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A Pilot Evaluation of Psychosocial Support for Family Caregivers of Relatives with Dementia in Long-Term Care: The Residential Care Transition Module

Dr. Joseph E. Gaugler, PhD,

Associate Professor, McKnight Presidential Fellow, School of Nursing & Center on Aging

Mark Reese, MA, LPC, LMFT, and

Study Counselor, Families and LTC Projects, School of Nursing

Jill Sauld, MSN

PhD Candidate, School of Nursing, University of Minnesota, Minneapolis, Minnesota

Abstract

This multiple method pilot evaluation aimed to generate preliminary data on the effectiveness of the Residential Care Transition Module (RCTM). The RCTM is a six-session, 4-month psychosocial intervention designed to help families manage their emotional and psychological distress following residential care placement of a cognitively impaired relative. Seventeen family caregivers of relatives in a nursing home or assisted living memory care unit were randomly assigned to the RCTM treatment condition and 19 family caregivers were assigned to a usual care control group. Caregivers in the treatment condition reported significantly ($p < 0.05$) less emotional distress at 4 and 8 months on self-reported surveys than those in the control group. Post-RCTM focus groups emphasized the importance of readily available psychosocial support for families following the placement transition. The findings suggest that the provision of skilled psychosocial support can help families manage emotional distress and crises in the months following a cognitively impaired relative's admission to residential long-term care.

Admission of a relative into a nursing home or similar setting may be accompanied by feelings of stress, guilt, anger, anxiety, depression, and continued burden (Grant et al., 2002; Schulz et al., 2004). Residential care placement often introduces new challenges for family members as their responsibilities change and their roles shift from provision of hands-on care to that of visiting, monitoring care, and serving as an advocate for their institutionalized relative (Gaugler, 2005a). Improving family caregivers' adaptation to residential long-term care (RLTC) placement (e.g., nursing home, assisted living memory care) may improve family members' well-being as well as relatives' quality of life and quality of care (Cohen et al., 2014; Gaugler, 2006; Grabowski & Mitchell, 2009; Hamann, 2014; Mitchell & Kemp, 2000; Penrod, Kane, & Kane, 2000; Zimmerman, Gruber-Baldini, Hebel, Sloane, &

Address correspondence to Joseph E. Gaugler, PhD, Associate Professor, McKnight Presidential Fellow, School of Nursing & Center on Aging, University of Minnesota, 6-153 Weaver-Densford Hall, 1331, 308 Harvard Street S.E., Minneapolis, MN 55455; gaug0015@umn.edu.

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Magaziner, 2002). However, the overwhelming majority of community-based long-term care services are designed for at-home family caregivers (Logsdon, 2008). RLTC placement is often considered an outcome to be prevented or delayed in these various service models. Those few efforts that focus on family involvement following a relative's RLTC admission tend to focus on building positive family–staff relationships and often do not consider family members' psychosocial needs (Gaugler, 2005b). One exception includes a pilot study of a telephone-based counseling support program for families of residents in nursing homes (Davis, Tremont, Bishop, & Fortinsky, 2011).

The objective of the current multiple method pilot evaluation was to ascertain whether and how the Residential Care Transition Module (RCTM), a psychosocial intervention designed for families following RLTC placement, reduced negative experiences associated with a cognitively impaired relative's admission to a 24-hour RLTC facility (e.g., family members' depression, stress, conflict with facility staff). The structure and content of the RCTM is adapted from the Coleman Care Transitions Intervention (Parry, Coleman, Smith, Frank, & Kramer, 2003) and the New York University Caregiver Intervention (NYUCI; Mittelman & Bartels, 2014), both of which have generated high-quality evidence supporting their use in improving hospital discharge and dementia caregiver outcomes, respectively. The RCTM is similar to these approaches in that the intervention helps family members identify potential stressors arising from a key health transition (i.e., RLTC placement of a cognitively impaired relative) and then helping them use coping strategies and build support to modify responses to these stressors.

The RCTM includes six sessions with a transition counselor (TC; M.R.) that take place immediately after a pre-RCTM baseline survey. Sessions 1 through 3 are scheduled approximately 1 week apart and Sessions 4 through 6 are scheduled approximately 1 month apart. During Session 1, the TC builds rapport with the family member, obtains an autobiography of the family care experience, and establishes four to five key topics to explore in future sessions. In the remaining five sessions, the TC uses psychosocial consultation, mindfulness practices, and cognitive-behavioral and narrative-based therapeutic techniques to reduce the family member's perceived level of stress and strengthen resiliency. At the family member's discretion, sessions can include other family members or decision makers involved in the relative's residential care. Additional ad hoc sessions may take place via telephone, e-mail, or in-person based on the family member's needs and whether potential crisis events occur. The duration of each session ranges from 60 to 120 minutes. Table 1 summarizes the clinical content of the RCTM.

The current study used quantitative data to assess the preliminary effectiveness of the RCTM and qualitative data to describe how well the RCTM worked according to family caregivers. The questions guiding this pilot evaluation of the RCTM were as follows:

1. Is receipt of the RCTM associated with statistically significant differences in stress and negative mental health and greater family adaptation to RLTC at 4 and 8 months following enrollment in the intervention? (As this was a pilot study, the principal goal was not to test a hypothesis but to generate preliminary effect sizes for power analyses to guide sample size estimation for a larger randomized

controlled trial [Arain, Campbell, Cooper, & Lancaster, 2010; Becker, 2008; Conn, Algase, Rawl, Zerwic, & Wyman, 2010].)

2. Among those who used the RCTM, why was this intervention perceived as helpful or not helpful?

METHOD

Feasibility

A feasibility study was initially conducted to refine the RCTM model. Fifteen dementia caregivers who had admitted their relatives to a RLTC setting participated. Descriptive empirical analysis found that several measures (e.g., perceived stress) decreased over a 4-month interval. A content analysis of the qualitative data collected from participant interviews as well as TC notes revealed several mechanisms of benefit, including the formation of a therapeutic relationship, provision of psychoeducation related to dementia and its progression, and explorations of guilt and stigma. Caregivers repeatedly stated how surprised they were at the positive effects of telling their story in a linear and sequential manner. The success of the feasibility phase of the RCTM informed the development of the RCTM treatment protocol evaluated in the current pilot study.

Sample

Family caregivers were recruited from the University of Minnesota Caregiver Registry, which included more than 300 family members and professionals interested in participating in research on memory loss and long-term care maintained by the first author (J.E.G.). Inclusion criteria to participate in the pilot project were as follows: (a) the relative was admitted to a RLTC facility in the past 12 months; (b) the family member was the individual most responsible for caring for the relative; (c) the family member could speak and understand English; and (d) the family member could hear adequately. A total of 36 individuals were recruited and eligible to participate.

Procedure

Initial baseline interviews were conducted by the TC (M.R.) in-person at the University of Minnesota, the family caregiver's home, or at another location identified as convenient by the family caregiver. The TC then randomized caregivers (via an online program) to the RCTM intervention ($n = 17$) or a usual care control group ($n = 19$). Following randomization, family members in the RCTM treatment condition were introduced to the six-session protocol of the RCTM. Family members in the usual care condition were provided with quarterly check-in calls by the TC but were not provided with any psychosocial consultation. Throughout delivery of the RCTM, the TC maintained detailed checklists and counselor notes to assess the frequency, duration, and clinical content of each RCTM session. The TC also conducted follow-up interviews in-person, over the telephone, or via e-mail survey with family members at 4- and 8-month follow-up intervals; thus, the TC was not blinded to group assignment. Four- and 8-month intervals were used as these mirrored those of the NYUCI and similar psychosocial interventions for family caregivers of individuals with dementia. In addition, preliminary descriptive work conducted on family

caregivers' burden and depressive symptoms before and following RLTC admission suggested that placement-related stressors may occur during similar post-admission time periods (Gaugler, Mittelman, Hepburn, & Newcomer, 2009).

All caregivers in the RCTM were invited to participate in three focus groups moderated by the TC following the six-session RCTM intervention (Kitzinger, 1994; Krueger, 2009). Telephone focus group sessions were used so that the complex schedules of family caregivers could be accommodated. Eleven RCTM caregivers participated (eight women and three men). Each focus group lasted 55, 44, and 50 minutes, respectively. The focus group sessions were recorded and transcribed. Study procedures were approved by the University of Minnesota Institutional Review Board (IRB#1203S11723).

Data Collection

Measures were selected that have shown strong reliability and validity in dementia caregiving (Gaugler, Kane, & Langlois, 2000) and RLTC contexts. All measures were summed unless indicated, and baseline Cronbach alpha reliability estimates are presented. With the exception of sociodemographic variables, all measures were administered at each time point.

Sociodemographic Context—A number of sociodemographic characteristics and context of care variables were assessed in the baseline RCTM interviews (Table 2).

Dementia Severity—The severity of the care recipient's cognitive impairment (seven items, alpha = 0.87; item range = 1 [*not at all difficult*] to 5 [*cannot do at all*]; Pearlin, Mullan, Semple, & Skaff, 1990), activities of daily living (ADL) dependencies (six items, alpha = 0.86; item range = 0 [*no help*] to 2 [*a lot of help*]; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), instrumental ADL (IADL) dependencies (five items, alpha = 0.91; item range = 0 [*no help*] to 2 [*a lot of help*]; Lawton & Brody, 1969), and neuropsychiatric symptoms (12-item Neuropsychiatric Inventory Questionnaire [NPI-Q], alpha = 0.79; item range = 1 [*mild*] to 3 [*severe*]; Cummings et al., 1994; Kaufer et al., 2000) were measured.

Caregiver Stress—A 7-item version of the Zarit Burden Interview (ZBI) relevant for post-placement (alpha = 0.86; item range = 0 [*never*] to 4 [*nearly always*]; Gaugler et al., 2009; Zarit, Reever, & Bach-Peterson, 1980), the 10-item Perceived Stress Scale (PSS; alpha = 0.91; item range = 0 [*never*] to 4 [*nearly always*]; Cohen, 1988), the 3-item role overload measure (alpha = 0.89; Pearlin et al., 1990), and the caregiver distress scale of the NPI-Q (alpha = 0.84; item range = 0 [*not at all*] to 5 [*extremely disruptive*]) were used to assess caregivers' stress.

Depressive Symptoms—The 20-item Center for Epidemiologic Studies-Depression scale (CES-D; alpha = 0.90; item range = 1 [*rarely or none of the time*] to 4 [*most of the time*]; Radloff, 1977) and the 30-item Geriatric Depression Scale (GDS; alpha = 0.84; item range = 0 [*no*] to 1 [*yes*]; Yesavage, Rink, Rose, & Aday, 1983) measured caregiver depressive symptoms.

Caregiver Adaptation to Placement—The mean of family members' degree of satisfaction with residential care staff (25-item Family Caregiver Perception Role, $\alpha = 0.93$; item range = 1 [*strongly disagree*] to 7 [*strongly agree*]; Maas et al., 2004), the mean of family caregivers' satisfaction with RLTC (six items, $\alpha = 0.74$; item range = 1 [*very satisfied*] to 4 [*not at all satisfied*]; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995), and the mean of closeness of relationship with the relative (seven items, $\alpha = 0.81$; item range = 1 [*strongly disagree*] to 5 [*strongly agree*]; Aneshensel et al., 1995) were included.

Post-Evaluation Semistructured Focus Group Guide—The questions guiding the focus groups are presented in Table 3. The open-ended questions explored the placement transition and how the RCTM helped family members and enhanced engagement with relatives or residential care staff.

Analysis

Descriptive statistics and a series of correlations were conducted within the RCTM treatment group ($n = 17$) to examine the process of RCTM implementation. As noted in Table 2, the lack of statistically significant bivariate baseline differences between the RCTM treatment and usual care control groups led the authors to address the first research question with a series of one-way analyses of variance. Specifically, the RCTM treatment assignment variable served as the independent variable of interest, and the 4- and 8-month (i.e., post-RCTM delivery) caregiver stress, depressive symptoms, and caregiver adaptation to placement variables served as the dependent variables of interest.

Miles and Huberman's (1984; Miles, Huberman, & Saldaña, 2013) sequential data analysis approach provided a framework for systematic analysis of the post-RCTM focus group/qualitative data (Question 2). Data reduction occurred throughout the project. Initially, transcripts were read and reread and analytic memos were made to document and reflect the coding process (Saldaña, 2013). The first (J.E.G.) and third (J.S.) authors discussed the analysis approach, identified the process for coding, and then used NVivo10 for data selection, focus and management, and code development. NVivo nodes were reviewed and categorized between the first and third authors. The next step was data display. NVivo nodes were reviewed, discussed, revised, reviewed, and discussed further by the first and third authors until a consensus of themes was established. The data (e.g., themes, NVivo codes, participants, examples) were displayed in table format to simplify the complex narratives and help further understanding of the data as well as the process of analysis (Miles et al., 2013, p. 118). Conclusion-drawing and verification took place during the first and third authors' final reviews of the qualitative findings.

RESULTS

Process Data

The 17 caregivers in the treatment condition completed a total of 97 RCTM counseling sessions (mean = 5.71 counseling sessions). Of these, 88 counseling sessions were individual and nine were family. The average duration of each RCTM individual session was 73.75 minutes ($SD = 17.44$), whereas the average duration of the RCTM family session was

106.67 minutes ($SD = 15.81$). All RCTM counseling sessions provided emotional support to participating caregivers. Twenty-six (29.6%) individual and three (33.3%) family counseling sessions addressed relatives' behaviors. Approximately 40% of all individual sessions addressed caregivers' issues with the relative's facility compared with only one family session. Eight (9.1%) individual sessions and one (11.1%) family session addressed a crisis situation. Caregivers also engaged the RCTM TC in a total of 27 ad hoc sessions. Of all sessions, 103 (83.1%) were conducted in-person, 20 (16.1%) were completed over the telephone, and one (0.8%) session was completed via e-mail exchange.

Several patterns of RCTM use appeared correlated with improvements in key outcomes. For example, caregivers who used more sessions to address crises indicated greater decreases in depressive symptoms over 4 months (GDS, $r = -0.64$, $p < 0.01$; CES-D, $r = -0.73$, $p < 0.01$). Over 8 months, caregivers who used more ad hoc sessions to address crises also appeared considerably more likely to report decreases in depressive symptoms (GDS, $r = -0.89$, $p < 0.001$). Total sessions addressing physical illness were also associated with decreases in caregiver stress over a 4-month period (role overload, $r = -0.60$, $p < 0.05$; ZBI, $r = -0.64$, $p < 0.05$).

Question 1: Pilot Outcome Evaluation (Quantitative Analysis)

The RCTM treatment and control groups did not differ significantly on any baseline variables, although the small sample may have obscured statistical variations (Table 2). Seven care recipients died during the 8-month follow up (six prior to the 4-month interview and two prior to the 8-month interview). Baseline comparisons on key RCTM outcomes among caregivers whose care recipients died and the remainder of the RCTM sample did not detect any statistically significant differences.

As summarized in Table 4, caregivers in the RCTM treatment group indicated significantly less distress on the NPI-Q at 4-month follow up compared to caregivers in the control group ($p < 0.05$). Caregivers in the RCTM treatment group reported less overload at 8 months compared to usual care controls ($p < 0.05$). Due to the small pilot sample, a number of findings did not achieve statistical significance below the $p < 0.05$ threshold but trended in the expected clinical direction ($p = 0.10$; role overload at 4 months; PSS at 4 months; PSS and ZBI at 8 months).

Question 2: Post-RCTM Telephone Focus Groups (Qualitative Analysis)

As shown in Table 5 (which provides specific codes and exemplar quotes derived from the qualitative data), four themes emerged in the post-RCTM focus groups. Participants discussed their individual paths of transitioning their family members from the home environment to and from various RLTC settings (*challenges related to the facility transition*). Although the majority of participants identified various challenges, including facility location, finding a facility that had an opening, physically having to move belongings to and from facilities, and having problems when expectations of facilities did not match what was said or advertised, several participants expressed feelings of gratitude that the facility transition was successful. Caregivers also described how feelings of guilt, worry, feeling alone, not knowing what to do, or having to deal with family dynamics required some time

to adapt and adjust (*adaptation process*). Even when family members believed that they had “adjusted well” to their new circumstances, participants still reported having to adapt to lifestyle changes. Discussions of external support involved the importance of the RCTM, family support, not feeling alone, obtaining information and discovering suggestions, and tips and ideas of what to expect (*benefits of external support*). Members of all three focus groups expressed varying opinions as to whether a specialty support group would be helpful in their circumstances. Multiple strategies to obtain and/or receive information to meet caregiver needs were also described (*information and support needs during the placement transition*). Participants expressed how beneficial it was when talking to someone “knowledgeable” about Alzheimer’s disease or dementia. Some participants also expressed the need for further education for families, friends, health care providers, facilities, and communities.

DISCUSSION

The RCTM was significantly associated with less caregiver stress. Reports of role overload/feelings of exhaustion, burden, negative reactions to neuropsychiatric symptoms of the care recipient, and overall perceptions of stress were lower at 4 and/or 8 months for participants who received the multi-session RCTM than usual care controls. The RCTM was designed to reduce the psychological and emotional stress experienced by caregivers as they transitioned their relatives into a residential facility while also increasing coping skills. The empirical outcome results align with the clinical content revealed in the process data; all individual and family sessions focused on the provision of emotional support, which was due to the expressed needs of RCTM participants. Furthermore, a review of the TC notes yielded several reasons why the clinical content of the RCTM led to lower emotional distress on the part of family caregivers. The RCTM was specifically developed to address the common stressors reported by caregivers during the transition process (Table 1), and the provision of psychosocial support may have allowed caregivers to manage their emotional distress during this time.

As apparent in the post-RCTM focus group data, the placement transition was difficult for various reasons. The RCTM intervention was viewed as helpful during these challenging episodes. Some caregivers stated that the RCTM provided valuable information, whereas others suggested that the tips offered by the TC were beneficial because caregivers did not know what to expect or what to ask of RLTC staff. Other caregivers stated that just knowing someone was available to talk to if needed (e.g., the TC) was comforting.

Several limitations are important to consider when interpreting the quantitative and qualitative findings, including the small sample that adversely influenced statistical power, the lack of ethnic/racial diversity in the sample, a non-blinded randomized design, and the limited nature of the telephone focus groups (including technical difficulties). The use of multiple inferential tests may have increased the chance for Type I error. Time since admission may have influenced the results; a correlation analysis found that although resident length of stay was not significantly associated with most 4- and 8-month outcome measures, residents with a longer length of stay had lower quality of life as perceived by

caregivers ($r = -0.48$, $p < 0.01$) and had caregivers who reported higher perceived stress ($r = 0.33$, $p = 0.05$) at 4 months.

IMPLICATIONS FOR NURSING PRACTICE

The findings from the current multiple method pilot evaluation have several important scientific and clinical implications. Because of shifts in care responsibility and roles following RLTC placement of a relative, effective measures that focus on family–staff interaction, family satisfaction with care staff and the facility, and assessments of stress factors germane to placement may be more representative of the realities of residential care. Subsequent larger-scale evaluations of the RCTM should consider more pertinent measures of psychosocial distress during RLTC placement to better ascertain how this protocol can reduce emotional distress associated with institutionalization. The multiple method findings of the current pilot RCTM evaluation also imply the potential clinical benefits of providing support to families after the placement transition. With an appropriate and comprehensive intervention model, caregivers can cope with and manage key stressors in the months following the transition process and in so doing can experience positive benefits (Davis et al., 2011).

To facilitate translation of the RCTM, a detailed treatment manual to guide implementation of the RCTM is now available, and the authors anticipate that the RCTM model could help enhance current clinical practice in nursing homes, assisted living memory care, or community agencies. A key clinical point to consider when implementing the RCTM is that the TC (whether a nurse, social worker, or similarly skilled professional in providing psychosocial support) must have training and experience moderating the complex dynamics that often arise during family sessions or crisis events. One aspect of the RCTM that can help mitigate translational concerns is that the counseling can take place over the telephone as well as in-person. In addition, the authors acknowledge that the RCTM may not be relevant for all families of newly admitted residents, as some family members may experience greater distress than others. The authors have developed a set of easy-to-administer, brief prognostic tools (Gaugler, Mittelman, Hepburn, & Newcomer, 2014) that could help directors of nursing or social workers identify family members who experience clinically relevant burden or depression and thus may be more appropriate for and receptive to the multi-session RCTM. Acknowledging the needs of families following RLTC placement of a relative via the use of the RCTM or a similar protocol (Davis et al., 2011) will help further the ideal of offering ongoing psychosocial support to family members during and following key transition points throughout the dementia caregiving trajectory.

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TABLE 1**Clinical Content of the Residential Care Transition Module (RCTM)**

Psychoeducation
• Critical stressors and crisis situations are identified during the intake interview
• A “curriculum” is developed that uses conversation, presentations, and online information and support
Promotion of Communication
• Family members’ skills in communicating and establishing positive relationships with other family members and staff are strengthened
• Facilitated family sessions are also conducted that provide a safe and moderated environment to explore issues, including past and current family dynamics
Problem Solving
• Individual and family counseling sessions help caregivers identify ways to effectively manage problems
• Caregivers’ recognition and acceptance of new roles are facilitated
Patient Behavior Management Strategies
• Instruction and practice focuses on acquisition of skills and strategies to manage reactions to unpredictable behavior outbursts during visits
Concrete Planning
• Goals for optimal care for relatives in residential long-term care (RLTC) and methods to achieve such goals in collaboration with staff are developed and refined
• These goals are made concrete in a family care plan for the relative in RLTC
Making Families Aware
• Knowledge about the psychopharmacological, medical, and rehabilitative treatments used in RLTCs to effectively manage dementia symptoms is achieved
Ad Hoc Counseling
• Ongoing, informal counseling on the telephone, in-person, or via e-mail with the transition counselor at the request of the family caregiver is provided to respond to immediate issues of need

TABLE 2

Baseline Sociodemographic, Dementia Severity, Caregiver Stress, Depressive Symptoms, and Adaptation to Placement and Bivariate Comparisons ($N = 36$)

Variable	Treatment Group ($n = 17$)	Control Group ($n = 19$)	Total
Sociodemographic/Context of Care			
Caregiver ($n, \%$)			
Female	15 (88.2)	14 (73.7)	29 (80.6)
Caucasian	17 (100)	19 (100)	36 (100)
Married/living with partner	15 (88.2)	14 (73.7)	29 (80.6)
Working full-time	5 (29.4)	7 (36.8)	12 (33.3)
Spouse	9 (52.9)	8 (42.1)	17 (47.2)
Care recipient ($n, \%$)			
Female	9 (52.9)	10 (52.6)	19 (52.8)
Caucasian	17 (100)	19 (100)	36 (100)
Married/living with partner	10 (58.8)	11 (57.9)	21 (58.3)
Died during evaluation	5 (29.4)	2 (10.5)	7 (19.4)
Caregiver age (years)	62.88 (10.87)	62.47 (14.38)	62.67 (12.67)
Caregiver number of children	2.68 (2.54)	2.37 (1.49)	2.52 (2.03)
Highest level of education ^a	6.18 (1.51)	6.11 (1.60)	6.14 (1.53)
Total household income in past year ^b	8.18 (2.74)	8.58 (1.68)	8.39 (2.22)
Care recipient age (years)	77.41 (11.18)	79.79 (12.37)	78.67 (11.72)
Care recipient number of children	3.12 (2.83)	2.89 (1.41)	3.00 (2.17)
Care recipient highest level of education ^a	4.53 (1.88)	5.26 (1.94)	4.92 (1.92)
Care recipient length of stay in facility (days)	152.17 (142.53)	131.06 (115.29)	141.03 (127.43)
Dementia Severity ^c			
Severity of cognitive impairment (range = 1.63 to 4.75)	3.15 (1.01)	3.18 (0.59)	3.17 (0.80)
Sum of ADL dependencies (range = 0 to 12)	6.00 (4.11)	4.13 (2.75)	5.01 (3.53)
Sum of IADL dependencies (range = 0 to 10)	9.12 (1.73)	8.74 (2.60)	8.92 (2.21)
NPI-Q severity (range = 0 to 30)	8.24 (4.84)	11.37 (7.54)	9.89 (6.52)
Caregiver Stress ^c			
Role overload (range = 1 to 5)	3.59 (1.25)	3.68 (0.96)	3.64 (1.09)
ZBI (range = 7 to 30)	17.82 (5.33)	19.76 (6.56)	18.85 (6.01)
PSS (range = 1 to 35)	18.18 (8.07)	19.18 (7.71)	18.71 (7.79)
NPI-Q distress (range = 0 to 35)	9.12 (6.92)	12.84 (10.65)	11.08 (9.15)
Caregiver Depressive Symptoms ^c			
CES-D (range = 21 to 68)	37.24 (11.28)	35.68 (10.92)	36.42 (10.96)
GDS (range = 0 to 12)	4.77 (4.07)	4.13 (3.05)	4.43 (3.53)
Caregiver Adaptation to Placement ^d			

Variable	Treatment Group (<i>n</i> = 17)	Control Group (<i>n</i> = 19)	Total
Satisfaction with facility environment (range = 2.5 to 4)	3.41 (0.40)	3.56 (0.48)	3.49 (0.44)
Satisfaction with relationship with relative (range = 1.14 to 3.43)	2.03 (0.55)	2.13 (0.73)	2.09 (0.64)
FCPRS (range = 2.57 to 6.6)	5.24 (0.72)	5.26 (1.13)	5.25 (0.94)

Note. ADL = activities of daily living; IADL = instrumental activities of daily living; NPI-Q = Neuropsychiatric Inventory Questionnaire; ZBI = Zarit Burden Interview; PSS = Perceived Stress Scale; CES-D = Center for Epidemiologic Studies-Depression Scale; GDS = Geriatric Depression Scale; FCPRS = Family Caregiver Perception Role Scale.

No statistically significant ($p < 0.05$) differences were noted between the treatment and control groups. All values mean (*SD*), unless otherwise indicated. The ranges reported are the response ranges provided by the study participants.

^a Item range = 1 (*did not complete junior high*) to 8 (*graduate degree*).

^b Item range = 1 (<\$5,000) to 10 (\$80,000).

^c Higher scores represent greater dementia severity, caregiver stress, and caregiver depressive symptoms.

^d Higher scores represent more positive adaptation to the relative's placement.

TABLE 3

Post-Residential Care Transition Module Semistructured Focus Group Guide

The following questions guided each focus group.	
1.	Brief introduction (e.g., name and where participants were in the caregiving process).
2.	What were some obstacles and barriers during the transition process?
3.	Was psychosocial support helpful, and if so, how did it help you?
4.	Is there a need for a specialty support group or educational group during this time?
5.	What other services would have been helpful during the transition process?
6.	During the transition process you can be faced with a financial system used by residential care facilities that you might not understand. Was this a stressor? What resources would have helped with this issue?
7.	How did you access support and resource information during this time? How and when would you like to have that information delivered?

TABLE 4

Analyses of Variance Results of 4- and 8-Month Residential Care Transition Module Outcomes

Outcome	Treatment Group (<i>n</i> = 17) (Mean, <i>SD</i>)	Control Group (<i>n</i> = 19) (Mean, <i>SD</i>)	<i>F</i>	<i>p</i> Value
Caregiver Stress				
Role overload				
4 months	3.15 (1.12)	3.83 (0.89)	3.31	0.08
8 months	2.97 (0.92)	3.71 (0.77)	5.00	0.04
ZBI				
4 months	17.39 (5.81)	19.75 (6.35)	1.07	0.31
8 months	15.27 (4.47)	20.07 (7.15)	3.83	0.06
PSS				
4 months	15.71 (7.74)	19.82 (6.45)	2.84	0.10
8 months	14.42 (8.26)	20.50 (7.94)	3.89	0.06
NPI-Q distress				
4 months	7.84 (6.27)	14.50 (7.87)	6.13	0.02
8 months	8.18 (6.29)	12.73 (9.84)	1.80	0.19
Caregiver Depressive Symptoms				
CES-D				
4 months	33.47 (9.77)	35.18 (10.79)	0.23	0.63
8 months	33.50 (9.49)	36.94 (11.93)	0.67	0.42
GDS				
4 months	3.00 (3.08)	3.88 (3.04)	0.71	0.41
8 months	4.58 (4.27)	3.59 (0.90)	0.01	0.91
Caregiver Adaptation to Placement				
Satisfaction with facility environment				
4 months	3.39 (0.37)	3.32 (0.63)	0.12	0.73
8 months	3.44 (0.46)	3.35 (0.46)	0.27	0.61
Satisfaction with relationship with relative				
4 months	1.97 (0.80)	2.23 (0.80)	0.79	0.38
8 months	2.19 (0.69)	2.16 (0.79)	0.01	0.93
FCPRS				
4 months	5.22 (0.83)	5.15 (1.01)	0.05	0.83
8 months	4.91 (1.07)	5.02 (1.11)	0.06	0.81

Note. ZBI = Zarit Burden Interview; PSS = Perceived Stress Scale; NPI-Q = Neuropsychiatric Inventory-Questionnaire; CES-D = Center for Epidemiologic Studies-Depression Scale; GDS = Geriatric Depression Scale; FCPRS = Family Caregiver Perception Role Scale.

TABLE 5

Post-Residential Care Transition Module (RCTM) Focus Group Themes, Codes, and Exemplar Quotes

Themes/NVivo Nodes	Focus Group/Sex	Exemplar Quote
Adaptation Process		
Family (16 references)	1/Female	"One of the barriers that I had is there's six of us children, and so getting us all going in the same direction so the boats, all the oars are going in one way.... We needed to find a location that...was convenient.... We all want to participate."
Hardest part for me (77 references)	1/Male	"We all go into this blind...it's like you're going on a family vacation but you have no idea what town you're going to.... Once you're starting placement, how do you figure out where there are even places, can you afford them, what do they offer? So you almost need a consultation in the front end to give you a road map, so that you can navigate the journey."
Transition went really well (4 references)	3/Female	"Transition actually went, it went really, really well. She just fell into the routine. She's still active and participates in most of the activities."
Benefits of External Support		
Support (21 references)	1/Male	"I have attended one support group periodically that's an Alzheimer's Association facilitated group. And, yes, what we share with each other and how we handle those problems and help each other is much more helpful than what I get, got through either the homecare service that I had to hire or the facility."
RCTM benefit (71 references)	3/Female	"Yes, it was very helpful. I was seeing a therapist before I started see you, Mark, who didn't really know what a lot about Alzheimer's, but was not willing to say I don't know the answer to that. And so would offer advice which I'm not sure was always the best advice. It was nice to know your background, history with Alzheimer's and dementia, to feel that I could say things to you that I couldn't say to others. It helped me feel I wasn't really so alone in this."
Challenges Related to the Facility Transition		
Journey to find a place (24 references)	2/Female	"The obstacles were we have independent living, assisted living, and memory care in the residence where I live. After he was in the hospital, he wasn't able to come live with me unless I moved into assisted living.... After doing that he didn't want to do what I wanted him to do.... We just had a lot of disagreements....more disagreements than we've had most of our life.... Then he went into a nursing home, before that he also went into the memory care unit.... He fell and broke a hip...landed back in a nursing home...he was in the Alzheimer unit, didn't get along there...he's in another unit and seems to be doing okay."
Moving issues (29 references)	2/Female	"Moving in the place...it was pretty much of a home-like atmosphere, kind of a big cabin up North.... We had to bring own furniture and whatnot...it was hard because we had to physically move things into his room...had to hurry up and get out and buy a new bed...then after 2 weeks they said he needs a hospital bed."
Expectations did not match (13 references)	1/Male	"My barriers were more the expectations and the explanations of what I thought I could expect didn't match.... I guess I have too high expectations of facilities. They have to go by their regulations, and they have to fill out all of their paperwork, and what they profess that they will try to do with you is not exactly what they can do...and the multiple changes and the dictatorial attitude."
Help from a specialty group (4 references)	3/Female	"...the answer is a big old fat yes. It is such a difficult decision...it's the most stressful thing I've ever done in my life...there's nowhere really to turn...the facility to some degree is able to help you but not to the extent that you need...you need someone to lean on...there really isn't that support out there in like the Alzheimer community, just about transition and decisions on when it's time to make the move and it's hard to find that specific type of support."
Information and Support Needs During the Placement Transition		
How to receive information (38 references)	1/Multiple participants	"Alzheimer's Association"; "Once diagnosed I got all kinds of information"; "Diagnostician, family doctor, neurologist, geriatrician"; "support group"; "AA-Meeting of the Minds"; "Joe Gaugler at the U"; "e-mail"; "I still like to see it on paper"
Financial—Whole system is complicated (54 references)	1/Male	"...jumped from \$4,000 to \$14,000 a month in a matter of 5 days...and a fourth choice was to hire 24-hour skilled nursing...I wasn't going to jump to \$20,000 a

Themes/NVivo Nodes	Focus Group/Sex	Exemplar Quote
		month...I'm paying rent, their services, plus home health aide, plus.... But in the care center, which is a nursing home, that is all state regulated. You never know, they will never tell you if it is a care center. They never tell you what it is they rated on and sent to the state...state sends you a ranking...like L21 or L31...and then you have to go figure out what that means in dollars."
Legal consultation for eldercare (6 references)	3/Female	"If there was a legal aspect to it, counseling with lawyers that handle eldercare. I happened to hit on a good one...but they are extremely costly. So it would be nice to have some kind of legal consultant available to make sure that all your ducks are in order for the huge financial and legal issues that come up."
Need for more community support and education (13 references)	2/Female	"I'm open about his condition and I call it Alzheimer's. I just feel there are so many people that misunderstand what Alzheimer's is really all about.... The public is not too aware of what Alzheimer's really is from what I see.... Community education, maybe some local education for extended families, friends, stuff like that.... It's a lot of ignorance."