilled Care in an SNF
- C. How to Pay for an SNF
- D. How to Find and Evaluate an SNF-Skilled Nursing Facility
- E. Admission Agreements
- F. Staffing- Who Does What, Including the Role of the Physician
- G. Preparing for the Initial Meeting with Facility Staff
- H. Family Involvement
- I. What to Do When Problems Arise

Week 6: "Facility Visit." During the sixth meeting, caregivers toured an out-of-home care facility (assisted living, board and care and/or SNF) in their neighborhood. This experience was designed to teach caregivers how to evaluate a facility before placement. The outline for the sixth class session is presented below.

VI. Facility Visit

A. Facility Evaluation Check List

Week 7: "Review and Panel Discussion." At the seventh and final meeting participants had the opportunity to interview a panel of two caregivers who had already experienced the placement process. The panel members were guest caregivers, arranged by the instructor, who had already experienced the placement process. Following the panel interview, the class participants reviewed the material covered in the class including an open discussion about their thoughts of the facility visit. At the conclusion of the class, the participants completed the post-test, following the same measures included in the pre-test. The outline for the seventh and final class session is presented below.

VII. Review and Panel Discussion

A. Discussion of Facility Visit

B. Panel of Caregivers Who Have Placed Their Loved One

C. Course Review

1. What has been learned?

D. Evaluation of the Class and Post-test administered
After the Last Class

At the end of the last class session, in week seven, class participants were given a post-test. The post-test was identical to the pre-test, using the same format and measures used in the pre-test. The control group participants, who had received no intervention, also received the post-test after a lapse of seven weeks to mirror the time spent in the class sessions. Both, treatment and control groups, were given the debriefing statement in compliance with the Institutional Review Board requirements (Appendix H and I).

Two weeks after the last class session, each class participant was contacted via the telephone by a member of the clinical staff at ICRC. The staff member contacting the caregiver was not the same person who taught the class. This precaution was taken to avoid "loyalty answers" and to give the caregiver an opportunity to be more candid about his or her experience

in the class. The phone interviewer asked participants three basic questions regarding their experience in the class: to what extent did the class explain the placement process; did the class help them identify their feelings about placement; did the class help them feel better prepared to make the placement decision. (Appendix J).

CHAPTER THREE

RESULTS

It was hypothesized that caregivers who participated in the psychoeducational intervention, To Place or Not to Place... That is the Questions, would increase their knowledge of the placement process. It was also hypothesized that if knowledge increased, coping would improve and depression would decrease.

The first analysis was an independent samples t-test comparing the pre-test scores of the treatment group with those of the control group. Results showed no significant differences between these groups for any of the variables (Coping, Depression, and Knowledge), indicating that both groups were about equal before the treatment group received the intervention (Table 2).

Next, a paired samples t-test comparing pre- and post-test scores on Coping, Depression, and Knowledge for the treatment group was computed. Results showed that there was a significant increase for Knowledge ($p < .004$). Surprisingly, however, no significant differences between the pre- and post-test scores for Coping or Depression were found (Table 3).

Table 2. Independent Samples t-test for Pre-test Scores for Treatment versus Control Groups

	Treatment (n = 21)		Control (n = 18)		Sig.
	M	SD	M	SD	
Coping					
a) Task-oriented	24.81	3.49	22.28	6.29	.122
b) Emotion-oriented	21.62	5.55	18.33	6.77	.104
c) Avoidance-oriented	17.57	4.76	20.39	4.38	.064
Depression	6.48	1.94	6.06	2.44	.552
Knowledge	35.14	4.39	38.56	7.44	.084

Table 3. Paired Samples t-test Comparing Pre- versus Post-test Scores on Coping, Depression and Knowledge for Treatment Group (n=21)

	M	df	SD	Sig.
Coping				
a) Task-oriented				
Pre-test	24.81	20	3.49	.782
Post-test	25.10	20	4.81	
b) Emotion-oriented				
Pre-test	21.62	20	5.55	.086
Post-test	19.71	20	4.95	
c) Avoidance-oriented				
Pre-test	17.57	20	4.76	.675
Post-test	17.14	20	6.33	
Depression				
Pre-test	6.48	20	1.94	.427
Post-test	6.05	20	1.91	
Knowledge				
Pre-test	35.14	20	4.39	.004
Post-test	41.62	20	7.13	

Then, an independent samples t-test comparing the post-test scores for the treatment and control groups was computed (Table 4). It was expected that the treatment group would have higher Knowledge and Coping scores and lower Depression scores than the control group. However, there were no significant differences between the treatment versus the control groups for these scores. There was a non-significant trend for Avoidance-oriented Coping, with the control group scoring higher than the treatment group.

Finally, the results of the post-class phone interview with the treatment group indicated that, overall, participants felt they benefited from their participation in the class. As shown in Table 5, participants felt that the class was effective in explaining the placement process and that it helped them identify their feeling and beliefs about placing their loved one in out-of-home care. A large majority felt that they were better prepared to make the placement decision after taking the class. This qualitative response coincides with the results for knowledge in Table 3.

Table 4. Independent Samples t-test for Post-test Scores for Treatment versus Control Groups

	Treatment (n = 21)		Control (n = 18)		Sig.
	M	SD	M	SD	
Coping					
a) Task-oriented	25.10	4.81	22.72	5.19	.147
b) Emotion-oriented	19.71	4.95	20.22	7.01	.793
c) Avoidance-oriented	17.14	6.33	20.67	4.72	.060
Depression	6.05	1.91	6.28	2.72	.759
Knowledge	41.62	7.13	40.28	6.29	.540

Table 5. Post-Class Phone Interview (n=21)

	Agree %	Neutral %	Disagree %
Did you find the class effective in explaining the mechanical process of placement? That is, the methods of payment and the placement process.	71.4	19	9.5
Has the class helped you understand your own feelings and beliefs on placement?	71.4	14.3	14.3
Do you feel you are better prepared to make the decision to place your loved one in a residential care facility after taking this class?	85.7	14.3	0

CHAPTER FOUR

DISCUSSION

Conclusions Relevant to Research and Hypotheses

The results of this exploratory study support the expectation that this psychoeducation class, *To Place or Not to Place... That is the Question*, could assist caregivers making the placement decision. As expected, the findings suggest that for the treatment group, knowledge of the placement process increased. However, contrary to expectations, the results of this study showed that the current psychoeducational intervention did not positively affect the coping variable or decrease the depression scores. The hope of increasing coping by increasing knowledge was not fulfilled, as demonstrated by the non-significant relationship between these two factors. The current results are consistent with Biegel and Schulz (1999) findings. Their study indicated that psychoeducational interventions were effective in the knowledge component but not in psychological outcomes.

Knowledge

As expected, the treatment group increased in knowledge after attending the class. Curiously, there

was no significant difference between the treatment and control groups on the post-test scores for knowledge. A comparison on the pre-test scores between the two groups showed that the control group scored slightly higher than the treatment group on knowledge, indicating that the control group's baseline knowledge was higher than the treatment group's. Perhaps those in the control group did not respond to the class invitation because they felt they already had the knowledge needed to make the placement decision.

Previous research (Wakerbarth, 1999) has established that knowledge is an important component in the decision-making process. According to Janis and Mann (1997), the decision-maker needs to gather valid information, evaluate alternatives, and then make the most appropriate choice. This psychoeducational class provided caregivers with valid information surrounding the placement process.

As a result of attending the class, most participants were able to: identify the different levels of care available in the community; be familiar with the payment mechanisms involved in placement; increase their familiarity with the procedures involved in placing someone in out-of-home care; understand that the

caregiving role is continually changing; identify resources to assist them with their caregiving challenges; and identify the "pros" and "cons" of out-of-home care. The participants also received tools to assist them in identifying their personal thoughts and feelings about the placement decision. When caregivers who attended the class were asked if they felt that the class was beneficial in helping them with the placement decision, they responded that they believed they were better prepared to make the placement decision after attending the class.

Having a clearer understanding of the issues surrounding placement will empower the caregiver to make the most appropriate decision based on their resources and circumstances. As found in Rashkis' (1981) research, having valid knowledge to facilitate good reasoning in the decision-making process has a higher likelihood that the decision made will be viewed as positive over time. The findings of this study support the theory that cognitive factors are involved in the placement decision-making process (Wakerbarth, 1999).

Coping

The results of this study showed that coping did not improve as result of participation in the class. There were no significant differences between the pre- and post-test scores in the treatment group and no significant differences between the treatment and control groups.

Researchers (Dellasega & Mastriam, 1995; Gallaher-Thompson et al. 2000) have identified that seeking services and support demonstrate positive coping skills that are reflected in the caregiver's well-being. Therefore, the results from this study were very surprising. The caregivers who attended the class voluntarily responded to the invitation to attend the class. Their behavior would indicate that they were motivated to seek out support and services. They were also motivated to complete the class, if for no other reason than to be in an environment where they could find support and encouragement. Yet, the coping scores for the treatment group did not reflect a positive increase in coping.

In contrast, the control group did not seek out services. The coping score in the Avoidance-oriented

category were non-significantly higher at baseline (pre-test) for the control group as compared to those of the treatment group. Comparing the pre-test scores of the treatment group with those of the control group showed a non-significant trend for Avoidance-oriented Coping ($p > .06$). Repeating this study may yield a better understanding of how the current psychoeducation intervention affected the Coping variable.

Although we found no significant changes in coping in this study, the importance of coping and its implication on the placement decision-making process should not be ignored. As suggested by Gallagher-Thompson and her colleagues (2000), future studies might explore and incorporate less traditional forms of coping such as prayer and other spiritual support, meditation, physical exercising, and pet therapy.

Depression

Unexpectedly, there were no significant differences between the post-test scores of the treatment versus the control groups and the pre-test versus the post-test scores of the treatment group. The expectation that there would be a relationship between knowledge, coping, and depression was not supported by this study. Contrary

to the findings of Gallagher-Thompson and her colleagues (2000), caregivers who participated in this study did not decrease their depression scores.

When considering out-of-home care for a loved one, caregivers often experience painful feelings and are in the midst of a grieving process. Many researchers have identified that the placement process is associated with feelings of grief, loss, sense-of-failure, guilt, and sense-of-helplessness (Dellasega & Mastrian, 1995; Halpert, 1991; Johnson, 1990; Matthiesen, 1998; Penrod & Dellasega, 1998).

In the psychoeducational intervention done by Gallagher-Thompson and her colleagues (2000), the researchers focused on increasing life satisfaction and increasing problem solving skills associated with daily caregiving challenges. In contrast, the current intervention focused on one specific issue: placement. Given the nature of the material covered and the topic under consideration in the current class, it should not be surprising that the depression scores did not decrease. Perhaps depression, as a product of grief, loss, sense-of-failure, guilt, and sense-of-helplessness, is a natural outcome in the placement process. Instead

of looking to decrease depression, professionals might refocus their efforts by helping family caregivers process their abject feelings.

Other Findings

Observations of the Class Interactions

Two interesting observations were noted consistently in all the classes conducted. First, the class instructor had difficulty keeping the participants focused on the current topic of discussion. Caregivers were easily distracted from the topic and refocused on their own caregiving experience. Often they would fixate on one particular problem they were facing and would make persistent attempts to repeat their concern during the discussion. This behavior was not isolated to a few caregivers in the group, but was displayed by most participants. For example, the caregiver would express frustration because the patient's behavior made them late when they needed to leave the house. When a new topic of discussion was introduced, the caregiver would bring up the abovementioned concern. Repeatedly, the instructor was challenged to validate the caregiver's concerns and refocus the class on the current topic of discussion.

Caregivers appeared to come to the class with many other unresolved caregiving issues that burdened the process of assimilating and processing new information. Perhaps scheduling a few sessions before the class instruction (course outline) begins would allow participants an open forum to express the feelings and frustrations they are experiencing.

Secondly, although caregivers were aware that the class was designed to discuss the placement process, they were reluctant to "own" their circumstances (i.e., acknowledge that they were personally wrestling with the placement dilemma). Two examples illustrate this point. First, in the second class session a vignette was presented describing a caregiver who had exhausted all their physical and emotional resources and placement was the best option. Class participants, even if their situation was identical to that of the vignette, easily recognized that the best option was placement and made the recommendation that the caregiver in the vignette place their loved one in out-of-home care. However, when asked to reflect on their own situation, they concluded that they would not place their loved one. Typically,

reasons for them not placing their loved one were emotional or financial.

The second example comes from the third class session. During this class session, there was an exercise where caregivers were asked to identify the feelings they experienced when they considered the placement decision. Caregivers would respond by considering their caregiving situation and avoided considering the placement decision. These examples clearly show that although caregivers come to the class to acquire skills to assist them with the placement process, there seems to be an inherent resistance to the topic.

Limitations of the Current Study

Several limitations have been identified in this study. First, the sample size was very small. Although significant effort was made to increase the number of participants by offering more class sessions in various communities, several classes were canceled due to low enrollment.

Secondly, even though participants who attended the class were clearly motivated to obtain further

information and support, the fact that they self-selected into the class means they may not, in general, accurately represent caregivers making the placement decision.

Participants for both the treatment and control groups were self-selected by responding to ICRC's invitation. Thus, the study participants were not randomly assigned to treatment or control groups.

The level of readiness to accept and deal with the course material on the part of the participant is another limitation that may have affected the results. As mentioned, many participants were not ready to focus on the topics covered due to denial issues associated with the placement decision process.

Another limitation to this study is that the participants were all caring for a loved one with a cognitive impairment. Therefore, they were unable to involve the care recipient in making the decision to place. Those caregivers who are caring for a loved one without a cognitive impairment (i.e., cancer patients, heart patients, end stage renal failure patients, etc.) can involve the care recipient in the decision-making process.

Lastly, the caregiving phenomenon for loved ones with no hope of recovery and facing certain deterioration results in a downward emotional spiral that cannot be alleviated. Given the aforementioned limitations, the results of this study may not be generalized to all caregivers facing the placement decision.

Implications for Future Research

The current study has provided a starting point for interventions designed to assist family caregivers as they make the decision to place their loved one in out-of-home care. Future research may incorporate different methods of coping and consider other variables such as life-satisfaction and well-being.

Replicating this study over time would provide a better understanding of the effect of psychoeducational interventions, such as the one represented in this study, on the decision-making process of placement.

The participants in this study were all caring for a loved one with a cognitive impairment. Therefore, as already mentioned, the experience of caregivers who are providing care to someone with only a physical limitation

may be qualitatively different. Future studies may extend to multiple caregiving scenarios.

Summary and Conclusion

The present study adds to our understanding of how professionals can help families struggling with the decision to place their loved one in out-of-home care. The results show that psychoeducational interventions can have positive effects on assisting family caregivers with the placement decision. More specifically, the psychoeducational class, *To Place or Not to Place... That is the Question*, does provide family caregivers with increased knowledge about the placement process.

This study has also shown that when considering the human condition and the heart-wrenching emotions associated with the placement decision, no amount of knowledge will alleviate the emotional trauma and the state of grief experienced from placing a loved one in out-of-home care.

APPENDIX A
ANNOUNCEMENT FLYER
ADVERTISING THE CLASS



**Inland Caregiver
Resource Center
and
Riverside County
Ombudsman Program
Present**

***“To Place or Not to Place...
That is the Question”***

Deciding if, when and where to place a loved one is often a heart-wrenching experience. Many family caregivers continue providing care far beyond their physical and emotional capabilities before they even consider placement as an option. This series of seven classes is designed to assist family members in the difficult decision-making process of whether or not to place a loved one in residential care.

Mondays

September 17 – October 29, 2001

1 p.m to 3 p.m.

at

**David Libert, PhD.
Consulting and Health Psychology
27393 Ynez Road, Suite 153
Temecula, California 92591**

An Educational Series
brought to you as part of the
Family Education Program
of

Inland Caregiver Resource Center

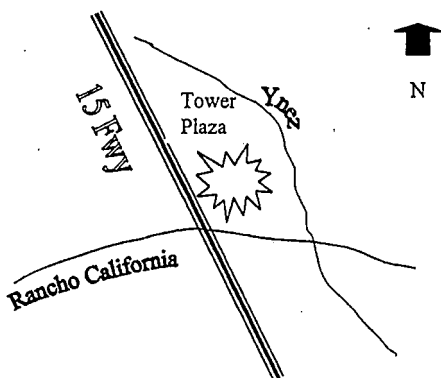
(A private, non-profit organization serving family caregivers of persons with adult-onset brain disorders. These debilitating disorders include Alzheimer's, multi-infarct disease, stroke or aneurysm, Parkinson's, Huntington's, Multiple Sclerosis, etc.)

in cooperation with

David Libert, PhD.

**Counseling and Health Psychology
and**

Riverside County Ombudsman Program



In Tower Plaza near Armstrong Garden Center

Who should take this course?

Spouses, adult children or other family members who care for a person with a brain-impairing condition (Alzheimer's, stroke, Parkinson's, Multiple Sclerosis, traumatic brain injury, etc.) or a frail elderly person, and who are considering placing their loved one in a residential care facility.

Course Leader

Adriana Bailey, BA, will lead this course. She is a Family Consultant at Inland Caregiver Resource Center. Ms. Bailey facilitates support groups for stroke survivors and their families, and family members of persons with Alzheimer's Disease.

What Participants Will Gain

As a result of taking this course, participants will:

- Understand the transitional nature of the caregiving role
- Become aware of support available in caring for a loved one at home
- Identify specific thoughts and feelings that impact the decision to place
- Learn more about residential care facilities.

Cost:

To cover the cost of materials there will be a charge of \$20.00 per participant (\$10.00 for 2nd member of same family.)

How to Register:

Complete the information on this flyer and mail it with a check (made payable to "Inland CRC") to:

Inland Caregiver Resource Center
1881 Commercenter E., Ste. 132
San Bernardino, California 92408

Deadline for Registration:

September 10, 2001

Registration will be limited to no more than fifteen participants, so do not wait to register. In order for the class to begin, a minimum of eight participants must be registered.

For More Information:

Call I.C.R.C. at (800) 675-6694
Ask about options for respite care if you need help in arranging care for your loved one in order to attend.

Registration Form:

Complete the information below and mail with your check for \$20.00 (made payable to "Inland CRC") to:

**Inland Caregiver Resource Center
1881 Commercenter East
Suite 132
San Bernardino, CA 92408**

Name _____

Address _____

City _____

Zip Code _____

Phone _____

Your relation to the person you are caring for:

I am unable to attend this course; please send me information about future courses. _____

APPENDIX B
INFORMED CONSENT FOR CONTROL
GROUP

Evaluation of an Intervention Program to Assist The Family Caregiver
with the Placement Decision
Informed Consent

This study is conducted by Adriana Bailey and Inland Caregiver Resource Center under supervision of Dr. Laura Kamptner, Professor of Psychology at California State University, San Bernardino (CSUSB). The Psychology Department Human Subject Review Board from CSUSB has approved this study.

Experience has shown that deciding to place a loved one in out-of-home care is very difficult and caregivers are often unprepared to make such a decision. This study looks at some of the issues involved in long-term care.

Participation in this study is voluntary. You will be asked to complete a questionnaire that asks about your experience as a caregiver and your decisions for long-term care. The questionnaire will take approximately 15 minutes to complete. After a period of seven weeks you will be asked to complete a second questionnaire that will also take approximately 15 minutes to complete.

Your participation and responses are completely confidential. No identifying information will be recorded. You are free to discontinue your participation anytime without any penalties. The group results of this study will be made available to you upon completion.

There is no anticipated risk to you as an individual for your participation in this study. However, the information obtained from this study will be helpful in understanding how to help caregivers with long-term care planning.

Thank you in advance for your participation in this study. Should you have any questions or concerns, please feel free to contact me.

Sincerely,

Adriana Bailey
Family Consultant, ICRC

Laura Kamptner, PhD
Professor, Human Development
and Psychology, CSUSB

By placing a mark in the space below, I acknowledge that I have been informed and understand the nature and purpose of this study, and that I freely consent to participate. By this mark, I further acknowledge that I am at least 18 years of age.

Give your consent to participate by making a check or "x" mark here: _____
Today's date: _____

APPENDIX C

INTAKE

FAMILY/CAREGIVER INTAKE

SECTION A: Caller/Caregiver											
Client I.D. (CRC Site/Client Number)			Intake Staff		Intake Date Updated			<input type="checkbox"/> By phone		<input type="checkbox"/> Add to Mail List	
								<input type="checkbox"/> In Person			
Caller/Caregiver Last Name					First Name					M.I.	
Address					City						
State		Zip Code			County Code			Home Phone ()			
								Office Phone ()		Ext.	
Referral Source Code CMP FRD MHS OBD CRC OTH FAM HCS MPB RDS SSV 999					Name of Referring Agency					Racial/Ethnic Identity AFR HSP OTH ASI WHT 999	
Name and Title of Referral Source				Language		Sex M F		Date of Birth M ___/D ___/Y ___		Age	
Relationship to Impaired Person WIF DAU BRO MOM FRD SIL OTH HUS SON SIS DAD DIL S 999			Lives w/Impaired Person Y N S 9		Primary Caregiver Y N S 9		If answer to previous question is YES, complete Section C only. If NO or SELF, complete Sections B and C.				
SECTION B: To Be Completed ONLY if Different From Caller											
Last Name					First Name					M.I.	
Address					City			State		Zip	
County Code		Home Phone ()			Office Phone ()			Ext.			
Date of Birth M ___/D ___/Y ___		Age	Sex M F		Relationship to Impaired Person WIF DAU BRO MOM FRD SIL OTH HUS SON SIS DAD DIL S 999				Lives w/Impaired Person Y N 9		
SECTION C: Adult With Brain Impairment											
Last Name					First Name					M.I.	
County Code		Date of Birth M ___/D ___/Y ___		Age		Sex M F		Living Arrangement ALO REL HOS RBC OTH SPO NON REH SNF 999			
Primary Diagnosis Code CVA TBI 999 AD AID ALS HD OND TUM MID MS ODD PD			Primary Diagnosis			Secondary Diagnosis Code CVA TBI 999 AID AD ALS HD OND TUM MID MS ODD PD			Secondary Diagnosis		
Diagnosis Confirmed Y N 9		Diagnosis Date M ___/D ___/Y ___		Onset Date Year ___		Medi-Cal Y N 9		SSI/SSP Y N 9		Regional Center Services (DDS) Y N 9	
OPTIONAL SECTION											
Other (Non-BI) Diagnosis				IHSS Y N 9			Veteran Y N 9				
SECTION D: Major Problems/Needs Identified (can check more than one)											
<input type="checkbox"/> General Information/Orientation to Brain Damage <input type="checkbox"/> Behavior Management Advice <input type="checkbox"/> Diagnostic/Medical Advice <input type="checkbox"/> Direct Care of Brain-Impaired Adult <input type="checkbox"/> Emotional Support <input type="checkbox"/> Financial Advice/Aid					<input type="checkbox"/> Legal Information/Advice <input type="checkbox"/> Placement Help (Out of Home) <input type="checkbox"/> Public Policy Research <input type="checkbox"/> Rehabilitation <input type="checkbox"/> Respite Care (for caregiver) <input type="checkbox"/> Other						

APPENDIX D
INFORMED CONSENT FOR TREATMENT
GROUP

EVALUATION OF AN INTERVENTION PROGRAM TO ASSIST THE FAMILY
CAREGIVER WITH THE PLACEMENT DECISION

Informed Consent

This study is conducted by Adriana Bailey and Inland Caregiver Resource Center under supervision of Dr. Laura Kamptner, Professor of Psychology at California State University, San Bernardino (CSUSB). The Psychology Department Human Subject Review Board from CSUSB has approved this study.

Experience has shown that deciding to place a loved one in out-of-home care is very difficult and caregivers are often unprepared to make such a decision. This study will evaluate the effectiveness of a class designed to prepare the family caregiver to make long-term care decisions.

Participation in this study is voluntary. You will be asked to complete a questionnaire that asks about your experience as a caregiver and your decisions for long-term care. The questionnaire will take approximately 15 minutes to complete. At the end of the seven sessions you will be asked to complete a second questionnaire that will also take approximately 15 minutes to complete. You will receive a phone call from an ICRC staff member two weeks after the completion of the class to discuss your perception of the class.

Your participation and responses are completely confidential. No identifying information will be recorded. You are free to discontinue your participation anytime without any penalties. The group results of this study will be made available to you upon completion.

There is no anticipated risk to you as an individual for your participation in this study. However, the information obtained from this study will be helpful in understanding how to help caregivers with long-term care planning.

Thank you in advance for your participation in this study. Should you have any questions or concerns, please feel free to contact me.

Sincerely,

Adriana Bailey
Family Consultant, ICRC

Laura Kamptner, PhD
Professor, Human
Development and Psychology,
CSUSB

By placing a mark in the space below, I acknowledge that I have been informed and understand the nature and purpose of this study, and that I freely consent to participate. By this mark, I further acknowledge that I am at least 18 years of age.

Give your consent to participate by making a check or "x" mark here: _____
Today's date: _____

APPENDIX E
COPING INVENTORY FOR STRESSFUL
SITUATIONS-CISS: SITUATION
SPECIFIC VERSION

People react differently when facing a difficult decision or a specific situation. Please circle a number from 1 to 5 for each item below. Show how much you engage in these types of activities as you consider the decision to place your loved one in a residential facility.

1. Take some time off and get away from the situation.
 Not at all 1 2 3 4 5 Very much

2. Focus on the problem and see how I can solve it.
 Not at all 1 2 3 4 5 Very much

3. Blame myself for having gotten into this situation.
 Not at all 1 2 3 4 5 Very much

4. Treat myself to a favorite food or snack.
 Not at all 1 2 3 4 5 Very much

5. Feel anxious about not being able to cope.
 Not at all 1 2 3 4 5 Very much

6. Think about how I solved similar problems.
 Not at all 1 2 3 4 5 Very much

7. Visit a friend.
 Not at all 1 2 3 4 5 Very much

8. Determine a course of action and follow it.
 Not at all 1 2 3 4 5 Very much

9. Buy myself something.
 Not at all 1 2 3 4 5 Very much

10. Blame myself for being too emotional about the situation.
 Not at all 1 2 3 4 5 Very much

11. Work to understand the situation.
 Not at all 1 2 3 4 5 Very much

12. Become very upset.
 Not at all 1 2 3 4 5 Very much

13. Take corrective action immediately.
 Not at all 1 2 3 4 5 Very much
14. Blame myself for not knowing what to do.
 Not at all 1 2 3 4 5 Very much
15. Spend time with a special person.
 Not at all 1 2 3 4 5 Very much
16. Think about the event and learn from my mistakes.
 Not at all 1 2 3 4 5 Very much
17. Wish that I could change what had happened and how I
 felt.
 Not at all 1 2 3 4 5 Very much
18. Go out for a snack or a meal.
 Not at all 1 2 3 4 5 Very much
19. Analyze the problem before reacting.
 Not at all 1 2 3 4 5 Very much
20. Focus on my general inadequacies.
 Not at all 1 2 3 4 5 Very much
21. Phone a friend.
 Not at all 1 2 3 4 5 Very much

APPENDIX F
CENTER FOR EPIDEMIOLOGICAL
STUDIES-DEPRESSION SCALE
(CES-D)

Mailed to caregiver:
M D Y

BELOW IS A LIST OF THE WAYS YOU MAY HAVE FELT OR BEHAVED RECENTLY. FOR EACH STATEMENT, CHECK THE BOX THAT BEST DESCRIBES HOW OFTEN YOU HAVE FELT THIS WAY DURING THE PAST WEEK.

	Rarely or None of the Time	Some of the Time	Occasionally	Most of the Time
DURING THE PAST WEEK:				
a. I was bothered by things that don't usually bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I felt that I could not shake the blues even with help from my family and friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I felt that I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. I felt that people disliked me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX G
DECISION-MAKING AND
PLACEMENT KNOWLEDGE
QUESTIONNAIRE

Below are some thoughts and concerns caregivers may have about the decision-making process to place a loved one in a residential care facility. There are no right or wrong answers. Please indicate to what extent each of the following statements apply to you. For each statement, please circle the most appropriate number.

1. I believe that I would no longer be my loved one's caregiver if her or she is placed in a residential care facility.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

2. If I have to place my loved one in a residential care facility, I know and can identify my own reasons for placing.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

3. I can identify my own feelings, reasons, and beliefs that would be barriers in making the decision to place my loved one in residential care.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

4. I know what level of care and the type of facility my loved one would need should he or she need to enter residential care.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

5. I have a clear understanding of the levels of care available in my community, i.e., Day Care, Assisted Living, Board & Care, SNF-Skilled Nursing Facility, etc.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

6. I am **unable** to identify at least two sources of support for my own caregiving needs.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

7. I have a basic understanding of the payment mechanisms, including the MediCal Long-term program, involved in funding residential care.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

8. I **do not** feel that I have the knowledge to evaluate a residential care facility.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

9. I am uncertain and will probably have difficulty in recognizing when I can no longer provide the quality of care my loved one needs in my home.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

10. I believe I have enough information and support to make the decision to place my loved one in a residential care facility should the need arise.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

11. I know which type of facility (Assisted Living, Board and Care, Skilled Nursing, etc.) would best meet my loved one's needs.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

APPENDIX H
DEBRIEFING STATEMENT FOR
TREATMENT GROUP

Evaluation of an Intervention Program to Assist The Family
Caregiver with the Placement Decision

Debriefing Statement

Thank you for completing the questionnaire for this study. The purpose of this study is to evaluate the effectiveness of the *To Place or Not to Place, That is the Question* class. Specifically, we are interested in better understanding how professionals can assist family caregivers with the placement decision-making process.

To date, the research literature has identified that the placement decision process is very difficult for family caregivers. Very little is known about the impact of intervention programs in assisting family caregivers with the difficult decision of out-of-home care. This study will hopefully help us understand how best to help caregivers when they face the placement decision.

We anticipate that the group results of this study will be available after June 15, 2002. Please contact us after this time if you are interested in the outcome of this study.

Please contact, Adriana Bailey (1-800-675-6694) or Dr. Laura Kamptner (909 880-5582) if you have any questions or concerns about your participation in this study.

Finally, we want to thank you for your participation in this study. Your contribution has been very helpful in furthering our knowledge on this subject.

Sincerely,

Adriana Bailey
Family Consultant, ICRC

Laura Kamptner
Professor of Human
Development and
Psychology, CSUSB

APPENDIX I
DEBRIEFING STATEMENT FOR
CONTROL GROUP

Evaluation of an Intervention Program to Assist The Family
Caregiver with the Placement Decision

Debriefing Statement

Thank you for completing the questionnaire for this study. The purpose of this study is to evaluate the effectiveness of an intervention program. Specifically, we are interested in better understanding how professionals can assist family caregivers with the placement decision-making process.

To date, the research literature has identified that the placement decision process is very difficult for family caregivers. Very little is known about the impact of intervention programs in assisting family caregivers with the difficult decision of out-of-home care. This study will hopefully help us understand how best to help caregivers when they face the placement decision.

We anticipate that the group results of this study will be available after June 15, 2002. Please contact us after this time if you are interested in the outcome of this study.

Please contact, Adriana Bailey (1-800-675-6694) or Dr. Laura Kamptner (909 880-5582) if you have any questions or concerns about your participation in this study.

Finally, we want to thank you for your participation in this study. Your contribution has been very helpful in furthering our knowledge on this subject.

Sincerely,

Adriana Bailey
Family Consultant, ICRC

Laura Kamptner
Professor of Human
Development and
Psychology, CSUSB

APPENDIX J
PHONE INTERVIEW QUESTIONNAIRE

Each class participant responded to the following questions:

1. Did you find the class effective in explaining the mechanical process of placement? That is, the methods of payment and the process of placement.

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

2. Has the class helped you understand your own feelings and beliefs on placement?

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

3. If you had to make the placement decision, do you feel you are better prepared to make the decision to place your loved one in a residential care facility after taking this class?

Strongly Agree	Slightly Agree	Neutral	Slightly Disagree	Strongly Disagree
1	2	3	4	5

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