

# The Effects of a Dementia Nurse Care Manager on Improving Caregiver Outcomes

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Iowa's Administration on Aging's Alzheimer's Disease Demonstration Grant to the States was a project to implement and evaluate a nurse care management model of service delivery for persons with dementia or care recipient and their family caregiver that was integrated with the case management system. The goal of the nursing service delivery model was to maintain persons with dementia safely in their homes, by connecting them with appropriate services and providing support to the care recipient and caregivers. Outcomes

measures were evaluated over time. This article defines the role of dementia nurse care management and shares the results of the outcomes measurements. The evaluation showed that caregivers assisted by nurse care managements were more likely to show improvement in their stress levels, endurance potential, and well-being. This improvement was consistent over time.

**Keywords:** nurse care manager; case management; caregiver outcomes

Alzheimer's disease and related disorders (ADRD) significantly affect persons with the disease and their caregivers (CGs). The loss of memory and function that are characteristic of dementia can be tragic for the afflicted individual. The losses complicate the care of the person with the disease and the management of co-morbidities, such as arthritis and heart disease that are common among older persons.<sup>1</sup> Caregiver's often neglect their own emotional and physical health as well.<sup>2-5</sup> Persons with chronic illnesses, such as ADRD, require early diagnosis, evidenced-based strategies for intervention, educational interventions for CG and client care management, and social and emotional support.<sup>6</sup> The care for persons with chronic illnesses has often been found to be fragmented, too rushed, and inadequate to meet the needs of those being served.<sup>6</sup>

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## Project Description

The Iowa AOA demonstration project, "Building a Seamless Dementia-Specific Service Delivery System for Rural Aged", was a 4-year renewable grant funded by the Administration on Aging from July 1999 to June 2004 to improve service delivery in rural Iowa communities to persons with dementia and their informal CGs. The intent of the demonstration project was to implement and evaluate an enhanced model of assistance for client dyads integrated with the traditional case management (Case Management Program for the Frail Elderly [CMPFE]) system. The goal was to maintain care recipient (CR) safely in their homes as long as they and their families chose by connecting them with appropriate services and support. Geographically isolated and often underserved persons with dementia and their families who could not or did not access the current delivery system were targeted. Collaboration with existing community services and partners was an integral component of the project to affect the desired system change outcome. The service delivery model tested care and coordination by nurse care managers (NCMs)

specially trained in dementia care strategies. The evaluation plan compared client and CG outcomes in 4 counties where service delivery enhanced with an NCM was implemented with 4 counties where the traditional CMPFE service delivery model was in place.

The Department of Elder Affairs of the state of Iowa oversees the CMPFE. This state run program is designed to prevent early institutionalization and other complications from chronic diseases. Provision of services are reserved for the individual in need and service for the CG is only serendipitous, for example, respite. Services of the CMPFE program include, but are not limited to, case management, adult day care services, meals on wheels, and homemaker services.<sup>7</sup> The Rural Iowa Alzheimer's Demonstration Project proposed an enhancement to the existing traditional case management model to persons with dementia (CR) and their families. The project used nurses specially trained in dementia care as *care* managers. The NCM worked with CRs and their CGs in dealing with the cognitive, emotional, social, and physical problems that accompany the disease.

## Purpose

This article describes the NCM role implemented in the Iowa Administration on Aging's Alzheimer's Demonstration Grant to the States (ADDGS) and the methods used to evaluate the NCM role. Outcomes for the person with dementia and their family CGs who were assisted by the traditional case management system and for the CR and their CG whose care was managed by the NCMs are described and compared. When the CR and CG are considered a group, they will be referred to as the client dyad. Implications of the results of the evaluation of the demonstration of the NCM for the CR, the CG, nursing, and interdisciplinary practice are discussed.

## Background

Nurse care managers were responsible for CR and CG outcomes in the service delivery demonstration project and were the intervention for the evaluation research. A few studies have evaluated nurses in the case management role for persons with dementia.<sup>6,8,9</sup> Nurses are educated to understand the holistic implications of chronic illnesses. The nurses specifically trained in dementia understand the neurological bases of cognitive, emotional, social, and physical manifestations as well as how other

chronic conditions can interact with dementia to exacerbate these manifestations. The nursing clinical management process is a holistic case management process, enabling nurses to be more effective case managers than many providers from other disciplines.<sup>9</sup> Traditional nursing care planning and assessment are related to positive results for those with Alzheimer's disease.<sup>8</sup> Consistent with Gwyther's findings, the authors see nurses more appropriately referred to as care managers and care coordinators and reject the depersonalizing notion of managing a case. For example, CGs of persons with Alzheimer's disease are "not cases, do not wish to be referred to as cases, and have no desire to be managed."<sup>10</sup> Gwyther's findings supported the conceptualization of the role of the NCM as it embodies the intent of the role to assist and empower the CG and CR to manage the circumstances surrounding the manifestations of the disease. Empirical support for the outcome effectiveness of NCM and coordination programs for persons with chronic illnesses is substantial and increasing.<sup>6,11</sup>

In this project, NCMs were registered nurses who used the nursing, disease management, and case management processes, along with community health nursing principles to assist client dyads. Importantly, the registered nurses (RNs) incorporated a keen knowledge of the rural population in the care management and coordination processes to develop an individualized plan for community-based dementia care.

## Methods

### Setting

A total of 8 counties were selected for the demonstration and evaluation based on their rural demographics. To decrease variation in available services, philosophy of service delivery, and resource distribution in the counties to be compared, counties were selected in pairs of those served by the same Area Agency on Aging and Alzheimer's Association Chapter. The counties in which the enhanced model and NCM were to be implemented were selected randomly.

### Participants

Client dyads residing in the 8 counties were enrolled based on the minimal inclusion criteria of memory impairment and county of residence. The criteria were established to identify persons who often do not meet existing service delivery criteria. Care recipients only had to have "suspected" memory impairment to be eligible to be included. Arbitrary barriers that often

make existing services inaccessible; such as a specific diagnosis, minimum set of problems, age, the absence of a CG or income level were eliminated. Care recipient were not excluded by age or economic criteria, even though the traditional case management system serves only those over 60 years of age and most services are typically reserved for those who qualify for service provision from other funding sources that often have more stringent income guidelines. Participant discontinuation from the project occurred when the person with dementia was placed in a residential facility, moved out of the county, died or after repeated attempts at establishing a trusted relationship refused further services.

### Enrollment and Referrals

In the intervention group (client dyads in counties with the NCM), the NCM received the referrals and enrolled each client dyad. The comparison group received the traditional CMPFE service approach. Participants in the comparison group were enrolled through a “Local Project Facilitator” (LPF) who collected baseline and follow-up data and made a referral to CMPFE. Referrals and enrollment were similar for both NCM and LPF, coming into case management by self or family referral, physicians or public health or social service workers by calling the local area agencies on aging or case management offices.

*Intervention.* The intervention for this study was the NCM. The following sections will discuss the NCM role and the role of the traditional case management control group. The term LPF was the designation used for the person working in the agency that typically performed the enrollment of persons into case management. In the grant, 4 of the counties were designated as the control counties, meaning they used the traditional CMPFE system and 4 counties were designated as intervention counties and used the NCM.

*Nurse care manager role description.* The NCMs were specifically hired for their role and received intensive specialized training in dementia management and assessment. The role of the NCMs was to work with the CRs and their CGs to identify, assess, and meet ongoing challenges and changing needs using an array of traditional and nontraditional methods. Although they worked with the CMPFE system and

clients were often enrolled in CM, the NCM developed the service plans to promote communication, collaboration, and cooperation within and between community service providers, CGs, and other informal supports. Nurse care managers strove to provide a “seamless service delivery system”, based on successful models of dementia care; the Progressively Lowered Stress Threshold model (PLST)<sup>12,13</sup> and Care Managed Role Reconciliation (CMRR).<sup>14</sup>

The NCM intervention included an assessment with both the CR and the CG. Based on the assessment, the interventions focused on meeting needs and finding ways of coping with mutually identified problems. This included obtaining the care and resources to sustain living at home with optimal quality of life or to assisting in determining that an alternative care setting was needed and helping with the transition. Assessment instruments were used to identify areas of need or problems and guide the development of a comprehensive interdisciplinary, yet individualized plan of care. Home visits depended upon needs, often frequently as weekly in the beginning, decreasing in frequency as CG confidence increased or other resources were used. There was always at least monthly contact, and the NCM was available by phone whenever the CG wished to call. In addition, because of the progressive nature of the disease, periodic reassessment was essential to modify the plan as needs changed. Other specific interventions included reminiscence; role supplementation; environmental restructuring for health and safety; and mobilization of resources. Role supplementation through teaching, role modeling, and anticipatory guidance helped the CG develop the skills and confidence to care for the person with dementia. Information was provided about the disease and its progression, symptom management, and available resources. The NCM provided assistance to the CR to accomplish basic and instrumental activities of daily living to demonstrate strategies to the CG tasks (role modeling) and provided respite. The NCMs often encouraged client dyads to “try” new services such as adult day or respite services, enabled by grant funding, to expose families to other service possibilities. Caregiver support groups were also encouraged to provide additional support to the CG.

### Control Group

Traditional case management services (CMPFE). The traditional case management (CMPFE) system works exclusively with the clients and vicariously with the CGs. Enrollment in CM and subsequent

service provision is determined upon the assessed financial ability to qualify for service assistance, though anyone may have an assessment completed and a case plan developed. Traditional case managers make the initial assessments, develop a service plan in cooperation with service providers, and present the plan to the client for agreement. The focus is on coordination of services for the client, not delivery of direct services by the case manager. In the CMPFE model, follow-up is done with a monthly phone contact and a quarterly face-to-face contact.

The LPF role was designated to a person who already worked as a case manager and was given added the responsibilities for recruitment and data collection required by the grant. These responsibilities included the community activities, data collection, and additional assessments for the grant. They did not follow the client or provide direct services that the NCM role provided. The LPF recruited clients in the traditional manner in which they had been enrolling clients, obtained consent to participate from clients, completed the traditional state required assessment forms (IOASIS) in addition to the grant assessment tools. Data collection, as per grant protocol, was obtained at baseline, 6 and 12 months in person. The timing of this face-to-face contact differed from the traditional model of case management service delivery, which consequently affected timing of follow-up data collection. Often the data collection points were delayed because it did not coincide with contact points required by the case management system.

## Outcomes

The outcome measures were taken at baseline, first and second follow-up. The first follow-up occurred between months 3 and 6 of enrollment and the third follow-up occurred between months 9 and 15 of enrollment. Data were collected by the NCM for the intervention group and by the LPF for the control group.

Care recipient outcomes included the following (Table 1): cognitive status measured by the Mini-Mental Status Exam (MMSE)<sup>15</sup> and the Global Deterioration Scale (GDS)<sup>16</sup> which are very standard measures for persons with dementia with strong psychometric properties; activities of daily living/instrumental activities of daily living (ADL/IADLs), measured using Lawton and Brody's<sup>17</sup> modified IADL/ADL measure; kinds and frequency of behaviors using the Behavior Rating Checklist<sup>18</sup>; and relocation as reported by the family. For the analysis,

only 13 of the behaviors on the rating scale were summed and used as outcomes. The 13 items represented negative behaviors and reflected difficult behaviors that CGs may manage as they care for the CR.

Caregiver outcomes included health status, well-being, stressors, and CG endurance potential. Table 1 presents the scoring and psychometric properties for each of the measures. Health status was measured using 2 general health items from the MOS 36 SF<sup>19,20</sup> instrument to reflect the CGs perception of their health, particularly physical health. The last 3 outcomes were measured using outcomes developed by the Nursing Outcomes Classification (NOC) at the University of Iowa.<sup>21</sup> The NOC contains outcomes for individuals, family CGs, the family and the community that can be used in all settings. The NOC is research-based using multiple methods including clinical site field testing. The outcomes were evaluated for interrater reliability, validity, and usefulness in the clinical sites, which represented the care continuum and are shared by all disciplines although NOC emphasizes outcomes that are most responsive to nursing interventions. The NOC outcomes are developed with a definition, overall outcome statement, and indicators. The number of indicators varies from 1 outcome to another. Indicators help the rater establish the rating for the outcome scale and also assist in identifying areas where intervention should be focused. For example, an indicator for the CG Stressors is "lack of usual diversional activity." This would guide the assessor to work on ways to help the CG have some way of doing his or her regular diversional activities. Although the NCMs used the indicators in planning care with the family, only the overall rating was used in the analysis presented here.

## Data Collection

All grant staff were trained in the assessment and data collection protocols. Outcome measures were collected beginning in January 2000 and follow-up data collection was continued through June 2003, the end of year 3 of the grant. All baseline measures were collected prior to implementing the NCM role with each client dyad.

## Data Analysis and Methods

Descriptive statistics for demographic and baseline characteristics of CRs and CGs were assessed and compared between the intervention and comparison

**Table 1.** Care Recipient Outcomes Measures & Caregiver Outcomes Measures

Variable	Instrument	Psychometrics
<b>Care Recipient Outcomes</b>		
Cognitive status	Mini-Mental Status Exam (MMSE); Folstein and Folstein. <sup>15</sup> Rating from 1 to 30, 1 = more cognitive loss	Test–retest reliability (0.89); interrater reliability (0.82)
Stage of dementia	Global Deterioration Scale (GDS); Reisberg et al. <sup>16</sup> Rating = 1-7, 1 = less functional and behavioral impairment	Test–retest reliability (0.82-0.92); interrater reliability (0.92-0.97); Construct validity est. with MMSE (0.89, $P < .001$ )
Functional status	Functional Assessment II, Groff, R.L. (unpublished data, 1997). Rating from 1 to 3, 1 = less assistance required	Not available
Functional ability	Modified IADL/ADL's from Lawton and Brody. <sup>17</sup> Rating 1-5, 1 = unable to do task alone	
Behaviors	Behavior rating checklist. Garrity and Klein <sup>18</sup>	Interrater reliability correlation between 0.42 and 0.64
Health status	Selections from the SF-36, Ware and Sherbourne <sup>20</sup> ; McHorney et al. <sup>19</sup> Rating 1-5, 1 = perception of excellent health	RP for global items (0.67-0.81) <sup>22</sup>
Relocation	Report of family	
<b>Caregiver Outcomes</b>		
Health status	Selections from the SF-36, Ware and Gandek. <sup>22</sup> Rating 1-5, 1 = perception of excellent health	
Well-being	NOC (Moorehead et al <sup>21</sup> ). Rating 1-10, with 11 an overall rating, 1 = extremely compromised	Internal consistency (Cronbach's $\alpha = .88$ ); Test–retest reliability (0.75); Construct validity est. with Zarit Burden interview scores of $P < .0001$ ; CES-D scores $P < .0001$
Endurance potential	NOC (Moorehead et al <sup>21</sup> ). Rating 1-10, with 11 an overall rating, 1 = not adequate	Internal consistency (Cronbach's $\alpha = .88$ ); Test–retest reliability (0.75); Construct validity est. with Zarit Burden interview scores of $P < .0001$ ; CES-D scores $P < .0001$
Stressors	NOC (Moorehead et al <sup>21</sup> ). Rating 1-14, with 15 an overall rating, 1 = extensive stress	Internal consistency (Cronbach's $\alpha = .86$ ); Construct validity est. with Caregiver Strain Index

Abbreviation: CES-D, Center for Epidemiologic Studies Depression Scale; NOC, Nursing Outcomes Classification.

group participants using the 2-sample *t* test or Wilcoxon rank-sum test for the continuous and ordinal variables and Fisher exact test or chi-square test of association for the categorical variables. The linear mixed model analysis for repeated measures was used to assess CR GDS, MMSE, Activities of Daily Living, and behavior rating scores from baseline to 3 to 9 and 9 to 15 months follow-ups within each group and to compare these mean changes between the NCM and comparison groups. The factors in the linear mixed model analyses were group, time, and group–time interaction. The model also included presence/absence of a CG. For the analysis of the CG outcomes, scale scores were dichotomized to test for the effect of the intervention on the CG outcomes over the 3 time periods, logistic regression analysis using the GEE (generalized estimating equations) method was used. The logistic regression model included group (NCM versus comparison), time, and group–time

interaction as the independent variables. The use of the GEE method for this analysis took into account the correlation between responses from the same participant over the 3 time points. For these 2 analyses involving the CR and CG, Bonferroni's method was applied to adjust the *P* values to account for the multiple tests that were performed. Bonferroni adjustment ( $P < .05$ ) for 4 tests was applied for the test comparing 3 to 9 months and 9 to 15 months from baseline within each of the 2 groups, and for 2 tests for comparison between NCM and comparison at each of the 2 follow-up periods, with a Bonferroni. In addition, analyses to test for the association of CR variables (GDS, MMSE, ADL index, behavior rating index, functional abilities rating, and age) and CG characteristics (age, education, health) with CG stress, well-being, and endurance potential (EP) were performed by extending the logistic regression model in the previous analysis

**Table 2.** Client Family Enrollment

	Total	NCM	Control
Total	249	167	82
With caregivers	168	114	54
Live alones	89	57	28
NH placements	97	67	30
Died	44	33	11
Withdrew			
With follow-up between 3 and 9 months	125	93	32
With follow-up between 9 and 15 months	87	64	23

Abbreviation: NCM, nurse care manager.

to include 1 covariate at a time. For each of these covariates, the odds ratio for an unfavorable outcome associated with the covariate was estimated.

## Results

In the first 3 years of the study, 71 CRs were placed in nursing homes and 35 died. Table 2 presents the enrollment and disposition of the CRs by treatment group. Of the total of 252 CRs, 170 in the NCM intervention group and 82 in the comparison group, 147 (107 NCM and 40 comparison) had at least 1 follow-up measure of each outcome within a 15-month period. Results of analyses were based on the 147 CRs with at least 1 follow-up outcome measure.

## Demographics

### Care Recipients

Table 3 presents the demographic and baseline characteristics of the CRs in the NCM and comparison groups. The CRs in the NCM group were significantly older (mean age 82.4;  $P = .012$ ) and a smaller proportion had a diagnosis of Alzheimer's disease based on an evaluation by a physician (32.7%;  $P = .015$ ) compared with the comparison group (mean age 78.5 with 51.4% with diagnosed Alzheimer's disease). The NCM group also had a significantly lower annual income compared with the comparison group ( $P = .043$ ). The largest percentage of CRs was women between the ages of 75 and 85 or older, with two-thirds living with other persons in the home. There were no significant differences between the NCM group participants and those elders in the comparison group at baseline on GDS or MMSE scores. The median MMSE was 21 for the NCM group and 19 for the comparison group, and the

GDS median was 4 for both groups. The mean baseline ADL index of the NCM group was significantly lower compared with the comparison group ( $P = .029$ ).

The CRs' GDS, MMSE, ADL index, and behavior rating index were assessed over the 2 follow-up periods, at 3 to 9 months and at 9 to 15 months from baseline. There were follow-up data for these variables for 125 (93 NCM and 32 comparison) and 87 (64 NCM and 23 comparison) CRs for the 3 to 9 month and 9 to 15 month follow-up periods, respectively. The mean ( $\pm$ SE) estimates obtained from the linear mixed model analysis, adjusted for the presence/absence of CG, are shown in Table 4. Compared with baseline, there was a significant increase in the ADL index at 3 to 9 months ( $P = .003$ ) and at 9 to 15 months ( $P < .0001$ ) in the NCM group, with no significant change observed in the comparison group ( $P > .80$ ). The mean ADL index at the 2 follow-up periods did not differ significantly between the NCM and comparison groups ( $P > .46$ ). Both the NCM and comparison groups showed no significant change in behavior rating index ( $P > .20$ ), MMSE ( $P > .90$ ), and GDS ( $P = .12$  in NCM and  $P = .79$  in comparison) during the follow-up period. There was no significant difference in the mean behavior rating index ( $P > .90$ ), MMSE ( $P > .85$ ), and GDS ( $P > .14$ ) between the NCM and comparison groups at the 2 follow-up periods.

A comparison was made of CR baseline characteristics of the intervention group who stayed in the study with those that died or were placed in nursing homes (Table 5). Age was the only statistically significant difference between the 2 groups. The mean age for CRs who remained in the study was 80 (SD 9.7) compared with the mean age of the CR group who died or were placed which was 82.8 (SD 6.6). Other characteristics examined included, gender, marital status, income, rural/urban, income, functional assessment, GDS scores, MMSE, ADLs, and behaviors. There was also no significant difference in CG health between these 2 groups.

### Family Caregivers

Table 6 gives the baseline demographic and outcome measure characteristics of the CGs for the intervention and comparison groups. The CGs in the NCM group were slightly younger (mean age of 63.9 vs 69.2) with a greater percentage single or widowed (30.7% vs 11.8%) compared with the comparison group. A significantly higher percentage of the CGs in the NCM group were the child or child-in-law of

**Table 3.** Care Recipient Baseline Characteristics in NCM and Control

Characteristic	NCM (n = 107)	Control (n = 40)	P Value
Gender (female)	73 (68.2%)	23 (57.5%)	Fisher exact test $P = 0.247$
Age	(n = 105)		$t$ test $P = 0.012^*$
Mean (SD)	82.4 (8.2)	78.5 (8.6)	
25th-75th percentile	79.3-88.2	74.0-84.5	
Range	43.0-95.4	53.6-91.5	
Marital status	(n = 102)	(n = 39)	Chi-square test exact $P = .205$
Single	5 (4.9%)	0 (0.0%)	
Married/with partner	46 (45.1%)	24 (61.5%)	
Widowed	48 (47.1%)	15 (38.5%)	
Other	3 (2.9%)	0 (0.0%)	
Have Alzheimer	(n = 104)	(n = 37)	Chi-square test exact $P = .015^a$
Yes, diagnosed	34 (32.7%)	19 (51.4%)	
Yes, suspected	0 (0.0%)	2 (5.4%)	
Probably	44 (42.3%)	9 (24.3%)	
No	26 (25.0%)	7 (18.9%)	
Geographic location	(n = 105)		Fisher exact test $P = .131$
Rural/farm	47 (44.8%)	12 (30.0%)	
Small city or town	58 (55.2%)	28 (70.0%)	
Where care recipient resides	(n = 106)		Chi-square test exact $P = .235$
In house/apartment w/ others	69 (65.1%)	28 (70.0%)	
Alone in house/apartment	37 (34.9%)	11 (27.5%)	
Group environment w/ asst	0 (0.0%)	1 (2.5%)	
Total annual income	(n = 92)	(n = 39)	Wilcoxon rank sum test exact $P = .043^a$
<US\$8000	25 (27.2%)	6 (15.4%)	
US\$8000-US\$11 999	21 (22.8%)	9 (23.1%)	
US\$12 000-US\$14 999	16 (17.4%)	6 (15.4%)	
US\$15 000-US\$19 999	16 (17.4%)	4 (10.3%)	
US\$20 000-US\$29 999	8 (8.7%)	8 (20.5%)	
≥US\$30 000	6 (6.5%)	6 (15.4%)	
Live with caregiver	75 (70.1%)	34 (85.0%)	Fisher exact test exact $P = .089$
Gen health, compared same age	(n = 104)		Wilcoxon rank sum test exact $P = .161$
Excellent	4 (3.9%)	1 (2.5%)	
Good	59 (56.7%)	20 (50.0%)	
Fair	31 (29.8%)	9 (22.5%)	
Poor	8 (7.7%)	9 (22.5%)	
Very poor	7 (1.9%)	1 (2.5%)	
Health changed last 12 months	(n = 103)		Wilcoxon rank sum test exact $P = .004^a$
Much better	0 (0.0%)	0 (0.0%)	
Somewhat better	3 (2.9%)	1 (2.5%)	
About the same	63 (61.2%)	15 (37.5%)	
Somewhat worse	30 (29.1%)	15 (37.5%)	
Much worse	7 (6.8%)	9 (22.5%)	
Functional abilities rating	(n = 95)		Fisher exact test $P = .817$
1	40 (42.1%)	17 (42.5%)	
2	20 (21.1%)	6 (15.0%)	
3	35 (36.0%)	17 (42.5%)	
GDS score	(n = 105)		Wilcoxon rank sum test $P = .062$
Median	4	4	
25th-75th percentile	3-5	3-5	
Range	1-7	1-6	
MMSE	(n = 103)	(n = 33)	Wilcoxon rank sum test $P = .147$
Median	21	19	
25th-75th percentile	15-24	14-23	
Range	0-30	0-26	
ADL Index	(n = 105)		$t$ test $P = .029^a$
Mean (SD)	2.28 (0.75)	2.57 (0.63)	

(continued)

**Table 3.** (continued)

Characteristic	NCM (n = 107)	Control (n = 40)	P Value
Behavioral rating index	(n = 101)		Wilcoxon rank sum test $P = .774$
Median	1.69	1.67	
25th-75th percentile	1.38-2.25	1.34-2.04	
Range	1.00-4.15	1.00-3.60	

Abbreviations: GDS, Global Deterioration Scale; MMSE, Mini-Mental Status Exam; NCM, nurse care manager.

<sup>a</sup> Denotes significance of  $P$  value  $\pm < .05$  level.

**Table 4.** Mean (+SE) Estimate<sup>a</sup> of ADL Index, Behavior Rating Index, MMSE, and GDS

Care Recipient Assessment	NCM	Control
ADL index (1-5, 1= more care)		
Baseline	2.14 $\pm$ 0.07	2.48 $\pm$ 0.15
3 to 9 months follow-up	2.31 $\pm$ 0.07 <sup>b</sup>	2.50 $\pm$ 0.15
9 to 15 months follow-up	2.45 $\pm$ 0.07 <sup>c</sup>	2.55 $\pm$ 0.14
Behavior rating index (1-13, 1= less negative behaviors)		
Baseline	1.71 $\pm$ 0.06	1.60 $\pm$ 0.11
3 to 9 months follow-up	1.67 $\pm$ 0.06	1.80 $\pm$ 0.13
9 to 15 months follow-up	1.58 $\pm$ 0.06	1.72 $\pm$ 0.13
MMSE (1-30, 1= more impairment)		
Baseline	20.76 $\pm$ 0.64	20.41 $\pm$ 1.45
3 to 9 months follow-up	21.66 $\pm$ 0.66	20.70 $\pm$ 1.80
9 to 15 months follow-up	21.15 $\pm$ 0.76	20.60 $\pm$ 1.67
GDS (1-7, 1= less impairment)		
Baseline	4.0 $\pm$ 0.1	3.4 $\pm$ 0.3
3 to 9 months follow-up	4.2 $\pm$ 0.1	3.6 $\pm$ 0.3
9 to 15 months follow-up	4.3 $\pm$ 0.1	3.7 $\pm$ 0.3

Abbreviations: GDS, Global Deterioration Scale; MMSE, Mini-Mental Status Exam; NCM, nurse care manager.

<sup>a</sup> Least square mean estimate from mixed model analysis adjusted for presence/absence of caregiver.

<sup>b</sup>  $P \leq .003$ .

<sup>c</sup>  $P \leq .0001$ .

the CR (52.0% vs 29.4%;  $P = .034$ ). Caregivers in the NCM and the comparison groups differed significantly in baseline EP ( $P = 0.035$ ) with 21.1% of the CGs in the NCM group having inadequate EP and 24.4% with substantially adequate EP. In contrast, only 3.2% of the CGs in the comparison group had inadequate EP with 41.9% having substantially adequate EP. There was no significant difference between the groups in baseline CG stress or CG well-being.

Caregiver outcomes (stress, well-being [WB], and EP) were also assessed at 3 to 9 months and at 9 to 15 months from baseline. Of the 107 CRs with a CG that had follow-up, 63 (40 NCM and 23 comparison) and 45 (29 NCM and 16 comparison) CGs had follow-up data for the CG outcome variables at the 3 to 9 months and 9 to 15 months follow-up periods, respectively. During the 15 months follow-up period, the NCM and the comparison showed significantly different patterns of change over time for all 3 CG outcomes, as indicated by a significant group–time

interaction ( $P = .014$  for stress;  $P = .002$  for WB; and  $P = .006$  for EP).

For CG stress (Figure 1), the proportion of CGs with extensive or substantial stress did not significantly change in the NCM group during the follow-up period ( $P > .38$ ). In contrast, there was an increase in the proportion of CGs with extensive or substantial stress in the comparison group at the 3 to 9 month follow-up ( $P = .077$ ), although the stress score decreased at the 9 to 15 month follow-up. At the 3 to 9 month follow-up, the CGs in the comparison group were more likely to have had extensive/substantial stress compared with the CGs in the NCM group (odds ratio: 5.56; 95% confidence interval [CI]: 1.27, 24.37;  $P = .019$ ).

The proportion of CGs with extremely or substantially compromised WB increased significantly in the comparison group at the 3 to 9 months follow-up ( $P = .018$ ; Figure 2) and remained at this level at the 9 to 15 months follow-up. In the NCM group, the proportion of CGs with extremely or substantially compromised WB decreased during the follow-up



**Table 5.** Comparison of CR Baseline Characteristics Among Those With Follow-up That Died or Were Placed in Nursing Home Versus Those That Stayed in the Study

Characteristic	Stayed in Study; (n = 76)	Placed/Died; (n = 71)	P Value
Gender (female)	48 (64.7%)	47 (66.2%)	Chi-square test $P = .826$
Age	(n = 75)	(n = 70)	$t$ test $P = .038^a$
Mean (SD)	80.0 (9.7)	82.8 (6.6)	
25th-75th percentile	74.6-87.6	80.3-86.9	
Range	43.0-95.4	62.6-95.3	
Marital status	(n = 73)	(n = 68)	Chi-square test exact $P = .074$
Single	4 (5.5%)	1 (1.5%)	
Married/with partner	39 (53.4%)	31 (45.6%)	
Widowed	27 (37.0%)	36 (52.9%)	
Other	3 (4.1%)	0 (0.0%)	
Have Alzheimer	(n = 72)	(n = 69)	Chi-square test exact $P = .643$
Yes, diagnosed	25 (34.7%)	28 (40.6%)	
Yes, suspected	2 (2.8%)	0 (0.0%)	
Probably	27 (37.5%)	26 (37.7%)	
No	18 (25.0%)	15 (21.7%)	
Geographic location	(n = 74)		Chi-square test $P = .764$
Rural/farm	31 (41.9%)	28 (39.4%)	
Small city or town	43 (58.1%)	43 (60.6%)	
Total annual income	(n = 68)	(n = 63)	Wilcoxon rank sum test exact $P = .474$
<US\$8 000	13 (19.1%)	18 (28.6%)	
US\$8 000-US\$11 999	20 (29.4%)	10 (15.9%)	
US\$12 000-US\$14 999	9 (13.2%)	13 (20.6%)	
US\$15 000-US\$19 999	8 (11.8%)	12 (19.1%)	
US\$20 000-US\$29 999	11 (16.2%)	5 (7.9%)	
≥US\$30 000	7 (10.3%)	5 (7.9%)	
Lives with caregiver	56 (73.7%)	53 (74.6%)	Chi-square test $P = .894$
Gen health, compared same			Wilcoxon rank sum test exact $P = .921$
Age	(n = 74)	(n = 70)	
Excellent	1 (1.4%)	4 (5.7%)	
Good	42 (56.8%)	37 (52.9%)	
Fair	22 (29.7%)	18 (25.7%)	
Poor	9 (12.2%)	8 (11.4%)	
Very poor	0 (0.0%)	3 (4.2%)	
Health changed last 12 months	n = 74	n = 69	Wilcoxon rank sum test exact $P = .570$
Much better	0 (0.0%)	0 (0.0%)	
Somewhat better	4 (5.4%)	0 (0.0%)	
About the same	34 (46.0%)	44 (63.8%)	
Somewhat worse	30 (40.5%)	15 (21.7%)	
Much worse	6 (8.1%)	10 (14.5%)	
Functional assessment II	n = 73	n = 62	Wilcoxon rank sum test exact $P = .869$
1	29 (39.7%)	28 (45.2%)	
2	17 (23.3%)	9 (14.5%)	
3	37 (37.0%)	25 (40.3%)	
GDS score		(n = 69)	Wilcoxon rank sum test $P = .154$
Median	4	4	
25th-75th percentile	3-5	3-5	
Range	1-7	1-7	
MMSE	(n = 70)	(n = 66)	Wilcoxon rank sum test $P = .565$
Median	20.5	21	
25th-75th percentile	15-23	14-25	
Range	1-30	0-30	
ADL Index	(n = 75)	(n = 70)	$t$ test $P = .602$
Mean (SD)	2.39 (0.64)	2.33 (0.82)	
Behavioral rating index	(n = 74)	(n = 67)	Wilcoxon rank sum test $P = .042$
Median	1.78	1.62	
25th-75th percentile	1.46-2.23	1.25-2.09	
Range	1.00-4.15	1.00-3.08	

Abbreviations: GDS, Global Deterioration Scale; MMSE, Mini-Mental Status Exam.

<sup>a</sup>  $P \leq .05$ .

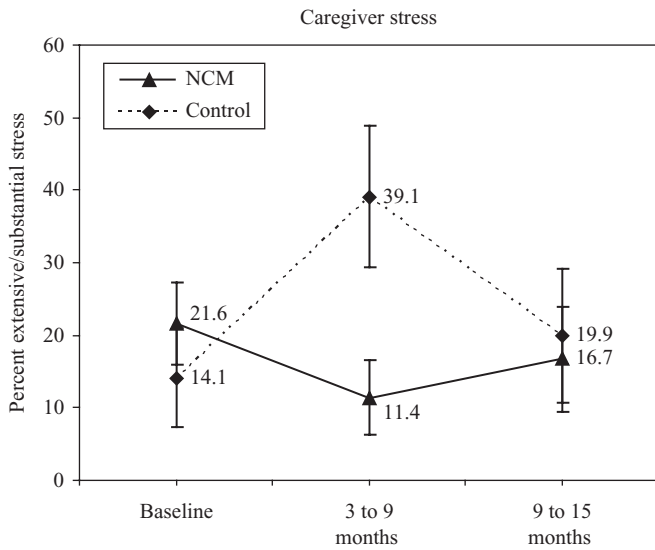
**Table 6.** Caregiver Baseline Characteristics in Nurse Care Manager (NCM) and Control

Characteristic	NCM (n = 75)	Control (n = 34)	P Value
Gender (female)	56/74 (75.7%)	21/33 (63.6%)	Fisher exact test $P = .246$
Age	(n = 70)	(n = 33)	$t$ test $P = .071$
Mean (SD)	63.9 (14.7)	69.2 (11.5)	
25th-75th percentile	53.2-75.9	62.3-77.9	
Range	31.1-92.3	46.6-85.7	
Marital status			Chi-square test exact $P = .069$
Single	15 (20.0%)	4 (11.8%)	
Married/with partner	51 (68.0%)	30 (88.2%)	
Widowed	8 (10.7%)	0 (0.0%)	
Other	1 (1.3%)	0 (0.0%)	
Relation to care recipient			Chi-square test exact $P = .034^a$
Spouse/partner	32 (42.7%)	24 (70.6%)	
Child/child-in-law	39 (52.0%)	10 (29.4%)	
Sibling	1 (1.3%)	0 (0.0%)	
Other relative	3 (4.0%)	0 (0.0%)	
Education	(n = 69)		Wilcoxon rank sum test exact $P = .161$
8th grade or less	7 (10.1%)	3 (8.8%)	
Attended high school	7 (10.1%)	2 (5.9%)	
High school graduate	33 (47.8%)	12 (35.3%)	
Some college or post high school	9 (13.0%)	8 (23.5%)	
Associate degree	3 (4.4%)	3 (8.8%)	
Bachelor's degree	6 (8.7%)	4 (11.8%)	
Graduate degree	4 (5.8%)	2 (5.9%)	
Total annual income	(n = 53)	(n = 26)	Wilcoxon rank sum test exact $P = .687$
<US\$8 000	15 (28.3%)	5 (19.2%)	
US\$8 000-US\$11 999	6 (11.3%)	5 (19.2%)	
US\$12 000-US\$14 999	5 (9.4%)	2 (7.7%)	
US\$15 000-US\$19 999	8 (15.1%)	3 (11.5%)	
US\$20 000-US\$29 999	8 (15.1%)	7 (26.9%)	
US\$30 000-US\$39 999	6 (11.3%)	1 (3.9%)	
≥US\$40 000	5 (9.4%)	3 (11.5%)	
Gen health, compared same age	n = 70		Wilcoxon rank sum test exact $P = .482$
Excellent	9 (12.9%)	9 (26.5%)	
Good	46 (65.7%)	16 (47.1%)	
Fair	12 (17.1%)	9 (26.5%)	
Poor	2 (2.9%)	0 (0.0%)	
Very poor	1 (1.4%)	0 (0.0%)	
Health changed last 12 months	n = 71		Wilcoxon rank sum test exact $P = .311$
Somewhat better	2 (2.8%)	1 (2.9%)	
About the same	49 (69.0%)	27 (79.4%)	
Somewhat worse	18 (25.4%)	5 (14.7%)	
Much worse	2 (2.8%)	1 (2.9%)	
Caregiver stress (overall rating)	n = 69		Wilcoxon rank sum test exact $P = .812$
Extensive	9 (13.0%)	1 (3.2%)	
Substantial	5 (7.3%)	4 (12.9%)	
Moderate	23 (33.3%)	12 (38.7%)	
Limited	21 (30.4%)	9 (29.0%)	
None	11 (15.9%)	5 (16.1%)	
Caregiver well-being (overall rating)	n = 69	n = 32	Wilcoxon rank sum test exact $P = .842$
Extremely compromised	7 (10.1%)	1 (3.2%)	
Substantially compromised	9 (13.1%)	1 (3.2%)	
Moderately compromised	12 (17.4%)	12 (37.5%)	
Mildly compromised	25 (36.2%)	12 (37.5%)	
Not compromised	16 (23.2%)	6 (18.8%)	

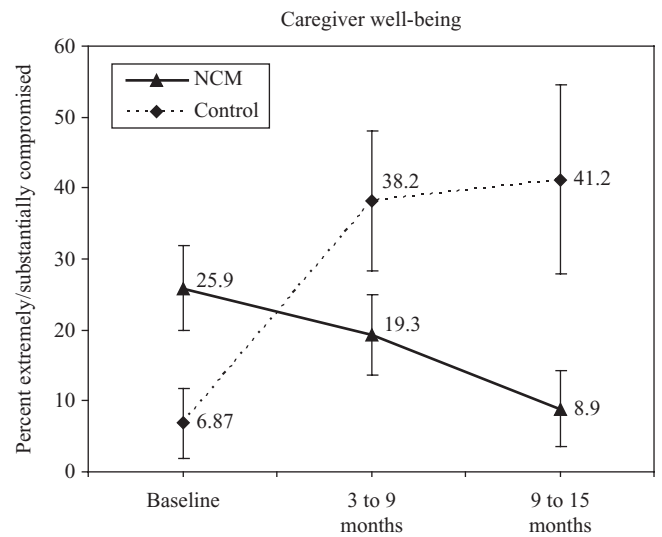
(continued)

Caregiver endurance (overall rating)	(n = 66)	(n = 31)	Wilcoxon rank sum test exact $P = .035^a$
Not adequate	14 (21.1%)	1 (3.2%)	
Slightly adequate	5 (7.6%)	2 (6.5%)	
Moderately adequate	22 (33.3%)	10 (32.3%)	
Substantially adequate	16 (24.2%)	13 (41.9%)	
Totally adequate	9 (13.6%)	5 (16.1%)	

<sup>a</sup> Denotes significance of  $P$  value  $\pm < .05$  level.



**Figure 1.** Comparison of caregiver stress over time. NCM, nurse care manager.

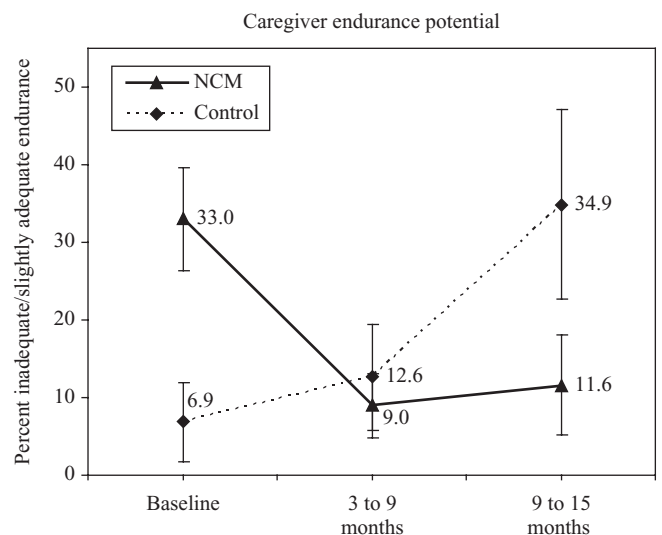


**Figure 2.** Comparison of compromised caregiver well-being over time. NCM, nurse care manager.

period but was not statistically significant. At the 9 to 15 months follow-up, the CGs in the comparison group were more likely to have had extremely/substantially compromised WB than the CGs in the NCM group (odds ratio: 8.07; 95% CI: 1.10, 59.32;  $P = .038$ ).

In examining the CGs with inadequate EP, the proportion of CGs with inadequate or slightly adequate EP was higher in the NCM group at baseline ( $P = .013$ ), but decreased significantly at the 3 to 9 months follow-up compared with baseline (Figure 3). In contrast, a change in the opposite direction was observed in the comparison group, although that change was not statistically significant.

In all, 3 CR variables and 2 CG characteristics were found to be significantly associated with at least 1 of the CG outcomes. For each of these significant covariates, the estimate of the odds ratio (with 95% confidence interval) for an unfavorable outcome associated with the covariate is listed in Table 7. A higher CR behavior rating index was significantly associated with extensive/substantial stress ( $P = .005$ ) and extremely/substantially compromised WB ( $P = .035$ ) of the CG. The CR functional ability rating of 2 (vs 1;



**Figure 3.** Comparison of inadequate caregiver endurance potential over time. NCM, nurse care manager.

$P = .057$ ) and a higher CG health change ( $P = .014$ ) also showed a significant association with CG WB ( $P = .057$ ). Younger CGs ( $P = .02$ ) and younger CRs

**Table 7.** Covariates Associated With Caregiver Outcomes

Caregiver Outcome	Covariate	Odds Ratio (95% CI)	P value
Stress: extensive/substantial Well-being: extremely/substantially compromised	Behavior rating index (per unit increase)	3.52 (1.81, 6.83)	.005 <sup>a</sup>
	Functional ability rating		
	3/1	7.85 (0.94, 65.63)	.057
	2/1	5.58 (0.70, 44.50)	.105
	Behavior rating index (per unit increase)	2.28 (1.20, 4.35)	.035 <sup>a</sup>
	Caregiver health change (per unit increase)	2.10 (1.23, 3.59)	.014 <sup>a</sup>
Endurance: inadequate or slightly adequate	Care recipient age (per 5-year decrease)	1.61 (1.30, 5.18)	.027
	Caregiver age (per 10-year decrease)	1.61 (1.13, 2.29)	.020 <sup>a</sup>

<sup>a</sup>  $P \leq .05$ .

( $P = .027$ ) were significantly associated with inadequate CG endurance.

### Limitations

The biggest limitation with this project was with follow-up evaluations. The follow-up evaluations were not always done in a timely fashion. The progressive nature of the disease is 1 of the reasons timing is so important in research with persons with dementia. Of greater concern than the untimeliness, however, is the extent to which the lack of follow-ups decreased the number of participants for analysis.

The 2 CR groups enrolled at baseline were significantly different in age, diagnosis, income, health change, ADL, and GDS. This made it more difficult to compare outcomes over time. There were also significant differences between CGs of CR in NCM counties and the CGs in the comparison counties. The intervention county had fewer CGs that were spouses/domestic partners (43% in NCM vs 71%). Because relationship to CR affects CG outcomes,<sup>23-26</sup> the difference in outcomes may have been attributable to the relationship and not the intervention. Statistical methods were used to control for this difference.

### Discussion

The dementia NCM in the Iowa AoA Demonstration Project was responsible for achieving measurable outcomes. The only CR measure reflecting significant difference from baseline to follow-up was the ADL Index, a measure of functional ability. The NCM CR group was significantly more dependent at baseline than the comparison group. Functional ability significantly decreased from baseline to each follow-up collection period for the NCM group but not the comparison group. Although the functional ability declined in the NCM group, it was not enough to make a significant difference in the GDS rating

scale. It was anticipated that the NCM could work with the CGs and CRs to improve or maintain functional abilities of the CRs, but this was not reflected by the ADL measures.

The CG outcomes (stress, WB, and EP) for the NCM group were substantially more positive than for the comparison group. The amount of CG stress did not increase in the NCM group despite the fact that ADL function of the CR declined. In contrast, in the follow-up data for the comparison group, the CR had minimal changes in functional ability, whereas CG stressors continued to increase. The CG WB increased in the NCM group and was significantly decreased in the comparison group. EP improved substantially in the NCM group, whereas it declined in the comparison group. The fact that EP increased for the NCM CGs, however, demonstrated some ameliorating effects of the NCM intervention perhaps because of the increase in support and knowledge of the CG, and the decreased experienced stress.

Importantly, 43% of CGs in the NCM group were spouses or domestic partners, whereas 71% of the CGs in the comparison group were spouses or domestic partners. The NCM CGs were younger on average, which may lead 1 to anticipate better coping ability, health, and EP. Studies have shown, however, that nonspouse CGs are likely to experience more stress, less endurance, and deteriorating WB.<sup>24-26</sup> In contrast to those studies, even though the NCM group had more nonspouse CGs, those CGs showed significantly lower levels of stress, and greater WB, and endurance over time. Mittleman and colleagues<sup>3</sup> demonstrated that intensity and quality of support for spousal CGs made a significant difference in CG distress. The results of this study also support similar findings with NCM interventions with nonspousal CGs. In a study by Gold et al,<sup>23</sup> gender was shown to affect outcomes, with women CGs reporting more burden and more aspects of caregiving as enjoyable.

Research studies of the effect of case management type interventions and their outcomes is conflicting.<sup>8,9,27-29</sup> In an analysis of case management interventions for dementia CGs, only 1 of the reviewed studies reported results that suggested a decrease in a negative outcome, that outcome being CGs stress.<sup>27</sup>

Analysis of data from the Alzheimer's Disease Demonstration Program suggested that behavioral and cognitive measures, such as ADL/IADL and CGs appraisal of dementia, declined, but these may be expected as the course of dementia became more severe with time.<sup>8</sup> Consistent with some of the findings of the Iowa AoA study, CG mood and burden generally improved with the NCM intervention. It is noteworthy that the baseline comparison characteristics of the group who stayed in the study with those who were placed or died during the study were essentially the same except for age. The group who were placed or died was older, with a mean age of 83 compared with a mean age of 80 for the group who remained in the study. There were no differences in the health of the CG for the 2 groups.

It is also notable that the NCM CGs were younger than the CGs in the comparison group. Yet, CG endurance was found to be significantly related to the age of the CG (odds ratio 1.61,  $P = .027$ ). Therefore, this is the inverse relationship of what other researchers have found where adult children usually suffer more stress and burden and lower endurance potential. Other studies that have also demonstrated increased levels of stress and burden in adult children CGs over spousal CGs.<sup>24,28,30</sup> In this study, however, CG endurance increased significantly in the NCM group, whereas it decreased in the comparison group. This is an important finding to consider in planning for future care delivery systems because widowed women are the largest group of CR in rural areas.<sup>31</sup> Thus, especially in rural areas adult children will more often be CGs and mechanisms to help them maintain caregiving without negative impact on their lives and health is critical to prevent less desirable institutionalization of their parents with dementia.

It is noteworthy that the NCM group enrolled twice as many participants who were further advanced in their disease and had limited services previously. The visibility of the NCM in the community whose position was dedicated services for persons with dementia increased the number of referrals. With earlier intervention offered by the NCM, institutionalization may be prevented longer. This was supported anecdotally by client

dyads, who reported that they would have put their loved one in a nursing home earlier had it not been for the support and interventions of the NCMs. The lack of early intervention may be part of the explanation for the increased rate of nursing home placement in the NCM group. The lack of diagnosis of Alzheimer's disease or even suspicion of the disease in 67% of the CRs points out the need for earlier and improved evaluation of persons with memory problems.

The positive results with the NCM are encouraging. The NCM intervention, however, is not specified to dose (frequency and intensity) or specific activities, making it more difficult to replicate or identify the specific components of interventions that have the most positive effects for CGs. The enactment of the NCM role was dependent upon the skills, knowledge, and experience of the NCM and the specific and individual needs of the CR and CGs. At a minimum, more quantification of the time spent and types of interventions used should be collected in future studies for further understanding of the intervention and the ability to replicate it.

Although findings support that the NCM made a difference for the CG, we are not able to say that it was because this person was a nurse or that it was merely because there were more opportunities for the CG to have support from someone knowledgeable and empathetic to their situation. Anecdotal evidence from this project supports that by having a nurse involved in the situation, there were instances for both CR and CG of the identification of other health concerns. Once these were managed, improved health status, sometimes including cognitive ability, was the outcome, thus improving the life situation. The results demonstrated that in the NCM counties, an increased number of persons with dementia in the community were identified. These elders and their family CGs had not previously accessed the current CM system or other community resources. Thus, the NCM intervention enabled more persons to receive dementia-specific care and resources.

The results of this study substantiate that providing ongoing support and education focused on the needs of the CG and CR makes a difference with the ability to keep the person with AD in the home longer without compromising the health and well-being of the CG. The NCM is one model that holds promise for providing the support and education and merits further testing with increased specification of the intervention.

## Acknowledgments

“This project was supported, in part, by a grant, number 90AZ2366, from the Administration on Aging, Department of Health and Human Services, Washington, DC 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.” This grant was awarded to the Iowa Department of Elder Affairs and implemented in collaboration with the University of Iowa College of Nursing and Center on Aging. The grant was entitled “Building a Seamless Dementia Specific System in Rural Iowa.” Special thanks to Michael Dodds, graduate nursing student, for his work on the project as well as Blake Robinswood from the Center on Aging for statistical assistance. Presentation: Specht J, Bossen A. Community nurse dementia specialists: implementation, preparation and evaluation. Paper presented at: 6th International Conference on Care Management by the American Society on Aging; October 26-29, 2003; Philadelphia, PA.

## References

1. HMO Workgroup on Care Management: *Improving the Care of Older Adults With Common Geriatric Conditions*. Washington, DC: AAHP Foundation; 2002.
2. Family Caregiver Alliance. *Fact Sheet: Alzheimer's Disease*. 2002. Available at: <http://www.caregiver.org/factsheets/alzheimers.html>. Accessed May 6, 2003.
3. Mittleman MS, Roth DL, Coon DW, Haley WE. Sustained benefit of support intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *Am J Psychiatry*. 2004;161:850-856.
4. Wright LK. Family caregiving for elders—Can we prepare for the caregiving role? In: Gueldner SH, Poon LW, eds. *Gerontological Nursing Issues for the 21st Century: A Multidisciplinary Dialogue Commemorating The International Year of Older Persons*. Indianapolis, IN: Center Nursing Press; 1999:chap 6;75-80.
5. Zarit S, Stephens M, Townsend A, Greene R. Stress reduction for family caregivers” effects of adult day care use. *J Gerontology*. 1998;5:S267-S278.
6. Chen A, Brown R, Archibald N, Aliotta S, Fox PD. *Best Practices in Coordinated Care*. Submitted to: Health Care Financing Administration Submitted by: Mathematica Policy Research, Inc. Division of Demonstration Programs. Contract No: HCFA 500-95-0048 (04). MPR Reference No: 8534-004, 2000.
7. Iowa Department of Elder Affairs. *CMFE Activity Report (Fiscal Year 2003)*. 2003. Available at: <http://www.state.ia.us/elderaffairs/ldocuments/reports/CMPFE-FY2003Activity.pdf>. Accessed February 25, 2003.
8. Arnsberger P, Fox P, Zhang X. Case manager defined roles in the medicare alzheimer's disease demonstration: relationship to client and caregiver outcomes. *Care Manag J*. 1999;1:29-37.
9. Noelker LS. Case Management for Caregivers. United States Department of Health and Human Services. Center for Communication and Consumer Services. Administration on Aging. 2003. Available at: <http://www.aoa.gov/naic/notes/carecasemanagement.html>. Accessed April 15, 2003.
10. Gwyther LP. *The Nation Family Caregiver Support Program: From Enactment to Action. Highlights From the US*. Administration on Aging Conference; September 6–7, 2001; Washington, D.C. Prepared by The Lewin Group. Care Management For Family Caregivers: An Overview. 2001.
11. Naylor M, Brooten D, Campbell R, et al. Comprehensive discharge planning and home follow-up of hospitalized elders: a randomized controlled trial. *J Am Med Assoc*. 1999;28:613-620.
12. Hall GR. Caring for people with Alzheimer's disease using the conceptual model of progressively lowered stress threshold in the clinical setting. *Nurs Clin North Am*. 1994;29:129-141.
13. Hall G, Buckwalter K. A conceptual model for planning and evaluating care of the client with Alzheimer's disease. *Arch Psychiatr Nurs*. 1987;1:399-406.
14. Kelley LS, Lankin JA. Role supplementation as a nursing intervention for Alzheimer's disease: a case study. *Public Health Nurs*. 1988;5:146-152.
15. Folstein MF, Folstein SE. Neuropsychiatric assessment of syndromes of altered mental state. In: Hazard WR, Bierman EL, Blass JP, Ettinger WH Jr, Halter JB, Andres R, eds. *Principles of Geriatric Medicine and Gerontology*. 3rd ed. New York: McGraw-Hill; 1994: 221-228.
16. Reisberg B, Sclan SG, Franssen E, Klugger A, Ferris S. Dementia staging in chronic care populations. *Alzheimer Dis Assoc Disord*. 1994;8:S188-S201.
17. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969;9:179-186.
18. Garrity TF, Klein R. Behavioral rating checklist for nursing personnel. In: Ward MJ, Lindeman CA, *Instruments for Measuring Nursing Practice and Other Health Care Variables*. Vol. 1. Hyattsville, MD: U.S. Department of Health, Education, and Welfare; 1978:173-175.
19. McHorney CA, Ware JE, Rogers W, Raczek AE, Lu JF. The validity and reliability precision of MOS short-and long-form health status scales and Dartmouth COOP charts. Results from Medical Outcomes Study. *Med Care*. 1992;30:MS253-MS265.
20. Ware JE, Sherbourne CD. A 36-item short form health survey (SF-36): conceptual framework and item selection. *Med Care*. 1992;30:473-481.

21. *Iowa Outcomes Project: Nursing Outcomes Classification (NOC)*. 3rd ed. Moorehead S, Johnson M, Maas M, eds. St. Louis, MO: Mosby; 2004.
22. Gandek B, Ware JE. Methods for validating and norming translations of health status questionnaires: the IQOLA Project approach. *International Quality of Life Assessment*. *J Clin Epidemiol*. 1998;51:953-959.
23. Gold C, Cohen C, Shulman C, Andres D, Etezadi J. Caregiving and dementia: predicting negative and positive outcomes for caregivers. *Int J Aging Hum Dev*. 1995;41:183-201.
24. Grau L, Teresi J, Chandler B. Demoralization among sons, daughters, spouses, and other relatives of nursing home residents. *Res Aging*. 1993;15:324-345.
25. Ingersoll-Dayton B, Starrels ME, Dowler D. Caregiving for parents and parents in law: is gender important? *Gerontologist*. 1996;36:483-491.
26. McCarty EF. Caring for a parent with Alzheimer's disease: process of daughter caregiver stress. *J Adv Nurs*. 1995;23:792-803.
27. Cox C, Albusu K. The Alzheimer's connection demonstration program: instituting a national case management program. *Am J Alzheimers Dis Other Demen*. 2001;16:279-284.
28. Christianson JB. The evaluation of the National Long Term Care Demonstration: the effect of channeling on informal caregiving. *Health Serv Res*. 1988;23:99-117.
29. Lowenstein A. A case management demonstration project for the frail elderly in Israel. *Case Manag J*. 2000;2:5-14.
30. Stephens MA, Franks MM. Spillover between daughter's roles as caregiver and wife: interference or enhancement. *J Gerontol: Psychol Sci*. 1995;50B:9-17.
31. Buckwalter KC, Russell C, Hall G. Needs, resources, and responses of rural caregivers of persons with Alzheimer's disease. In: Light E, Niederehe G, Lebowitz BD, eds. *Stress Effects on Family Caregivers of Alzheimer's Patients: Research and Interventions*. New York, NY: Springer Publishing Company; 1994: 301-315.

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